



50TH

CNS ANNUAL MEETING

100

PAST • PRESENT • FUTURE

SEPTEMBER 29 - OCTOBER 2, 2021

BOSTON • MASSACHUSETTS

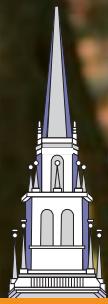


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Looking Back: 50th Annual Meeting

From “A” (Ann Arbor) to “B” (Boston)

Five years ago, in a wide-ranging conversation videotaped at the Kansas City meeting, old friends and CNS Founders Kenneth Swaiman, N. Paul Rosman, and G. Dean Timmons looked back on the pathways that inspired them to go into child neurology in the 1960s and, in October 1972, led them to the campus of the University of Michigan in Ann Arbor for the first meeting of the newly founded Child Neurology Society.

Of the 225 child neurologists in the US at the time, 170 expressed interest in joining a newly created CNS and 130 actually attended to the first meeting, double the number Ken and local host, Dr. Richard Allen had originally hoped might come. “The energy and the cohesiveness was evident immediately,” Dr. Swaiman recalls. “People began talking, embracing each other physically and linguistically....I’ll never forget the feeling of it.

Acknowledging Dean Timmons’ role in establishing the Hower Award, first given two years later, Dr. Swaiman archly noted that “the best way to keep a society going is to pretend that it’s been going for 50 years before you.” Fifty years later the need to pretend had long since passed. But the sense of newness, the energy and excitement of doing – or seemingly doing – something for the first time? That was there every minute of every day the CNS met in Boston. And if social distancing and safety protocols kept people from embracing physically, there was no stopping the 800 child neurologists gathered for the first time in two years from doing so “linguistically.” The same doubts, the same hopeful-but-not-too-hopeful sense of uncertainty over how many people would come marking the run-up to the 1st euphoric meeting were there for the 50th.

“Thanks” to COVID-19 and the Delta-curved doubts shrouding the planning process all through the spring and summer of the pandemic’s second year, no one really knew – or professed to know – whether anyone would gather at the Hynes Convention Center in Boston to celebrate the Child Neurology Society’s 50th anniversary meeting. In late August, when the AAP announced it was



[Click to view video.](#)



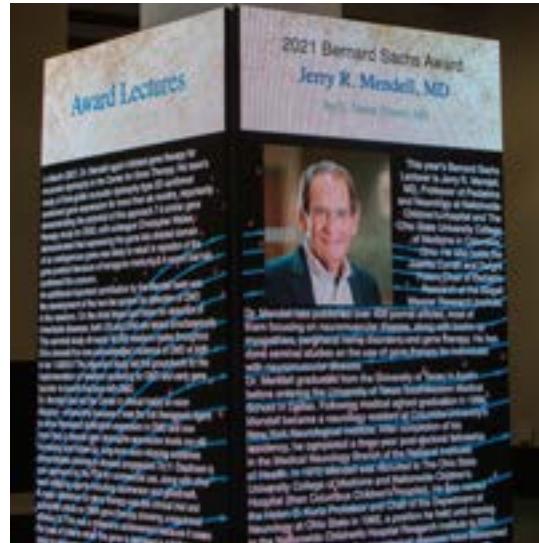
shutting down its in-person October meeting and going virtual, many were convinced it was time for the CNS to face the music: time to turn off the lights, boot up the computer, and stay home.

That’s not what happened, however. Not by a long shot. Instead, the band played on, because, as luck would have it, the President in charge of this meeting was an accomplished jazz musician

who knew the difference between keeping a beat and being beaten, coming to a full stop and easing into a slow fade...before leaping back into a lively and loving recapitulation and reinterpretation of the opening theme.

So, yes: WE DID IT! We met in Boston and not only celebrated history, we made it. Fully 600 members attended virtually, while 800 members attended in-person, including nine who attended the first meeting in Ann Arbor. Over 1/4 of those in Boston last fall were young enough that one can easily imagine them gathering at the 100th Anniversary Meeting of the CNS to swap stories about what it was like at the 50th. It may well be that as we move toward Cincinnati in October, "Where the Next 50 Years Begins" this youthful cohort of "next-gen-neurologists" may come to see this moment in time as a Second Founding, and themselves as Second Founding generation. But first, let's take one last look back at the 50th Anniversary Meeting through Suzanne Shaff's camera lens, through the collected "Countdown to Boston" entries, (including two never-before-published entries – "B" and "A"), and through the uniquely privileged perspectives of two CNS Presidents, Phil Pearl and Bruce Cohen, who have partnered in guiding the Child Neurology Society through this pivot point in history, this "Second Founding."

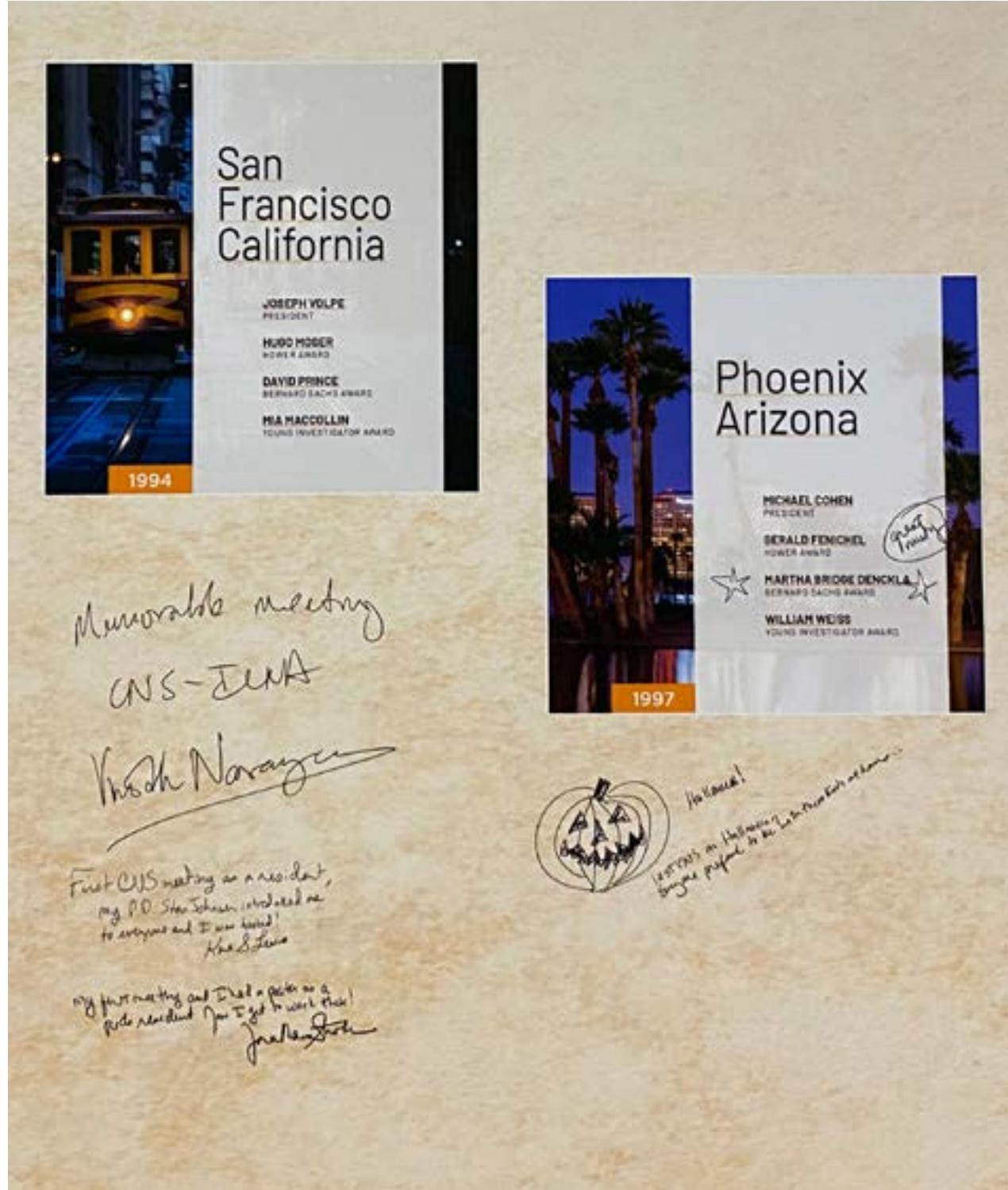






The Wall





1st CNS
meeting
spectacular
Kevan
Michael Srebnik



1st CNS Meeting
for cancer-related patients
Shelli

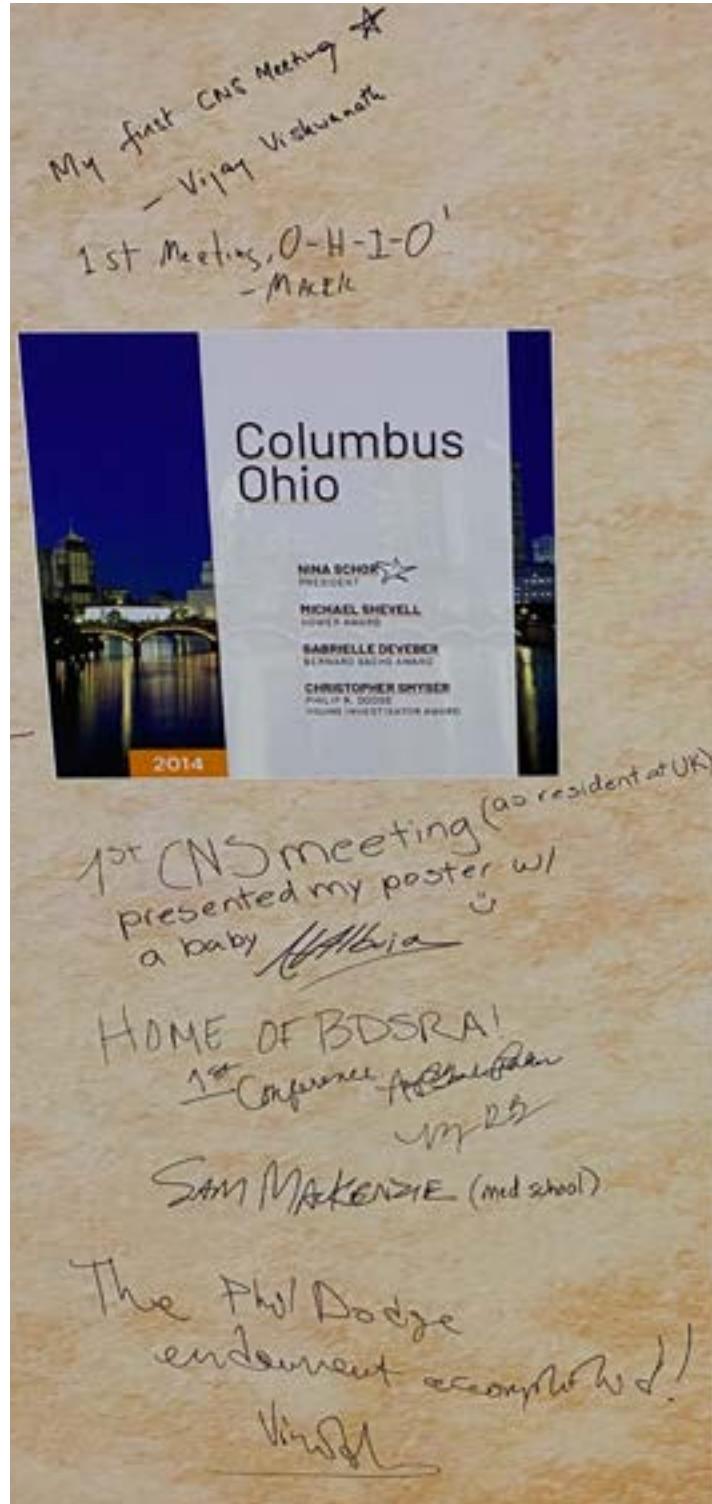
My first CNS
meeting in Great City
great time
Good Year
RD

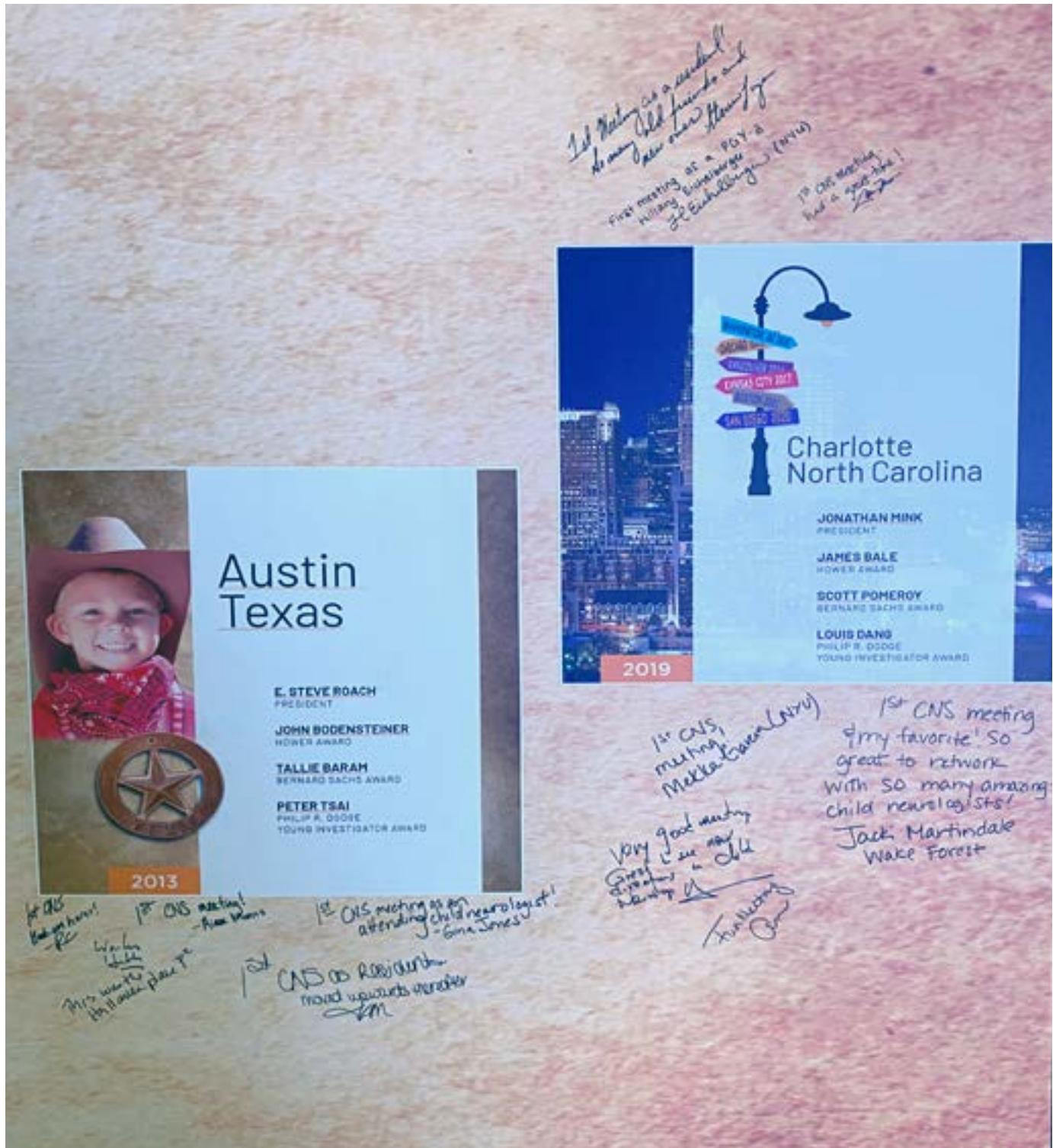
Great meeting
Great CNS
Audrey Brumback
- the city of
the arts

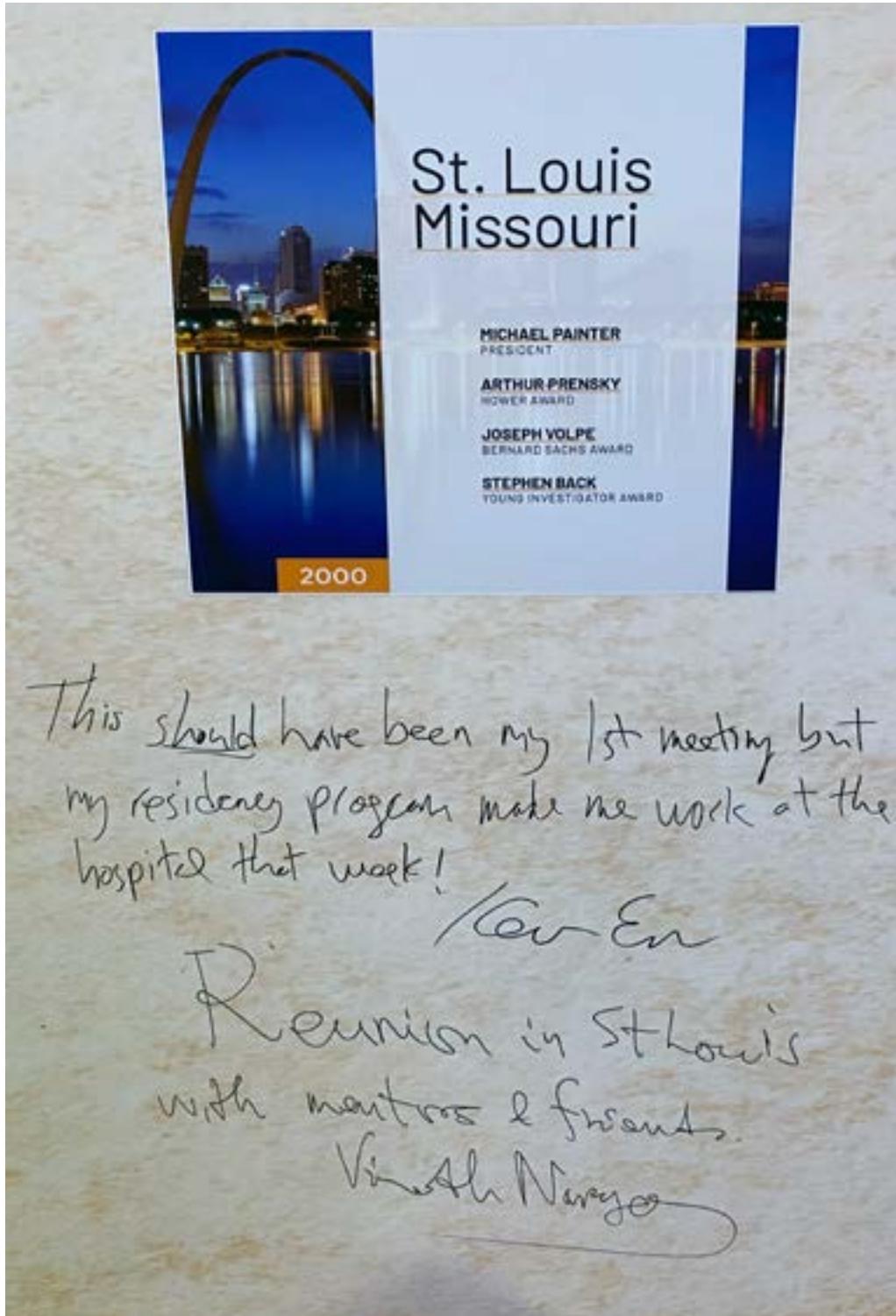
1st CNS meeting
at a time of medical advance!
Shelli

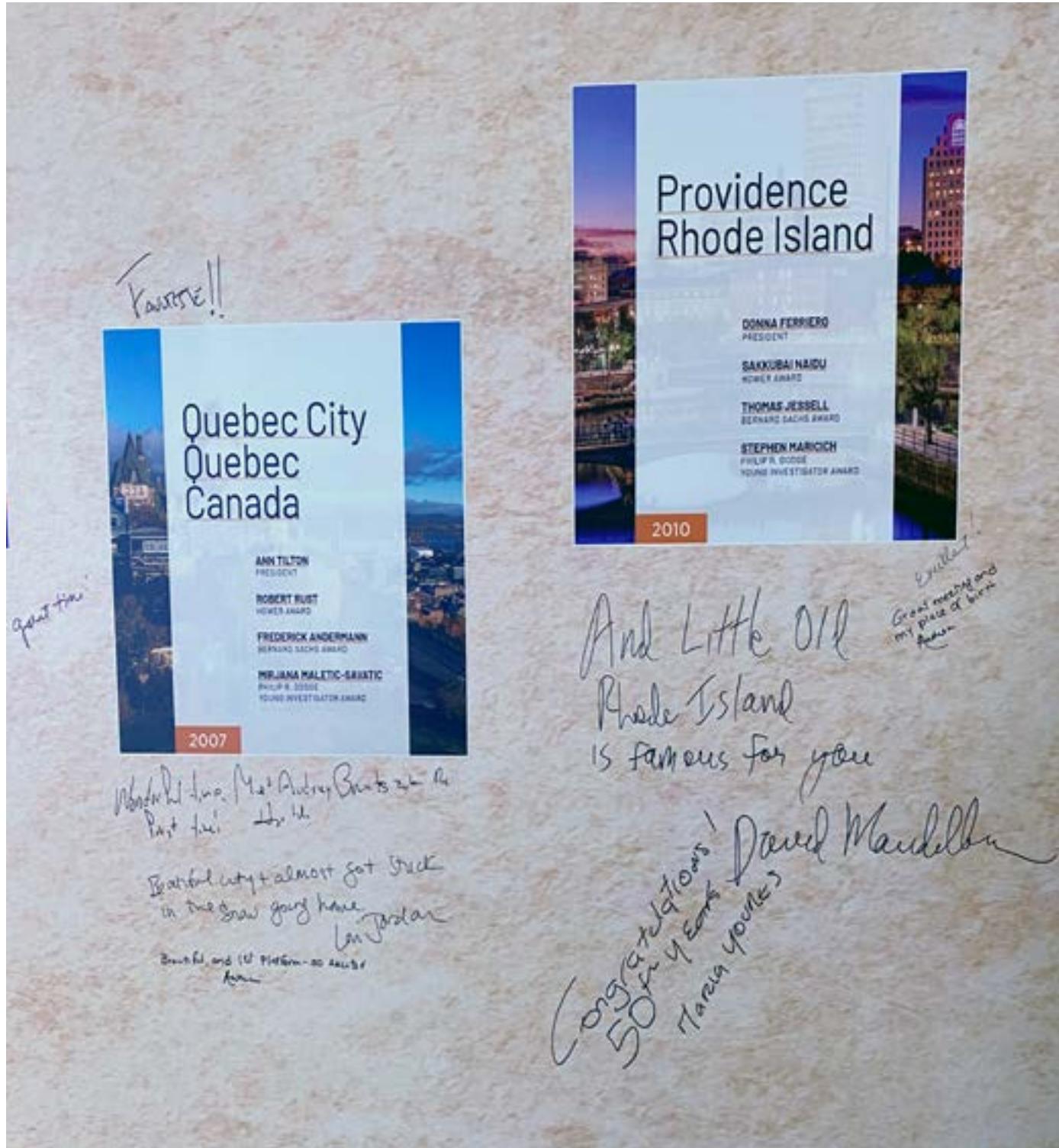
Huge art gallery (esp. Mexican)
outstanding networking
just now! Refreshing!

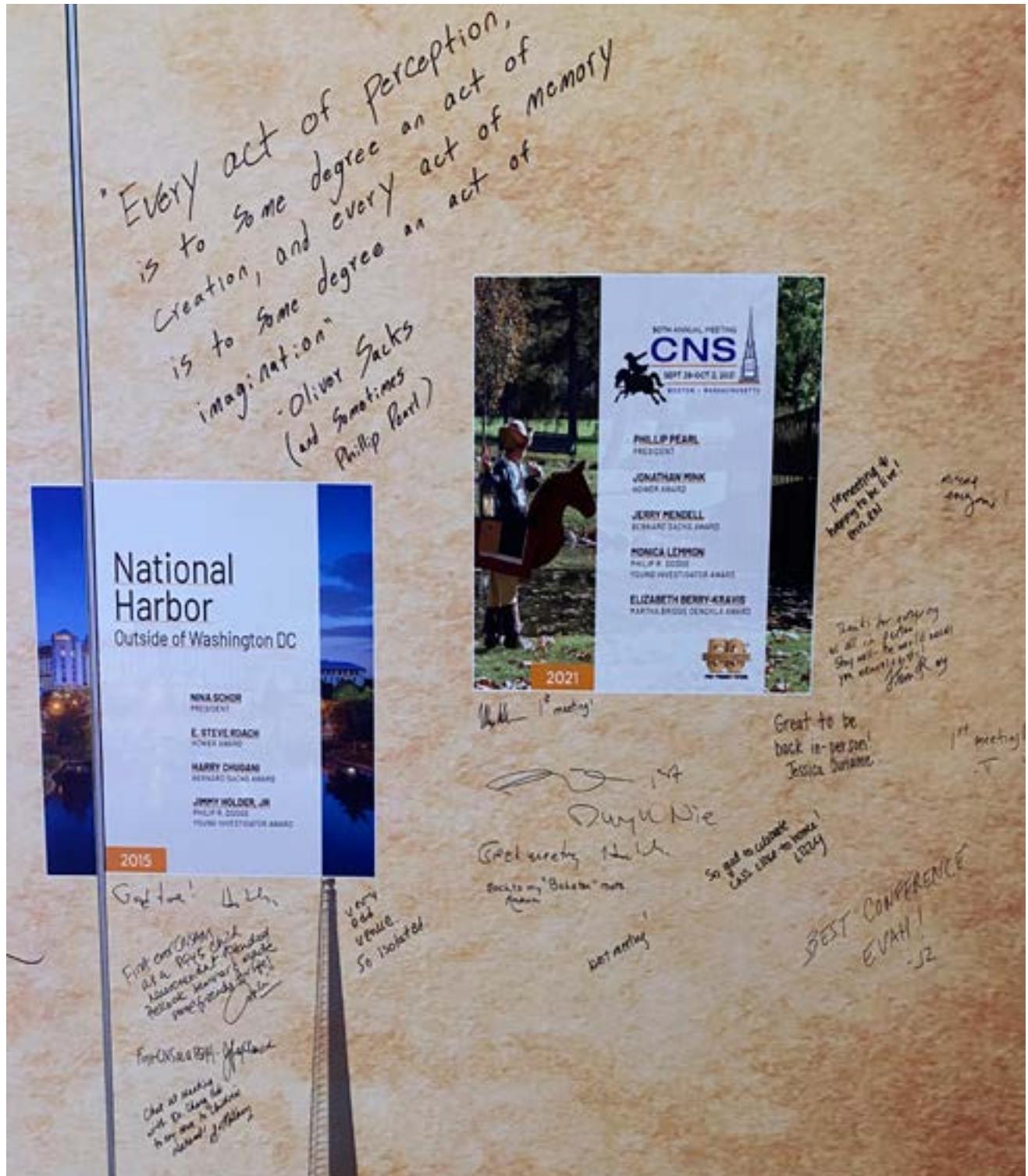
My 1st meeting and was fantastic!!
My favorite session!! &



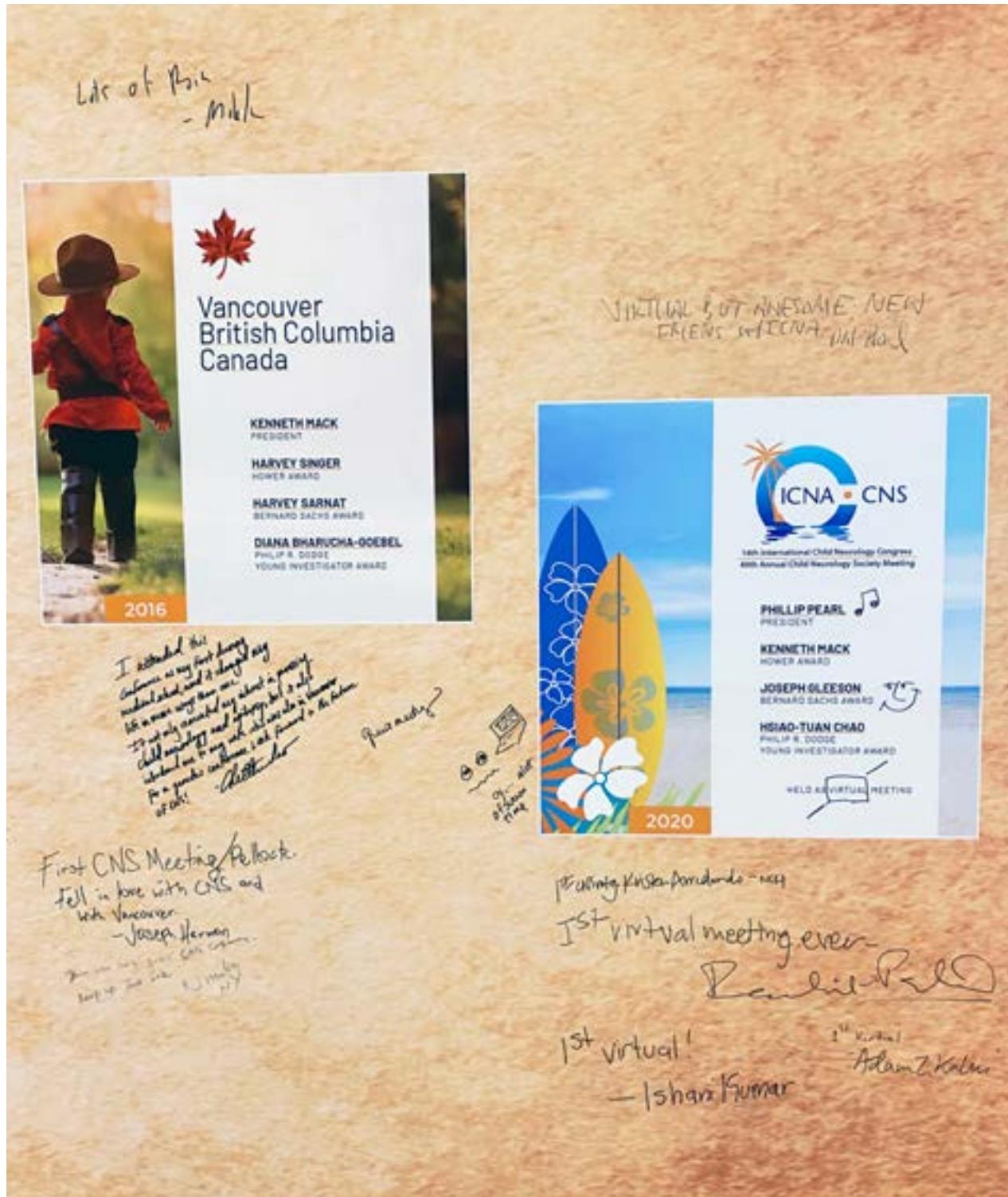








By the Numbers



Favorite Meeting - Top 11

372	Boston, MA - 2021
167	Vancouver, BC, Canada - 2016
140	Charlotte, NC - 2019
124	Chicago, IL - 2018
85	Virtual - 2020
49	Huntington Beach, CA - 2012
44	Austin, TX - 2013
37	Kansas City, MO - 2017
36	Washington, DC - 2015
35	Savannah, GA - 2011
31	Quebec City, QC, Canada - 2007

The 2016 Meeting in Vancouver was (Boston 2021 excepted) the #1 favorite meeting. The 2020 Meeting in San Diego likely would have been, had COVID-19 not forced it on-line. Good News! We'll be back in Vancouver in 2023 and on the ground in San Diego in 2024!

50th Annual Meeting Attendance

804	In-person
603	Virtual
235	Exhibitor Representatives

Attended in 1972 and 2021

Peter Camfield, MD	Halifax, NS	Virtual
Patricia Crumrine, MD	Pittsburgh, PA	In-Person
Gerry Erenberg, MD	University Ht, OH	In-Person
Marvin Fishman, MD	Houston, TX	Virtual
Robert Greenwood, MD	Chapel Hill, NC	In-Person
Morris Levinsohn, MD	Willoughby, OH	In-Person
Sakkubai Naidu, MD	Richmond, VA	In-Person
N. Paul Rosman, MD	Chestnut Hill, MA	In-Person
Harvey Sarnat, MD	Calgary, AB	In-Person
G. Dean Timmons, MD	Stow, OH	In-Person
Sandran Waran, MD	Morristown, NJ	In-Person

First Meeting - Top 10

365	Boston, MA - 2021
83	Charlotte, NC - 2019
62	Virtual - 2020
56	Vancouver, BC, Canada - 2016
53	Chicago, IL - 2018
46	Washington, DC - 2015
46	Austin, TX - 2013
40	Columbus, OH - 2014
34	Kansas City, MO - 2017
32	Louisville, KY - 2009

CNS Annual Meeting Locations

1972	Ann Arbor, MI	1989	San Antonio, TX	2006	Pittsburgh, PA
1973	Nashville, TN	1990	Atlanta, GA	2007	Quebec City, QC, Canada
1974	Madison, WI	1991	Portland, OR	2008	Santa Clara, CA
1975	Hamilton, ON, Canada	1992	New Orleans, LA	2009	Louisville, KY
1976	Monterey, CA	1993	Orlando, FL	2010	Providence, RI
1977	Charlottesville, VA	1994	San Francisco, CA	2011	Savannah, GA
1978	Keystone, CO	1995	Baltimore, MD	2012	Huntington Beach, CA
1979	Hanover, NH	1996	Minneapolis, MN	2013	Austin, TX
1980	Savannah, GA	1997	Phoenix, AZ	2014	Columbus, OH
1981	Minneapolis, MN	1998	Montreal, QC, Canada	2015	Washington, DC
1982	Salt Lake City, UT	1999	Nashville, TN	2016	Vancouver, BC, Canada
1983	Williamsburg, VA	2000	St. Louis, MO	2017	Kansas City, MO
1984	Phoenix, AZ	2001	Victoria, BC, Canada	2018	Chicago, IL
1985	Memphis, TN	2002	Washington, DC	2019	Charlotte, NC
1986	Boston, MA	2003	Miami Beach, FL	2020	Virtual 2020
1987	San Diego, CA	2004	Ottawa, ON, Canada	2021	Boston, MA
1988	Halifax, NS, Canada	2005	Los Angeles, CA		

Celebrating the Society's Legacy

Legacy Reception & Founders Book Signing









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Celebrating the Society's Legacy

2021 Award Recipients



Hower Award: Jonathan Mink, MD, PhD



Bernard Sachs Award: Jerry Mendell, MD



Roger & Mary Brumback Lifetime Achievement Award: Robert Baumann, MD



Roger & Mary Brumback Lifetime Achievement Award: Sidney Gospe, Jr., MD, PhD



Arnold P. Gold Foundation Humanism in Medicine:
Mary Zupanc, MD



Martha Bridge Denckla Award:
Elizabeth Berry-Kravis, MD, PhD



Training Director Award: Miya Asato, MD



Philip R. Dodge Young Investigator Award:
Monica Lemmon, MD

Celebrating the Society's Legacy

CNS Hower Award Recipients

1974 Douglas Buchanan Chicago	1984 Peter Huttenlocher Chicago	1995 Salvatore DiMauro New York	2005 Alan Percy Birmingham	2016 Harvey Singer Baltimore
1975 Randolph K. Byers Boston	1985 Raymond D. Adams Boston	1996 William Bell Iowa City	2006 Michael Painter	2017 Nina F. Schor Rochester, NY
1976 Sidney Carter New York	1986 Jean Aicardi Paris	1997 Gerald Fenichel Nashville	2008 Stephen Ashwal Loma Linda	2018 Bernard L. Maria Morristown, NJ
1977 David B. Clark Lexington	1987 Isabelle Rapin Bronx	1998 N. Paul Rosman Boston	2009 Peter Camfield Halifax	2019 James F. Bale, Jr. Salt Lake City
1978 Philip R. Dodge St. Louis	1988 Bruce Berg San Francisco	1999 Marvin Fishman Houston	2010 Sakkubai Naidu Baltimore	2020 Kenneth J. Mack Rochester, MN
1979 Paul I. Yakovlev Boston	1989 Manuel Gomez	2000 Arthur Prensky St. Louis	2011 Deborah Hirtz Bethesda	2021 Jonathan W. Mink Rochester, NY
1980 John H. Menkes Beverly Hills	1991 Karin B. Nelson Bethesda	2001 Charles Barlow Boston	2012 Ann Tilton New Orleans	
1981 Kenneth F. Swaiman Minneapolis	1992 Darryl C. De Vivo New York	2002 Peter H. Berman Philadelphia	2013 John Bodensteiner Rochester, MN	
1982 Patrick F. Bray Salt Lake City	1993 Bengt D. Hagberg Goteborg	2003 Michael E. Cohen Buffalo	2014 Michael Shevell Montreal	
1983 Betty Q. Bunker Cleveland	1994 Hugo Moser Baltimore	2004 John Freeman Baltimore	2015 E. Steve Roach Columbus	

Bernard Sachs Award Recipients

1977 George Cahill Boston	1987 Hugo Moser Baltimore	1997 Martha Bridge Denckla Baltimore	2007 Frederick Andermann Montreal	2017 Solomon Moshé Bronx, NY
1978 W. Maxwell Cowan St. Louis	1988 Victor Dubowitz London	1998 Andrew Engel Rochester	2008 Michael Johnston Baltimore	2018 William B. Dobyns Seattle
1979 Fred Plum New York	1989 Salvatore DiMauro New York	1999 Carla Shatz Berkeley	2009 Gregory Holmes Lebanon, NH	2019 Scott Pomeroy Boston
1980 Dominick Purpura New York	1990 Roscoe O. Brady Bethesda	2000 Joseph Volpe Boston	2010 Thomas Jessell New York	2020 Joseph Gleeson San Diego
1981 Pasko Rakic New Haven	1991 Marcus E.Raichle St. Louis	2001 Huda Zoghbi Houston	2011 Laura Ment New Haven	2021 Jerry Mendell Columbus, OH
1982 John O'Brien La Jolla	1992 Louis M. Kunkel Boston	2002 Francis Collins Bethesda	2012 Roger Packer Washington, DC	
1983 Roger N. Rosenberg Dallas	1993 C. Thomas Caskey Houston	2003 Darryl C. De Vivo New York	2013 Tallie Z. Baram Irvine	
1984 William L. Nyhan La Jolla	1994 David Prince Stanford	2004 Karin Nelson Bethesda	2014 Gabrielle deVeber Toronto	
1985 Patricia Goldman-Rakic New Haven	1995 Gerald D. Fischbach Boston	2005 O. Carter Snead III Toronto	2015 Harry T. Chugani Detroit	
1986 Louis Sokoloff Bethesda	1996 Verne S. Caviness Boston	2006 Donna Ferriero San Francisco	2016 Harvey Sarnat Calgary	

Roger and Mary Brumback Lifetime Achievement Award Recipients

2004

Jean Holowach
Thurston
St. Louis, MO

2005

Robert Eiben
Cleveland, OH

2006

Raymond Chun
Madison, WI

Barry Russman
Portland, OR

2007

William Kennedy
Watertown, ME

Gordon Watters
Montreal, Quebec

2008

Cesare Lombroso
Boston, MA

2009

Mary Anne
Guggenheim
Helena, MT

2010

Russell Snyder
Albuquerque, NM

2011

Warren Grover
Philadelphia, PA

2012

Bhuwan Garg
Indianapolis, IN

2013

M. Richard
Koenigsberger
Demarest, NJ

2014

Arthur Rose
Brooklyn, NY

2015

Pat Crumrine
Pittsburgh, PA

Suresh Kotagal
Rochester, MN

2016

Kalpathy
Krishnamoorthy
Boston, MA

Doris Trauner
La Jolla, CA

2017

Abe Chutorian
New York, NY

W. Donald Shields
Los Angeles, CA

2018

Gerald Erenberg
Cleveland, OH

William Logan
Toronto, Ontario

Alfred Spiro
Bronx, NY

2019

Carol Camfield
Halifax, Nova Scotia

W. Edwin Dodson
St. Louis, MO

2020

No awards presented
due to programming
limitations of Joint
CNS-ICNA Meeting

2021

Robert Baumann
Lexington, KY

Sidney Gospe, Jr
Seattle, WA

Arnold P. Gold Foundation Humanism in Medicine Award Recipients

2010	2014	2018
Ruth Ness New York, NY	Kenton Holden Mt. Pleasant, SC	Audrey Foster-Barber San Francisco, CA
2011	2015	2019
Shaul Harel Tel Aviv, Israel	Robert Zeller Houston, TX	H. Terry Hutchison Fresno, CA
2012	2016	2020
Marvin Fishman Houston, TX	Oscar Papazian Miami, FL	No award presented due to programming limitations of Joint CNS-ICNA Meeting
2013	2017	2021
Douglas Postels East Lansing, MI	David Coulter Boston, MA	Mary Zupanc Irvine, CA

Training Director Award Recipients

2013	2016	2019	2021
Harvey Singer Baltimore, MD	David K. Uron Boston, MA	Karen Ballaban-Gil Bronx, NY	Miya Asato Pittsburgh, PA
2014	2017	2020	
Steve Leber Ann Arbor, MI	Sidney M. Gospe Jr. Seattle, WA	No award presented due to programming limitations of Joint CNS-ICNA Meeting	
2015	2018		
Robert Rust Charlottesville, VA	Bruce K. Shapiro Baltimore, MD		

Philip R. Dodge Young Investigator Award Recipients

1983

Michael Pranzatelli
Washington

1993

Jeffrey J. Neil
St. Louis

2003

Bradley Schlaggar
St. Louis

2013

Peter Tsai
Boston

1985

Richard J. Konkol
Milwaukee

1994

Mia MacCollin
Boston

2004

Terri Inder
Melbourne

2014

Christopher Smyser
St. Louis

1986

Faye S. Silverstein
Ann Arbor

1995

Adre J. du Plessis
Boston

2005

Mustafa Sahin
Boston

2015

Jimmy Holder, Jr.
Houston

1987

Vinodh Narayanan
Pittsburgh

1996

Michael Rivkin
Boston

2006

Elliott Sherr
San Francisco

2016

Diana Bharucha-
Goebel
Bethesda

1988

Huda Zoghbi
Houston

1997

William A. Weiss
San Francisco

2007

Mirjana Maletic-
Savatic
Stony Brook

2017

Audrey C. Brumback
Austin

1989

Scott L. Pomeroy
St. Louis

1998

Joseph Gleeson
Boston

2008

Laura Jansen
Seattle

2018

Christopher Elitt
Boston

1990

Harris Gelbard
Rochester, NY

1999

Amy Brooks-Kayal
Philadelphia

2009

Jeffrey Neul
Houston

2019

Louis Dang
Ann Arbor

Evan Y. Snyder
Boston

2000

Stephen Back
Portland

2010

Stephen Maricich
Cleveland

2020

Hsiao-Tuan Chao
Houston

1991

Kenneth J. Mack
Madison

2001

Daniel J. Bonthius
Iowa City

2011

James Dowling
Ann Arbor

2021

Monica Lemmon
Durham, NC

1992

Kelvin A. Yamada
St. Louis

2002

Nigel Bamford
New York

2012

Yoon Jae-Cho
Stanford

Bernard D'Souza International Fellowship Award Recipients

1989 Meral Ozmen Istanbul, Turkey	1996 Shan Wei Song Beijing, China	2004 Natalia A. Yermolenko Voronezh, Russia	2011 Kyaw Linn Mayanmar	2017 Charles Hammond Kumasi, Ghana
1990 Najoua Miladi Tunis, Tunisia	1997 Aleksandra Djukic Belgrade, Yugoslavia	2005 Lusine Kirakosyan Yerevan, Armenia	2012 Inga Talvik Tartu, Estonia	2018 Aye Mya Min Aye Yangon, Myanmar
1991 Sergi A. Antoniuk Curitiba, Brazil	1998 Ana Keleme Novi Sad, Yugoslavia	2006 Gia Melikoshvili Tbilisi, Georgia	2013 Samson Gwer Nairobi, Kenya	2019 Suvasini Sharma New Delhi, India
1992 Qin Jiong Beijing, China	1999 Magda L. Nunes Porto Alegre, Brazil	2007 David E. Kombo Dars Es Salaam, Tanzania	2014 Jithangi Wanigasinghe Dehiwela, Sri Lanka	2021 Nicolás Garófalo Gómez Havana, Cuba
1993 Anu Soot Tartu, Estonia	2000 Brahim Tabarki-Melaiki Brussels, Belgium	2008 Ikeolu Lagunju Ibadan, Nigeria	2015 Edward Kija Tanzania	Jitendra Kumar Sahu Chandigarh, India
1994 Lai Choo Ong Kuala Lumpur, Malaysia	2001 Dimitrios Zafeiriou Thessaloniki, Greece	2009 Uduak Mayen Offiong Abuja, Nigeria	2016 Arushi Gahlot Saini Chandigarh, Indian	2021 Chaw Su Hlaing Yangon, Myanmar
1995 Nina Barisic Zagreb, Croatia	2002 Vedrana Milic Rasic Belgrade, Serbia	2010 Parayil S. Bindu Bangalore, India	Tipu Sultan Lahore, Pakistan	Robert Sebunya Kabuye Nkonzi, Uganda
	2003 David Chkhartishvili Tbilisi, Georgia			Tavasoli Tavasoli Tehran, Iran
				Paulina Cecilia Tejada Santiago, Chile

Celebrating the Society's Legacy

CNS Past Presidents

1972-73 Kenneth Swaiman	1980-81 Paul Dyken	1991-93 Peter H. Berman	2007-09 John Bodensteiner
1973-74 Gerald Fenichel	1981-82 Mary Anne Guggenheim	1993-95 Joseph J. Volpe	2009-11 Donna Ferriero
1974-75 Manuel Gomez	1982-83 Raymond Chun	1995-97 Michael E. Cohen	2011-13 E. Steve Roach
1975-76 James Schwartz	1983-85 Robert Eiben	1997-99 Alan K. Percy	2013-15 Nina F. Schor
1976-77 Richard Allen	1983-85 Robert Eiben	1999-2001 Michael J. Painter	2015-17 Kenneth Mack
1977-78 Bruce Berg	1985-87 David Stumpf	2001-03 Stephen Ashwal	2017-19 Jonathan Mink
1978-79 N. Paul Rosman	1987-89 Marvin Fishman	2003-05 James Bale	2019-21 Phillip Pearl
1979-80 Arthur Prensky	1989-91 Darryl C. De Vivo	2005-07 Ann Tilton	2021- Bruce Cohen

CNS Presidents



CNS Presidents in Washington DC (2002): Kenneth Swaiman (1st), Gerald Fenichel (2nd), Marvin Fishman (14th), Bruce Berg (6th), Michael Cohen (18th), Ray Chun (11th), David Stumpf (13th), Peter Berman (16th), Michael Painter (20th), James Bale (22nd)



CNS Presidents in Boston (2021) : Seated (L-R): Kenneth Mack (28th),
 Ann Tilton (23rd), N. Paul Rosman (7th), Jonathan Mink (29th)
 Standing (L-R): Phillip Pearl (30th), John Bodensteiner (24th), E. Steve Roach
 (26th), Stephen Ashwal (21st), Bruce Cohen (31st)



Celebrating the Society's Legacy

CNS Past Secretary-Treasurers

1972-75 Richard Allen	1984-86 Marvin Fishman	1997-2002 Patricia Crumrine	2015-20 Bruce Cohen
1975-78 Raymond Chun	1986-89 Ira Lott	2003-04 Ann Tilton	2020- Lori Jordan
1978-81 Robert Eiben	1989-93 Peggy Copple (Ferry)	2004-10 Nina Schor	
1981-84 Lawrence Lockman	1993-97 Stephen Ashwal	2010-15 Harvey Singer	



CNS Past Councillors

1972-73	1981-83	1990-92	2001-03	2011-13
Isabelle Rapin	Peter Huttenlocher	O. Carter Snead	Michael Noetzel	Barry Kosofsky
Manuel Gomez	Michael Bresnan	Edwin Meyer	Carl Crosley	Suresh Kotagal
1972-74	1982-84	1991-93	2002-04	2012-14
John Menkes	David Stumpf	Israel Abrams	Julie Parke	Vinodh Narayanan
James Schwartz	Gwendolyn Hogan	William Logan	Roy Elterman	Jayne Ness
1973-74	1983-85	1992-94	2003-05	2013-15
Karin Nelson	Joseph Volpe	Mary Johnson	Marc Patterson	Bruce Cohen
1973-75	1984-86	1993-95	2004-06	2014-16
Raymond Chun	Barry Russman	Alan Percy	Donna Ferriero	Roger Packer
1974-76	1985-87	1994-96	2005-07	2015-17
Bruce Berg	Russell Snyder	Phyllis Sher	Leon Dure	Kevin Ess
Paul Dyken	Ian Butler	Gregory Holmes		Kara Lewis
1975-77	1986-88	1995-97	2006-08	2016-18
Arthur Prensky	W. Edwin Dodson	W. Donald Shields	Leslie Morrison	Peter B. Kang
N. Paul Rosman	Michael Painter	John Bodensteiner	Anne Anderson	Mary Zupanc
1976-78	1987-88	1996-98	2007-09	2017-19
Jack Madsen	Robert Zeller	Patricia Crumrine	Steven Leber	Donald Gilbert
Peggy Copple (Ferry)	Doris Trauner	James Bale	Jonathan Mink	Michael Shevell
1977-79	1987-89	1997-99	2008-10	2018-20
Joseph French	Darryl De Vivo	Alan Hill	Robert Rust	Lori Jordan
Francis Wright	Gary Goldstein	Ann Tilton	Wendy Mitchell	Mark Wainwright
1978-80	1988-89	1998-2000	2009-11	2019-21
Mary Anne Guggenheim	Robert Vannucci	Edward Kovnar	Warren Lo	Nigel Bamford
Gerald Golden		Richard Nordgren	Sakkubai Naidu	Nancy Bass
1979-81	1988-90	1999-2001	2010-12	2020-
Gerald Erenberg	Stephen Ashwal	E. Steve Roach	Gary Clark	Audrey Brumback
John Freeman	Jack Pellock	Faye Silverstein	Sidney Gospe	Sonia Partap
1980-82	1989-91	2000-02		2021-
Marvin Weil	Joseph Pasternak	Michael Johnston		Sucheta Joshi
Marvin Fishman	Patricia Duffner	Pauline Filipek		Janet Soul

First Board & Current Board



First CNS Executive Committee: L-R around the table: John Menkes, Manuel Gomez, James Schwartz, Kenneth Swaiman, Richard Allen, Gerald Fenichel, Isabelle Rapin



Audrey Brumback, Councillor for the South (Shown at 2014 CNS Meeting with husband and first child)



L-R: Bruce Cohen, Phillip Pearl, and Lori Jordan, Secretary-Treasurer



L-R: Sonia Partap, Councillor for the West; Sucheta Joshi, Councillor for the Midwest; and Yasmin Khakoo (Scientific Program Chair)



Janet Soul, Councillor for the Northeast (Shown at 2015 CNS Meeting)



2020-21 Executive Committee

Seated (L-R): Nigel Bamford, Lori Jordan, Nancy Bass

Standing (L-R): Roger Larson (Executive Director), Bruce Cohen, Phillip Pearl, Sonia Partap, Sue Hussman (Associate Director)

Not shown: Audrey Brumback



President's Annual Meeting Reflections



The Child Neurology Society observed a more peaceful and orderly transition of power in October 2021 than the country at large experienced in January as incoming President Bruce Cohen accepted the ceremonial gavel from outgoing President, and longtime friend, Phillip Pearl.



Phillip Pearl Reflections

First meeting: San Diego 1987

Marv Fishman thought it was important that the child neurology fellows (Leon Dure being my Baylor partner, and remains in some ways my professional partner for life) attend the CNS meeting. This was just one of many important "Marv role model" decisions, and I was knocked over when I saw John Freeman, the man who introduced the field to me while a Hopkins student. I was star struck by the names in the room. I could never have anticipated plans to return for a combined CNS-ICNA meeting in 2020 while serving as president, only to be thwarted by a virus called Covid-19...but looking forward to 2024!



Darryl DeVivo and Marvin Fishman



Leon Dure



John Freeman

Most formative meeting: Washington, DC 2002

I was tapped to give a talk on disorders of GABA metabolism in a pediatric neurotransmitter disorder symposium, after having just started working and publishing in that arena, and this catapulted my connections and subsequent career in inherited metabolic

epilepsies. At the same time, I had just taken over as chair of the Awards committee plus had a band of my favorite local players entertain for the opening reception. These events together brought my interest in the CNS to a new level. The President's Appreciation Reception at the Woodrow Wilson house was remarkable, and the camaraderie of the CNS really sunk

in. In terms of a full circle moment, my later hometown meeting, Boston 2021, during our 50th Anniversary and my own presidency, was something special. From the "Past, Present and Future" theme, to three consecutive gigs with Berklee faculty, to presenting with cherished colleagues on neurology and the arts, that was a meeting for the ages.

Most fun meeting: Quebec City 2007

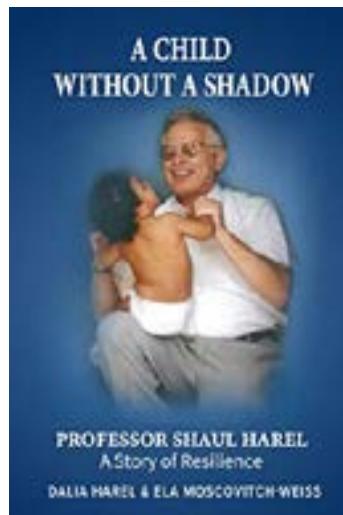
My musician friends traveled to play a seminar on neurological problems of great musicians in this charming city, my first visit there, whereby I combined my lifelong dreams of attending an international professional meeting and being on the road with a band!

*What's fun for
Phil is fun for
everyone...
(Clockwise: 2007,
2015, 2019, 2017, 2021)*



Most memorable moment:

The Society's thunderous standing ovation for Shaul Harel following his tearful remembrance of his parents, both Holocaust victims, on the occasion of Shaul's acceptance of the Arnold P. Gold Foundation Humanism in Medicine Award in Savannah, 2011. (Shown right: cover of Shaul's 2021 memoir; click to access 2011 Gold Award profile (<https://www.childneurologysociety.org/awards/shaul-harel-md/>)



Shaul & Dalia Harel

Most important collaborations:

TNTC, but special thanks to:

- Roger Packer for re-introducing me to the CNS after a hiatus and nominating me for the Awards committee which led to increasing societal involvement;
- Bill Gaillard for his partnership throughout the years and co-attendance at so many great meetings including the Halloween walk in Austin when the street partyers thought we were the ones in costume;
- Scott Pomeroy for speaking at a PCN meeting on training while I was PCN President that sparked (I think) a relationship that would

lead to a life changing opportunity for me to return to my training grounds;

- Steve Ashwal for the hardworking but fun back-and-forth and ultimately rewarding 2nd edition of the Founders and partnering on the Swaiman textbook editions 6 and now 7
- Harvey and Laura Sarnat for making time at most CNS meetings to share dinner and catch up
- Bruce Cohen for friendship and involvement in so many organizations together
- Roger Larson for shepherding the CNS and hanging in there with me through the pandemic presidency.



Roger Packer



Eileen & Steve Ashwal



Harvey Sarnat and Laura Flores Sarnat, with Phil at the 50th.



Children's National Medical Center colleagues: Taeun Chang, Adeline Vanderver, William Gaillard, Andrea Gropman



Scott Pomeroy, President, CNF; Bruce Cohen, President-Elect, CNS; Roger Larson, Executive Director, CNS; Amy Brin, Executive Director, CNF; Phillip Pearl, President, CNF; Anup Patel, President-Elect, CNF. (Note CNS and CNF Presidents rotated off at the end of the 50th Annual Meeting and were succeeded by their respective Presidents-elect)

President's Annual Meeting Reflections

Bruce Cohen Reflections

First Meeting: Boston, 1986

I traveled by train with five of my neurology friends – we all packed into a room at the Westin and first attended the ANA meeting and then I attended the CNS meeting at a conference center on the South Bay. The most memorable part of the meeting was spending two hours with Arnold Gold and Sidney Carter as they made “Poster Rounds” together. They would stop at each poster, read it and talk to each other (and me) about the poster. Along the way I met several child neurology icons, including Patty Duffner and Michael Cohen. I knew then that I had found my professional home.



Arnold Gold and Bernard Maria



Roy Elterman



Most Formative Meeting:

This is a tough decision. I counted about 35 presentations given at CNS meetings over the years. My first scientific presentation was in Halifax (1988), but my independent work really was first presented in Phoenix (1997) when I presented a breakfast seminar on ICD-9 and CPT Coding and delivered a paper on the use of Thalidomide to treat plexiform neurofibromas in NF1. Up until that point my presentations were still under the wings of my mentors, Roger Packer and Darryl De Vivo. That meeting was also significant for me thanks to then CNS President, Michael Cohen, inviting me to participate in a leadership development conference held a few days before the actual meeting.

I need to thank Roy Elterman for inviting me onto the Practice Committee after I wandered into the room, mistakenly thinking it was an open meeting. My guess is this occurred at the 1992 Atlanta meeting. That work sparked what would become a 30 year journey with CPT Coding. Victoria (2001) was the meeting when I presented three papers on various aspects of mitochondrial disease. Twelve years later Bernie Maria asked me to lead the 2013 (Austin) NDC Symposium on Mitochondrial Disease; for me this brought together much of my work and efforts in what was a spectacular program.

Most Fun Meeting:

Again, each meeting brought moments that I will cherish, but the most fun moment probably was during the 2011 (Savannah) meeting when the St. Louis Cardinals played in the World Series. I grew up in St. Louis, and have been a Cardinal fan all my life. The Series went the full seven games and a group of St. Louis child neurologists (I was the tag-along) went to a bar to watch the game and were treated to a victory over the Texas Rangers. I always have wanted to move back to St. Louis, but never made it back. That night in 2011, I was welcomed back by my St. Louis colleagues.

Another great meeting was Kansas City (2017). Almost afraid to admit it, but Jeff Buchhalter (whom I have known my entire career and became good friends with in the last decade), Neil Busis (a friend and adult neurologist who delivered a Presidential Symposium lecture on physician burnout) and I went to three different KC BBQ joints during the meeting, all after the CNS programming ended.



Darryl De Vivo, Michael Cohen, Bruce Cohen in Phoenix, 1997



BBQ Kings: Bruce Cohen, Neil Busis, Jeffrey Buchhalter

Most Memorable Moment:

Isabelle Rapin was the singular reason I became a child neurologist and she seldom missed a CNS meeting before her death in 2017. Everytime she stood up to speak, everyone listened with rapt attention, evoking a tremor of genuine excitement in me, knowing how magnificent and transformative her mentoring was for me. After one of my presentations, shortly before her death, she came up to me to let me know that she was proud of me. I was probably 55 years old at the time but it made me feel like a kid hitting a home run.

It was also a huge honor to be asked to introduce Roger Packer as the recipient of the Bernard Sachs Award in 2012 (Huntington Beach, CA). I think Roger is my #1 collaborator during my career. I was the first neurologist he trained as a neuro-oncologist, and value his leadership and friendship over 35 years. I remember well watching my two long-term partners at the Cleveland Clinic, David Rothner and Gerry Erenberg receive the Roger & Mary Brumback Lifetime Achievement Awards in 2013 and 2018, special moments for two highly deserving and kind men. Finally, given my new role as President, I was asked to participate in videotaped interviews with colleagues: these are posted on our website. I chose to interview Nancy Bass: the President of the PECN and past Councillor from the Midwest. Nancy was also a resident of mine in her training 30 years ago, and



Isabelle Rapin, Patti Duffner, Martha Bridge Denckla



Bruce Cohen and Roger Packer (2018)

although we have not worked together since 1995, we practice near each other and have mutual admiration. The interview uncovered many events that I had forgotten or had migrated into deep memory storage, making me realize that we all have influenced all of those around us.

Most Important Collaborations:

There are too many to count. At the top of the list are not collaborators in press but collaborators as brothers: Phil Pearl and Roger Larson. Interestingly, my friendship with Phil did not begin at a CNS meeting but while giving live patient exams for the ABPN. There counsel and friendship of these two men are among my most cherished collaborations.

An interesting collaboration that did not involve child neurologists, but occurred at a CNS meeting. In 1996 (Minneapolis) I lead one of the afternoon scientific symposia. One of the presenters was Robert (Bob) Naviaux. Bob is a visionary man, trained as internist and virologist, and in 1996 delivered a paper demonstrating the mitochondrial biochemical features in Alpers-Huttenlocher syndrome. In 1996 it had not been proven of such a link. After his presentation, I approached him, and we spoke for at least an hour. He told me that a new gene, POLG was just cloned and characterized by Bill Copeland. Bob was convinced POLG had something to do with Alpers. In 2004, he published the first series of patients that proved the link. Bob and I traveled to India in 2008 to present data in the first Indo-US Technology Forum, and on our 18-hour flight back, talked for 10 hours straight before both collapsing in sleep. Both Bob and Bill were two of the main speakers for the 2013 NDC and both gave memorable talks. have gone on to author several manuscripts with these mitochondrial giants



David Rothner and Gerald Erenberg

Training the Next Generation of Child Neurologists

Home / CNS Media Library / Training the Next Generation of Child Neurologists



[Click to view video.](#)

Scientific Sessions:

Planning the 50th Annual Meeting: from COVID Uncertainty to Complete Success

National Office Staff:



Sue Hussman, CNS Associate Director



Emily McConnell, CNS Professional Development Manager; and Kathy Pavel, CNS Office Manager



Roger Larson, CNS Executive Director, flanked by photographers Mekeea Larson and Suzanne Shaff; meeting photos in these pages from 2013-2021 are by Suzanne Shaff Photography. (Copies available upon request).

Scientific Program Chairs: Carl Stafstrom, MD, PhD and Yasmin Khakoo, MD



PLANNING COMMITTEE

Child Neurology Society Executive Board

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Bruce H. Cohen, President- Elect	Akron, OH
Lori Jordan, Secretary-Treasurer	Nashville, TN
Nigel Bamford, Councillor	New Haven, CT
Nancy Bass, Councillor	Cleveland, OH
Audrey Brumback, Councillor	Austin, TX
Sonia Partap, Councillor	Palo Alto, CA

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Yasmin Khakoo, Co-Chair	New York, NY	Ganeshwaran Mochida	Boston, MA
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Louis Dang	Ann Arbor, MI	Liu Lin Thio	St. Louis, MO
David Dredge	Boston, MA	Laura Tochen	Washington, DC
Leon Dure	Birmingham, AL	Keith Van Haren	Palo Alto, CA
Matt Elrick	Baltimore, MD	Jennifer Vermilion	Rochester, NY
Donald Gilbert	Cincinnati, OH	Amy Viehöver	St. Louis, MO
Howard Goodkin	Charlottesville, VA	Vijay Vishwanath	Los Angeles, CA
Ajay Gupta	Cleveland, OH	Elizabeth Wells	Washington, DC
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Sucheta Joshi	Ann Arbor, MI		
Ariel Lyons-Warren	Houston, TX		

National Office

Roger Larson, Executive Director
 Sue Hussman, Associate Director
 Kathy Pavel, Office Administrator
 Emily McConnell, Professional Development Manager

Scientific Sessions: Thank You

Expertise is great and the CNS is no different than any other major medical association in showcasing and offering it to members at its annual meeting. What sets the CNS apart from many organizations is the generosity its members consistently demonstrate by offering their expertise pro bono. Fifty-eight

CNS members served as faculty on one or more of the seminars and symposia offered at the 2018 CNS Annual Meeting. Their willingness to present pro bono continued a long and honorable tradition of CNS members making common cause with their colleagues to ensure high level CME without commensurately

high level registration and course fees by foregoing honoraria, per diems, waived registration fees, and other perks. So, before taking a backward glance at last fall's meeting in the 32 pages to follow, let's pause to offer a special thanks to CNS members for their generous gift of time and talent in Chicago:

John M. "Jack" Pellock Residency Seminar on Epilepsy

Phillip Pearl, MD
Renée Shellhaas, MD
Elaine Wirrell, MD
Christelle Achkar, MD
Luca Bartolini, MD
Giulia Benedetti, MD
Dave Clarke, MD
Dennis Dlugos, MD
Elizabeth Donner, MD
Howard Goodkin, MD
Cecil Hahn, MDCM
Linda Huh, MD
Charuta Joshi, MD
Kelly Knupp, MD
Katherine Nickels, MD
Heather Olson, MD, PhD
Eric Payne, MD
Scott Perry, MD
Joe Sullivan, MD
Julie Ziobro, MD

Symposium I: Child Neurology Foundation: Shortening the Diagnostic Odyssey

Scott Pomeroy, MD, PhD
Anup Patel, MD
Erika Augustine, MD, PhD
Christelle Moufawad El Achkar, MD
Heather Medford, MD, PhD
Annapurna Poduri, MD, MPH
Anne Berg, PhD
Louise Bier, MS, CGC

Krista Harding
Adam L. Hartman, MD

Symposium II: Presidential Symposium: CNS Past, Present & Future

Phillip L. Pearl, MD
Stephen Ashwal, MD
Alexander Li Cohen, MD, PhD
Darius Ebrahimi-Fakhari, MD, PhD
Christopher J. Yuskaitis, MD, PhD
Verena Staedtke, MD, PhD
Giulia Benedetti, MD
Bhooma Aravamuthan, MD, DPhil
Young-Min Kim, MD
Michael Lopez, MD, PhD
Anusha Yeshokumar, MD

Symposium III: Neurological Manifestations and Long-Term Sequela of Pediatric COVID-19 Infections

Laura A. Malone, MD, PhD
Yael Hacohen, MD, PhD
Ericka L. Fink, MD, MS
Claire Johns, MD

SYMPOSIUM IV: Progress in Child Neurology through the Lens of an NINDS

Career Development Program:
CNCDP
Brad Schlaggar, MD, PhD
Erika Augustine, MD, MS

Heather J. Fullerton, MD, MAS
Bhooma Aravamuthan, MD, DPhil
Aaron Boes, MD, PhD
Monica Lemmon, MD
Autumn Ivy, MD, PhD

Symposium V: Developing Treatments for Pediatric Epilepsies: from Models to the Clinic

Solomon Moshé, MD
Michael Wong, MD, PhD
Annapurna Poduri, MD, MPH
Aristea S. Galanopoulou, MD, PhD
Adam L. Hartman, MD

Symposium VI: The Tiny Elephant in the Room: Harnessing a Crisis to Recover, Maintain and Enhance Career Development in Child Neurology

Keith Van Haren, MD
Yasmin Khakoo, MD
Brenda Banwell, MD
Nina F. Schor, MD, PhD
Erika Augustine, MD, MS
Audrey C. Brumback, MD, PhD
Juliet K. Knowles, MD, PhD
Brad Schlaggar, MD, PhD

Symposium VII: Are We Poised for a Therapeutic Revolution in Child Neurology?

Louis T. Dang, MD, PhD
 Renée A. Shellhaas, MD, MS
 Huda Y. Zoghbi, MD
 David Liu, PhD
 Tim Yu, MD, PhD
 Erika Augustine, MD, MS

PECN Seminar: Neurology Education Reboot: Beyond the Pandemic

Nancy Bass, MD
 Jessica Goldstein, MD
 David Hsieh, MD
 Deonna Reese-White, MD, MBA
 Roxanna Nahvi, MD
 Margie Ream, MD, PhD

Seminar 1: Lessons Learned from Establishing an Adult Transition Clinic

Julia Frueh, MD
 Ann Tilton, MD
 Jessica Sanders, MD
 David K. Urion, MD

Seminar 2: Updates in pediatric COVID-19 for the Pediatric Neurologist

Grace Gombolay, MD
 Kerri LaRovere, MD
 Susan Palasis, MD

Seminar 3: The Brave New World of Pediatric Spinal Muscular Atrophy—Implications of Newborn Screening and Effective Treatment

Erin E. Neil, DO
 Richard Finkel, MD
 Jim Dowling, MD, PhD

Seminar 4: Neurological Implications of Youth Sports Participation

Sean Rose, MD
 Meeryo Choe, MD
 Jaclyn B. Caccese, PhD

Seminar 5: CP to You is Not CP to Me: Strategies for Mitigating Practice Variability in Cerebral Palsy Care

Bhooma Aravamuthan, MD, DPhil
 Young-Min Kim, MD
 Jenny Wilson, MD

Seminar 6: Medulloblastoma: New Clinical and Translational Insights

Roger J. Packer, MD
 Paul A. Northcott, PhD
 Kim Kramer, MD

Seminar 7: Disorders of Consciousness in Critically Ill Children: Curing Coma for the Developing Brain

Mark Wainwright, MD, PhD
 Jessica Carpenter, MD

Varina Boerwinkle, MD
 Leon G. Epstein, MD

Seminar 8: The Critical Period of Memory Development: Construction, Destruction and Reconstruction

Gregory L. Holmes, MD
 Pierre-Pascal Lenck-Santini, PhD
 Tallie Z. Baram, MD, PhD

Seminar 9: Neuro-Humanities: Neurologists and Neurology in Art, Comedy, Poetry and Music

Phillip Pearl, MD
 Joseph D. Pinter, MD
 Carl E. Stafstrom, MD, PhD
 Nina F. Schor, MD, PhD

Research Workshop

Ariel Lyons-Warren, MD
 Audrey Brumback, MD, PhD
 Adam Hartman, MD
 Jonathan Mink, MD, PhD
 Shafali Jeste, MD, PhD
 Renée A. Shellhaas, MD, MS



Scientific Sessions: Pellock Seminar







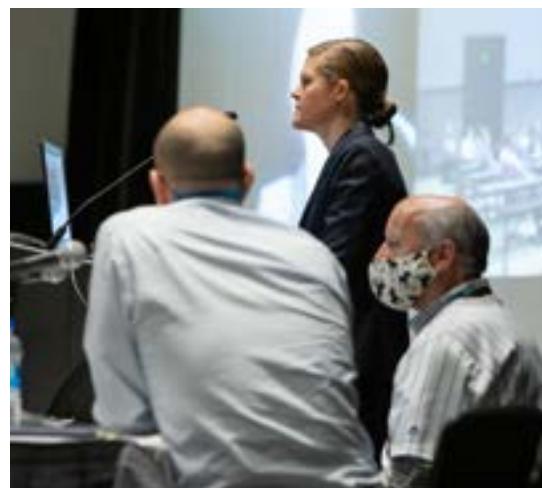
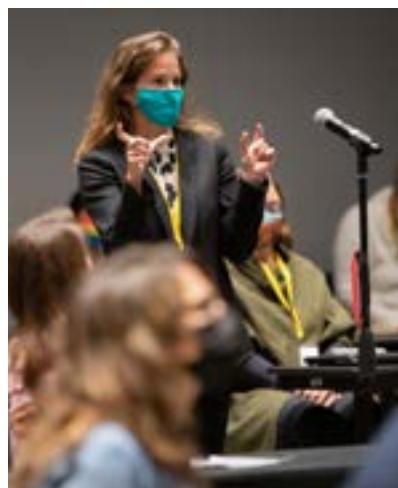


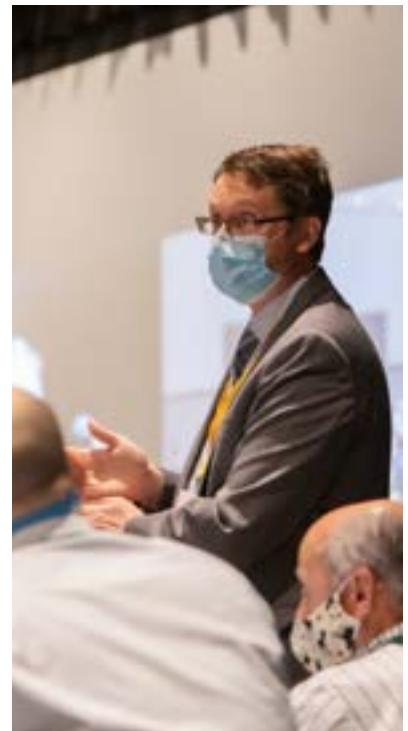
Scientific Sessions: CNCDP K-12 Retreat



CNCDP

CHILD NEUROLOGIST CAREER DEVELOPMENT PROGRAM (K12)



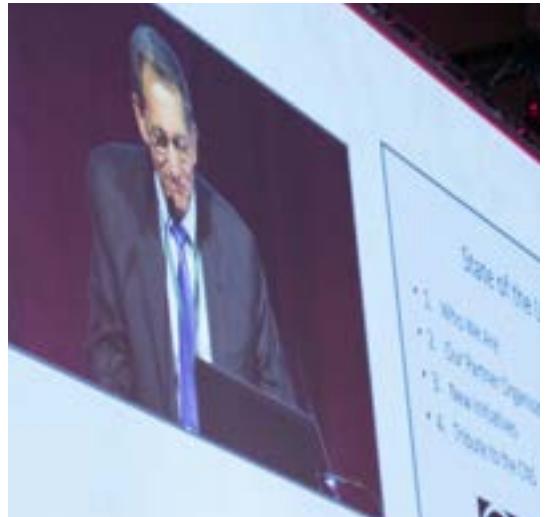


Scientific Sessions: Research Workshop

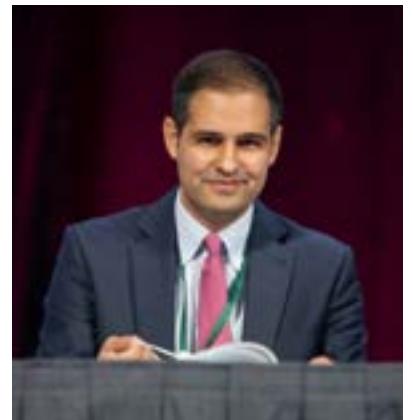


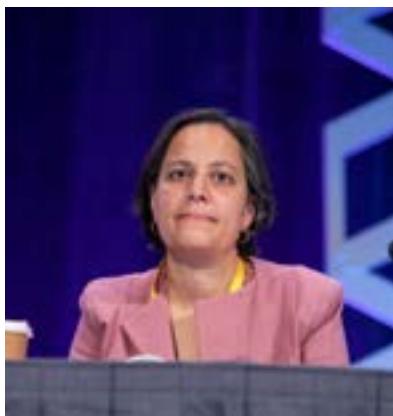


Scientific Sessions: Symposia









Scientific Sessions: Seminars

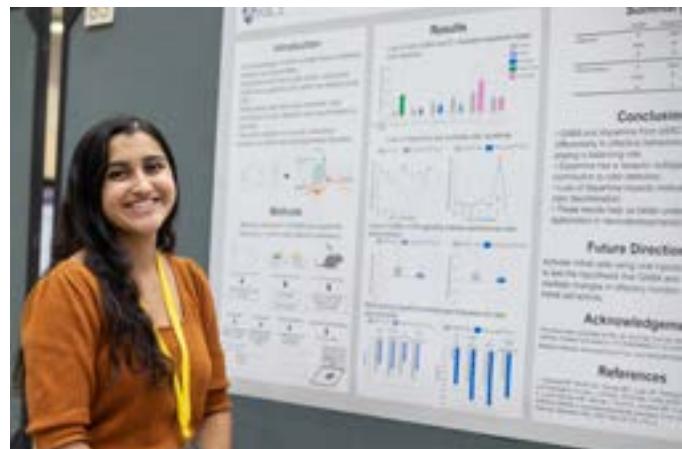


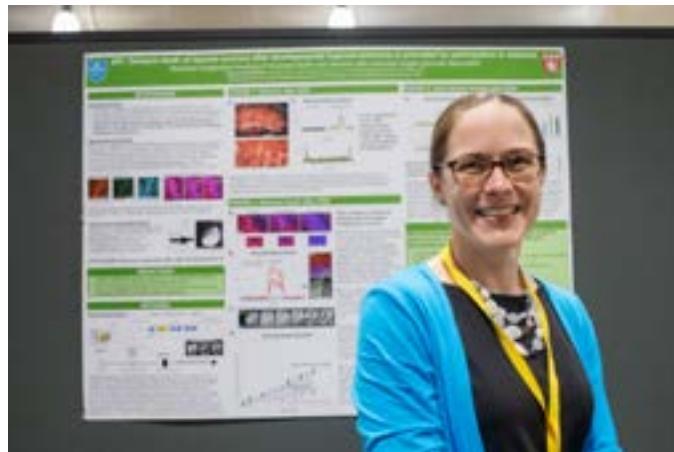


Exhibits & Poster Review

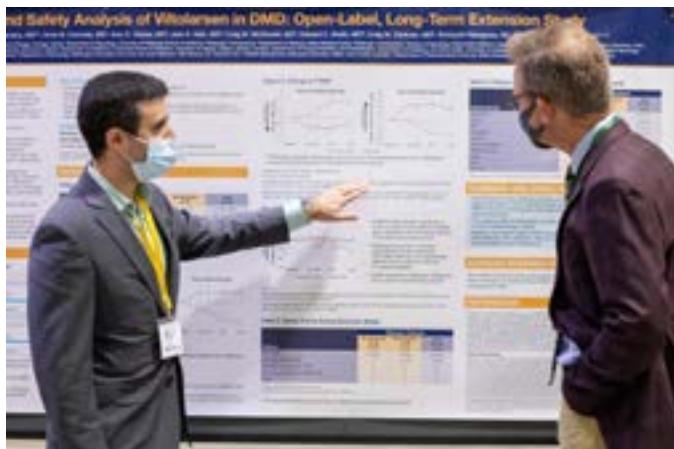
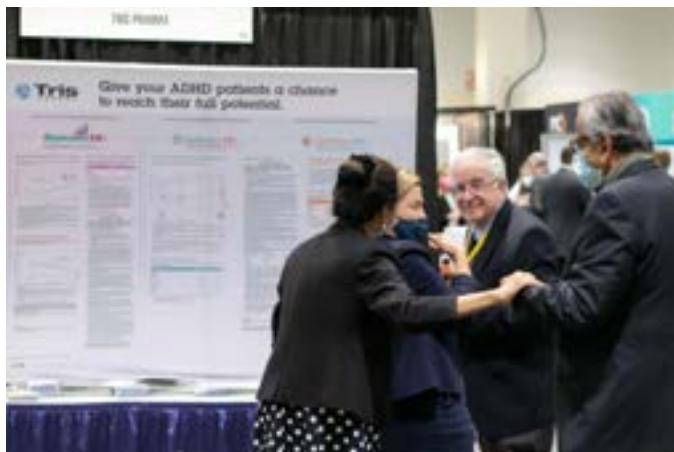
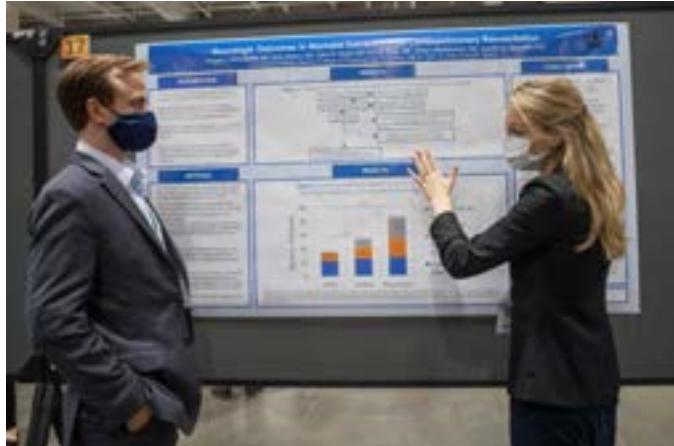












50TH
CNS ANNUAL MEETING

PAST•PRESENT•FUTURE

CNS Connections Editor, Dan Bonthius:

Oh, what a difference 27 years makes!

Daniel J. Bonthius, MD, PhD
CNS Connections Editor

I have a confession to make. My recollections of my first CNS meeting are not all rosy and warm. They are not memories of hugs from old friends and discussions of interesting scientific issues over glasses of wine with like-minded colleagues. When I first attended a CNS meeting in 1994, 27 years ago, I knew no one in the field, and no one knew me.

At that time, I was a first-year resident in child neurology at the University of Iowa. The residency program had only two residents in it – me and a senior resident. The other resident from my program did not attend the meeting that year, nor did any of the faculty. So, I went alone and knew not one soul at the meeting. I recognized the names of famous people who had written book chapters and articles that I had read: Volpe, DiMauro, Swaiman, DeVivo, and many others. But I was way too intimidated by their lofty fame and success to even think of introducing myself. Everyone else at the meeting seemed to be there with all of their friends. They were laughing and slapping each other on the back. I wandered around like a kid with no friends. Because that's what I was.

I also didn't know much about the science that was hot at that time. All of the talk in that year was of apoptosis, mitochondrial genetics, and excitotoxicity. These were new concepts then. I didn't understand any of it, and I was too afraid to ask questions for fear that I would appear woefully ignorant – which is exactly what I was.

And so, for the first day or two of the meeting, I sulked around in my isolation and ignorance. But this self-pity and exile could not last for long at the CNS meeting. Child neurologists are way too friendly, and the subject of child neurology is way too interesting to allow a fledgling resident to wallow in self-pity for very long. Soon, I was making friends and having conversations. Residents from other institutions were introducing themselves to me and asking about my program, career, science, and life. Many of these then-trainees became my life-long friends: people like Stephen Back, Nigel Bamford, and Michael Rivkin.

But the people who struck up conversations with me were not just the other young residents my age, but also the more senior and already famous and successful leaders of the field – people like



Michael Rivkin, MD, PhD



Shown here as CNS Young Investigator Awardee at the 2001 meeting in Victoria, alongside a representative from Sigma Tau Pharmaceuticals, provider of unrestricted funding for the award for many years prior to its being renamed in honor of Phillip R. Dodge in 2004 and fully endowed in 2014.



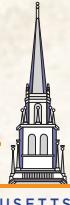
Announcing past Young Investigator Awardees at the 2021 Legacy Luncheon along with 2002 Young Investigator Awardee and longtime friend, Nigel Bamford.

Meeting Reflections

50TH ANNUAL MEETING

CNS

SEPT 29-OCT 2, 2021



BOSTON • MASSACHUSETTS

John Bodensteiner, Michael Painter, Donald Shields, and Roy Elterman. To my astonishment, they showed a genuine interest in me and my career. They introduced me to people, and my circle of friends began to grow. By the end of that first meeting, I had moved from feelings of isolation and darkness to a sense of connection and light. I was beginning to feel that I belonged in the field of child neurology.

Seven years later, in 2001, the most amazing and shocking of all CNS meetings occurred. The meeting took place in wonderful Victoria, British Columbia. The meeting was amazing not just because of the incredible venue, but because it took place in the immediate aftermath of the 9-11 attacks. Everyone was unsure whether anyone would dare to travel, especially on international flights, to a CNS meeting after an event like that. But travel they did. The membership turned out in force, probably as a message to terrorists that child neurologists are not easily intimidated.

The meeting was also shocking – at least to me – because I was chosen to receive the Young Investigator Award. News that I had won that prestigious award left me

slack-jawed and dumbfounded. I could hardly believe it then and can still hardly believe it now. Standing on that stage in Victoria was the proudest moment of my professional life. The award was not just an honor, it was an affirmation from the people whose opinion I value most that my work had value.

Since attending my first CNS meeting, I have hardly ever missed one. For me, missing the CNS meeting would be like a diabetic missing his insulin shot. It wouldn't be good for my health. At every meeting, I cherish my old friends. But even more so, I look forward to meeting new friends and learning new ideas from people with common values. Unlike the meeting 27 years ago, the most recent meeting in Boston was rosy and warm. This time, it did include hugs from old friends and discussions of interesting scientific issues over glasses of wine with like-minded colleagues. I look forward to my next 27 meetings. By then, I'll know everybody.



With friend and mentor of my "youth," Jim Bale.



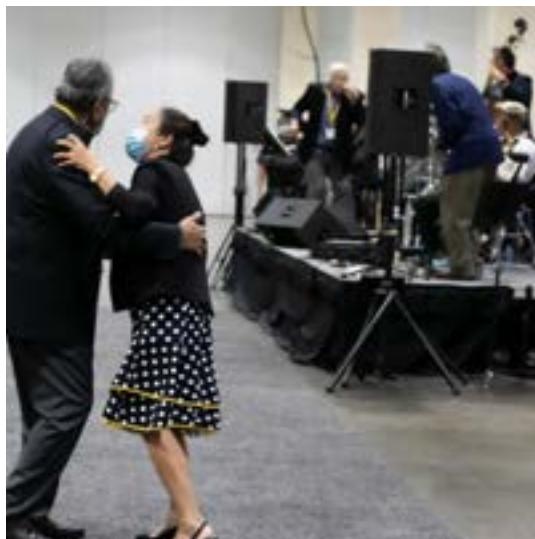
With Steve Roach, who honored me with appointment as Editor of CNS Connections.

Networking





















50TH
CNS ANNUAL MEETING
PAST • PRESENT • FUTURE

The Countdown to Boston





The Countdown Begins



The long awaited, once-in-a-lifetime CNS 50th Annual Meeting in Boston is now little more than seven weeks away.

Beginning tomorrow, and each day for the next 50 days, we will count down to the opening day of the CNS Meeting in Boston: Wednesday, September 29.

And we'll have a little fun doing so (I will, anyway). By going down through the alphabet from "A-Z" and back up to "A" again, skipping only three days for the Labor Day Weekend, each daily eConnections will lightly touch on one or more

aspects of CNS Annual Meetings (Past, Present and Future) linked to that day's mnemonic.

For example: August 10 (50 Days before the meeting) will lead off with a topic beginning with the letter "A" – Ann Arbor, site of the 1st CNS Meeting in 1972; August 11 (49 Days before the meeting), will touch on topics starting with the letter "B" – Boston, as luck would have it. Likewise, August 12 (48 Days) will cross the border to "Canada," while August 13 (47 Days) will look at "Dodge" and "De Vivo" (with "Denckla" and "D'Souza" slated for the second time "D" comes up, September 25 – 4 Days out).

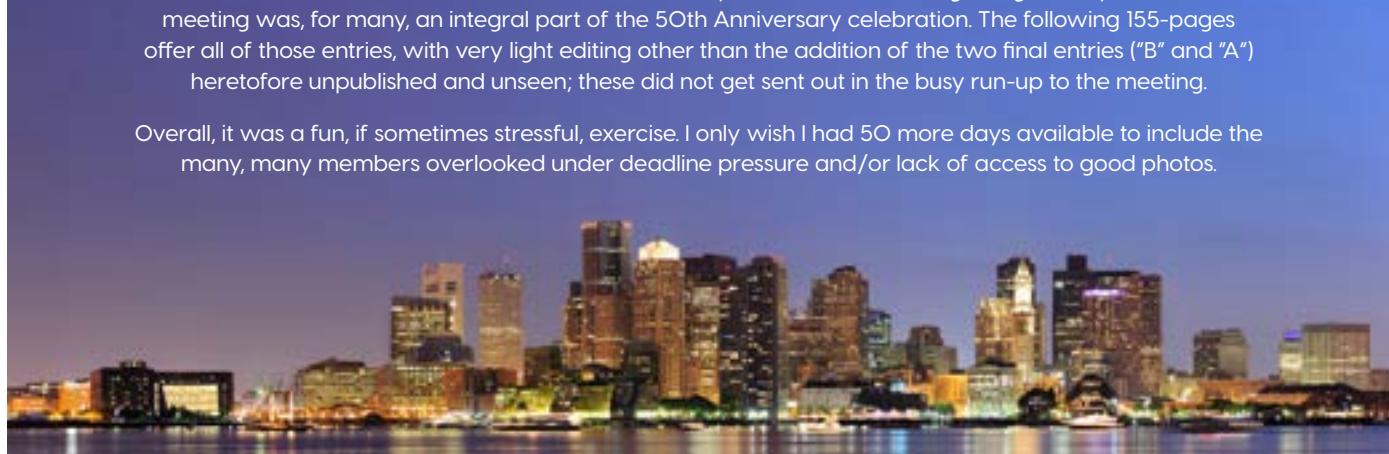
The range and roster of topics is meant to be suggestive, even playfully so, rather than comprehensive or pedantic. And – full disclosure – it will be highly subjective, filtering the last 50 years through my privileged perch on the sidelines of CNS history.

The "Countdown to Boston" eConnections will be sent midday each day. I hope you enjoy the journey and I hope to see you in Boston in, well, 51 days.

Regards,
Roger Larson, CAE Executive Director

NOTE: The Countdown to Boston entries emailed daily to CNS members beginning 50 days before the meeting was, for many, an integral part of the 50th Anniversary celebration. The following 155-pages offer all of those entries, with very light editing other than the addition of the two final entries ("B" and "A") heretofore unpublished and unseen; these did not get sent out in the busy run-up to the meeting.

Overall, it was a fun, if sometimes stressful, exercise. I only wish I had 50 more days available to include the many, many members overlooked under deadline pressure and/or lack of access to good photos.



Meanwhile, a word about the where things currently stand:

- At this point, the CNS fully intends to move forward with plans for a hybrid meeting, combining a full program of live/in-person educational sessions and social events at the Hynes Convention Center and Sheraton Boston Hotel, with a full line-up of live-streamed and On Demand sessions and events available on a virtual meeting platform for those unable to travel to Boston.
- Given the high vaccine rates in the Commonwealth of Massachusetts and in Boston, and the high political stakes involved in shutting down a second time (including cancellation of the rescheduled Boston Marathon on October 11), it seems all but certain that Boston will not "shut down" a second time. It is equally certain that we, the CNS, will not either. We are fully committed to welcoming live/in-person however many members, guests and exhibitors wish to attend and celebrate this milestone meeting. Our decision is based, in part, on the following:
- The current number of CNS members living within an hour's drive of the convention center surpasses the total number (125) attending the first CNS Meeting in Ann Arbor in 1972.
- Fully 40% of all CNS members are within a day's drive of Boston and can still make a late decision to come after waiting out what looks to be 4-5 weeks of rising case numbers followed (we hope) by a UK-mimicking precipitous drop in infection levels.
- All, or nearly all of our attendees and exhibitors are vaccinated and all are accustomed to "masking-up" in public. This will not be a deal-breaker for us, unlike other associations' meetings.
- 400 people have registered to come to Boston so far; 40 have registered for the Virtual Meeting. The Sheraton Boston is filling fast, flights are filling faster, and the price of those flights is going up faster yet. The CNS won't cover the cost of cancelled hotel rooms or rescheduled flights, but it will convert all live F2F registrations to Virtual Meeting Registrations should the need arise.
- The last day to order a hard copy of the Founders book to be picked up in Boston for signing by profile subjects and/or authors is this Friday, August 13. Copies (hard cover and eBook) can still be ordered at the special 50% registration discount, but those ordered after August 13 will not be available for you at the Convention Center.



50 Days to Boston

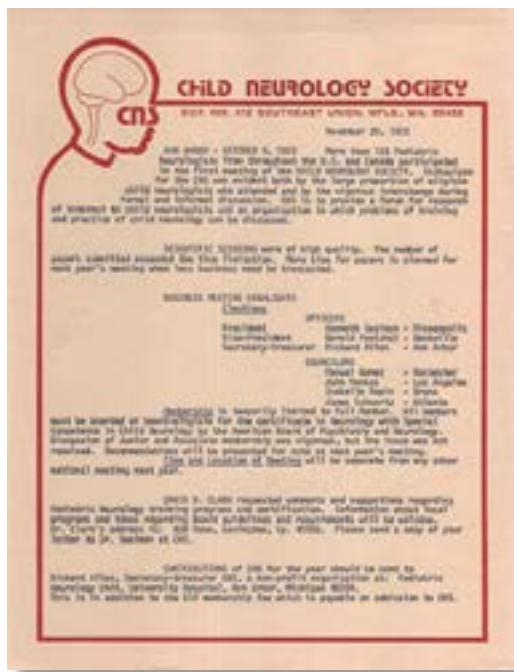
"A" is for Ann Arbor

What better way to begin our 50-Day journey to Boston than at the very beginning, with Ann Arbor, Michigan?

Not many are still with us from among the 125 gathered at the Towsley Center for Medical Education on the campus of the University of Michigan on October 5, 1972. Of the seven board members elected to serve on the 1st CNS Executive Committee, only Gerald Fenichel remains with us. And he, unfortunately, sent regrets last week that he will not be joining us in Boston next month: "My travel days are over and I must decline. Best wishes to all and good luck with the meeting."



The First Meeting of the Executive Committee of the Child Neurology Society elected in Ann Arbor in October 1972 are pictured above on January 26, 1973 in Nashville, Tennessee at first winter meeting (L-R): John Menkes, Isabelle Rapin, Gerald Fenichel, Kenneth Swaiman, Richard Allen, Manuel Gomez, James Schwartz.



Six hearty souls who attended in 1972 have registered for the 50th Anniversary Meeting, however; all will be recognized at the Kenneth F. Swaiman Legacy Luncheon on Wednesday, September 28, along with all past officers and award recipients and the recipients of this year's Brumback Lifetime Achievement Awards, Gold Humanism in Medicine Award, and the CNS PECN Training Director Award.

With 1400+ attending recent CNS Annual Meetings – more than 10x those gathered in 1972 – the odds of having another annual meeting

in Ann Arbor are slim (about the same as the Wolverines winning the NCAA Football Championship... or beating Ohio State). Still, the CNS continues to benefit from the Michigan program's contributions: three Young Investigator Awardees (Faye Silverstein, James Dowling and Louis Dang), three Councillors for the Midwest (Faye Silverstein, Steve Leber, and Renée Shellhaas), a past PCN secretary-treasurer and 2014 Training Program Director Awardee (Steve Leber), and, signally, the Society's first Secretary-treasurer (1972-75) and fifth President, Richard Allen.



Phase I		Phase II	
1.1	1.1.1	1.1.1.1	1.1.1.2
1.1	1.1.2	1.1.2.1	1.1.2.2
Phase III		Phase IV	
2.1	2.1.1	2.1.1.1	2.1.1.2
2.1	2.1.2	2.1.2.1	2.1.2.2
2.2	2.2.1	2.2.1.1	2.2.1.2
Phase V		Phase VI	
3.1	3.1.1	3.1.1.1	3.1.1.2
3.1	3.1.2	3.1.2.1	3.1.2.2
3.2	3.2.1	3.2.1.1	3.2.1.2

“A” is also for “Alumni Receptions”

The situation is still very fluid in Boston, making it difficult to know which rooms will be available when and for how long. A portal will be available beginning next week for training programs to sign up for reception space at the Hynes Convention Center on Wednesday, Thursday or Friday evenings. A representative from the Boston CVB will also be available for help in booking off-site venues.

49 Days to Boston

“B” is for Boston

Oh, boy. Where to begin? Harder yet: where to end?

We could spend the next 49 days sorting through photos reaching back more than five decades, limiting ourselves to just the true giants of neurology – not even the sub-luminaries who, though they were prominent in their time are no longer well-remembered outside of Boston. Even then, we would run out of space and readers would run out of time. But that is not the point of these daily musings. And we could, and probably should touch on the only other time the CNS met in Boston, in 1986, when the Red Sox were also in town that October playing in yet another cruelly doomed World Series (more “B’s, as in “Bambino – Curse of” and “Bill Buckner”).

So, yes, we could touch on Randolph Byers or Paul Yakovlev, both

recipients of the Hower Award in the Society’s first decade, or Charles Barlow, Hower Awardee in 2001 and holder of Certificate #1 issued by the American Board of Psychiatry and Neurology (ABPN) in 1968. If Phil Dodge wasn’t scheduled for Friday, when “D” comes up the first time in the alphabetic rotation, we could easily talk briefly about him today. But, then, someone would surely ask, “Well, then, what about Raymond Adams? Why wasn’t he mentioned yesterday? Will Cesare Lombroso come up tomorrow with ‘C’ or later on with ‘L’?” To which, I would politely reply: “neither.”

Which makes this an opportune moment, perhaps, to remind readers that this 50-Day Countdown/Journey to Boston is meant to be no more than my personal musings, based on my privileged perch on the sidelines going back to the early 80s. I have met and, in most

cases, come to know and respect all but one of the 30 CNS Presidents, all of the Secretary-treasurers, and all but a handful of the 101 Councillors elected to serve on the Executive Committee. I could not tell you the first thing about their neurologic expertise, but I can speak to their significance to the Child Neurology Society over time. This 50-day journey, then, is about the Child Neurology Society, not “Child Neurology”. Think of each day’s entry as a capsule film review minus the thumbs up or thumbs down. The people, places and things presented briefly are meant to be emblematic, not encyclopedic, and the musings largely mine, reflecting my personal perspectives, not official CNS policy or positions. Now, let’s get on with it, shall we?

Alumni get-togethers will be a big part of the 50th Anniversary Meeting in Boston and, true to



form, Boston Children's Hospital has consistently shown how it's done (including great group photos taken every year by Suzanne Shaff; shown above is the BCH gathering at the last live CNS meeting, in Charlotte, back in 2019). A cynic might suggest those pictured here are just a bunch of Hollywood-handsome stand-ins. But, those willing to spend a weekend binge-watching the 40+ BCH recordings featured in the CNS Conversations section of the CNS website ([Click here to view.](#)) will come across no less than a dozen of those pictured, and several who aren't, including David Coulter (Gold Humanism, 2017), Louis Kunkel (Sachs, 1992), David Urian (Training Program Director Award, 2016), and Joe Volpe (Hower, 1990; Sachs, 2000; CNS President, 1993- 95).

I should also mention here that Boston Children's Hospital has provided a generous grant in support of the 2021 meeting, following a tradition of "Local Hosts" reaching back to 2013 when Steve Roach first broached the idea and Texas Children's Hospital took the lead, setting an example that all have followed since.

Boston is to the CNS what the USA is to the Olympics: no city has taken home more "Gold Medals": Hower (6), Sachs (6) and Dodge Young Investigator Awards (8)". This is a composite achievement, of course, with Massachusetts General Hospital and the Boston University and Tufts programs sharing in the spoils. Mention Mass General and one thinks immediately of Elizabeth Dooling, Verne Caviness (pictured at right accepting the 1996 Sachs Award from CNS President, Mike Cohen), Kalpathy Krishnamoorthy (2016 Lifetime Achievement

Awardee pictured with one-time MGH colleague, Barry Kosofsky) and Kevin Staley (pictured here with his protégé from Colorado days, 2017 Dodge YIA, Audrey Brumback).

A quick aside: This might normally be a good place to pause and talk about Audrey's late father, the beloved Roger Brumback. Rest assured: he will come up later in the rotation, either in conjunction with "G-Generations"; "J- Journals"; "L-Legacy & Lifetime Achievement Awards" or, at the very least and latest, when "B" comes up a second time in the rotation, two days before the Boston meeting begins.

No account of Boston neurology is complete without prominent mention of Paul Rosman, the 7th President of the CNS (1978-79). Paul received the Hower Award in his native Montreal when the CNS met there in 1998 and could easily come up again in multiple future "Countdown" entries if space allowed (e.g., "C" for Canada, "F" for Founders, "H" for Hower, "P" for Presidents). If there was an entry for "MC" (Master of Ceremonies), Paul would get top billing. Pictured at right is Paul presenting a gift to his good friend, Ken Swaiman, following his wryly humorous, still- well-remembered introductory "roast" of Ken at the 25th CNS Annual Meeting in Minneapolis in 1996.

Following Dr. Rosman's retirement, the Tufts/BUMC program remained in highly capable hands. Pictured on the right are current co-chiefs, Karl Kuban and Laurie Douglass, attending the 2018 Professors of Child Neurology (PCN) meeting; Karl is currently Secretary-treasurer of the newly renamed Professors & Educators of Child Neurology (PECN).



49 Days to Boston

“B” is also for Bowties...and Babies

If I had to choose one set of opposing images to suggest one of the more noteworthy demographic changes in CNS meetings since I attended my first in 1988, it would be the shift from bowties to babies.

Of the 125 attendees at the first CNS Meeting in 1972, 19 were women (15%). The meetings in Chicago in 2018 and Charlotte in 2019, each with 1400+ total attendees, marked the first time women reached and pushed past the 50% threshold. Not all (or many) brought their new offspring along for the ride – probably the same number proportionate to attendees overall as the number of men wearing bowties is to men, women or non-binary attendees overall – but enough of them did such that the parity between bowties and babies has been eclipsed and a new era has begun.



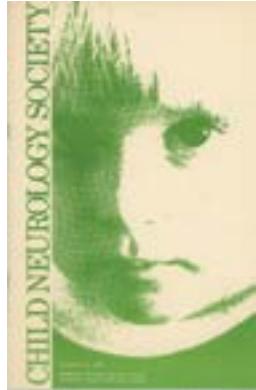
48 Days to Boston

“C” is for Canada

If I could travel back to any season and year in my life, I might choose Fall of 1975.

I was 21 years old, had a girlfriend, was on track to go to grad school in American Studies or History, and while hitchhiking from Minnesota to Boston somehow found myself waking up in a farmhouse in New Hampshire to the irresistible siren call of Bruce Springsteen's new album, Born to Run.

But aside from all that, and more in tune with my serial reflections on and your interest in “CNS: Past, Present, and Future,” time traveling back to the Fall of '75 would give me the chance to meet the only CNS President I never knew: James Schwartz. And it would give me a chance to attend the only annual meeting out of the seven held in Canada that I missed: the 4th Annual Meeting in Hamilton, Ontario.



It must have been quite a meeting. Who wouldn't be impressed, paging through the program and seeing names like Alfred Brann, John Menkes, Ruth Mary Duel, Karin Nelson, Shaul Harel and Eileen Oulette pop out at you? But, still, who could have guessed an entire Broadway musical would come out of it, winning a bucket full of Tony Awards, becoming the toughest ticket in town, and wowing the entire world in the process?

Kinda makes you wonder how anyone could still refer to child neurology as “medicine's best kept secret.”

Fortunately, there have been six other CNS meetings in Canada: Halifax (1988), Montreal (1998), Victoria (2001), Ottawa (2004), Quebec City (2007), Vancouver (2016). including my very first: Halifax in 1988. All of them have been special (although none have inspired Broadway plays like the 4th) and some will be looked at more closely later as the “Countdown to Boston” continues. As is true of so much in life, nothing quite matches “The First”: Halifax. Looking back, I remember three first meetings from that maritime meeting:

- **Meeting #1:** Huda Zoghbi, the 1988 Young Investigator Award recipient who went on to be Sachs Lecturer in 2001 (in Canada again), and her mentor Marvin Fishman, who will come up again later in this series for special acknowledgment. What I most remember is being amazed that two people so incredibly bright and accomplished could be so sweet and kind, making a point of introducing themselves and thanking me, a veritable “nobody,” for helping them (in what way or ways, I can't recall).
- **Meeting #2:** Looking out at the remarkable seascape through a window in a remote upstairs rotunda, I marveled aloud at the stunning vista: “Who could possibly take their eyes off this?” I asked. Whereupon a rich, deep voice on the other side of a row of 4 x 8 poster boards rasped irritably, “Good question! I want to know who's going to look at my poster?” The voice belonged to Harvey Singer, winner of the first CNS-PCN Training Director Award in 2013, and the Hower Award in 2016. What seemed a “rasp” at first, became over time a welcome and comforting “golden growl” (not quite a “purr”), through my many years working with him on the BOD when he was CNS Secretary-treasurer. But long before all that, in an instant, he unwittingly taught me a lesson I never forgot: the main thing is to keep the main thing the main thing. Which is this vis a vis CNS meetings: my job was and still is to give

48 Days to Boston



CNS members the best opportunity possible to present their best work to their peers. Period.

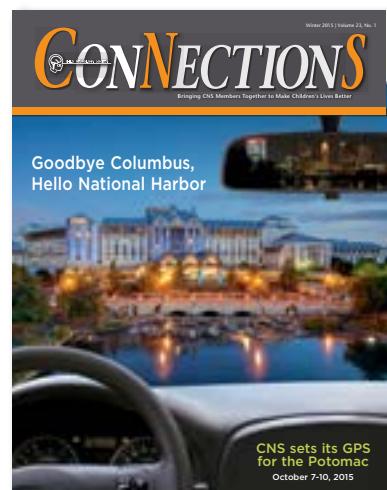
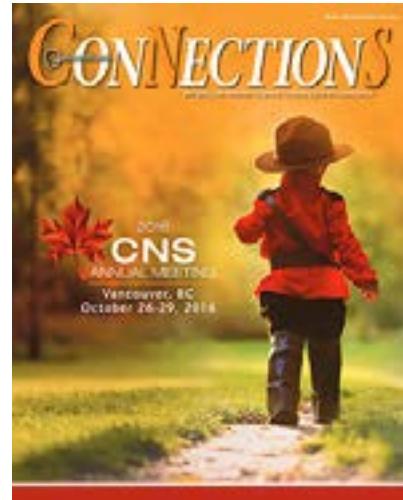
• **Meeting #3:** 2009 Hower Awardee, Peter Camfield and his wife Carol, winner of the 2019 Roger and Mary Brumback Lifetime Achievement Award, hosted a reception at their house. One of the few things I dread more than socializing in a crowded room is the feeling as I walk in a room that I am the dumbest person in attendance with nothing to bring to the conversation. I have learned over 30+ years of sitting through Scientific Planning Committee meetings and Executive Committee meetings to tamp that feeling down, but you can imagine the epic unease I felt at my very first CNS meeting. As luck would have it, however, a cheerful teenager was bobbing about the Camfield's abode. I could talk to her, I thought, and all would be well. But, as luck would have it, and as you no doubt guessed, I found myself cornered by the Camfield's brainiac daughter, Renée. She was sweet and kind, like Drs. Fishman and Zoghbi, but also funny and enthusiastic, eager to help and put me at ease. She still is.

As nearly everyone in the CNS of a certain age knows by now, running into the Camfields at CNS Meetings or at AES in December is one of the great pleasures in life. And matching Renée's enthusiasm and meeting her high standards is an ongoing, and endlessly rewarding challenge. What would the CNS be without them?

And what, one might ask, would it be without so many other Canadians – and Canadian meetings? Among the 49 previous CNS meetings this year's registrants had to choose from as

their favorite, Vancouver easily took highest honors, with Halifax, Ottawa and Quebec City all cracking the Top 10. Right up there with them in that Top Ten list, appropriately for today's letter, "C", is Columbus, OH, site of the 2014 CNS meeting. Mentioning that might seem anomalous in the middle of busting out with "O Canada!". Until you stop to realize that the two widely acclaimed and well-remembered marquee lectures at that meeting were delivered by Canadians: Toronto's Gabrielle deVeber and Montreal's Michael Shevell. I can't address the scientific excellence behind Gabrielle's selection as the Sachs Lecturer, but I can make mention of her signal achievement of taking the new idea introduced by Steve Ashwal in 2002 – organizing Special Interest Groups (SIGS) at CNS meetings – and turning it into the legendarily robust and successful multi-center Stroke consortium that operates year round and still meets for a full day on the front end of CNS Annual Meetings. And I can't speak to Mike Shevell's leading role in cerebral palsy research and education, but I can attest to his invaluable wise and lively presence on the BODs of both CNS and ICNA, his magnificent Hower Award Lecture, and the sheer delight I have taken through the years talking to him about music, theater, literature, history and, of course, hockey.

My favorite "Maple Leaf moment," in fact, centers on hockey, a hockey center, no less. It came in Quebec City, in 2007, when I had the chance to shake hands with and talk to the 2007 Lifetime Achievement Awardee, Gordon Watters (shown





on the right), with that year's Sach's Lecturer, his colleague at McGill, Frederick Andermann, standing at his shoulder). As a lifetime fan of Minnesota Gopher hockey, I had spent the previous 15 winters looking up at a giant mural of past Gopher greats. Suddenly, at the President's Reception, I found myself facing off with the biggest and most commanding figure on that mural, an older and wiser version of the 1951 Gopher All-American center (from Manitoba), who passed on the NHL to pursue a career in medicine. Dr. Watters studied under the first Hower Awardee, Douglas Buchanan, in Chicago, before putting in four years at Harvard/Boston Children's with Charles Barlow and subsequently a quarter-century at McGill in Montreal. What a thrill!

Other Canadians come readily to mind. I remember in particular Alan Hill and William Logan, both of whom I worked with on the CNS



Executive Committee. Dr. Logan received the Roger & Mary Brumback Lifetime Achievement Award in 2018 in Chicago, on which occasion I had the good sense to put him and four fellow Canadians in front of the camera and let them talk. You can catch their conversation on the CNS website by [clicking here](#).



(L-R): Steven Miller, Michael Shevell, William Logan, Alan Hill, Keith Meloff

Last, but not least, there is Elaine Wirrell, a classically gracious Canadian, who along with Renée Shellhaas and Phil Pearl launched and continues to masterfully organize the annual CNS Pellock Resident Seminar on Epilepsy. And how much more Canadian (or Canadien?) can a Montreal émigré get than Janet Soul, turning up at a CNS meeting a few years ago wearing a sling following her on-ice injury playing in a league hockey game in Boston?

48 Days to Boston

“C” is also for Currey

One cannot talk about the past 50 years of CNS history without recognizing – without celebrating! – the 40 years of selfless service Mary Currey gave to the Society.

Arriving in the Twin Cities in the mid-60s from Crows Nest Pass, Alberta, Mary was hired by Michael Blaw, head of the University of Minnesota Medical School's Division of Pediatric Neurology, then stayed on to work for his successor, Ken Swaiman, tirelessly choreographing the flood of correspondence coming in, first from the midwestern US, then from around the country as Dr. Swaiman moved implacably forward in his determination to establish a national association of child neurologists. She saw many residents come and go at the U of M, including Steve Ashwal, Warren Lo, Bhuvan Garg and Mark Scher.

Mary hired me in 1981 following an interview that lasted about two seconds for every year I subsequently went on to work for the CNS. In 1989 she and I moved out of the University of Minnesota to establish the free-standing national office the CNS needed and deserved. I learned a great deal from Mary, not least the money-saving value of meeting in Canada and the matchless charm those northern cities retained, unlike their bulldozed counterparts in the US. There is an art to “dealing with” the variety of quirks and egos medical specialists of any kind can present at the upper levels. Mary mastered that art; watching



Steve Ashwal and Mary Currey

her has served me well since succeeding her as Executive Director in 2012, humbly realizing each day since that I will never match her almost old-fashioned (Canadian?) variety of solicitude and kindness, her obsession with detail, and certainly not her unblemished record for showing up not just on time for everything and everybody, but obscenely early. Those who remember Mary fondly and well may look forward to an appreciation written by past-CNS President, John Bodensteiner for the Fall/Annual Meeting edition of CNS Connections.

47 Days to Boston

“D” is for Dodge, De Vivo....and Debts

I live about a mile east of the river and take sunset walks along its east bank two or three nights a week.



When I say “the river” with my casual midwestern, provincial presumption, I mean THE River. Not the Charles, not the Hudson, certainly not the East River, but THE River: the Mississippi River. The Father of Waters, Mother of Metaphors and constant travel companion, north to south, of Dylan’s Highway 61.

I have sometimes thought that an enterprising child neurologist could take a map of the United States, trace a finger or point a laser along the Mississippi, straight through the nation’s middle, north to south, and offer up a pretty decent capsule history of child neurology in the United States. Starting out in Minnesota and drawing a circle that took in Lacrosse, Wisconsin 60 miles south on the east bank of the Mississippi, and Rochester, Minnesota 40 miles to its west (we’ll get to them later in August), one could pontificate a bit about the AAN and ANA, both headquartered for decades in the Twin Cities (the AAN remains in Minneapolis), and the ABPN, HQ’d in Rochester when it issued the first certificates in child neurology in 1968. All the plotlines are there for a nifty little prologue to the founding narratives spun around Ken Swaiman and his midwestern cohort laying out plans on the back of a napkin to create a new Society.

Sliding down to Saint Louis, you could talk for 10 minutes – or 10 hours – about Phil Dodge and the gifted progeny he spawned at Wash U before dropping down to New Orleans to touch on Ann Tilton, who continues to nurture and inspire a new, emerging generation of women in child neurology, altering their sense, not so much of the science, but of the sociology or ecology of the field: how child neurologists relate to other physicians and physician organizations; to industry; to family research, advocacy and support groups; to patients and their families; to one’s own family, even. And to oneself.

That will all come later. But, pause first in the middle of the map, in the middle of the timeline, in the middle of everything peds neuro, and there he stands: Phil Dodge. Born outside of Boston, educated in New Hampshire and New Haven, trained in medicine in Rochester, NY, he moved on quickly to create the pediatric neurology department at Mass General before going west as a young man, from the banks of the Charles River to the banks of THE River, the Mississippi. It was there, in St. Louis, that his career, and the future of child neurology really took root and took off.



How and why that happened at Wash U all of you know far better than I. I could maybe tell you five good stories about Dr. Dodge. Most of you could tell me 50 better ones. So I’ll leave it to you to fill in the blanks. I’m more interested today in his legacy, his progeny if you will.

It’s tempting to say that if Phil Dodge is himself the Mississippi River of child neurology, much of the story of the past 40 years can be told by starting out in St. Louis and tracing one’s finger along a few noteworthy tributaries. Three stand out: one

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at Baylor/Texas Children's Hospital near the banks of the San Jacinto River; another back East again, near the Charles River at Harvard/Boston Children's; and a third at Columbia nestled between the Hudson and East Rivers. That's bad geography, admittedly, and even worse physics. But, it's great genealogy, highlighting Dodge's seminal influence on three giants of the Child Neurology Society's middle years: Marvin Fishman, CNS President from 1987-89, Hower Awardee in 1999, and Gold Humanism Awardee in 2012; Joseph Volpe, President from 1993-95, Hower Awardee in 1990, and Sachs Awardee in 2000; and Darryl De Vivo, President from 1991-93, Hower Awardee in 1992, and Sachs Awardee in 2003. Dr. Fishman's and Dr. Volpe's time will come. Today, however, is "D" Day, so the rest of this ramble belongs to Darryl De Vivo and his role in raising awareness of, and money for ensuring his mentor's legacy.

As was true in the first three installments, and will be true for those to follow, I can't speak to Dr. De Vivo's accomplishments as a medical scientist, although I have a vague sense – it quite literally goes without saying – that they are considerable. Nor can I begin, as a layperson, to truly appreciate the nature and scope of the intellectual and professional debt he and his generation, and the generations to follow all owe Phil Dodge. What I can appreciate is the honest and earnest effort shown by his generation to recognize and repay the debt owed Dodge and his generation, and in so doing passing on a rich legacy to succeeding generations of child neurologists.



Philip R. Dodge, MD

Honor a
founding
giant in child
neurology...
...help find and
fund new ones.

First established and presented in 1983 (to the late Michael Pranzatelli), the Young Investigator Award was funded for many years through Darryl's successful solicitation of grant support from Sigma Tau Pharmaceuticals. Thanks to Darryl and a host of others, the award was renamed in Phil Dodge's honor in 2004, with the first presentation of the newly renamed Phillip R. Dodge Young Investigator Award going to Terri Inder, in Ottawa. Phil was very much there at that meeting, in full "tennis-shoed" regalia.

An "Old School" realist, who knew that sustaining an award – and a legacy – cost money, Dr. De

Vivo launched a campaign a few years later to establish a \$1 million permanent endowment built on the notion that the best way to "honor a founding giant in child neurology (was to) help find and fund new ones," Enlisting, and energetically driving, a small cohort of Dodge protégés and enthusiasts, the Darryl and the fundraising committee successfully reached and celebrated that milestone at the 2014 CNS Annual Meeting in Columbus. Phil Dodge's legacy lives on in large measure because of Darryl De Vivo's drive, discipline and devotion, and through the generous support of several CNS members and non-members, many of whom we will get to in this Countdown to Boston....all in good time.

That the Dodge legacy lives on is not owing simply to money, however; we all wish the \$30,000 grant given as part of the award was larger



Flanking Dodge Endowment Fundraising Chair, Dr. Darryl De Vivo, on stage at the Gala celebration were CNS President, Dr. Nina Schor, and Dodge Steering Committee members (l-r) Drs. Mary Johnson, Vinodh Narayanan, Scott Pomeroy, Bradley Schlaggar, Jonathan Mink, Stanley Johnsen, Gary Clark, and Sid Gospa. All Steering Committee members gathered on-stage personally contributed \$5,000 or more.

Although it did not count toward the PERF Challenge Grant, the \$50,000 solicited by Scott Pomeroy and Gary Clark from each of their institutions – Boston Children's Hospital Neurology Foundation, and Texas Children's Hospital – "set the stage" for the PERF grant by making the \$1 million goal seem plausible.

and more commensurate with the honor, recognition and affirmation it bestows. It lives on as well through and because of the character and continuing willingness to repay a debt, "in kind" if not in currency, by its young (and, with time's passing, maybe not-so-young) recipients.

It is no small coincidence that five of the 38 recipients of the Dodge Young Investigator Award have gone on to serve on the CNS Executive Committee (four before it was renamed after Dodge): Faye Silverstein (1986 YIA), Vinodh Narayanan (1987 YIA), Ken Mack (1991 YIA), Nigel Bamford (2002 YIA), and Audrey Brumback (2017 Dodge YIA). More will surely follow that path and sense of purpose. Nor is it surprising that one of them, Ken Mack (1991), should become CNS President (2015-17) and receive the Hower Award (2020), or that another, Amy Brooks-Kayal (1999 YIA) would become President of the American Epilepsy Society a few years ago.

Three past Young Investigator Awardees have gone on to win Sachs Awards: Huda Zoghbi (1988 YIA, 2001 Sachs), Joe Gleeson (1998 YIA, 2020 Sachs), and Scott Pomeroy, (1989 YIA, 2019 Sachs); Scott is currently "giving back" as President of the Child Neurology Foundation. Others have selflessly contributed substantial time and energy to ensuring the present and future success of the Society through committee work and SIG leadership, including Nigel Bamford (2002 YIA) and Laura Jansen (2008 Dodge YIA; also now at Wash U); both have done superb work chairing the Awards Committee, infusing the review and selection process with real and meaningful mentorship. In addition to serving on the Awards Committee, Dan Bonthius (2001 YIA) is the longtime editor of CNS Connections, often highlighting the work of young researchers, and is co-creator, essentially, with CNS President Phillip Pearl, of the newly added clinical briefs section, *Child Neuro Synapses*.

In mentioning Phil, it is worth noting at this point, quoting from the Winter 2015 issue of CNS Connections, that as PCN President (at that time), "Phillip Pearl's stirring appeal for leadership by example issued to members of the Professors of Child Neurology in August 2014 was critically important to closing the gap in the weeks before the Columbus meeting."

Repaying one's debts takes real effort and leadership by example, something we will get to with tomorrow's entry, as luck would have it.

46 Days to Boston

“E” is for Elections and Effort

Timing is everything. I didn't plan on posting and sending out notice of the upcoming election of officers on the day "E" came up in the rotation.

Nor did I cynically and manipulatively search for a random quote about “Effort” to add ballast to today's entry. I actually used the William James quote below in last year's special Election and Awards Nomination issue. And I'll probably use it again next year, if I'm still around.

We measure ourselves by many standards. Our strength and our intelligence, our wealth and even our good luck, are things which warm our heart and make us feel ourselves a match for life. But deeper than all such things and able to suffice unto itself without them, is the sense of the amount of effort we can put forth...S/He who can make none is but a shadow; s/he who can make much is a hero.

– William James

“What we are talking about then,” I wrote, announcing the upcoming 2021 On-line Election of Officers, August 20-September 19 in the Special Summer 2021 Connections ([click to view](#)) is the Jamesian sense of “effort put forth.” Let me be clear about this: every child neurologist I have known in my 30+ years with the CNS is, in my mind, something of a Jamesian “hero”. And while relatively few have been nominated to run for office and only half of them have been elected, no child neurologist caring daily for patients or probing the diseases and disorders besetting the brain could ever be accused of making no effort or be dismissed as a mere shadow.

Still, some do stand out for expending extra effort, as this year's cluster of deadlines for electing new officers and nominating award recipients reminds us. It is one of the quiet glories of the Child Neurology Society that it has always openly and democratically left it to the members to decide who would be nominated to serve as its officers or be honored with one of its awards. Doing so has required some effort on the part of its members; minimal effort in the case of voting – it takes less than a minute, really – a little more when submitting nominations honoring career-and lifelong contributions.

At bottom, what is really being asked of each member in terms of effort is relatively simple, if not necessarily easy: it is an exercise in self-reflection and self-knowledge. In voting for officers or nominating someone for an award, each member is essentially asking themselves why they went into child neurology, why they remain so

passionately committed to it, what tangible and intangible personal rewards they have reaped, what hopes they might have sown. That latter question is particularly crucial this year as those elected will determine how – and how well – the CNS pivots from its first 50 years to its next 50 years. By submitting a nomination or casting your vote in the election you are putting forth the effort to honor and support those colleagues and mentors whose efforts reflect and project, embody and extend your own at this pivotal point in time where past, present and future so critically, and creatively, hang in the balance.

What is required, at bottom, is “putting forth the effort” to seriously ask yourself two questions:

1. Who in the past put forth the effort needed to make child neurology a calling that I felt drawn to?
2. Who among these candidates will put forth the effort needed to help me continue on that path with the kind and level of passion, commitment and sense of fulfillment that will compel the next generation – a truly diverse generation – to put forth the effort needed to follow after me and chart new hope-filled paths in an emerging new age of daunting challenges, dazzling opportunities and dizzying uncertainties?

The on-line election portal opens August 20 and closes September 19. The awards nomination portal will remain open until October 20. The choice is yours. The chance is yours to put forth the effort to honor the past and shape the future.

2021 CNS BOARD OF DIRECTORS



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President



Bruce Cohen
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Lori Jordan
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Nigel Bamford
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Nancy Bass
Councillor



Audrey Brumback
Councillor



Sonia Partap
Councillor

46 Days to Boston

“E” is also for Elterman

In thinking about “effort”, it struck me that it would take real effort – and it would be wasted effort – to draw up a list of private practitioners elected to serve on the CNS Executive Committee. If Roy Elterman is not the only one (although I think he is), he is definitely the last one; “last” meaning “most recent,” not “last ever” (hope springs eternal).

As previously noted, “some do stand out for expending extra effort.” Few stand out more than Roy Elterman. I had the pleasure and privilege of working closely with Roy when he served on the Executive Committee from 2002-2004, as well as when he chaired the Legislative Affairs Committee in what might aptly be called “the pre-Bennett (Lavenstein) Era”. I have also, and more recently (and frequently) had the pleasure of cashing checks Roy signed as President of the Pediatric Epilepsy Research Foundation, the 501(c)(3) non-profit organization Roy founded along with Don Shields in the wake of work done and rights owned by the two of them in clinical trials studying the use of vigabatrin in treating refractory infantile spasms.

It would have been easy, I imagine, for Roy and Don to, essentially, “pocket the money” and move on



to enjoy lives of relative luxury and ease (relative to being practicing pediatric neurologists, anyway). That they didn’t move in that direction, but chose instead to invest substantial personal commitment and effort toward directing the royalties earned to support a wide range of research and educational efforts by young and upcoming pediatric neurologists (not just epileptologists) is more than remarkable. It is epochal: something worth remembering and recounting as part of the history of child neurology, the Child Neurology Society, and the Child Neurology Foundation.

True as all of the above may be, including the pleasure I have had of cashing Roy’s checks, the greater pleasure by far is simply that of having known Roy for the past quarter-century, of having enjoyed his easy banter (that part is easy), and explored in earnest his many creative projects and proposals (that takes a bit more effort, but it’s worth it).

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“F” is for Fishman

Today's letter is “F”, so let's begin with “Full Disclosure”: I would not be writing this, and you would not be reading this were it not for Marvin Fishman, MD.

Mary Currey interviewed me, Larry Lockman hired me, Ken Swaiman more or less put up with me, but without Marvin Fishman, none of you would have ever even heard of me. By the time I first met Dr. Fishman at my first CNS Annual Meeting in Halifax, in 1988, I had done, or decided I was done with, a number of things – all starting with “F” – that might well have put me on another path in life. I was tired of writing film reviews and weary of constantly pitching, and less frequently filling, assorted freelance writing assignments. Writing fiction was a long-term dream and notions of making a living at it delusional. And I had a family now: my first-born, Soren, initially balked at the notion of waiting 40 weeks to make a grand entrance, forcing my wife into a few weeks of strict bedrest and me into cancelling plans to attend my first CNS meeting in San Diego in 1987. (Perhaps the cosmic convergence of San Diego, the CNS and me is simply not meant to be).



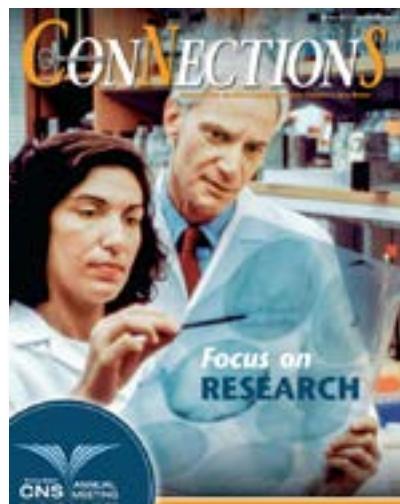
I was touring the Alamo in the spring of 1989 when Mary Currey hurried over from the San Antonio Hyatt where we were doing a site visit for that fall's CNS Annual Meeting. She had just gotten off the phone with Dr. Fishman, CNS President at the time. I have always loved the ironic dislocation involved in that call: the CNS Executive Committee was meeting in, and Marvin was calling from his native hometown of Chicago, while Mary and I were in his adopted home state of Texas; not quite Houston, but a town and site associated with Sam Houston.

Moving Mary and me out of the Division of Pediatric Neurology at the University of Minnesota into the Society's first, independent office space (a quaint, ivy-covered brick building less than a mile from where I live now), was a risky decision, one that was not then, nor for many years to come, universally embraced. Dr. Fishman took full responsibility for the decision at the time, but not, characteristically, full credit years later when, in retrospect, it appeared to be the absolutely correct, even essential decision. He did so largely on faith, another “F” word, having talked with me at length only once or twice. Yet, somehow, he felt confident that I could provide adequate back-up support for Mary in launching and maintaining this challenging new venture.

I like to think that Marvin's confidence in Mary and me was yet another, if lesser, expression of what I later came to appreciate as his remarkable gift for discerning and developing talent. Take a look at the four pictures and you'll see what I mean, if you don't know already.

Huda Zoghbi, 1988 Young Investigator Awardee and Sachs Award lecturer in 2001, was a Baylor Med School peds resident interested in cardiology – not the superstar geneticist she later became and we know her as – when Marvin persuaded her to think about going into child neurology.

Alan Percy had a great pedigree that included degrees from Harvard, Stanford, and Hopkins when he joined the faculty at Baylor/Texas Children's. He would likely achieve iconic status following any number of paths, but the path that found



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him walking and working alongside Marvin at Baylor was seminal in shaping a career that includes being President of both the Child Neurology Society (1997-99) and Child Neurology Foundation, a Hower Award in 2005, and development of a great program at Alabama-Birmingham.

The remarkable growth of the Baylor/TCH program in Houston under Gary Clark's tenure is directly attributable to his multiply diverse, yet smoothly integrated institutional vision and skill, but Gary would be the first to tell you his success owes a great deal to the fact that he succeeded Dr. Fishman, building on the solid foundation Marv established after being recruited by Ralph Feigin to leave Wash U (and Phil Dodge) to start something special in Houston. Well-mentored by Marvin, Gary has himself contributed substantially to the CNS, serving as Councillor for the South on the CNS Executive Committee from 2010-12, and as President of the Professors of Child Neurology (PCN, now PECN) from 2014-16.

And then there is Gloria, one of those people you occasionally meet who truly does light up a room. I don't know who chose who. Nor can I tell, looking at the photo of them dancing, who is leading and who is following. That's part of what makes Marvin so special: it isn't about him. It's never only, or even mainly, about him: it's about those he brings together or joins together with to get the job done.

Rob Rust, a dear friend of mine and so many others in the CNS, who for many years wrote the long, Whitmanian profiles of Award recipients we all admired and now miss, wrote the following in his profile of Dr. Fishman in 2013 when the CNS presented the Arnold P. Gold Foundation Humanism in Medicine Award to Marvin (he previously received the Hower Award in 1999):



"Among the sources of his particular effectiveness in all of his roles is the manner in which he seamlessly combines an acute and critical intellect with unfailing curiosity, the desire always to do the right thing, devotion to hard work, a dry sense of humor, and genuine caring and empathy. The combination has at least one additional important virtue: unfailing equanimity. having all of these characteristics so naturally at his fingertips accounts not only for his skills as a teacher but also as a listener and communicator. He is a practical person that asks of others what he always asks of himself – essentially, to 'do the best you can.'"

I have tried over the years to do the best I can, to make good on, and to allow Marvin to feel good about the huge risk he took 32 years ago. I never dreamed – who could have? – that the path he helped set me upon in Texas would wind up in Boston for the 50th/Golden Anniversary CNS Meeting. I'm grateful it did....or will, in 45 days.

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“G” is for Gold

After a weekend spent binging on Texans (Roy Elterman and Marvin Fishman), it might be wise to try a slow taper rather than risk giving up the Lone Star State cold turkey.

A potion of one part Texas, two parts Midwest and Mountain states, and one final pinch of Texas just might do the trick.

Most people associate Arnold Gold with New York, and rightly so. He was a forceful presence on a formidable faculty at Columbia University College of Physicians and Surgeons for more than fifty years. What most people don't know is that, despite being born and raised in New York City, he was sent away to high school in Galveston, TX, then sandwiched three years as a navy corpsman in World War II in between beginning and ending his undergraduate studies at the University of Texas (albeit without ever quite learning how to convincingly say "Y'all!").

Completing a master's at the University of Florida, he moved on to attend medical school at the University of Lausanne in 1954, followed by an internship in New Orleans and residency at the Cincinnati Children's Hospital, where he worked with Dr. Albert Sabin on the first polio vaccine. Only then, as if drawn by destiny, did he return to New York for good. In much the same way that Phil Dodge captured the hearts and minds and souls of a new, emerging generation of giants in child neurology, Sidney

Carter's magnetic brilliance had the same effect on a whole host of child neurologists matriculating through Manhattan. He drew Arnold into the field on the strength of a mesmerizing one-month rotation at the Neurological Institute of New York. The rest, as they say, is history,

I can't follow the labyrinthine path through labs, clinics and hospital wards, as you well know. But, what I can grasp and appreciate with my background in the humanities is Dr. Gold's passion for reinfusing medicine with humanistic purpose. In a touching tribute co-authored by Nigel Bamford and Darryl De Vivo for the Winter 2018 CNS Connections, following Dr. Gold's passing, they wrote the following:

"A charter member of the Child Neurology In Society and recipient in 2005 of the Society' Lifetime Achievement Award, Gold is perhaps best known for founding, in 1988 along with his wife, Dr. Sandra Gold, the Arnold P. Gold Foundation, dedicated to fostering humanism in medicine. With a grant from the Robert Wood Johnson Foundation, he gathered fifty medical school deans together to discuss ways to offset the diminishing emphasis on the humane aspects of medicine. He proposed mechanisms that would inculcate these humanistic behaviors in medical students at the beginning of their careers; behaviors that he regarded as fundamental to the practice of medicine.

One outcome was the White Coat Ceremony that medical and dental students participate in at the beginning of their training. The



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"Much has changed in medicine since Dr. Arnold Gold began his career, but his ideals and teachings have not, and now live on in many, if not all, practicing child neurologists."

(From a tribute written by Drs. Nigel Banfield and Daniel De Vito, published in Winter 2018 CNS Connections.)



Heartfelt thanks to Dr. Arnold Gold,
"one of our own"
Charter member of the Child Neurology Society
2005 CNS Lifetime Achievement Awardee

Congratulations and thanks to
The Arnold P. Gold Foundation
for supporting the annual presentation of the
Humanism in Medicine Award
and the biennial staging of the
Humanism in Medicine Luncheon at CNS National Meetings

DR. ARNOLD GOLD SOCIETY
www.childneurology.org

first ceremony was in 1993 at the Columbia University College of Physicians and Surgeons; it has since spread to nearly every medical and dental school in the United States and more than a dozen countries overseas. The white coat is a symbol that emphasized the ethical, moral and humane imperatives that medical students accept upon matriculation."

In 2010, the Arnold P. Grant Foundation supported presentation of the first Humanism in Medicine Award at the CNS Annual Meeting in Providence to Dr. Ruth Nass. Dr. Nass, who passed away in 2019, trained under Dr. Gold at Columbia University. Fittingly, this year's recipient of the Gold Humanism Award, Mary Zupanc, was Arnold's colleague at Columbia early in her career, thus bookending for the 50th Annual Meeting two of Arnold's acolytes receiving the award named, supported and presented in his honor. No award was presented last year during the virtual joint meeting owing to ICNA not having an equivalent award, but prior to that, tracing backwards,

the following CNS members have also received the Arnold P. Gold Foundation Humanism in Medicine Award: Drs. H. Terry Hutchison, Audrey Foster-Barber, David Coulter, Oscar Papazian, Robert Zeller, Kenton Holden, Douglas Postels, Marvin Fishman, and in 2011, Shaul Harel.

Dr. Harel plans to travel from Israel to join us in Boston for this year's meeting, and he has consented to be available to sign copies of his memoir, published in June, *A Child Without a Shadow*. No one sitting in on Dr. Harel's brief speech accepting the Gold Humanism Award at the 40th Annual CNS Meeting in Savannah in 2011 can forget his stirring story of being rescued at age 5 from his parents' fate at Auschwitz by a young woman working with the Belgian resistance. This book tells that story in greater, gripping detail and goes on to recount his amazing tale of overcoming this and other traumas and challenges to become, in time, an internationally renowned and revered pediatric neurologist.



Shaul is pictured below with friends, Paolo Curatolo and David Stumpf to his left.

“G” is also for Guggenheim...

Mary Ann Guggenheim began her two-year term as the first female President of the Child Neurology Society in October 1981 at the 10th Annual Meeting held in Minneapolis. My boss, Larry Lockman, began his tenure as CNS Secretary-treasurer at the same time. While I worked at the meeting for a few hours and may have sat in on Ken Swaiman's Hower Award address delivered on Friday night (back then it was part of the closing gala/reception and social gatherings were anathema to me), I don't think I met Dr. Guggenheim then, or maybe even five years later in Phoenix, when the picture above was taken with Peggy Copple (to her right/our left; and Mary Ann's longtime partner, Jan Donaldson on her left/our right). Dr. Copple was another "pioneering" female pediatric neurologist back when they were few in number, almost none in "positions of power"; she served on the CNS Executive Committee from 1989-93 as the first female Secretary-treasurer.

I do vividly recall talking to Mary Ann in 2009 when she received one of the two Lifetime Achievement Awards presented in Louisville, along with Dean Timmons. I knew second hand from Larry that she was head of the program at the University of Colorado, and that some years later, beguiled by the beauty of "God's Country," she moved to Montana to set up private practice, passing the directorship at Colorado on to her protégé, David Stumpf, who soon afterward became CNS President (1985-87) and was the architect of the first, and hugely successful joint CNS-ICNA meeting in San Francisco in 1994.

I was struck in talking to Mary Ann by her passion for fly-fishing and woodworking, both items on my bucket list. I would love to follow her back to God's Country and learn a bit about both from a master, but time keeps slipping away and the chances of that happening float downstream and out of sight. Still, a guy can dream, can't he?



...and Garg...

If Arnold Gold could fill a room with his presence, Bhuwan Garg could instantly brighten it with his smile. Although he trained at the University of Minnesota before my time, subsequently moving on to a long and celebrated career infusing the program at the University of Indiana with his wisdom and energy, he introduced himself to me at my first meeting and made a point of seeking me out at every meeting thereafter. I assumed he did so

because of our shared Minnesota connection, but I later came to see it was more likely because that's who he was and how he lived: he sought everyone out and everyone sought him out. I can't think of too many members more beloved than Bhuwan. When he passed away in March 2012, and his family came to the CNS meeting in Huntington Beach in the Fall to receive the Lifetime Achievement Award on his behalf, one could almost palpably



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sense throughout the Spring and Summer and early Fall a long, slow collective sigh of grief and sadness let out within the CNS. His avid devotion to the High School Neuroscience Award program conducted in collaboration with the AAN, was aptly recognized by renaming the annual award in his honor. The photo on the previous page shows him with High School

Neuroscience Awardee, Henry Marr at the 2003 meeting in Miami Beach.

The 2021 recipient of the Bhawan Garg High School Neuroscience Award is Meagan Ryan, from Ossining, NY. Meagan will be enrolled as a first-year student at Northeastern University, mere blocks away from the CNS meeting site.

....and Goddard-Finegold

.More "Gold" ("Fine" Gold, even), and a final pinch of Texas for our taper....

This has been a hard entry to write, with three of the four featured no longer with us. Jan Goddard-Finegold trained at Baylor College of Medicine in the early 70s and remained on faculty for nearly 30 years, focusing on neurodevelopmental pediatrics. All of the Baylor faculty and residents back then (and now) were open and friendly; all seemed to constantly hang out around the registration area at CNS Annual Meetings, due in large part to Nancy Ivy's gregarious presence behind the counter. Nancy was Dr. Fishman's assistant, enlisted to help out beginning in 1994 when the joint CNS-ICNA

Meeting in San Francisco upped the ante on staffing; she continued in that role for another two decades. Jan was among the most open and friendly of that Texas cohort. She was also a uniquely gifted amateur photographer, generously volunteering to fill that role for the CNS at annual meetings for years. Many of the photographs from the 90s you have seen this past week or will see in the weeks to come were taken by Jan. I don't recall the nature of her prolonged illness, but I do know that photos taken by her drop off around the new millennium, when she was no longer able to come to meetings. She retired from Baylor in 2005 and passed away in October 2019, a few weeks before the CNS meeting in Charlotte.



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“H” is for Hower

If there is such a thing as sacred space within the CNS, it may, perhaps, be found in that one hour occupied on the final morning of each increasingly busy, over-scheduled annual meeting by the Hower Award Lecture.

Having said that, I will do something I almost always end up doing these days by walking it back, looking it over, seeing (with a little help from my friends) where I got it wrong, then trying a second, third, or tenth time to get it right. Which, in this case, means appreciating how many directions, most of them ill-founded, some of them insane, my opening reference to “sacred space” might be taken. “Sacred space” suggests a religious or theological orientation foreign to, if not incompatible with medical science. It makes priests, in this case, of past recipients of the Hower Award. Which they are not. Nor are they prophets, at least not in a conventional sense, although this comes closer to the mark. The conventional notion of prophets as lone voices speaking truth to power, punctuated perhaps by dire predictions of fast-approaching cataclysm and doom doesn’t work so well when one considers that of the 48 Hower Award Lecturers (including this year’s awardee, Jon Mink), 20 have been CNS Presidents, including 7 of the last 10. Not exactly outside agitators.

But, if we take a broader and deeper view of prophets as being poets or poetic souls reclaiming, reinterpreting, and re-energizing the original essence and animating impulses informing a given community’s defining traditions, then we might be able to make

the metaphorical leap required to think about the Hower Award in the context of what, within the world of pediatric neurology, might pass for “sacred.”

Any history of the Hower Award must begin with “The Dean”: G. Dean Timmons, MD, the second child neurologist to set up shop in Ohio (Past CNS President Bob Eiben being the first), and the first to do so in Akron. I encourage everyone to find the time between now and the 50th Annual Meeting to tune into the videotaped conversation between Dean Timmons, Ken Swaiman and Paul Rosman. Dean enters the frame a few minutes in, recounting at the 15-minute mark the means and motivation behind his successful solicitation of support for an award lecture from one of Akron Children’s Hospital’s leading philanthropists, the Hower Foundation ([click to view video](#)). Those still inclined to access information by reading may enjoy Rob Rust’s profile of Dean from 2009, when he was presented the Lifetime Achievement Award (alongside Mary Ann Guggenheim) at the CNS Meeting in Louisville ([click to read](#)).

The first Hower Award Lecture was presented by Douglas Buchanan at the 3rd CNS Annual Meeting held in Madison, Wisconsin in 1974. In the early years, the Hower Award Lecture was given as part of the closing, Friday evening formal dinner. Legend has it this practice was abandoned after the 9th Hower Lecture, delivered by Patrick Bray at the CNS Annual Meeting in Salt Lake City, the notion being that a quiet cup of coffee on Saturday morning might be more conducive to appreciative listening than the heady mix of wine, chatty child neurologists



(L-R) Drs. Dean Timmons, Roger Hudgins (a neurosurgeon and Director of the NeuroDevelopmental Science Center at Akron Children’s at the time), Deborah Hirtz, and incoming CNS President, Bruce Cohen.

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and clanging plates and silverware served up on Friday nights.

Those accoutrements all were and are still are available, however, at the Hower Award Dinner hosted in Akron each spring following the CNS meeting. Each Hower Awardee's Ohio pilgrimage includes presentation of a lecture in the evening followed by Grand Rounds the next morning at Akron Children's Hospital. Bruce Cohen graciously provided the photo from the 2012 Hower Award Dinner in Akron, featuring 2011 Hower Award Lecturer, Dr. Deborah Hirtz, well-known to all for her longtime leadership at the NINDS.

It is worth noting that Deborah Hirtz was only the 4th of 7 women chosen to receive the Hower Award; her predecessors include Betty Banker (1983), Isabelle Rapin (1987), Karin Nelson (1991), and Sakku Naidu (2010), while those who followed include Ann Tilton (2012) and Nina Schor (2017).

Dr. Naidu's Hower Award Lecture in 2010 in Providence calls to mind one aspect of the prophetic nature of the award that is integral to its significance to the Child Neurology Society. Again, discarding the old, conventional notions of prophets as lone voices crying out in the wilderness, and trading up to a more modern understanding of them as representative poets speaking for and from within a community and a tradition, one could not help but be struck in listening to Sakku's lecture of the close working relationship she enjoyed with colleagues at Kennedy Krieger, most especially with 1994 Hower Awardee, Hugo Moser, and his wife and co-researcher, Ann. I met, but did not know Dr. Moser.

Sakku, on the other hand, has been dear to me going back many, many years, perhaps never more so than in Belgium in 2018 when, at a meeting of the International Child Neurology Association BOD, I had the good fortune to spend hours talking to her over lunch, dinner, a long walk around Liege, and an even longer, colder wait for a cab willing to come to our rescue. ([Click to read Rob Rust's 2010 Profile of Dr. Naidu.](#))

Multiple other "Hower Genealogies" can be traced by looking over the roster below, including but not limited to Ken Swaiman & Steve Ashwal, Phil Dodge/Joseph Volpe/Darryl De Vivo/Marvin Fishman, and Mike Painter/Nina Schor/Jonathan Mink. Jon might just as easily be linked genealogically to Wash U or to fellow "Master of Movement Disorders," Harvey Singer, just as Darryl De Vivo could be linked to Sidney Carter and Salvatore DiMauro, or....you get the picture.

Similar genealogical links are evidenced in pictures below showing Jim Bale (with CNS President Phillip Pearl, and his introducer for the lecture, longtime Utah colleague, Fran Filloux) and William Bell (shown here with Kathy Mathews). Jim delivered the last live presentation of the Hower Award at the CNS Meeting in Charlotte in 2019. Dr. Bell, one of the midwestern cohort who founded the CNS, received the Hower Award at the 25th/Silver Anniversary Meeting of the CNS in Minneapolis in 1996. Another Iowan in the Hower Award lineage, not pictured, would be 2013 Awardee, John Bodensteiner (John will come up in future Countown entries).



CNS Hower Award Recipients

1974 Douglas Buchanan Chicago	1986 Jean Aicardi Paris	1999 Marvin Fishman Houston	2012 Ann Tilton New Orleans
1975 Randolph K. Byers Boston	1987 Isabelle Rapin Bronx	2000 Arthur Prensky St. Louis	2013 John Bodensteiner Rochester, MN
1976 Sidney Carter New York	1988 Bruce Berg San Francisco	2001 Charles Barlow Boston	2014 Michael Shevell Montreal
1977 David B. Clark Lexington	1989 Manuel Gomez	2002 Peter H. Berman Philadelphia	2015 E. Steve Roach Columbus
1978 Philip R. Dodge St. Louis	1991 Karin B. Nelson Bethesda	2003 Michael E. Cohen Buffalo	2016 Harvey Singer Baltimore
1979 Paul I. Yakovlev Boston	1992 Darryl C. De Vivo New York	2004 John Freeman Baltimore	2017 Nina F. Schor Rochester, NY
1980 John H. Menkes Beverly Hills	1993 Bengt D. Hagberg Goteborg	2005 Alan Percy Birmingham	2018 Bernard L. Maria Morristown, NJ
1981 Kenneth F. Swaiman Minneapolis	1994 Hugo Moser Baltimore	2006 Michael Painter 2008	2019 James F. Bale, Jr. Salt Lake City
1982 Patrick F. Bray Salt Lake City	1995 Salvatore DiMauro New York	2009 Stephen Ashwal Loma Linda	2020 Kenneth J. Mack Rochester, MN
1983 Betty Q. Bunker Cleveland	1996 William Bell Iowa City	2010 Peter Camfield Halifax	2021 Jonathan W. Mink Rochester, NY
1984 Peter Huttenlocher Chicago	1997 Gerald Fenichel Nashville	2011 Sakkubai Naidu Baltimore	
1985 Raymond D. Adams Boston	1998 N. Paul Rosman Boston	2012 Deborah Hirtz Bethesda	

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“I” is for Icon: Isabelle

Blue lead in...

In his 1999 book *Lost Icons*:

Reflections on Cultural Bereavement, the then Archbishop of Canterbury (and my favorite theologian), Rowan Williams noted: “The word ‘icon’ has come down in the world. It is probably more familiar as a term of art in the world of communication technology than as the designation of a sacred image; perhaps for most people its commonest use is to designate a particular kind of public figure.’

Like so many things in our woefully wired world (“www,” right?), the word has come down even further since then, trimmed and tapered in a way that twitters away depth and meaning, but some of what Williams goes on to offer still holds: “An icon... is a classic statement of a particular kind of life; ‘iconic status’ means something more like becoming part of the code of a community, becoming in some way an image that binds people together, provides a common point of reference and a common touchstone of acceptability.”

Often, though not always when we think of cultural icons, we think of those who come instantly to mind with mere mention of their first name: think Oprah, Beyoncé or Baryshnikov on “the Big Stage.” Smaller stages, subcultures or subcommunities will have their icons as well, although they may not cross boundaries and be instantly recognizable on the bigger stages. Mention “Miles” among jazz enthusiasts and they will know without thinking you mean Miles Davis, whereas someone younger, less familiar with jazz, may flash

instead on Platinum or Gold airline perks.

Child Neurology is a small world, after all. But within that world few figures loom larger, and no first name is more self-contained and iconic than “Isabelle.” Younger child neurologists not immersed in neurobehavioral and neurodevelopmental topics may need to hear the full name, “Isabelle Rapin” to join in the conversation, but for those working in that subspecialty, and for all neurologists of a certain age, “Isabelle” says it all. As her colleague at Einstein, and winner of the 2019 Outstanding Training Director Award, Karen Ballaban-Gil, MD noted in a tribute written for the CNS in 2017: “Isabelle Rapin was professor emerita in the Saul R. Korey Department of Neurology and the Department of Pediatrics at the Albert Einstein College of Medicine. A longtime colleague and friend, mentor to generations of child neurologists in the US and world-wide and one of the pioneers in child neurology Dr. Rapin was born in Lausanne, Switzerland, the eldest of three children, to a Swiss father and American mother. In an age when it was unusual for women to attend university, let alone attain advanced graduate degrees, the then ten-year-old Isabelle decided she wanted to become a physician.”

She went on to become more than just “a” physician. She became, in time, someone the outside world knew through casual reading as “the mother of Autism,” or as the New York Times put it with a dash more class, “the doyenne of Autism.” Within the CNS and the International Child Neurology Association (ICNA), she



was simply – or not so simply – “Isabelle.” For me, anytime her name comes to mind it comes in the shape or sound of David Stumpf’s voice calling out “Isabelle?” from the podium of the joint CNS-ICNA meeting in 1994 as she stood patiently waiting by a floor microphone. There is in David’s voice a quality of excitement and delight that seemed almost made for that moment or so many more like it in so many meetings like it where neurologists or speech and language specialists were gathered in conference and Isabelle stood next to the floor microphone, calmly, patiently, even humbly waiting her turn. Like Dave Stumpf’s in that 1994 instant, many others, I’m sure, have called on Isabelle in a tone of voice that carried both an air of expectancy and an edge of anxiety, the moderator knowing that the moment about to unfold might contain both brilliant commentary and one or more piercing, illuminating, wonderful-to-think-about-but-hard-to-answer questions; either way, the witless or unwitting panelist had better be ready.

I remember talking to Sarah Spence, MD, PhD at Boston Children’s Hospital last year and smiling as she recounted a meeting where she thanked the organizers for having her speak after Isabelle rather than before her “so that she couldn’t correct everything I said. And I got her to laugh.” That, Sarah noted, was the beginning of a beautiful friendship, one many others in the field can recall with equal fondness. (The story can be heard around the 21:00 minute mark of the video hosted on the CNS website, CNS Conversations. The whole video is worth watching. Sarah is a great

conversation partner; talking to her in the morning will wake you up and put you in a good mood for the day better than the best cup of dark roast coffee.)

Channeling Dr. Ballaban-Gil again (Karen is pictured below, top row-center, in a group shot taken on the occasion of Solomon “Nico” Moshé, MD receiving the 2017 Sachs Award): “Over the course of her career, she helped train over 100 child neurology residents, as well as scores of adult neurologists. Many of those 100 child neurology trainees specifically choose to train at Einstein in order to have the opportunity to be taught by her, and some credit their decision to become a child neurologist to her influence. Not only did she teach her trainees clinical neurology, she also educated them in research, critically reviewing of the literature, preparing lectures and writing manuscripts. Dr. Rapin mentored many academic child neurologists at various stages of their careers and provided particular encouragement to women in training at a time when women were very much a minority in the field.”

One of those young trainees who fell under her spell was CNS President-elect Bruce Cohen, who recalls how as a med student interested in neurology, he had what could have been an awkward conversation with his mentor, Albert Spiro, MD, the 2018 recipient of the Brumback Lifetime Achievement Award. Innocently thinking at the time that Dr. Spiro was an adult neurologist specializing in muscle disorders, Bruce expressed particular interest in doing a child neurology rotation



Pictured above are a few of those who have enjoyed moments like that one or more times through the year: (L-R) Drs. Pasquale Accardo, Bruce Shapiro, Doris Trauner, and Isabelle Rapin.

Click to view video.



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with Isabelle Rapin, hoping thereby to "learn from the best teacher in the field." In a moment that reveals much about both Einstein Med School giants, "Dr. Spiro leaned back in his chair, paused for a moment, then laconically replied, "Yes, she is the best."

One cannot talk about Isabelle without noting that, in a manner befitting an icon, she also embodied the virtues of loyalty and longevity: Over a half-century on faculty at Albert Einstein College of Medicine, and 58 years of marriage to Harold Oaklander, a PhD candidate at Columbia when they met, who went on to become the Founder and Director of the Alliance for the Prevention of Unemployment. Together they raised four children, including one, Ann-Louise Oaklander, MD, PhD, who became an adult neurologist at the Massachusetts General Hospital.

When she passed away in the spring of 2017, we all rued the certain knowledge that we would not see her at another CNS meeting. She was and has been with us in spirit, however. I remember receiving an email from her the previous winter, relating how pleased she was that her longtime colleague and friend at Einstein, Nico Moshé, whom she had nominated for the Bernard Sachs Award, and an icon in his own right, would be receiving that award and delivering that lecture at the CNS Annual Meeting in Kansas City. In delivering a eulogy on the opening morning of the 2017 meeting for

one of the first ABPN boarded child neurologists, a member of the first CNS Executive Committee, and recipient of the 1987 Hower Award, CNS President, Ken Mack marveled: "The breadth and depth of her knowledge was exceeded only by her collaborative spirit and her unfailing willingness to engage younger colleagues in conversation who sought her wise counsel at Einstein Medical Center or at any number of national and international meetings."

In closing – and how else can one close but by giving Isabelle herself the last word? – I offer you an excerpt from her autobiographical reflections published in the Journal of Child Neurology in 2001:

"The message I would give a young colleague is that child neurology is a wonderfully rewarding field, intellectually and personally, because of the families you will meet. In order to have it all, that is, be married, have children, restore and furnish an antique house, work in the garden, enjoy a lot of what life offers, and have a great job, you need a supportive and generous mate, adequate baby sitting and house help, flexibility, good humor, and a nose for the unusual. Consider every patient a potential source of new knowledge, describe what you see, pursue your interests vigorously, and learn to cut corners and prioritize. Find a good mentor, enjoy what you do, and be lucky."



41 Days to Boston

“J” is for Jazz

The gap between what I know about child neurologists and what I can tell you about neurology is roughly equivalent to the gap between what I know about musicians of any stripe (despite being married to one for 32 years and father of another) and what I can tell you about Jazz. The main difference is that while I would politely demur if someone were to ask me about the one, I would be utterly panic-stricken if asked about the other. About Jazz, that is.

And so, “staying in my lane,” I will offer only a few brief comments about how this relates to the CNS in general, and to the upcoming 50th CNS Annual Meeting in particular. Thanks to Phil Pearl, the aural delights and joyful, rhythmic release of Jazz have become an integral part of the landscape of CNS (and AES and AAN) meetings for decades now. Last year, COVID forced them indoors and on-line. That turned out to be a good thing, on balance; not the same, but still good – very good – not least because of its constant availability.

Last year, as many of you recall, Phillip Pearl, David Urian, and a few musicians from Boston’s renowned Berklee School of Music, where Phil is on faculty, recorded a 10-part series of videos for the enjoyment of those attending the virtual joint CNS/ICNA meeting. The series was based on the combined words & music programming Phil and David put together for the weekly Boston Children’s Hospital town hall meetings staged virtually by the Neurology Department beginning in the early days of the pandemic when, as David recalls, “we were struggling to figure out what to do, where we were going, how to navigate all this.”

Much to our collective surprise (and chagrin, falling somewhere between anxiety and ennui) we are still trying to figure all this out more than a year later as we approach a second CNS Annual Meeting under a looming, even growing cloud of uncertainty. Barring any shocking upticks or downturns that might force Boston’s hand and cause them to close down a week before the rescheduled Boston Marathon (not likely, given the optics and financial stakes involved), we will be meeting live in Boston.

How many of us will be at the Hynes Convention Center, only time will tell. But, regardless of whether the majority of us attend live, face-to-face, or on-line via the virtual platform, either way we will all have access to this year’s new series of music and words put together by Phil and David.

Finally, a quick clarifying note: while few of the literary or musical pieces directly reference New England, the creative and performative genius behind and on display throughout the series is more than enough to inspire and justify the moniker “New England Music & Muses”.

Below is a listing of the artists presenting, as well as links to five pairings hosted on-line. A full series of 10 will be offered on the virtual meeting platform beginning September 29, and running for a full month, to October 29.

We are grateful to the following Gold Level Sponsors for financially supporting both this program and the full 50th CNS Annual Meeting: Eisai, Inc; Greenwich Biosciences; and Novartis Gene Therapies. Thanks as well to our local host, The Department of Neurology, Boston Children’s Hospital.



Reader/Storyteller: David Urian, MD



Piano: Phillip Pearl, MD

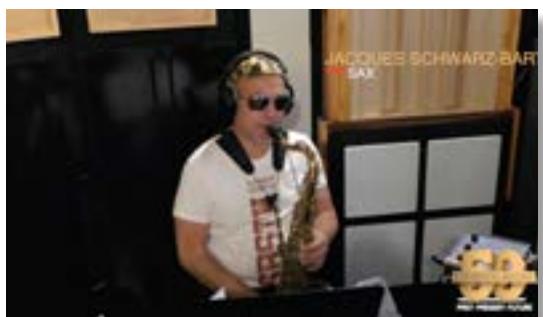
41 Days to Boston



Bass: Dan Fox



Drums: Yoron Israel



Sax: Jacques Schwarz-Bart

Pairing #1: Spring Can Really Hang You Up the Most

Muse: T.S. Eliot, *The Waste Land*
Music: Spring Can Really Hang You Up the Most
Music by Tommy Wolf
Lyrics by Fran Landesman

[Click to watch video.](#)

Pairing #2: Body and Soul

Muse: 1) Rumi, "Although the road is never ending...";
2) Marge Piercy: "To Be of Use"
Music: Body and Soul
Music by Jonny Green
Lyrics by Edward Heyman, Robert Sour and Frank Eyton

[Click to watch video.](#)

Pairing #3: My Favorite Things

Muse: 1) David Urian, "Reflection"
Music: My Favorite Things
Music by Richard Rodgers
Lyrics by Oscar Hammerstein II

[Click to watch video.](#)

Pairing #4: When Sunny Gets Blue

Muse: 1) James Baldwin, "Sonny's Blues" (excerpt)
Music: When Sunny Gets Blue
Music by Marvin Fisher
Lyrics by Jack Segal

[Click to watch video.](#)

Pairing #5: Our Love is Here to Stay

Muse: Louise Glück, *The Red Poppy*
Music: Our Love is Here to Stay
Music by George Gershwin
Lyrics Ira Gershwin

[Click to watch video.](#)

40 Days to Boston

“K” is for KW

Of all the emails, eConnections, and Letters from the Executive Director I've written over the past 10 years, none have come close to garnering the kind and level of attention – good and bad, appreciative or outraged – aroused by the Letter published in the Fall 2017/Annual Meeting issue of CNS Connections handed out in Kansas City.

I'm too young (67) to be putting out a "Greatest Hits" collection, and you need more than one hit to justify the "s" and call it a "collection." But you have to start somewhere, so why not here, with a re-issue of the Fall 2017 missive, "KW, KC, and the Future of CN"?

KW, KC, and the Future of CN

(originally published in 2017 Fall/ Annual Meeting CNS Connections)

My favorite video clip posted on the CNS website "Careers – Getting In" section features this year's Philip R. Dodge Young Investigator Awardee, Audrey Brumback, explaining how she ended up in San Francisco for



peds neurology training: "The thing that really struck me about the UCSF program was the kickass women!" she exclaimed, looking straight into the camera (In my head, I could hear her late father, Roger, erupting in laughter.)

"At most of the other programs," she continues, "it was a lot of people who looked like my dad; it was, you know a bunch of middle-aged white men." (Now, I could see him jumping to his feet and doing a little dance in sheer, giddy delight). But, when she came to UCSF, Audrey noted, there "was just this amazing cadre of women who were totally kicking ass in their careers and had families and seemed like nice people – Donna Ferriero, Audrey Foster-Barber, Yvonne Wu, Heather Fullerton – and I just thought, 'this is who I need to be around at this phase of my career. I'll be starting a family at some point, and these are the people who are actually going to be able to provide mentorship and be role models at this phase in my life.' ([Click here to view the referenced clip](#))

"Kickass Women" (henceforward, "KW")

Pictured above (L-R): Deborah Hirtz (NINDS; Hower Award, 2011); Faye Silverstein (University of Michigan; Young Investigator Award, 1986; CNS Councillor, 1999-2001); Donna Ferriero (CNS Councillor, 2004-06; Sachs Award, 2006; CNS President, 2009-11); Jan Goddard-Finegold (Baylor/TX Children's Hospital; also "G is for Goddard-Finegold" sent 8/16).

"Her words, not mine," as Melissa McCarthy would say, playing Sean Spicer on Saturday Night Live.



Pictured above (L-R): Deborah Hirtz (NINDS; Hower Award, 2011); Faye Silverstein (University of Michigan; Young Investigator Award, 1986; CNS Councillor, 1999-2001); Donna Ferriero (CNS Councillor, 2004-06; Sachs Award, 2006; CNS President, 2009-11); Jan Goddard-Finegold (Baylor/TX Children's Hospital; also "G is for Goddard-Finegold" on page 104).



Audrey Foster-Barber
(UCSF; Gold Humanism Award, 2018)



Heather Fullerton
(UCSF)

40 Days to Boston

Because on my own? I couldn't bring myself to type or say it aloud, certainly not in a boldfaced title. You see, unlike Audrey, I'm neither young, nor a woman. Nor did I, like her, spend my formative years in Oklahoma and Texas. I come from Minnesota where, as Garrison Keillor could tell you, we just don't talk like that; the Lutherans won't let us.

And then there was Isabelle Rapin, who I intended to reference in my letter. (Featured on p 108: "I is for "Icon: Isabelle"). Isabelle would not approve. Of "KW" spelled out, I mean. Oh, she would more than merely "approve" of Audrey, herself; and she would be passionately interested in learning more about her autism research. But "KW"? Not so much.

One of my favorite Isabelle stories, shared last May when she passed away, came from a past-CNS President who remembers observing her at the 1997 meeting in Phoenix, reading the profile Rob Rust had written on her for the "Women in Neurology" Archives display, and hearing her exclaim in that inimitably commanding Isabellian cadence, "...am...not... venerable!" But, of course, she was. Because, if she wasn't, who this side of Maria Montessori was? If she took umbrage at "venerable," I shudder to think what she might have made of the more colloquial "KW."

Well, times have changed. Twenty years ago, the ratio of female to male CNS members was 1:3. Today it's a near dead-even 1:1. Where women make up only 23% of Emeritus Members today (consistent with the 1:3 ratio in 1997), they account for 47 percent of Active Members. Fully 69 percent of Junior

Members – residents in training – are women. Contrast that with the photo on page 5 showing "All the Young Dudes" at the Wash U training program in 1987.

That sea change in gender parity/dominance will be dramatically evident, indeed, its directional movement almost mimicked, in our meeting in the heartland this year. All four Emeritus Members honored at the Wednesday evening Legacy Reception are men (each of them unquestionably venerable): Dave Coulter, Abe Chutorian, Don Shields, and Ken Swaiman. Fast forward to Saturday morning, however, and you'll find all but one presenter at the three breakfast seminars, Hower Award Lecture, and Pediatric Neuro-oncology symposium are women (a 14:1 ratio, for those keeping score).

But before ending with Saturday's programming, let's pause for a moment to look at Friday, noting that all four recipients of the CNS Outstanding Junior Member Award are women (Ka Ye Clara Chan, Hsiao-Tuan Chao, Rachel Goldstein Hirschberger, Carla Watson), as are both recipients of this year's CNF Shields and PERL research grants (Melissa Walker and Tracy Gertler), the Bhuvan Garg High School Neuroscience Award (Lauren Singer), and the aforementioned 2017 Phillip R. Dodge Young Investigator Award Lecturer (Audrey Brumback). Isabelle will be there in spirit as longtime colleagues and friends from Einstein take the stage with Karen Ballaban-Gil introducing the 2017 Sachs Lecturer, Nico Moshé following the Dodge lecture.

Saturday's Hower Award lecture may summon echoes of that priceless Rapin-Rust moment in 1997.

In much the same way that Isabelle might exclaim, "I am not venerable" 20 years ago, Nina might take exception to being called a "KW". But, of course, she is. Because, if she isn't, who, sandwiched between Isabelle Rapin and Audrey Brumback, is? After Jon Mink, Nina's colleague at the University of Rochester, brings the room to order as the new CNS President, Nina's twenty-something twin sons, Jonathan and Stanford, will introduce their mom with the kind of pride and panache befitting a true "KW". They, along with their third sib, Asher, and their father, Bob, a vestibular neurophysiologist, could easily put together a compelling video, starring Nina, showing how one goes about scaling the heights of excellence and colleagues' esteem in one's field while raising a family and maintaining a remarkable work-life balance.

It would be a great companion video to the "Three Amigas" clip posted on the CNS website Careers section featuring Nina, Ann Tilton and Pat Crumrine. ([Click here to access.](#))

I've watched that clip a dozen times, each time wondering where we are going to find the next cohort of "KW" to match those three and a couple dozen others of their generation that I've had the privilege to work with over the years. Who will carry the flame? Or, more prosaically, who will chair committees, run for office, or represent the CNS as this cohort has at a marathon's worth of meetings with the AAN, ANA, AES, AUPN, AAP, RRC, ACGME, AUPN, ABPN, NINDS, UCNS and others too numerous to name? It's not as if raising families – or other, equally worthy life choices – alongside charting a career in academics/practice/research, and being actively involved



in professional associations, has gotten easier. It hasn't. However much the gender balance in child neurology has shifted in women's favor, it hasn't shifted to the same degree or in the same direction when it comes to work-life balance.

The challenges ahead are real. But so are the resources needed to meet them. Starting with the fortuitous – and enviable – gender balance among CNS members. "Enviable" because, given the Society's relatively small size and comparatively communal and collaborative impulses and orientation, we as a Society are well-suited to model for other medical societies – and, for the larger society, as well – how to address burnout, how to find a rewarding work-life balance, how to encourage, support and reward excellence in pursuit of individual meaning and collective mission for both women and men – KW and KM alike. KC seems like as good of a place as any to start taking on that challenge in earnest.

(Postscript: Although neither earned CME credit, presented a poster, or even attended a SIG meeting, Audrey's two infant daughters have both attended CNS Annual Meetings. If that doesn't qualify them as "pre-KW," what would?)

Until tomorrow, (a sequel – "KW2" – there's just too many "KW" – Past, Present, and Future – for one entry to feature)



39 Days to Boston

“K” is for KW2

In signing off yesterday, I suggested Saturday’s entry would be a sequel: “KW2”. The CNS just has too many “KW” (“kickass women,” to quote Audrey Brumback) to come anywhere near doing them justice in one day; two barely moves us any closer to the goal, but it’s a good start. So, today (“KW2”) and tomorrow (“KW3”), I’ll put myself on mute and let you kick back and enjoy a representative sampling of CNS “KW”.

Remember: today’s entry, like all entries, is merely emblematic, certainly not exhaustive in its approach. While each individual photo in the “KW-series” speaks volumes (worth 10,000 words, at least), and together they tell a story about the CNS during one part of its 50-year history (ie, my tenure as Executive Director, 2012 - ??), they do not tell anywhere near the whole

story. Nor could they possibly showcase all the actors – in starring or supporting roles – who made and make the CNS what it is today. What I’m hoping is that over time you will send me stories and photos that I can use for the next leg of the journey, beginning after the Boston Meeting ends and carrying on through the Society’s 50th year as it moves toward the 51st Annual Meeting next year in Cincinnati.

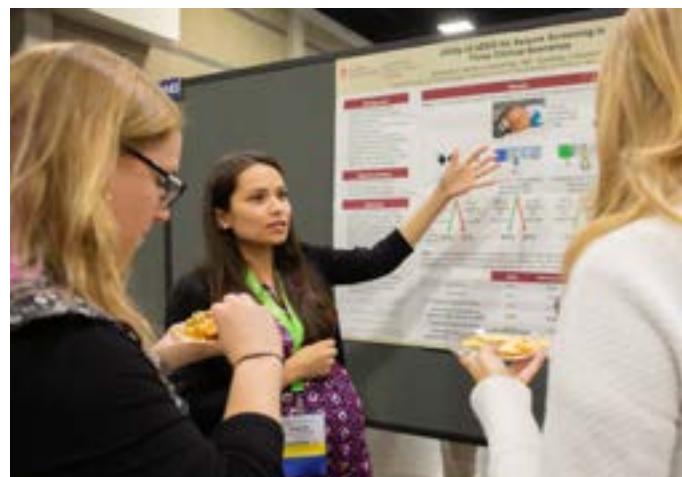
We’ll pick up with “L” on Monday. Meanwhile, enjoy the photos (all taken by a major “KW” herself, Suzanne Shaff). Have a great weekend.

Until tomorrow (“K is for KW3”)





39 Days to Boston



38 Days to Boston

“K” is for KW3

Much of what I remember from my misspent youth is mercifully fading now, but I do still vividly recall from my years writing film reviews that the only thing more tawdry and depressing than a sequel (*Godfather II* excepted) is a second sequel. Which begs the question: why would I then issue not just one sequel (“KW2”), on Saturday, but follow-up with a second on Sunday (KW3)? The answer is simple: “KW2,” featuring photos of all those remarkable child neurologists, was as good as *Godfather II*. And “KW3” might be even better. (OK, slight overstatement in re Art. But in terms of the “good” they do, the excellence they exemplify, the impact they have on the real lives of patients, families, colleagues and the larger communities they are part of and serve? No contest.)

My only regret is that I couldn’t fit more photos in these past three days: there are hundreds more from which to choose. True, I could set aside all shame and issue as many, or more, KW sequels than the *Rocky* or *Marvel Comics* superhero franchises (for a wee bit less money). But, then we’d never make it through the alphabet once, let alone twice. Boston awaits, as does tomorrow’s focus on the letter “L” with a brief look back at *Lacrosse et la Serviette* (“Ah, French cinema,” you say; “Comme c’est excitant!”) and a preview of the upcoming star-studded Legacy Luncheon on Wednesday, September 29.

À demain,
Roger



38 Days to Boston





37 Days to Boston

“L” is for La Crosse

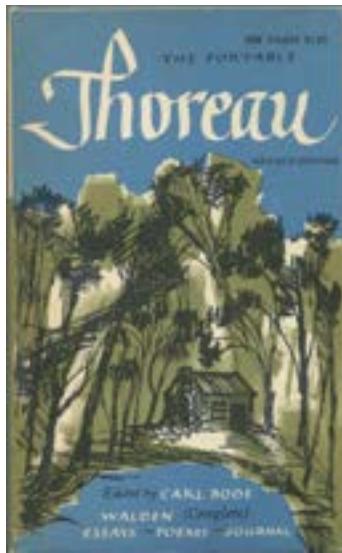
I have always shaken my head in wonder at the matchless chutzpah Dean Acheson displayed calling his 1969 memoir about the making of the post-WWII world, *Present at the Creation*.

It's a title I'd love to steal for today's look back at the Child Neurology Society's creation myth. But I wasn't actually present when the CNS began, so part of me feels I shouldn't. And yet, I was so close, so innocently and unwittingly close, that another part of me thinks I could: that part of me that would put a memoir by a stuffed shirt former diplomat back on the shelf to pull down a celebrated novel published the same year. The opening line, of Kurt Vonnegut's *Slaughterhouse-Five*, or, *The Children's Crusade* fits my overall approach to this 50-Day Countdown quite nicely, in fact: "All of this happened, more or less."

Maybe *Slaughterhouse Five* is a little too tooney for my take on the CNS creation myth. Maybe Disney's 1953 animated masterpiece, *Ben and Me*, about a fictional church mouse's faux-forgotten role in making Ben Franklin a Founding Father is a little more like it. Even that may be claiming too much for what follows. Maybe my claim to being present at the creation is more like your pet Golden Retriever claiming credit for you being a child neurologist, having curled up at your feet while you studied for the MCATs. With that in mind, I suggest you read this and all past and future entries warily: they are interpretive takes on CNS history, not authoritative by any stretch of the imagination, mine or yours.

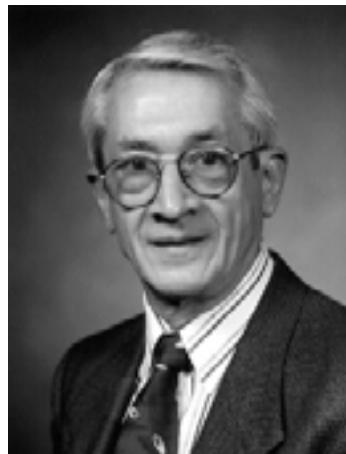
I have written before about starting my 9th grade year at Central Junior High in Rochester, MN a few weeks after and three blocks away from where the American Board of Psychiatry and Neurology (ABPN) issued the first six certificates in Neurology with Special Competence in Child Neurology in the summer of 1968. Turning in a science project the previous spring that could charitably called "Our Friend the Chipmunk: a dioramic case study in plagiarism and pastiche" pretty much closed the door on any future in medicine I might have shared with my classmates, the sons and daughters of Mayo Clinic physicians. And it closed off, or seemed to anyway, any conceivable reason I might have for working with the ABPN in the future. But History follows its own crooked path....more or less.

There simply is no straight line from the 15-year-old me to the 67-year-old me preparing to celebrate the 50th Anniversary Meeting in Boston of ABPN-certified child neurologists. And yet, in walking past the ABPN offices to buy *The Portable Thoreau* at the Lucy Wilder Bookstore, I did, unwittingly, take that crucial first step in the general direction of Boston (or nearby Walden Pond, anyway). And who's to say that what Thoreau had and has to offer isn't part of the mental make-up of many (most?) of the child neurologists who would also end up in Boston in September 2021: "If a man (sic) does not keep pace with his companions, perhaps it is because he hears a different drummer. Let him step to the music which he hears, however measured or far away."



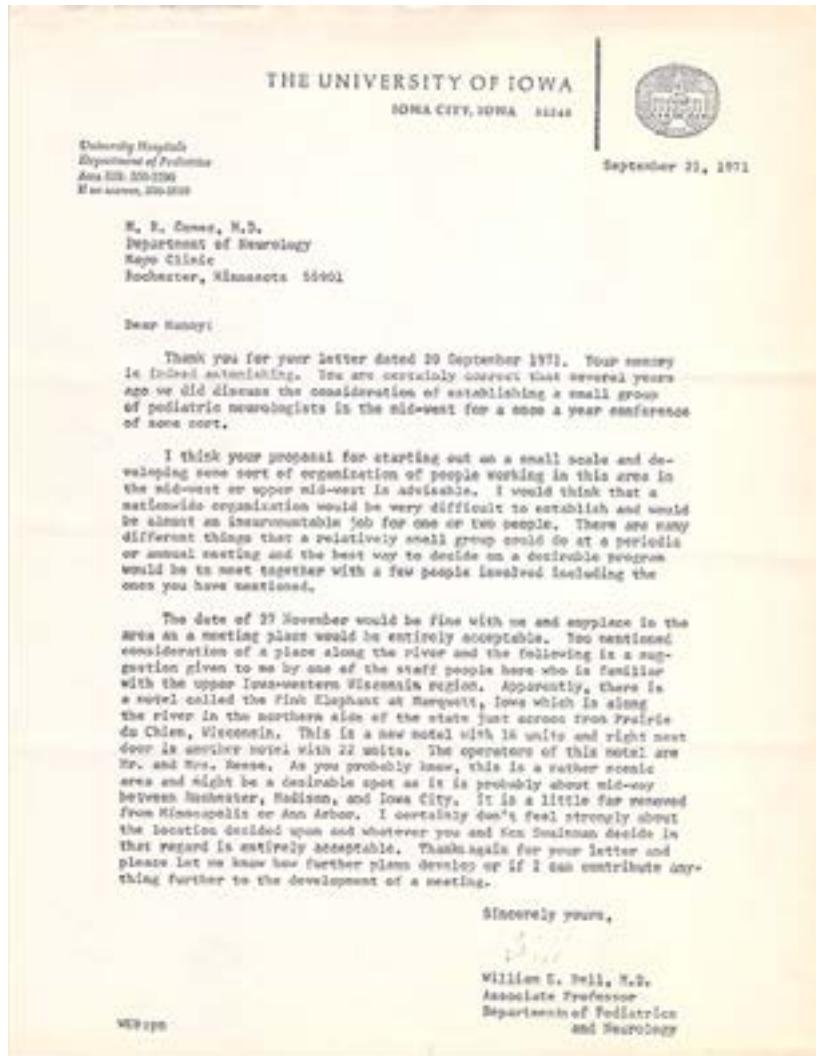
In February 1971, Ken Swaiman discussed forming a national organization of child neurologists with J.T. Jabbour in Memphis, then engaged Richard Allen in the same conversation in Ann Arbor in May. Both colleagues were enthusiastic and encouraging. In August, Manuel Gomez invited Ken to drive down to Rochester to meet him at the Mayo Foundation House (originally William Mayo's house, on 4th Street SW). Meanwhile, my senior year at Mayo High School had just begun. Bill Dobyns had just graduated from Mayo the previous spring, thereby dropping the average IQ of the 1500 students filing in for the new school year by at least a dozen points. No matter, we would press on, albeit in a more literary than scientific direction, resigned as most of us were to the futility of following in Bill's footsteps. In that vein, my favorite book read over the summer was *The Great Gatsby*; I spent many moonlit nights in the late summer and early fall wandering through the back gardens of the Mayo Foundation House that Drs. Swaiman and Gomez met at, trying to imagine myself as Nick Carraway sizing up Jay Gatsby's mansion next door. Twenty-five years later, in September 1996, while the CNS was meeting in Minneapolis to celebrate its 25th anniversary, St. Paul celebrated F. Scott Fitzgerald's 100th birthday. I missed much of that CNS meeting to attend the unveiling of the Fitzgerald sculpture in Rice Park created by my good friend (and Godfather to my two kids), the late artist, Michael Price. Many CNS attendees may remember staying through Saturday night to attend the special live Prairie Home Companion show with Garrison Keillor, and the Gala at the Ordway that followed, bringing the Fitzgerald centenary celebration to a close.

In October 1971, Dr. Swaiman followed up on his Rochester meeting, inviting Dr. Gomez to join seven other midwestern child neurologists at the Holiday Inn in La Crosse WI on November 26 and 27. Everything was now lined up for the fateful meeting of the infamous La Crosse 8: Richard Allen, Ann Arbor; William Bell, Iowa City; Raymond Chun, Madison; Paul Dyken, Milwaukee; Manuel Gomez, Rochester; Kenneth Swaiman, Minneapolis; George Wolcott, Madison; Francis Wright, Minneapolis. In thinking about History



A historical newspaper clipping from the St. Paul Pioneer Press, dated September 12, 1996, page 1B. The headline reads "Fitzgerald Centennial: St. Paul Celebrates". The article discusses the 100th anniversary of F. Scott Fitzgerald's birth, featuring events like the sculpture unveiling, the Prairie Home Companion show, and the Gala at the Ordway. It quotes Michael Price, the artist who created the Fitzgerald sculpture.

37 Days to Boston



and Memory, it's worth noting that in his 1996 review article, "The Organization of the Child Neurology Society: A Personal View," published in *Pediatric Neurology*, Ken got the dates of the crucial La Crosse meeting wrong, (assuming, that is, the multiple letters involving multiple authors, all referencing November 26 and 27 both before and after, got it right in real time, while Ken mis-remembered the meeting a quarter-century later as taking place November 18, 1971).

Dr. Swaiman writes the following in that 1996 mini-Present at the Creation memoir: "The evening session began and ended in the Holiday Inn's bar. We struggled to name pediatric neurologists in the Midwest, writing the names on a cocktail napkin." Out of which came the one and only sacred relic from the Society's founding: "la Serviette de La Crosse." A younger generation, when told this story, would likely look up from the smartphone nestled in their hand, thumbs poised above the keys, to ask in utter perplexity, "Why would someone write on a napkin?"

"We had even greater difficulty naming pediatric neurologists in other sections of the country," Ken continued, "a problem that was to consume time and energy in the coming months. Our later discussions centered on whether or not we should attempt to form a midwestern group with such broad geographic coverage. Would the organization have enough attendance and enough scientific papers to make it worthwhile? The next morning we resolved this issue and agreed to hold a spring meeting in Madison, Wisconsin. The debate became very heated over the feasibility of forming a national organization. No one wished to be a member of an organizing committee of a society which would not succeed, but many felt that there was a need for such a group. We decided to poll pediatric neurologists around the country to ascertain their interest in forming such a society."

"The previous evening," Ken noted, Paul Dyken had begun to search for a name for the society. After several outrageous suggestions were vetoed as inappropriate, he suggested 'CNS,' the 'Child Neurology Society.' In a most unusual sequence of events, the name of the society was chosen before the concept of organization was accepted."

I don't know that I've ever been in the Holiday Inn in La Crosse, or whether it even still exists. If I were making a movie now, however, I would absolutely have the 17-year-old me sidle in and take a table next to those eight venerable gents, maybe even have him ask if this new organization they were talking about forming might be interested in looking over his resume (he had none), or reviews of his 8th grade science project (there were none). I love the irony of the 17-year-old me fraternizing that fall with the sons and daughters of Mayo Clinic physicians busily forging fake IDs to get into Wisconsin bars 70 miles away (the drinking age in Wisconsin was 18) at the very same time the La Crosse 8 were trying to forge a genuine identity for child neurology. It would make for nice dramatic counterpoint and narrative tension: My misspent youth vs their missional drive and focus.

A few months later, the stars began lining up even more closely, such that I seemed destined to find myself in Boston 50 years later. In December 1971 I escorted a young beauty named Betsy to the Mayo HS Christmas Dance, learning later in the evening, among other things, that her father, head of cardiac surgery at Mayo, was about to take a job offer at Harvard Medical School (he ultimately passed on it). Like any smitten teenage boy, certain I had found "the One," I immediately fast-forwarded 50 years to family gatherings in Boston, perhaps even including walks around Walden Pond. Alas, it was not to be. In February, Betsy dumped me. My heart and faith in the future sank at roughly the same time and rate Ken Swaiman's, in Minneapolis, rose as he shared with the La Crosse 8 the results of the 189 questionnaires he sent out in December.



Or, should I say, "Mary Currey, his secretary, sent out?" Mary typed and photocopied all 189 questionnaires, folded and inserted them in the 189 envelopes she had previously manually typed addresses on, then sealed, stamped and dropped those 189 envelopes in a mailbox. As amazing as that seems now, what's even more amazing (staggering, actually) is the fact that fully 146 of them came back with responses. We're talking hand-written/checked, re-folded responses that someone inserted, sealed, addressed, stamped and dropped in the mailbox). That 77 per cent response rate, requiring 5x the time and effort of today's on-line surveys, is roughly 3x the rate of return any survey has seen in years.

37 Days to Boston



The results were amply encouraging. Fully 85 percent of those responding thought there was a need for a national organization of child neurologists, and 77 percent expressed interest in joining it. The road to Boston 50 years hence, seemed set.

The rest, as they say, is History: "All of this happened, more or less." Following a promising spring meeting in Madison, plans moved forward quickly toward a 1st CNS Meeting in Ann Arbor, a founding event touched on briefly with "A" at the outset of this Countdown, and one we will no doubt revisit when the Countdown journey ends on September 29 with the opening of the 50th Meeting in Boston.

I will be there in Boston on the 29th. Betsy won't.

Child Neurology Society Questionnaire		
Number of questionnaires sent:	189	
Number of returns 3-15-72:	146	
1. I believe there is a need for a national organization to provide a more detailed forum for interchange of scientific papers on Child Neurology and for promulgation of all aspects of Child Neurology.		
Yes	124	
No	16	
Ambivalent	6	
2. I am interested in joining and participating in such an organization.		
Yes	117	
No	16	
Ambivalent	6	
3. I am willing to submit a paper for presentation and/or attend a meeting of this group in Ann Arbor, Michigan in October of 1972.		
Yes	81	
No	36	
Ambivalent	19	

“L” is also for Logo

In that same 1996 review article on the Founding of the CNS, Ken Swaiman noted the following: “A solid organizational base was needed to provide a sense of stability and substance at the first meeting.

For example, we wanted a logo to place on the membership certificates. Denae Kasbi, an illustrator in the Department of Biomedical Graphics at the University of Minnesota and I, after some trial attempts, developed the logo that adorns the certificates and virtually all CNS materials to this day.”

The certificates have gone the way of most paper documents, but the logo lives on.



36 Days to Boston

“M” is for Minnesota Twins

Like most small-market major league baseball teams, particularly in the free-agency era of skyrocketing salaries and chronically neglected minor-league farm systems, the Minnesota Twins have had their ups and downs. I spent my early years of fandom singing the team's official song with little conviction ("We're gonna win Twins, we're gonna score") and the latter years belting out Bruce Springsteen's "Glory Days" with little joy. Still, the fact that there are glory days to sing of – unforgettable World Series wins in 1987 and 1991 – is something to treasure and celebrate. The same holds true of the two sets of metaphorical Minnesota Twins within the CNS touched on today; Ken Swaiman and Bruce Berg, undergraduate and med school classmates at the University of Minnesota in the early 1950s, and Karin Nelson and Samuel Drage, both undergraduates at the U of M when Swaiman and Berg were med students wandering around the hospital and campus overlooking the Mississippi River. We'll look at a third set of more recent vintage Minnesota Twins when "M" comes around a second time in September.

Much has been said of Ken Swaiman already. He was, as child neurologists of all ages and stages well know, a founding force and first President of the CNS in the early 70s, the PCN in the late 70s, and the Child Neurology Foundation in the new millennium. He and Frank Wright, a member of the La Crosse 8 officed next door to him at the University of Minnesota, issued the first two editions of a seminal textbook in

the 70s and 80s (I proofed and was acknowledged in the 2nd). Four editions have followed, thanks to the intellectual range and matchless drive of Ken's first and finest protoge at Minnesota, Steve Ashwal. It was Ken who birthed the journal *Pediatric Neurology* in the mid-80s, something younger CNS members might not know, mistakenly thinking current editor, Steve Roach has been taking it to new heights forever (in fairness, 10 years may very well seem like "forever" to someone in their late 20s; I don't recall).

As often happens with twins, identical or fraternal, one ends up being better known and more widely celebrated than the other. Ken has been amply recognized for his many contributions: a Hower Award in 1981, a special Founders Award in 1996, a special Legacy Award in 2017 and the naming of the Legacy Luncheon in his honor beginning with the upcoming 50th Anniversary Meeting in Boston. Less well known but worthy of equal celebration is his friend from St. Paul and the University of Minnesota, "the Big Swede," Bruce Berg. (Note: "the Big Swede" was a moniker Bruce picked up early in life, working a series of physically challenging jobs to earn money for school in his teens and early 20s. He and I enjoyed many conversations over the years, relishing the opportunity to freely "speak Minnesotan" as two born-and-bred North Star State Scandinavian-Americans, he a Swede, me a Dane; he roared with laughter when I suggested that Danes, after all, are essentially decaffeinated Swedes.)



Long associated with UCSF, the outstanding program he started in 1968 (and Audrey Brumback later celebrated for its "kickass women", many of whom Bruce recruited and mentored), Bruce strung together a trio of landmark accomplishments in the late 70s/early 80s that would stand up against anyone's CV within the CNS, two during his one-year term as President, the third shortly thereafter.

1. **Annals of Neurology.** In conversations begun in the Fall of '76 when Bruce was CNS President-elect and Fred Plum, then editor of Archives of Neurology, was a visiting professor at UCSF, Dr. Plum floated the idea of starting a new journal, *Annals of Neurology*, noting that, strategically, the ANA needed the numbers a partnership with the CNS would provide to get it off the ground.
2. **American Board of Psychology and Neurology (ABPN).** It's worth quoting in full a passage from

Bruce's remarkable reminiscences published in the *Journal of Child Neurology* in 1999. Noting that multiple child neurology training programs were beginning to spring up shortly after his and Paul Rosman's back-to-back CNS residencies (1977-79), Bruce wrote: "We now had a CNS, and PCN, but we had no representation on the ABPN, and there was notable resistance to any notion that child neurologists were an effective force. In 1981, at the time of the annual meeting of the ANA in San Francisco, Paul Rosman and I, as past presidents of CNS, arranged a meeting with some of the then present and past directors of ABPN, including Patrick Bray, Sidney Carter, Bob Fishman, Mel Yahr, and the late David Clark, to discuss the possibility of having a director's position on the board dedicated to child neurology. The facial expressions of the attendees were something less than interested or agreeable. The issues were cautiously introduced to the group and it seemed to me that there was little interest in our suggestion. However, before the end of the meeting, Sid Carter winked at me and David Clark nodded and slyly winked, but Paul and I thought that we had gained little for our colleagues and child neurology and headed in the direction of the bar. We must have accomplished something, however, for in 1983 there was a director's position for one child neurologist and we gained a second position in the subsequent year."



3. Professors of Child Neurology (PCN). Backtracking a few years before the ABPN "victory," Bruce worked closely with Ken Swaiman in creating the Professors of Child Neurology. Again, it's worth quoting at length from Bruce's own account, perhaps even more so this time, showing as it does, Bruce's innate charm and sophistication: "Not long after (the founding of CNS in 1972), during an evening when Ken Swaiman and I were having dinner at Le Trianon restaurant in San Francisco, and amiably incandescent after enjoying a bottle of Heitz Cabernet Sauvignon and a snifter of Otard cognac, our conversation turned to the fact that child



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neurologists in academic settings had certain problems that were different from those in practice. We thought there should be another society of the directors of child neurology training programs, during which time these special problems could be discussed. Since I was President of the CNS at that time, I had the opportunity to facilitate the formation of that new group, which became known as the association of Professors of Child Neurology. Ken became the first president of this group and I was the second."

Dr. Berg's professional progeny includes Donna Ferriero, past CNS President (2009-11) and Sachs Awardee (2006) who remembers "ripping up my internal medicine residency applications" and plans for a career in adult neurology after doing a one-month rotation with Bruce during her 4th year in medical school. It also includes Nancy Bass, with whom he shared years of friendship and mentorship at UCSF, including daily greetings ("How ya doin' kid?") and jalapeno bagels, before she returned to the Midwest, becoming in time, a current member of the CNS Board of Directors, and President of the PCN. The latter would please him enormously, for it was from Bruce Berg that Nancy learned to value, practice, even perfect the role of clinician educator. She has won several teaching awards and played a pivotal role, working with her colleagues on the PCN BOD (Karl Kuban, Tim Lotze, Soe



Mar, and Rujuta Wilson) in changing the name of the organization her mentor co-founded and she now leads by inserting the key word "Educators" to arrive at Professors & Educators of Child Neurology (PECN). Donna Ferriero recalls, Bruce's response to the notion that receiving a teaching award is an indication you're not paying attention to your research: "Hogwash! Do what your passion drives you to do." He did, Donna and Nancy have, and child neurologists and the children and families they serve, across the country and around the world, have all been the beneficiaries.

“M” is also for a 2nd set of Minnesota Twins

In bridging the gap from today's "M" to tomorrow's "N" (N is for the NIH-funded Neurobiology of Disease in Children, NDC), we could not hope to find a better or more fitting pair of Minnesota Twins than Karin Nelson and Samuel Drage. Both attended the University of Minnesota as undergraduates at the same time Ken Swaiman and Bruce Berg were enrolled as U of M med students (whether they knew each other then, I can't say, although it seems doubtful). Both went on to distinguished careers at NINDS, making lasting contributions that significantly shaped the paths and perspectives child neurologists adopted and now take for granted.

As noted in NINDS at 50: *An Incomplete History...*, Samuel "Sam" Drage, MD credits the Perinatal Project he served on as Acting Director "with changing concepts about the origins of cerebral palsy from birth injuries to earlier events when the fetus was still developing in the uterus. He also credits the project for validating the scoring system developed by Virginia Apgar, Professor of Anesthesiology at Columbia University.

Dr. Drage became Chief of the Developmental Neurology Branch in the mid-80s, working on the task force that sponsored studies linking aspirin to Reye syndrome and other studies linking folic acid deficiency to neural tube defects." Though not trained in neurology – his chosen specialty was pediatric endocrinology – his role at the NINDS and his contributions to child neurology compelled the CNS to welcome him as a member and he attended nearly every CNS annual meeting until his retirement in 1999.

Karin Nelson's path from undergraduate study at the University of Minnesota diverged from Sam Drage's: he remained in Minnesota for medical school, while she went to the University of Chicago, where she was first drawn to neurology by Douglas Buchanan, recipient of the first Hower Award in 1974. Her path converged with Sam's when she worked with him on the Perinatal Project before becoming Chief of the Epidemiology Branch of NINDS.

Dr. Nelson is one of only four CNS members to receive both the Hower Award (1991) and the Sachs Award (2004), the other luminaries being Joseph Volpe, Darryl De Vivo and William "Billy" DiMauro. She also served on the 3rd CNS Executive Committees in 1973-74 (shown on page 179; she is standing next to fellow-Minnesotan, Bruce Berg). The photo on the right, taken 25 years later, includes the 2nd President of the CNS, with whom she also served on the 1973-74 BOD, Gerald Fenichel, and my former boss at the U of M, Larry Lockman (Secretary-treasurer, 1981-84).

In composing his inimitably long, instructive, and elegantly insightful award profiles, Rob Rust wrote the following of Dr. Nelson in 2004: "Dr. Karin Nelson's name has become virtually synonymous with the intelligent study of the epidemiology and natural history of complex and poorly understood conditions. At the center of a research effort that has engaged the talents of many individuals, she has pioneered the application of well-selected and adapted epidemiological methodology to the cerebral palsies. She has employed the



same methods in the study of other important subjects, particularly febrile seizures, epilepsy, autism, childhood stroke. The efforts expended by Dr. Nelson and her colleagues have left a trail of discredited hypotheses, superficialities, and generalizations and have repeatedly made it clear that antecedents are not necessarily causes. These efforts have resulted in a new and much improved data on a wide variety of subjects, data that have permitted improved hypothetical formulations to be posed and retested....She has not so much challenged others to conform to her own high standards of investigation as she has demonstrated the virtue and productivity of such standards. In essence, she has elevated the level of discourse."

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“N” is for Neurobiology of Disease in Children (NDC)

Growing up in the 60s and 70s, I imagined the easiest paying gig anyone could ask for was Ed McMahon's job playing sidekick to Johnny Carson. You put a tie on, make sure your shoes were shined, sit up straight like your mother taught you, smile when you think the camera is on you, and laugh with faux gusto any time Johnny gave you "that look" or said something remotely funny. How tough was that?

In 2001, after 13 years of stressing out at the beginning of each CNS Annual Meeting, I not only found a way to take the stress out of those Wednesday mornings, I discovered that, quite by accident, I had come across a paying gig that made "Big Ed's" job look like a 12-hour shift in a coal mine. All I had to do was make sure

the AV crew had the microphone turned on when Bernie Maria climbed onstage to introduce that year's NDC Symposium, then show up 10 hours later at the Welcome Reception to ask him "How'd it go?" His answer was always "great!". And, why wouldn't it be? It was Bernie's show and "great" was his MO.

I can't tell you how relieved I was, two weeks into the 50-Day Countdown to Boston, to wake up this morning and realize it was Wednesday. A light bulb went off: Why change the magic, the secret sauce that got you through 20 years of high-stress Wednesdays?

So, with that in mind, I'll just say the two magic words and get out of the way: "Here's Bernie!"



Reflections on Neurobiology of Disease in Children (NDC) Symposia (1998, 2001-2020)

by Bernard L. Maria MD/MBA (Principal Investigator)

The field of child neurology has grown exponentially, due in part to our growing understanding of molecular neuroscience, brain pathology and genetics; but also due to improvements in neuroimaging and personalized medicine. Given the impressive rate of discovery in the field of child neurology, the ongoing challenge has been to translate this information into improved clinical outcomes and life-saving therapies that can be used by every child neurologist; a task that requires the cooperation of basic scientists, child neurologists and clinicians from many disciplines, lay organizations, and governmental agencies.

Starting in 1998 with a NIH-funded satellite symposium (Joubert

syndrome) at the Annual Child Neurology Society Meeting held in Montreal, Canada, and then continuously funded through four 5-year R13 NIH grants from 2001 through 2020, the Neurobiology of Disease in Children (NDC) symposia played an important role in child neurology. An annual in-depth forum focused on spreading the most up-to-date information on the clinical aspects, pathogenesis, therapeutic targets, translational opportunities, and future directions for a given neurological disorder affecting children. The attendance has included speakers and moderators who are among the most preeminent physicians and scientists, young investigators and scholars at different stages of career development, lay organizations and



associations who are champions for families of children affected from a variety of conditions, officials from the NIH, and members of the Child Neurology Society who then return to their respective communities with knowledge, values, skills and ideas on ways to move the field forward.

It is difficult to fully measure the impact of a conference or symposium, especially over more than 20 years. In fact, the same difficult question could be asked about the impact of the Annual Child Neurology Society Meeting over the last 50 years. One of the interesting things about our medical societies (CNS, ANA, AAN, APS, SPR, etc) is that they are centered on the needs of the respective practitioners (e.g. pediatricians, neurologists, ophthalmologists, geneticists, etc) who are members of their respective society. However, moving the field forward on any disease requires input from multiple clinical and scientific disciplines that may not regularly attend respective society meetings other than their own. I would say that the principal innovation of NDC has

been to include multiple disciplines in partnership with the NIH, respective foundations and associations, and the Child Neurology Society. In fact, while child neurologists were always among those speaking and moderating, they could easily represent the minority of speakers in the day-long symposium. NDC was "born" and then nurtured by the Child Neurology Society because of the "appetite" among child neurologists for an in-depth discussion or as former NINDS Director Dr. Story Landis used to say "soup to nuts" on a specific disorder. NDC was a home for communities of caregivers (Foundations/Associations) to build awareness and advocate for attention and research on their specific condition (Neurofibromatosis, Leukodystrophy, Tourette syndrome, others). NDC featured overlapping and complimentary multidisciplinary expertise and defined research priorities with active input from the child neurology community. NDC supported career development of many scholars and promoted interactions within the child neurology community, what I have



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come to call the "seeds of the field." NDC motivated partnerships between child neurology, communities of caregivers, and Federal funding agencies to move our field forward.

The proceedings of NDC over 20 years included hundreds of publications of both original and review articles, as well as summary podcasts posted to the meeting's website. I am especially proud to have catalyzed new collaborations among speakers (over 200 papers as first-time publications co-authored by NDC speakers), moderators, panelists and over 250 young investigators, 43% of whom were minority scholars.

As I reflect on the last 20 years of NDC and what Roger Brumback said about NDC after its first 10 years, I see the educational value of NDC much like I see the contributions from assembling a medical textbook. In 1999, I edited the first edition of *Current Management in Child Neurology* that ultimately had four published editions. Believe it or not, the first edition was the first medical textbook with a CD ROM! The purpose of the book was not that different from NDC in that both had the overarching goal of assembling knowledge from the experts and formatting it for an efficient and forward-looking clinical practice to better serve our patients. The advent of the internet, rapid pace of advances, shortened turnaround time needed for updates, evolution of internet libraries (Medlink Neurology, Up-to-Date, others), ease of access of information from multiple sources, and other important generational trends, made the practical

textbook, *Current Management in Child Neurology*, largely obsolete. When thinking about assembling a 5th edition, marketing analysis showed that the targeted segment of pediatricians, neurologists, and trainees had moved onto internet sources of information.

Like the medical textbook, I believe that NDC needs reinvention and innovation. The pandemic has forced rethinking our continuing medical education and while virtual connectivity has clear advantages, it cannot create the same 'human hub' of togetherness for interaction and collegiality that characterized in-person NDC. The audience has changed over the last 20 years and the younger mix has learned in ways that are quite different than boomer and silent generations. The values (including scholarly pursuits) of the four active practicing generations of pediatricians and child neurologists are probably still quite different from one another so how to incorporate 'mechanisms of disease' and 'translational opportunities' into future NDCs should probably be revisited. At a very basic level, advances in genetics have complicated matters and using leukodystrophy as an example, there were over 40 new leukodystrophies discovered between the original NDC symposium on the topic in 2002 and the updated one in 2017. In 2001, there were no clinical trials in neurofibromatosis but there were over 50 open clinical trials in 2016. While all of this is a measure of progress, it makes a future NDC symposium on NF or leukodystrophy potentially quite problematic. With over 5000 single gene disorders and 3500 conditions affecting

the developing nervous system, what should the next series of NDC meetings address?

A more pragmatic challenge has been funding for NDC. While the meeting costs approximately \$100,000 to hold in-person annually (AV costs, travel, personnel), no more than \$35,000 to \$50,000 was provided by the NIH. With audiovisual costs alone hovering around \$35,000 in recent years, finding co-sponsors to offset cost has been difficult because fewer Foundations/Associations have the requisite level of funding. While the Child Neurology Society has graciously served as cosponsor, it is not enough to make the meeting feasible in the usual in-person format. If anyone picks up the mantle to lead NDC into the future with the NIH (NINDS/NCATS) as the major sponsor, I envision a hybrid meeting that assembles speakers and panelists to interact in person with one another and young investigators and a small in-person audience of child neurologists and perhaps a larger virtual audience of child neurologists who could provide the requisite funding for NDC to flourish.

It has been a privilege to chair NDC since its inception. I have learned a great deal that has directly served the children in my practice as well as supporting my colleagues and mentees, especially with in-person interactions. Thank you for your support of NDC over the years and for recognizing some of what it has contributed in over 20 of our society's wonderful 50 years.

Thanks, Bernie



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“O” is for Ohio

Charlie Watts, the legendary drummer for the Rolling Stones, died on Tuesday. I never envisioned paying homage to Watts, or any other of the Rolling Stones for that matter, when I started out on this Countdown to Boston.



But, with the letter “O” for “Ohio” popping up two days after Charlie’s demise, how could I not? Cleveland, after all, is home to both the Rock & Roll Hall of Fame and the famed Cleveland Clinic, making the use of one or the other as a metaphor available, if not quite inevitable.

Most senior members of the CNS have already guessed, and more than a few, I’m sure, may both dread and fear where I’m going with this. So, I’ll put your mind at ease. I’m not suggesting (although some might) that the Cleveland Clinic’s dynamic duo of David Rothner and Gerry Erenberg are the Jagger and Richard of the CNS. Mick and Keith haven’t earned that distinction....not yet, anyway; and time (no disrespect to Charlie) is not on their side.

Where I am going with this is looking at the letter “O” through the lens of that staple of rock ‘n roll music: the 45 rpm record with its “A” side and “B” side. The first 45 rpm record I ever bought was in 1965 when, as an 11-year-old living in the cultural backwater of Rochester, Minnesota I felt sure my older brother and I were the only kids north of Chicago listening to WLS, and thus the first to hear the Stones’ “Get Off My Cloud,” the follow-up single to “Satisfaction” with Charlie’s signature drum solo intro that, to this day, I mimic while waiting for a slow computer screen to refresh. That song has played over and over in my head through the years: always in April when abstracts come pouring in and the requests for deadline extensions pour in even faster, then again in September/October when requests are different in kind and tone and the available remedies fewer and feebler and their reception less friendly (or so it seems).

In most cases the “A” side is just that, the “B” side is often an afterthought. In many cases their comparative merits even out over time; sometimes their roles are even reversed. It might be hard for anyone in the CNS to decide between those two old friends from Cleveland, David Rothner and Gerry Erenberg, which is the “A” side and which the “B”. The correct answer is “either”; or “both”. Both were born in Chicago. Both received training from an “A” list of the giants, titans and gods of early child neurology. Both spent the better part of five different decades at the Cleveland Clinic, Dr. Rothner distinguishing himself as a leading expert in pediatric headache, Dr. Erenberg pioneering research and



treatment protocols in Tourette syndrome. Both served the CNS in multiple capacities; Dr. Erenberg served on the Executive Committee as Councillor for the Midwest from 1977-79. Both are among the most respected and well-loved members of the CNS: as wise, witty and engaging in conversation as anyone you could hope to find, in or outside of the CNS. Both were honored with presentation of the Lifetime Achievement Award: Dr. Rothner at the CNS Annual Meeting in Austin, in 2013, and Dr. Erenberg at the 2018 meeting in his native Chicago. Each introduced the other. Both had the audience alternately enthralled and in stitches.

There are many others in Cleveland worthy of note, too many to mention or show photos of, I'm afraid. But I can't leave the shores of Lake Erie without at least giving a shout out to Wyllie, Scher, Wiznitzer & Bass, a group that, strung together, sounds a bit like the iconic Rock & Roll Hall of Fame "supergroup" Crosby, Stills, Nash & Young, albeit with life-saving rather than the life-shattering echoes of Neil Young's 1970 anthem, "Ohio."

Traveling south from Cleveland, one quickly comes to Akron. If Cleveland has the Rock & Roll Hall of Fame, Akron has the Hower Award Dinner, making it tough, for child neurologists, anyway, to decide which is the "A" side and which the "B". No city in the US has had a more sizeable or steadier stream of child neurology luminaries come to share what they have learned through decades of receiving and giving instruction, practicing under and alongside colleagues equally wise, compassionate and committed,

if less well-known or celebrated; "B" sides to their "A". Again, space prohibits including photos or mention of everyone, and I have touched on Dean Timmons and establishment of the Hower Award previously, but I feel compelled to include two CNS members from Ohio attending past Hower Award dinners: the aforementioned Mark Scher (a longtime friend; the first child neurology resident I met when I was hired at the University of Minnesota, shown here with 2006 Hower Awardee, Mike Painter); and Margaret McBride, whose tireless contributions to the CNS on multiple committees is a model all should emulate, and whose knowledgeable enjoyment of reading history and attending Chautauquas all should aspire to match in retirement (shown here with Dean Timmons and 2003 Hower Awardee, Mike Cohen).

Continue south and west and you come to Columbus, home of The Ohio State Buckeyes and Nationwide Children's Hospital, which once again begs the question: which is the "A" side and which the "B"? ("B" is for "Buckeyes," obviously, and surely "A" is for Anup, as in Anup Patel, incoming President of the Child Neurology Foundation.) I could go on and on about Steve Roach. Steve doubled the size of the Nationwide program as its longtime former Division Chief. He raised the impact factor of *Pediatric Neurology* after succeeding Ken Swaiman as editor. As CNS President (2011-13) he hired me in 2012 to succeed Mary Currey as Executive Director and made up for that with a half-dozen dazzling and substantial initiatives. And he continues to leave his impress on the future of child



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neurology by performing a labor of love on the closing afternoon of each CNS Annual Meeting since 2016, organizing and teaching the Biomedical Writing Workshop. Again, the best I can do in the space I have is mention names: Dara Albert, Emily de los Reyes (photo posted 8/21 along with two dozen other so-called "kickass women"), Warren Lo (CNS Executive Committee 2009-11), John Mytinger (author of numerous past award profiles, carrying on the tradition of his mentor, Rob Rust), Pedro Weisleder, and Jorge Vidaurre.

With Jorge we are presented with yet another "A" side vs "B" side case study. Few states are more solidly or classically midwestern isolationist (think Robert Taft), than Ohio. And yet, within the CNS, no state has offered up anyone or anything to match Jorge's energy and global vision. His leadership as chair of the CNS International Affairs Committee has been breathtakingly broad and substantial. We'll get to that in a few weeks when "I is for International" comes up.

Finally, one cannot leave Nationwide behind without bringing up Jerry Mendell, this year's Sachs Award Lecturer. Whether you are in Boston, attending the 50th Anniversary Meeting live (we hope you join the 625+ registered for the meeting thus far), or tuning in virtually, you will not want to miss his lecture on Friday morning, October 1.

Columbus also figures into "A" side vs "B" side conversations in at least two other key instances, presenting in reverse order: "B" is for "before coming" and "A" is for "after departing." Before coming to Columbus in 2014 for the CNS Annual

Meeting we had still not made the \$1 Million goal for endowing the Phillip R. Dodge Young Investigator Award. We both met and celebrated meeting that goal at the Friday evening closing gala in Columbus, the actual moment caught on camera (below) when Roy Elterman, President of the Pediatric Epilepsy Research Foundation (PERF), handed the new CNS President, Nina Schor, a check for \$170,000 that pushed us across the finish line.

Before coming to Columbus, the Child Neurology Foundation was in crisis; it met on the last day of the CNS Meeting to decide whether, in light of recent, troubling trends, it should close down or chart a new path forward. The board voted to take the latter track. After departing Columbus, incoming President, Don Shields and newly hired Executive Director (and dynamo) Amy Brin took on the challenge, turning things around and making the CNF the truly creative and impactful outreach and advocacy partner the CNS has always needed to fill out its mission of serving the larger child neurology community. Matching the movement from the 50th CNS meeting in Boston to the 51st in Cincinnati, the CNF Presidency will transfer at the end of this year's CNS meeting from Massachusetts (Scott Pomeroy) to Ohio (Anup Patel).

Two final "A" vs "B" notes, and then I'll let you get back to work:

If this year's 50th Anniversary Meeting ushers in the full 50th year of the Society's history (the "A" side), next year's meeting in Cincinnati is "Where the Next 50 Years Begins" (the "B" side). I wish I had more time and space available to touch on Don Gilbert's contributions to the CNS,



including his service on the Executive Committee from 2017-19, but I've gone on way too long already; that may have to wait for next year's countdown.

Finally, let me say a word about "A" vs "B" along the lines of symmetrical pairs, first and last as bookends, so to speak. The first CNS President I served under, albeit indirectly, was Bob Eiben. Dr. Eiben was the first child neurologist in Ohio (Dean Timmons was the second). Notably, this year in particular, his early work in medicine before turning toward child neurology was spent studying infectious disease, combating and controlling poliomyelitis.

Dr. Eiben was the first CNS President to serve a two-year term, succeeding Ray Chun in 1983, the year I started processing abstract submissions while working as a part-time student in the pediatrics

neurology division at the U of M. The last CNS President I will likely serve under is also closely identified with Ohio: Bruce Cohen from Akron Children's Hospital. There may not be two more straightforwardly honorable and estimable individuals in the CNS: Past, Present and Future. Closing out with a nod to recent Rock & Roll Hall of Fame inductees, Dire Straits, Bruce has been a "brother in arms" through the many ups and downs of the past 8 years during his successive terms as Councillor, Secretary-treasurer, and President-elect. I can't think of any better or more fitting way to bracket my years with the CNS than to begin ("A") and end ("B") with Bob Eiben and Bruce Cohen, two of Ohio's finest.



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“P” is for Pellock

Five years have passed since Jack Pellock died in the spring of 2016. It will be six years next month since we last basked in the sheer joy and exuberance of his company at a CNS meeting.

Today's entry, "P is for Pellock" gives me a much welcome reason to re-post two classic photos of Jack in his late prime, along with a few photos from that last "appreciation" staged on Jack's behalf at the meeting outside of Washington DC in 2015.

I miss Jack. We all do. If there was one person I wish I could call for reassurance and practical advice in these trying days and weeks of planning the CNS meeting under gathering clouds of uncertainty, it would be Jack. His initials, "JP" aptly capture his core being and express one of his core contributions to the CNS: "Joyful Pragmatism". I remember him telling me once when facing headwinds different in kind, but not degree, compared to those we're all leaning into now: "It's not a question of if you can make it through to the other side even stronger and better, it's a question of whether you can find enough people who believe that and are willing to work together to make that come true, or at least start to come true."

I am always leery of reflex nostalgia, so rather than slip into that mode (or slip into it any further), let me re-post something I wrote about Jack "in the moment," shortly after he died, published in the Summer 2016 CNS Connections:

In June 1968, the ABPN issued its first set of certificates in Neurology with Special Qualifications in Child Neurology (Charles Barlow received Certificate #1, Arnold Gold #6, Isabelle Rapin #9). Less than a year later, an ad agency in Richmond launched one of the most iconic tourism marketing campaigns of all-time with the tagline, "Virginia is for Lovers."

The connection might not seem obvious at first glance, but had you been with me at Jack Pellock's funeral in Richmond the third Saturday morning in May, or driven north to Charlottesville that afternoon to stroll around Monticello with Rob Rust, two weeks after he retired, you might have spotted it. As different as these two squires from the Commonwealth of Virginia were in temperament and appearance, both nurtured and generously shared with colleagues a vast wealth of knowledge in the unfolding mysteries of neurological development and disorders, Both richly personified Ray Bradbury's



I  Virginia



oft-quoted credo: "Do what you love and love what you do." And, both are, or were, not "merely" respected and revered, but genuinely and unabashedly loved by their colleagues, as witness Larry Morton's wonderful tribute to Jack posted on the CNS website, and Phillip Pearl's splendid profile of Rob Rust, published in the October 2015 CNS Connections in tandem with his receiving the Blue Bird Circle Training Director Award (also available on the website).



Physicians in general, and pediatric neurologists in particular, have a chronic tendency to communicate in acronyms. When texting and Twitter came along, they were ready for it. It should come as no surprise, then, that two three-letter acronyms spring immediately to mind when talking about Jack and Rob – JOY and AWE – with two more springing up along the way: PLA and PLW.

When I think of Jack, the word "joy" materializes almost unbidden: "joy" as in "a sense of well being," "exuberance," or "a source or cause of delight". The acronym serves equally well: "JOY as in "Just Offer Yourself." Jack didn't wait for someone else to fill a void or need. If there was a role he could fill, or a service he could provide, he didn't hesitate to make the offer and never failed to follow through and make good on it.

- As a respectful and well respected partner to and provocateur among pharmaceutical companies, Jack lobbied tirelessly and effectively for increased pediatric labeling and treatment options for children with epilepsy.

- As a past president of the American Epilepsy Society and past and present board member, respectively, of the Child Neurology Society and the Child Neurology Foundation, Jack generously offered his time, energy and vision to each in a manner that made plain to all that they were stronger standing and working together toward their complimentary missions than they were competing with each other and struggling apart.

- As the longtime friend and protege of Kiffin Penry, Jack carried on his legacy, enriching the epilepsy training of two generations of child neurologists, dating back to the mid-90s, by bringing together an impressive stable of experts in the field to stage a two-day epilepsy seminar for PGY5 residents immediately before the CNS Annual Meeting. Jack hoped that in time this would become a fully integrated feature of CNS annual meeting programming. And while he harbored no illusions that the transition from a pharma-funded satellite model to a Society-funded training and networking program might take time to fully evolve, he believed it was not merely worthwhile, but essential.

"These seminars aren't just about competence," he told me last year at what would, in fact, be his last CNS meeting. "They're about networking and building community." He didn't say it, but I will: as an extension of Jack himself, they were about continuing to cultivate a "JOYful" community ("Just Offer Yourself") of



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general and subspecialty pediatric neurologists including, but not limited to epileptologists. A community of “dual citizens” willing to remain fully engaged with each other, to stay in meaningful conversation with each other, to continue offering their time and talents to each other for the common good.

I can't speak for Ken Mack, but I have to think that, in looking back on his two years as CNS President (2015-17), he would regard as one of his proudest accomplishments negotiating a transition from the pharma-based satellite model Jack successfully staged for 20 years, to a CNS-staged two-day seminar for Junior Members of the CNS in their final year of residency. Ken was aided in this effort by the extraordinary creativity, resourcefulness, generosity of spirit and just plain Pellock-inspired “roll-up-your-sleeves-and-do-it” resolve of core organizers and faculty members Phil Pearl, Renée Shellhaas, and Elaine Wirrell, shown below. Below them is the founding cohort of residents gathered in Vancouver in 2016 for the 1st John M. “Jack” Pellock Resident Seminar on Epilepsy, and below that, the faculty overseeing the 2nd Pellock Seminar in Kansas City in 2017.

More than 300 residents have participated in the Pellock Seminar the past five years. Another 60 are signed up to participate this year in Boston, with another 12-15 registered to attend virtually. The program has been, as we hoped and as Jack would have greatly appreciated, a most welcome and,

in an increasingly virtual world, a much needed personal, in-person networking platform, a seedbed for what may well prove to be career- and life-changing friendships and professional collaborations among a new, emerging generation of child neurologists.

This year's 6th Annual CNS Pellock Seminar will be staged across two afternoons, Tuesday and Wednesday, September 28 & 29. Residents attending will receive fee waivers for the full CNS meeting, as well as three paid hotel nights. It's an expensive commitment on the part of the CNS, one made possible in no small part by the generous support of a five-year grant from the Pediatric Epilepsy Research Foundation (PERF). It also involves a generous commitment of time and talent on the part of the more than 20 faculty members who have contributed in the past five years, largely pro bono, consistent with the “pay-it-back, pay-it-forward” spirit that is a central part of the CNS legacy, one that will be celebrated at this year's Kenneth F. Swaiman Legacy Luncheon on Wednesday.

The Legacy Luncheon on Wednesday is, in fact, built in to the Pellock Seminar this year as the official lunch/opening session on Day 2. This will give those attending a once-in-a-lifetime immersive appreciation of the child neurologists, including Jack Pellock, who built the framework and established the foundation that they all benefit from now and will all grow into and build on, working together with their new-found friends and colleagues.





32 Days to Boston

“Q” is for Questions

I wrote a few days ago about how closely my life's path ran alongside the founding of the Child Neurology Society in 1971-72 without anyone on either path having the slightest clue about the other's existence, much less their future fate.

If there was a soundtrack for that period of my life, both at the time and as I remember it years later, it would be Crosby, Stills, Nash & Young's Déjà Vu. A 50th Anniversary pressing of that iconic album has just been released. The timing, as it relates both to me and the CNS, our paths now fully converged, couldn't be better.



Or, should I say "worse"? The doleful refrain from the album's title track – "We have all been here before" – is eerily and depressingly resonant with the position we all find ourselves in as another Summer turns toward Fall. Last year's once-in-a-generation joint meeting with ICNA in San Diego was certain to be the best CNS meeting ever, until COVID shut it down and forced us to go virtual. This year's once-in-a-lifetime 50th/Golden Anniversary

Meeting in Boston was a lock to be even better yet, topping whatever wild and wonderful pre-COVID hopes I originally had for the joint 2020 meeting. It still might, but the forward path toward finding out will be clouded with uncertainty and anxiety unlike any we have walked through together since Ann Arbor in 1972. Other than last year, that is. "We have all been here before."

Having been here before, having wearily and warily answered "yes" to Jimmy Hendrix's question, "Are you experienced?", we press on, taking care of business, making plans and coming up with answers to key questions. The opening cut of Déjà Vu plaintively references all those "questions of a thousand dreams" that mark our path through life; the song's title vows and invites us to "Carry On." So we do. And so we will.

So, let me put three questions to you, then give you a turn to put three questions to me:

In registering for the meeting you were asked to answer two questions:

- "What was the first CNS Meeting you attended?" and
- "What was your favorite CNS Meeting?"

I'll put a third question (or a series of related questions) to you now:

- In what ways did your career and life change in between the two meetings you cited?
- In what ways did your career and life change because of one or both of those two meetings, directly or indirectly?
- Was it a CME session or SIG meeting you attended?

- Was it, perhaps, an award lecture that particularly inspired you?
- What friends or mentors did you first encounter at those or other CNS meetings that have made a key difference in your career and life? What crossroads did you come to, what connections were made that sent you in one direction rather than another, defining or redefining your career, and along with it, perhaps, your life?

I remember Donna Ferriero talking about a chance meeting following a symposium at a CNS meeting years ago that led to a career-changing, life-enhancing collaboration with Laura Ment... or was it Gabrielle deVeber? I can't remember anymore, and jogging my memory with "the one who later won a Sachs Award" doesn't help; both did, Laura in 2011 and Gabrielle in 2014.

Bruce Cohen recalls poking his head into the door of a CNS Practice Committee meeting early in his career and innocently asking if he could sit in. Out of that came a decades-long investment of Bruce's time, talent and energy on practice-related issues that have benefited both the CNS and AAN immensely.

Then there is Tobias Loddenkemper, relating in a videotaped conversation I had with him in Boston back in early 2020 how formative and affirming CNS meetings were for him: "I found the Child Neurology Society meeting for myself really launched my career. What we built around this concept of treating seizures and acute seizures is ultimately a national research effort that is looking into acute seizures and status epilepticus. That was actually founded at a CNS

meeting. I basically reached out to many people by email that I knew were interested in the same field, actually extremely senior people as compared to myself. But they were remarkably



approachable. When I emailed them they said 'Yes.' We exchanged emails: 'Are you at the CNS meeting?' (Yes). 'Do you have time to meet us in the room?' (Yes.)

[Click here to view video.](#)

There are dozens, hundreds more stories like this, all of which when stitched together offer a compelling narrative history of the CNS. I would love to hear and share your stories, your answers to the questions raised above, or others in a similar vein that might occur to you. Please feel free to email me with them anytime. But, patience, please: as we approach the Boston meeting I somehow find myself "otherwise occupied" and unable to reply as quickly, eagerly and expansively as I might otherwise.

And now, your questions, the top three, anyway, that seem to be put to me most often these days:

1. **Are we still meeting live in Boston?** Yes, as long as the city of Boston or the Commonwealth of Massachusetts says we can. The question is not so much "are we meeting in Boston?" as it is "how many of us will be meeting in Boston?" That, I can't answer; only you can. As members make individual risk assessments or their institutions makes those assessments for them, the number will change in the coming week, then change again, if we're lucky and the current rising curves go down just prior to the meeting, following a pattern seen in the

UK (which may or may not make for an apt comparison, variables and variants being what they are). I don't see Boston shutting down a second time, what with the prospect of a Red Sox wild card playoff game three days after our meeting and the Boston Marathon nine days after. (The Marathon, as many of CNS runners know first-hand, finishes up on Boylston Street, just past and beneath the Hynes Convention Center and Sheraton Boston windows.) We may end up with mostly New Englanders and people driving up from NYC, Philadelphia and DC, and our numbers may only be 2x, 3x or maybe 4x the number attending the first meeting in Ann Arbor. But to the extent we can control our fate, we will have a live, in-person 50th/Golden Anniversary Meeting this Fall. Registration numbers today stand at 650 live in Boston, 150 attending virtually; still ahead of all previous meetings at this point, 4 weeks out.

2. **What happens if I can't come to Boston?** There's the beauty (and challenge) of this year's hybrid meeting. Rather than cancel your original registration for the live meeting in Boston and resign ourselves to muttering a now all-but-forgotten Boston Red Sox/Brooklyn Dodgers mantra – "wait 'til next year" – we will transfer your registration to the Virtual Meeting offered on-line. A great CME program crafted by Carl Stafstrom and Yasmin Khakoo featuring seven symposia, nine seminars, 200+ posters, breakfasts, workshops and luncheons will still be available the week of the regularly scheduled meeting and On-Demand thru October 29. Hugs, laughter, and life-changing chance encounters may not be.

3. **What is the next big date I need to keep in mind?** September 8. That's when ALL speaker presentations and all posters need to be uploaded to the virtual platform, whether the presenter plans on presenting live in Boston from a podium or alongside a poster, or is forced to stare into their laptop screen at an imagined audience while they deliver a live-streamed lecture from their office or kitchen table. Check your emails from Emily McConnell for updated guidelines sent on August 26 and 27.

Above all: "Carry On."



31 Days to Boston

“R” is for Roach

Earlier in this series I suggested that had it not been for Marvin Fishman, few of you would have known or met me, and likely none of you would remember me. That's a large burden of guilt for any one person to carry, even a Texan, so today I'll take half of it off of Marv's shoulders and place it squarely on Steve Roach's.

Steve was only a few months into his first term as CNS President in the Winter of 2012 when he charged the other six members of the 2011-12 CNS Executive Committee with the job of interviewing me individually by phone to determine whether or not his notion of hiring me to succeed Mary Currey as Executive Director was well-founded. I had known and worked with most of them for years and wondered why that might be necessary, but as I came to appreciate, working closely with Steve over the next two years, he is not one to take anything for granted or leave any stone unturned. And, to be fair, I did throw him off guard with my seeming insouciance a few months earlier when we both arrived in Savannah at the same time for the 40th Annual CNS Meeting. Many of you may recall that the CNS occupied two hotels that year, separated by a river which, to cross from one side to another, required a ferry boat that ran semi-regularly but reserved the right not to in inclement weather. Turning toward me at the hotel check-in counter, Steve looked me squarely in the eye and asked, “Do you have a back-up plan if a storm kicks up and the folks at the Hyatt can't catch a ferry to the convention?” To which I replied,

“Steve, if you can't forecast the weather accurately three years out when we sign these contracts, you don't belong in this business.” I don't remember what his exact response was, but the look on his face was somewhere between amused and alarmed. In retrospect, I'm surprised and relieved he didn't immediately follow up by asking, “How are you at predicting pandemics?” The answer, as it turns out, is “not very good.”

One of the conditions of being hired as the new ED was that I take courses from the American Society of Association Executives (ASAE) and pass their rigorous CAE exam within three years. Which I did, and I am grateful for the support and encouragement Steve and the board gave me to nurture my professional development. But the truth is I learned 10 times more working side-by-side with Steve for two years



than I have in the nearly 10 years of conferences and coursework since.

No one who has worked with Steve in any capacity would challenge my assertion that in terms of organizational prowess, he has no peer. Every training program he has been part of or in charge of has grown in numbers and excellence during his tenure, most notably Nationwide Children's Hospital in



Shown above, the combined 2012-13 CNS Executive Committee, including members rotating on and off: Bottom (L-R): Dan Bonthius (CNS Connections Editor), Roger Packer, Vinodh Narayanan, Sue Hussman (CNS Associate Director). Top (L-R): Roger Larson, Barry Kosofsky, Steve Roach, Nina Schor, Suresh Kotagal, Bruce Cohen, Harvey Singer.

Columbus, OH. Many of the young academic clinicians he recruited and/or mentored, and encouraged to actively participate in and contribute to the CNS, were shown on 8/26 ("O is for Ohio"); it's worth adding two more here (top and middle photos), John Mytinger (on the occasion of his winning the 2015 CNF Infantile Spasms "Hero Award") and Dara Albert, active in the PECN and the CNS History/Archives Committee.

At a time when most people would settle for kicking back and coasting into retirement, Steve traveled south take on a new challenge as co-chief of UT Health Austin Pediatric Neurosciences at Dell Children's and director of the pediatric neurology residency program. As he prepares to end his tenure as editor of *Pediatric Neurology*, having succeeded Ken Swaiman in 2012 after serving the previous 14 years as associate editor of *JAMA Neurology*, he does so knowing that he significantly strengthened the overall qualify of the journal, including raising its impact score by 140 per cent.

During Steve's tenure as CNS President, we devised or revised most of the organizational structure and policies that are currently still soundly in place. Working with his predecessor, Donna Ferriero, his successor, Nina Schor, and his counterpart at the CNF, Don Shields, Steve helped "reboot" the CNS-CNF relationship, setting it on track toward realizing the more closely and constructively collaborative partnership serving the larger child neurology community that it enjoys today. His keen eye for writing talent resulted in the appointment of Dan Bonthius as editor of *CNS Connections*, and

his passion for cultivating writing skills among an emerging generation of child neurologists has led to his voluntarily staying on the final Saturday afternoon of the past five CNS meetings to teach a limited-enrollment Biomedical Writing Workshop.

I have enjoyed in different ways and degrees working with every CNS President I've known since starting out as a part-time admin processing abstracts when Bob Eiben was President in 1983. People sometimes ask me if I have a favorite, and I always reply "whichever one is signing my next paycheck" (there's that insouciance again). The truth is, I have liked and respected all of them and have gotten to know and grown to like them even more over time. A few I consider friends. I have thoroughly enjoyed being hosted in Steve's splendid house in Columbus, getting a guided tour of his impressive collection of art and first edition books, savoring an expertly prepared meal he and Lisa prepared, petting their dog, Lucy. The lack of free time and my aversion to extreme heat has precluded visits to Texas, despite his frequent emailed invitations with photos of grazing deer and Texas bluebonnets in bloom. By virtue of his having taken a chance on hiring me as ED, having patiently coached and coaxed me through my first two years at the helm and made good on his offer to be available as a counselor and sounding board whenever I needed one thereafter, I consider Steve to be both Friend and Mentor. If he, or anyone else, had asked me 10 years ago if I could predict that outcome, I would have humbly responded – no glibness or insouciance – with a simple "no."

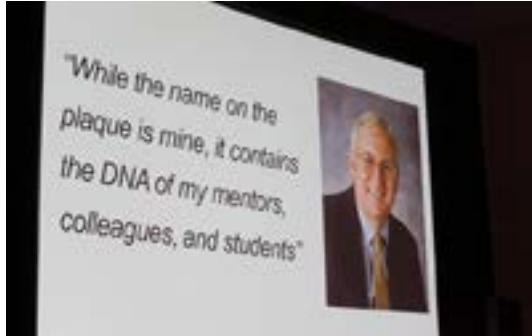


Thanking Dan Bonthius for accepting the assignment as new CNS Connections Editor.

31 Days to Boston



Presenting the 2013 Bernard D'Souza International Fellowship Award to Dr. Samson Gwer, from Nairobi, Kenya.



A telling slide presented as part of Steve's 2015 Hower Award Lecture.



Presenting the first M. Richard Koenigsberger Scholarship Award to Dr. Louis Dang, from the University of Michigan in 2013; Louis went on to later win the 2019 Phillip R. Dodge Young Investigator Award. I should note here that, to the best of my knowledge, the photo above does not show them placing a bet on the upcoming Michigan-Ohio State Football game, compassion being another of Steve's many virtues.



Two past-CNS presidents and longtime friends (and friends of mine, as well), John Bodensteiner and Steve Roach, with their wives, Donna and Lisa.

30 Days to Boston

“S” is for Sachs Award and Scientific Program Planning Chairs

Thirty-five years is, in theory and according to the Constitution of the United States, the length of time needed to travel from the womb to the White House. It is also roughly the length of time it took Joe Biden to make it from his first presidential campaign launch in 1987 to taking the oath of office in January 2021.

Thirty-five years is a long time to be in conversation with yourself and with others about your life, your life's work, your vision and values, and theirs. Which is essentially and ideally what, up until recently, politics and running for and being President was all about.

What interests me here is not presidential politics. It's the notion of conversation, of being connected to and in conversation with one's colleagues, one's career, one's calling, and one's community. Those of you have gone up to the new CNS website will recognize the latter four "C's" as the structural foundation, the organizing principles by which one can navigate the website and orient one's self in relation to – as being connected to and in conversation with – one's life as a child neurologist and member of the Child Neurology Society.

Thirty-five years ago, when the CNS convened in October 1986 for its 15th Annual Meeting; it was the first and only other time it met in Boston up until this year's 50th/Golden Anniversary Meeting. In looking over the program, I couldn't help but be struck by the line-up for the Specialty Symposia following the

Bernard Sachs Award Lecture. The symposium featured three future Sachs Award Lecturers: O. Carter Snead, III (2005), Greg Holmes (2009) and Solomon "Nico" Moshe (2017). Attendees in Boston opting for Neuroimaging over Epilepsy could sit in on talks given by two future Sachs Awardees: Harry Chugani (2015) and Roger Packer (2012).

What I find even more amazing, however, is that 35 years later three of those Sachs Award Lecturers are organizing sessions and giving talks at this year's meeting in Boston: Roger Packer (Seminar 6: "Medulloblastoma, New Clinical and Translational Insights: the path forward"); Greg Holmes (Seminar 8: "The Critical Period of Memory Development: Construction, Destruction and Reconstruction"); and Nico Moshe (Symposium V: "Developing Treatments for Pediatric Epilepsies: From Models to the Clinic"). Thirty-five years later they are still carrying on a conversation with their colleagues in child neurology. Remarkable!

It's that notion of carrying on conversations, important conversations connecting colleagues, career, calling and community within the CNS that strikes me most in thinking about all those years working closely with CNS Scientific Program Planning Committees and their Chairs. One of the most consistent and salient qualities all past and present Program Committee Chairs share in common is that tangible gift for sparking and sustaining meaningful conversations with and among their peers in the CNS. It should come as no surprise to anyone that many of them subsequently proved capable of "translational"



8:00 Welcome and Announcements
-8:15

8:15 Bernard Sachs Lecture

-9:15 Introduction
Darryl De Vivo, New York, NY

Postnatal Maturation Changes in Cerebral Circulation: Energy, Metabolism, and Function
Louis Sokoloff, Bethesda, MD

9:15 SPECIALTY SYPOSIA

-10:00 Epilepsy in the Developing Brain
Moderator: O. Carter Snead, III, Birmingham, AL

9:15 Seizures, EEG, and Brain Development
-9:45 *Greg Holmes, Newington, CT*

9:45 Neonatal Seizures
-10:15 *Cesare Lombroso, Boston, MA*

10:15 Break
-10:45

10:45 Experimental Epilepsy in Developing Animals
-11:15 *Solomon Moshe, New York, NY*

11:15 Neuropeptides and Epilepsy
-11:45 *O. Carter Snead, III, Birmingham, AL*

11:45 Discussion
-12:00

Neuroimaging in Child Neurology
Moderator: Harry T. Chugani, Los Angeles, CA

9:15 Cranial Ultrasonography in Neonates and Infants
-9:45 *L. Matthew Frank, Norfolk, VA*

9:45 MRI of Brain and Spinal Cord in Infants and Children
-10:15 *Roger Packer and Donald Yawkin, Philadelphia, PA*

10:15 Break
-10:45

30 Days to Boston

conversations, shifting from within the rarified realm of pediatric and developmental neuroscience, to the more open but equally complex realm of politics in the classic sense of figuring out how we might best organize ourselves collectively for the common good. Along those lines, more than a dozen past Scientific Program Planning Committee Chairs have gone on to be elected to serve on the CNS Executive Committee (Gerald Fenichel, Steve Ashwal, Doris Trauner, O. Carter Snead III, Alan Percy, Michael Johnston, Marc Patterson, Donna Ferriero, Leon Dure, Nina Schor, Jonathan Mink, Gary Clark, Barry Kosofsky, and Vinodh Narayanan. Half of them went on to serve as CNS President: Gerald Fenichel, Steve Ashwal, Alan Percy, Donna Ferriero, Nina Schor, and Jon Mink. Four have won Hower Awards, three have received the Sachs Award. Pictured below is a sampling of the those most gifted and giving past and present program chairs:





Mike Johnston (L) who organized the 1st Joint CNS-ICNA Meeting in 1994, working alongside CNS President, Joe Volpe; and Alan Percy (R), who planned the 1990 and 1991 meetings, working in partnership with CNS President, Darryl De Vivo. Alan subsequently worked closely as CNS President with his Scientific Program Chair, Leon Dure, planning the 1998 meeting in Montreal and the 1999 meeting in Nashville.



Erika Augustine (L) was the program chair charged with planning the highly successful 2018 and 2019 meetings in Chicago and Charlotte, working with CNS President, Jonathan Mink. She then stayed on the committee for a year, working with CNS Program Chair, Carl Stafstrom (R) in planning the 2nd Joint CNS-ICNA Meeting. Jon Mink came out of "program chair retirement" to serve as overall Joint CNS-ICNA committee chair. Carl is joined in the 2nd year of his term by co-chair, Yasmin Khakoo, the two of them overseeing planning for the once-in-a-lifetime 50th Anniversary Meeting in Boston.....and it's hybrid variant.



2021 CNS Program Planning Committee Co-Chair, Yasmin Khakoo (L), with her counterpart from nearly 20 years ago, Donna Ferriero (R). Donna planned the program for the 2002 meeting in Washington, DC and the 2003 meeting in Miami Beach, working alongside CNS President Steve Ashwal. Donna followed in the footsteps of Nina Schor, who chaired the committee in 2000 and 2001, working with Mike Painter, experience she drew on when, as President she worked with Jon Mink in staging the 2014 and 2015 meetings.

29 Days to Boston

“T” is for Twitter

I wrote yesterday about the role a handful of Sachs Awardees and Scientific Program Chairs have played in stimulating and sustaining essential conversations within the CNS and the larger child neurology community. It seems only natural to me to segue from there to an entry on one form of social media, Twitter, that seems to encroach upon and erode the social fabric and habits within which conversation can thrive, or perhaps even survive.

That was my initial take on Twitter, anyway, one colored, as nearly everything was the past four years by the nihilistic twitter-tantrums emanating from the black hole that once was the White House. I have, of late, begun to change my mind (every so slightly), or at least soften my senile fulminations aimed at Twitter and other social media, thanks in part to the work being done by a member of the CNS Electronic Communications Committee, Jaclyn Martindale, DO, a former trainee of Jon Mink's in Rochester, now on faculty at Wake Forest University School of Medicine in Winston-Salem, NC. I will, in fact, hand over today's entry to her, much



as I did a few days ago with Bernie Maria talking about NDC.

But first, a final anticipatory counterargument:

When Steven Colbert hosted MIT professor and prolific author, Sherry Turkle in 2011 on his original, Comedy Central Show, he asked her, with faux innocence, “Don’t all these little tweets, these little sips of online conversation, add up to one big gulp of real conversation?” To which she responded, “no,” an answer she expanded upon at greater length in

2015 with publication of her book, *Reclaiming Conversation: The Power of Talk in a Digital Age*. ([Click for video.](#))

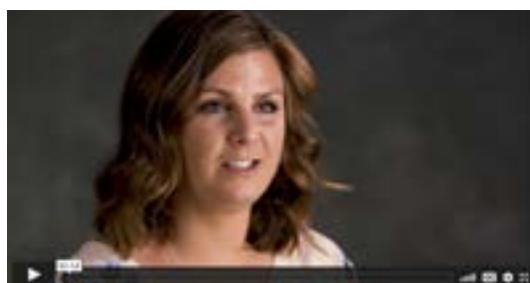
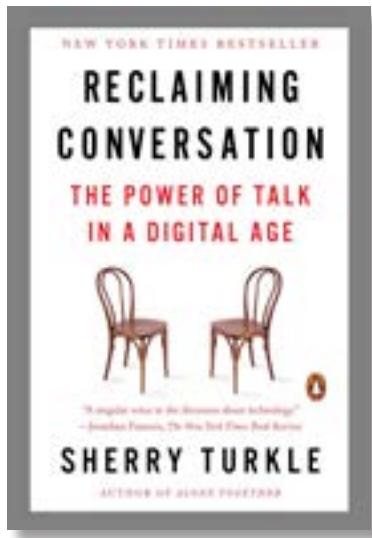
I flirted briefly in my pre-pandemic innocence with the idea of inviting her to take a short walk across the bridge from MIT to the Back Bay to talk to and with us at the 50th CNS Annual Meeting at the Hynes Convention Center, hoping she might read and expand upon a passage from an early section, “I’d Rather Text than Talk”: “The anxiety

about spontaneity and the desire to manage our time means that certain conversations tend to fall away. Most endangered: the kind in which you listen intently to another person and expect that he or she is listening to you; where a discussion can go off on a tangent and circle back; where something unexpected can be discovered about a person or an idea. And there are other losses: In person, we have access to the messages carried in the face, the voice, and the body. Online, we settle for simpler fare: We get our efficiency and our chance to edit, but we learn to ask questions that a return email can answer."

The result, she writes, is that "we are living moments of more and lives of less."

That might seem to be a singularly ungracious way to introduce Jacki's guest entry about Twitter, stacking the deck, so to speak; but, if we take seriously what Sherry Turkle writes and what we all know (or remember) about conversation, it's really no more or no less than basic point-counterpoint, leaving open questions about which position is more "privileged": having the first word or the last.

But before that, let me introduce Jacki to those of you who might not yet know her, approximating a face-to-face annual meeting intro by linking to a video clip on the Wake Forest Baptist Health website. ([Click for video.](#))



29 Days to Boston

“T” is also for Twitter

by Jaclyn Martindale, DO

In June 2021 the Child Neurology Society's Twitter account was relaunched in conjunction with the launch of the Society's new website. The account took on a new name @ChildNeuroSoc to make the CNS more readily searchable. The account is primarily run by Dr. Jaclyn Martindale (@dr_jmartindale) at Wake Forest School of Medicine (Winston-Salem, NC). Recently joining the social media team are Dr. Arpita Lakhota (@LakhotaNeuro) at University of Louisville School of Medicine (Louisville, KY), and Dr. David Hsieh (@dthsieh) at F. Edward Hebert School of Medicine (Bethesda, MD).

In three short months, the number of followers has tripled. There are over 600 followers and rising. Tweets (posts) have a monthly impact of 40-48K impressions. For those not familiar with twitter, impressions mean the number of times a tweet has been seen and are one of the indicators of brand presence.

Joining in with the expanding medical twitter community allows the Child Neurology Society to not only increase its presence on social media currently, it also allows opportunity to grow its presence over time. The COVID19 pandemic catapulted the medical community into the virtual realm – virtual conferences, meeting, interviews, open houses, etc. With so many things going electronic there are opportunities for the CNS to have further reach, attract new members

and gain recognition in ways that might not even be apparent right now.

As times have changes, so have forms of communication. Many young professionals utilize social media for medical information, self-branding and communication. A significant component of the medical twitter community is impacting and inspiring our future generation of child neurologists. There is a strong presence on twitter of incoming match candidates, trainees and residency programs highlighting their unique program features. This area yields opportunity for educational expansion of the Professors and Educators of Child Neurology (PECN) and Child Neurology Society combined.

At present, the content of the account is aimed at our members. As mentioned in earlier entries with the letter “K” (8/20-22), we have some pretty amazing members and love to highlight all of those “kickass women” and men alike. Content also focuses on professional development of our members including opportunities, networking and requests for applications.

During the annual meeting, make sure to use the official hashtag #CNSAM! It is a great way to network, connect with colleagues, share your experience, see highlights, and get meeting updates.



Twitter Tips and Tricks

Follow these accounts on Twitter.

- Child Neurology Society: <https://twitter.com/ChildNeuroSoc>
- Child Neurology Foundation: https://twitter.com/child_neurology/
- Your colleagues (ask them for their handle at the meeting)
- Check out our lists: <https://twitter.com/ChildNeuroSoc/lists>

Tag @ChildNeuroSoc and use #CNSAM or #childneurology in your posts.

Retweet, like, and share what others are saying by searching #CNSAM (https://twitter.com/search?q=%23CNSAM&src=typed_query&f=live) or #childneurology (https://twitter.com/search?q=%23childneurology&src=typed_query)

Share images, GIFs and videos when applicable.

Thank you, Jacki (and Arpita). And thanks to David and the entire Electronic Communications Committee he chairs for its ongoing commitment to multiple projects and a growing list of impressive outcomes. Watch for new case studies to be posted in the coming weeks on the CNS website, an update on the previously posted telemedicine guidelines with additional guidelines focused on examining neonates, a live webinar series to be launched post-Boston, and very promising proposal for an educational podcast series by Dr. Kathryn Xixis from the University of Virginia that the CNS Executive Committee will review in September for a possible October launch.

28 Days to Boston

“U” is for Updates

Are we still meeting in Boston?

Yes, we are still planning on meeting in Boston. At this point, four weeks out, only the city of Boston and/or the Commonwealth of Massachusetts can shut down the 50th/Golden Anniversary Meeting at the Hynes Convention Center. Cases are rising in many parts of the country, and beginning to plateau in others. There is no knowing what the situation will look like and what level of risk attendees will need to calibrate in four weeks. With 40-50% of our members within a day's drive of Boston, and this being the 50th/Golden Anniversary Meeting, I feel we need to hold on to the prospect of meeting in person as long as possible, hoping for movement in a positive direction a week or two before the meeting, prepared for the possibility there may not be. The virtual meeting platform will be fully ready for prime time the last week of September. Déjà vu all over again....

How many are registered as of September 1?

735 for Boston (785, including guests); 270 for Virtual.

What are the contingency plans?

Live in-Boston registrations can transfer to virtual registration any time (or vice versa) by contacting registration@childneurologysociety.org and referencing your confirmation #. If Boston/Hynes cancels, registration will automatically be assigned to the Virtual Meeting.

What basic protocols are in place for the meeting?

1. Masks will be mandatory in the convention center (speakers may remove their mask during presentation).
2. Vaccination is requested and, frankly, expected among our attendees, but there will be no active, across-the-board monitoring or enforcement related to proof of vaccination.
3. Social distancing will prevail almost by default, with # of attendees being 50 per cent or more below the originally anticipated 1800 attendee figure used to plan for the overall meeting and individual sessions.
4. We are cancelling the previously planned history-based scavenger hunt in the exhibit hall and the Friday reception will no longer be a 70s-themed gala; just "come as you are" and have a good time with great company, great food, and great music.

What deadlines apply to presenters?

1. Posters. PDF must be uploaded by September 8. See guidelines on CNS Website Annual Meeting page.

<https://www.childneurologysociety.org/colleagues/network/cns-annual-meeting/>

2. Speakers (symposia, seminars, platforms):

Presenting in Boston? Must upload and check in to Speaker Ready Room 24 hours before session begins.

Presenting virtually from home/office? Zoom link will be provided to present live, in real-time from your computer.

What about alumni receptions?

Program chairs and coordinators: [Click here to go to application portal \(SurveyMonkey\)](#).

Limited rooms available Wednesday, Thursday, Friday nights at the Hynes. Will refer to Boston CVB to help find and book offsite venues.

Further Updates:

Check CNS Website. Updates will also be included in daily Countdown to BostoneConnections.

“U” is also for Uh-oh...

The real struggle in writing today's entry is resisting the temptation to "drop the needle" on CSNY's Déjà vu all over again. As dicey, even dark, as the prospects of actually celebrating the 50th Annual CNS Meeting live in Boston might seem to some – even to me, sometimes – we have been here before. Maybe not under as deep and dark a cloud of uncertainty four weeks out from the meeting, but we've had a few "uh-oh moments" and come out on the other end alright.

I remember coming back from the site visit to New York on Valentine's Day in 1993, excited about the prospect of having the scientific posters circling the mezzanine of World Trade Center 1 when the full CNS met at the adjoining Vista Hotel in the Fall, and despondent about the certainty of losing money hands-over-fist on the meeting. Holding an event in New York was not going to be cheap. Nor was it in the cards. On February 26, ten days after I related my woes to a friend, he called and breathlessly asked, "Did you see they just blew up your hotel?" I hadn't, and not yet being hooked up to the internet (yes, dear residents, there was a time when we didn't all hold the world in our palm or see history unfold on our desktop), I had to turn the radio on to verify he was sane and sober. He was. And while it's not quite true that they blew up "my hotel," the bomb did go off in the parking garage right below the Vista Hotel ballroom in which all our general

sessions and receptions were to be staged; the ballroom was gone and the prospect of meeting in New York City with it. Mary Currey and I had less than seven months to come up with a Plan B, without the benefit of having Sue Hussman work her magic (Sue wouldn't enter our world until a year later). Finding enough meeting space and sleeping rooms on such short notice seemed all but impossible. But wait: couldn't Mickey and Uncle Walt somehow make our dreams come true? They could, and did, and the 22nd Annual CNS Meeting in Orlando worked out splendidly.

After that, anything and everything that came our way seemed inconsequential...until 2020, anyway. But, there were moments. The first joint CNS-ICNA meeting had its share of logistical, diplomatic and budgetary challenges. And there was a perilous hour spent pitching wildly from stern to bow on a boat full of child neurologists passing under the Golden Gate Bridge in the middle of a violent thunderstorm. In the end, 1/4 of world's child neurologists did not sink to the bottom of San Francisco Bay as I feared they might, and wait lists for initial appointments across the US did not jump from six months to a full year in the face of an even greater, unforeseen and tragic workforce shortage.

Things remained relatively quiet for the next few years, other than a food fight in Phoenix in 1997 and a series of small misadventures at Nashville's Opryland in 1999. There are better ways to start out a meeting than the way we did in 2000 in St. Louis when the Adams Mark Hotel Convention Service Manager we had worked with for



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months and spent 8 hours the day before going over everything in detail left a note on her emptied-out desk the next morning: "I quit." (I swear it had nothing to do with me.)

In 2001 we had another World Trade Center bombing to deal with: 9/11. Our 30th Annual Meeting was scheduled to be held at the Empress Hotel in Victoria, British Columbia. Suddenly, the prospect of flying anywhere and crossing the Canadian-US border seemed, for many, too risky and overwhelming to even think about. Calls flooded in asking if they could cancel their registration and asking us why we hadn't cancelled the meeting entirely. In the end, nearly 600 people came for what proved to be a terrific meeting, with a higher number of attendees, even, than the two previous meetings in Nashville and Montreal.

In 2002, the CNS meet at the Sheraton Wardman Park in NW Washington, DC in the middle of the three-week shooting spree involving the DC/Beltway Sniper, including four fatal shootings days before we arrived in DC. Going outside of the hotel was anxiety-inducing to put it mildly. When a fire alarm went off during the afternoon symposia and a voice on the overhead intercom instructed everyone to evacuate the hotel, few did. Doing so seemed insane.

Quebec City (2007) was, perhaps, my favorite annual meeting destination, as it was for many others. It's a pity many attendees' luggage never made it across the border to join in the fun. I flashed a slide onscreen in between sessions showing luggage piled up at the Newark Airport, adding the lyrics

2001 Bernard Sachs Award Lecturer
In one of his final acts in office, outgoing CNS President Michael Posner introduces Huda Zoghbi at the 2001 Bernard Sachs Award Lecture.

2001 Hower Award Lecturer
Charles Bailey addresses the audience's appreciative recognition of his lifetime achievement in research following an introduction by CNS President Stephen Arfvidson.

2001 Young Investigator Award Recipient
Daniel Brubaker, recipient of the 2001 Young Investigator Award, sponsored by Sigma Tau Pharmaceuticals, Inc., is greeted following an outstanding lecture by his mentor and colleague at the University of Iowa, Katherine Mathews.

2001 Scientific Award
CNSP Scientific Award Committee Co-Chair Dennis Freeman and Michael Johnson flank recipients of the two new \$10,000 research grants, Amy Brooks-Kayal (L) and Janet Rennertson (R).

"We'll meet again, don't know how, don't know when." As my daughter often says when I try to make light of her woes: "Too soon?"

In August, 2009, two months before meeting in Louisville, the Churchill Downs Museum at the Kentucky Derby racetrack was flooded following an epic storm, forcing us to relocate that year's President's Appreciation Reception for past officers, committee chairs, and award recipients.



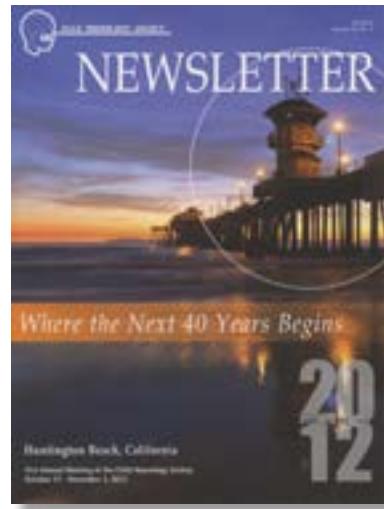
The 40th Anniversary Meeting in Savannah in 2011 went smoothly, despite Steve Roach's legitimate concerns about storms shutting down ferry service between the two hotels. The next year's meeting in Huntington Beach, overlooking a placid, picture-perfect Pacific Ocean, promised to be a crisis-free winner. What could possibly go wrong?

Plenty, as it turns out. Across the continent, on the eastern seaboard, Hurricane Sandy was wreaking havoc as it worked its way north from the Carolinas to New England, flooding hospitals and shutting down airports at all points in between. For a day or two, it looked like over 300 potential attendees would not be able make it to the meeting. In the end, less than 150 had to cancel, while the other 150 sipped drinks with little umbrellas in them as they sat watching the waves come in and regaled their colleagues with adventure tales recounting their cross-country trek overcoming hell and high water to join them. I remember talking to Nigel Bamford in the hotel foyer well past midnight, and exchanging knowing glances as a familiar figure strode through the door beaming triumphantly: "Of course!" we both marveled. "Why would anyone think a mere hurricane could keep Darryl (De Vivo) from showing up?"

Hurricane Sandy in 2012 overshadowed and deflected attention from what could not be hidden in Austin in 2013: for the second year in a row, the CNS Annual Meeting was scheduled on Halloween. I hated Halloween as a kid. My mom kept six kids well fed, well read and well bred on my dad's modest income; coming up with a less-than-lame Halloween costume was not a high priority for her, much to my annual chagrin and

embarrassment. I hated the holiday even more after suffering through the 28-inch Halloween blizzard of 1991 walking the neighborhoods of St. Paul with my 3-year-old son and his best friend, Peter, the greediest, most insatiable sugar/candy junkie I've ever known. So, I was taken aback when a flash mob of angry young parents and/or party-hearty twenty-, thirty-and forty-somethings assaulted me with non-stop emails introducing me to the new reality that Halloween was now a major holiday right up there with Christmas and New Year's Day. Clearly, I messed with the wrong holiday and the wrong generation. I have careful ever since not to encroach on the high holy day of masked reverie, and it is the very first piece of important information I will pass on to my successor.

There's no need, really, to recount anything related to last year's meeting and COVID-19. Frankly, it's all too painful. True, the Virtual Joint CNS-ICNA meeting ended up being great – our best virtual meeting ever, in fact. But the "might-have-beens" still haunt me and always will. The Marriott San Diego looked to be the best meeting venue the CNS has ever had or might ever have. So, patience, my friends: we will get there yet, in November 2024 (some of us, anyway). In the meantime, stay safe, centered, sane...and hopeful.



Service Alert Hurricane Sandy

In anticipation of the arrival of Hurricane Sandy:

- All planned voluntary service changes this weekend are canceled—with the exception of changes planned for Saturday, October 27, from 6pm-9pm EST and Sunday, October 28, from 6am-9am EST. Please monitor the site to stay abreast of changes for all utility services, as conditions demand.
- **During the storm:**
In anticipation of Hurricane Sandy, an emergency preparedness checklist is available online. This checklist includes items such as emergency supplies, necessary documents, and evacuation routes. It also provides instructions for staying safe during the storm.
- **After the storm:**
After the storm, it is important to check for damage and safety concerns. If damage is extensive, it may be necessary to leave the area. It is also important to check for power outages and to report them to the utility company. It is also important to check for water damage and to report it to the utility company.

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27 Days to Boston

“V” is for Volpe

Writers never really know how their readers are receiving and processing their work. Getting inside a character's head is hard enough. Trying to penetrate the readers' individual or group psyche is sheer madness.

Which is to say, I don't really know how this Countdown to Boston has been received. I have been pleased, even touched by the kind words of appreciation many have shared via email, but I don't really know how, or if, one particular vein of thought or another may be resonating. Or grating, perhaps sometimes even offending. I myself am surprised to find as I go along how fiercely fond and in awe of so many child neurologists I truly am, having never previously taken the time to write so many of these things down, which is how, after all – writing, I mean – we find out what we think and who we, and others, are.

Some of you may have anticipated that “V” would be “for vaccination.” Many of you may insist it should be. I will say only that it may yet be, when “V” comes up again next week as we wind our way back down the alphabet to “A” (which I dearly hope, playing off of my previous Déjà vu musings, does not end up being “A is for ‘Again?!?’).

Some of you, I know, may be growing concerned about my Ahabic pursuit of the Great White Whale, holding the 50th CNS Annual Meeting live in Boston, a pursuit that seems destined, some say, to end with one lone survivor clinging for life to a floating piece of wood; a coffin for Ishmael, a piano, perhaps,

for Phil Pearl. It is true, I do want very badly to get back to Boston. For Boston, really, is where it all began, or perhaps I should say, began again, with Joe Volpe, Chief of Neurology at Boston Children's Hospital in 1993-95 when he served as CNS President.

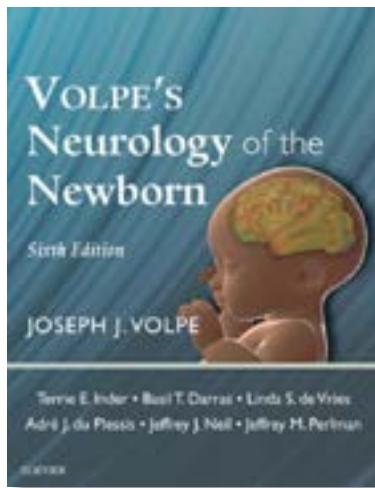
I was hired, as I noted previously, by Larry Lockman and Mary Currey in 1981 and began doing part-time work on the side for the CNS beginning in 1983. Mary and I found ourselves newly headquartered outside of the University of Minnesota in 1989, thanks to Marvin Fishman. And it was Steve Roach who offered me the chance in 2012 to succeed Mary as the Society's second Executive Director. But I would never have been around to accept Steve's offer were it not for Joe Volpe.

There have been two times over the years when I almost left the CNS for what, at the time, seemed like better offers; better for my family, better for my soul, better for my bank account. Both times my mind was made up: I was leaving. Both times I turned back. Each time it was largely because of the CNS President that I turned back and stayed on. That I am still with you today, looking forward to celebrating with you the 50th Anniversary Meeting in Boston, is owing largely to the high regard and deep devotion I had for Joe Volpe in 1995 and Ann Tilton in 2007.

In Joe's case (or “Dr. Volpe,” as I am still reflexively inclined to address him directly, despite his insistence I call him “Joe”) it was that quiet center of gravity he seemed to gather about himself and whoever he was working alongside of or engaged with in conversation. He



[Click to see video.](#)



was Prospero on the island, able to calm the winds and create this stillness within which things clarified and made sense. Those who know him well from training under or working with him know what I am talking about. It starts with, as it must, his remarkable gift for listening closely, even intimately, to the person or persons with him.

It goes without saying that the man is brilliant. One does not author six editions of the definitive textbook on neonatal neurology, one does not become known worldwide as "The Father of Neonatal Neurology" without having a few things going on in his mind, thought processes moving in ways and at lengths and speed like no one else's. But, I wouldn't know how to begin talking about that. And you wouldn't want me to even try.

What I can talk a little bit about, however, is Dr. Volpe's style and spirit. Joe Volpe is the definitive case study in "quiet authority": presence of mind creating quiet space around him for those present to truly be present, to be there in the moment. It's a "Zen thing," I suppose, although I can't imagine Joe being self-consciously aware of that, let alone claiming anything like that out loud. Pretension is not part of his make-up. He is one of those people you recognize as being remarkable in part because he makes no claims to being remarkable, yet doesn't disclaim with false modesty the intangible qualities or tangible achievements others cannot help but recognize and celebrate.

Dr. Volpe, as I have pointed out previously, is one of only two people to win the Triple Crown of Child Neurology: receiving the Hower

Award in 1990, the Sachs Award in 2000, and being elected by his peers to serve as CNS President, from 1993-95. The only other person to achieve that distinction is Darryl De Vivo, his colleague at Washington University during its Phil Dodge heyday.

Peter Berman frequently expressed amazement and pride at being CNS President sandwiched between those two Wash U luminaries. Dr. Berman was the rock that kept things solidly grounded through the 1993 crisis surrounding the bombing of our original meeting site at the Vista Hotel adjoining the World Trade Center and the subsequent move to Orlando for what proved to be a very successful meeting. He was succeeded in the helm by Joe Volpe, an accomplished sailor, who steered the CNS through the choppy waters of San Francisco Bay and the first joint meeting with the International Child Neurology Association (ICNA) in 1994, a role requiring great patience, discernment, diplomacy and, yes, quiet authority.

That was when things changed for me in relation to the CNS. Dr. Volpe invited me to sit in on, and actively participate in CNS Executive Committee meetings, something I had not previously done working as a part-time administrative assistant for Mary Currey. I was the father of two young children at the time, a 7-year-old son and a 1-year-old daughter. I mention that because I think now, looking back, that was the basis of the ease, trust, and mutual recognition in my early relationship with Joe. He was, as I mentioned, a gifted listener. I imagine him as being the consummate compassionate



**TWENTY-THIRD NATIONAL MEETING
OF THE CHILD NEUROLOGY SOCIETY
SEVENTH CONGRESS
OF THE INTERNATIONAL CHILD NEUROLOGY ASSOCIATION
AND
FIRST CONJUNCT MEETING OF THE CHILD NEUROLOGY SOCIETY
AND INTERNATIONAL CHILD NEUROLOGY ASSOCIATION**

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San Francisco, CA
October 2-8, 1994**

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clinician, listening closely in a way that gives comfort and instills confidence (in the double sense of the word) to parents of tiny, imperiled premature babies, as well as toddlers or young children. I see them standing together, the two or three parents and the expert physician, enclosed within a question that defines that space and time, both at that very moment in time and in memory thereafter: "Is our child going to be OK?"

I think it was that sense of me as a young parent that drew him to me, or me to him: two people who could converse openly and naturally, ask difficult questions and offer direct answers on important topics and issues, exchanging essential information in service to a progressively clarifying and compelling shared purpose.

He was not, it's true, the most dynamic speaker; sparks did not fly from the podium when he stood behind it. But in a sense, again, his quiet authority filled the space, the entire space onstage and in the meeting room. His talks were always structured and delivered with craftsmanlike precision: measured in pace and comprehensive in scope. No one, in all my years of recording post-meeting CME surveys, so consistently received higher marks from meeting attendees than Dr. Volpe, although many of his trainees and young faculty came close, including several Investigator Awardees he mentored: Evan Snyder (1990), Adre du Plessis (1995, shown below), Michael Rivkin (1996), Joe Gleeson (1998), Terri Inder (2004) and Mustafa Sahin (2005).

He wrote elegantly. I have written and edited many letters and

statements in and outside of the CNS through the years. Other than an admittedly obsessive and probably inappropriate insertion of a semi-colon or two, I never touched his drafts. I never had to. Which, without any pretension on his part, may have been the first subtle clue he picked up that I was a writer. We were obviously working in different genres, he on medical monographs and textbooks, me transitioning from short-form into long-form fiction. He would occasionally ask me about the novel and I confess, as further twisted tribute to my high regard for him, that I often avoided him at later CNS meetings, embarrassed to admit it was not finished or even progressing well. He might be cheered, or at least amused to know that the 16-year-old boy I began writing about in 1994, devastated by Kurt Cobain's suicide and anxiously watching his 43-year-old father wrestle with middle-age and the recent, untimely death of his mentor, is now in 2021 a 43-year-old father. (The book's working title is *Déjà Vu. Surprised?*). So I was deeply touched when, at age 41 in 1995, I received a gift from Joe upon ending his presidency: a Montblanc pen that I still write with today.

At the same time that I am coming full circle with my novel, I find that I am now coming full circle with my CNS "career" (not a term I associate with my years spent among you). By staying on with the CNS and not leaving to write, to go to seminary, or to take that job offer in 1995 – all because of Joe Volpe – I was able, in time, to grow into my role at CNS, to see it as a calling, even. And that, I see now, is one way in which I may have mirrored, however obscurely, what I find most compelling, most

genuine and quietly authoritative about Dr. Volpe. That notion came to me a few weeks back when re-re-re-reading Joseph Conrad's *Heart of Darkness* (yes, it's racist in a prototypically Victorian fashion, but we can debate its relative merits and demerits some other time).

The passage I am thinking about speaks to me not only about Joe Volpe, but of many of you as well, faithfully following your soul and Muse daily as you practice in a largely overlooked and undervalued medical specialty. In talking about the "battered, twisted, ruined, tin-pot steamboat" he captained, the narrator, Marlow concludes: "...(but) I had expended enough hard work on her to make me love her. No influential friend would have served me better. She had given me a chance to come out a bit – to find out what I could do. No, I don't like work. I had rather laze about and think of all the fine things that can be done. I don't like work – no man does – but I like what is in the work – the chance to find yourself. Your own reality – for yourself, not for others – what no other man can ever know. They can only see the mere show, and never can tell what it really means."



26 Days to Boston

“W” is for Wash U

As it happens, “W” is also for “What if?” That, of course, is the baseline question with which every exercise in counterfactual history begins.

A classic in the genre, posed by Winston Churchill in a 1931 essay, is “What if Lee had not lost at Gettysburg?” For my generation, the Baby Boomers, the classic, counterfactual question, posed with added poignance this past week following news that Sirhan Sirhan may be released from prison on parole, is “What if Robert Kennedy had not been assassinated in 1968?”

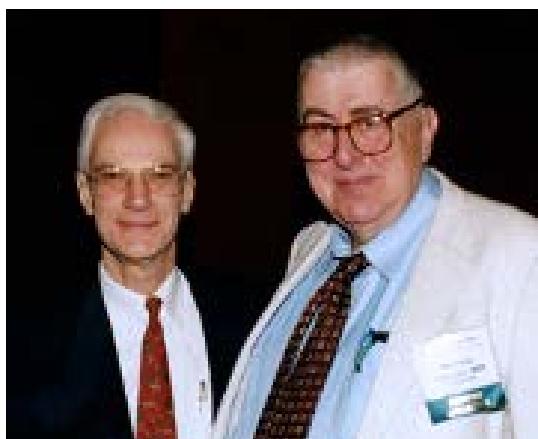
Raising that “What if?” question strikes me as being as good of an approach as any to writing a brief appreciation of Washington University’s contributions to child neurology and the Child Neurology Society. The key word is “brief.” How, after all, could anyone summarize in five or six paragraphs the central, irreplaceable role the program at Wash U has played in the development of child neurology and the CNS over the past five decades? It can’t be done. I won’t even try.

The best way, then, of not foolishly trying, may be to briefly engage in a bit of counterfactual history: What if Phil Dodge had not turned his back on the Charles River in Boston and moved west to St. Louis, on the banks of the Mississippi River? What if, in consequence, there being no Wash U program to lure them, no Phil Dodge to inspire and mentor them, the trio of Darryl De Vivo, Marvin Fishman and Joseph Volpe had not gone into child neurology, opting instead to do research in Parkinson’s Disease or neonatal cardiology? Who would have served

as CNS President in 6 of the 8 years stretching from 1987-1995 and how different would the arc of history between then and now have been in consequence?

But, even before then, what of the entire decade of the 80s during which time they each served as Councillors for the Midwest on the Executive Committee, as did their Wash U colleague, Ed Dodson (1985-87), recipient in 2019 of the Roger & Mary Brumback Lifetime Achievement Award (presented by CNS President, Jon Mink, himself a Wash U alum)? Or, going back further, to the Founding Decade of the 1970s, what subtle changes of vector might have occurred had Phil Dodge’s towering partner, Arthur Prensky not served as Councillor on the Executive Committee from 1975-77 and as CNS President in 1978-79? Would we even have thought about holding the CNS Annual Meeting in St. Louis in 2000, and presenting Art Prensky the Hower Award and Joe Volpe the Sachs Award at that meeting? Not likely.

Suppose we travel north to pose a set of counterfactual questions from the distant perch of the 2004 CNS Annual Meeting in Ottawa: What would that meeting have looked and felt like had it not been the occasion of renaming the Lifetime Achievement after Phil Dodge, with Phil present to be honored? Or had Terri Inder not been present to receive the newly renamed award Dodge Young Investigator Award? What if Jean Holowach Thurston had not been present the day before to receive the first-ever CNS Lifetime Achievement Award? And what of the diaspora of other colleagues and trainees (too numerous to be mentioned or



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shown here) who passed through the program and left St. Louis with its inimitable imprint on them? It would make for a great variation on that other parlor game, "Six Degrees of Separation". Are there any members of the CNS whose careers and lives have not been shaped in some way, large or small, through meaningful contact one or two degrees removed from one or more Wash U programs or alumni?

An epic version of the counterfactual history parlor game could be played using the photo below that I have previously and playfully dubbed "All the Young Dudes". It might look, at first glance, like the movie poster for the 1982 film, *Diner*, (which included "Mr. Six Degrees," himself, Kevin Bacon). But, it's actually a photo taken five years later of a remarkable cadre of smiling, and surprisingly well-coifed, residents and fellows at Wash U. Four of them won Young Investigator Awards before it was renamed in Phil Dodge's honor: Scott Pomeroy (1989), Ken Mack (1991), Kel Yamada (1992), and Jeff Neil (1993). Steve Leber moved north from St. Louis to Ann Arbor (and an arguably better football program), serving on the CNS Executive Committee from 2007-09, and later as Secretary-treasurer of the Professors of Child Neurology. He was the 2nd recipient, in 2014, of the CNS-PCN Training Director Award. That award was the brainchild of Gary Clark. As program chief at Baylor/Texas Children's Hospital, Councillor for the South on the CNS Executive Committee (2010-12) and President of the PCN (2013-15), Gary first proposed the award and got funding for it from the Blue Bird Circle at his home institution.

What about all the lives those estimable "young dudes" went on to touch, the careers in child neurology and neurodevelopmental pediatrics they launched and shaped over the next 30+ years? Would Christopher Smyser have taken the stage to give the Dodge Young Investigator Award Lecture in 2014 had he not been mentored by Jeff Neil, who introduced him? Let us not forget, before moving on, the shaping influence during the "young dudes" collective tenure at Wash U of Mike Noetzel, who was elected to serve on the CNS Executive Committee from 2001-03. And how do we even begin to measure the contributions that will be made in child neurology in the next 30 years as a result of 2003 Young Investigator Awardee, Brad Schlaggar's seminal role in nurturing an entire emerging generation of child neurologists through his direction of the Child Neurology Career Development Project (CNCDP) and the program at Kennedy Krieger Institute?

What would the field of child neurology and the Child Neurology Society be like if the pathways taken through life by all those dudes, young and old, had not passed through Wash U? What would it – what will it – look like had those admirably brilliant white males not been succeeded by a cadre of equally brilliant, but significantly more diverse child neurologists? That cadre includes, but is hardly limited to Soe Mar (currently serving on the PECN Board of Directors), Laura Jansen (2008 Dodge Young Investigator Awardee and current Chair of the CNS Awards Committee), Bhooma Avaramuthan (first recipient of the Post-Graduate



"All the Young Dudes," Wash U, 1987. (Front row, l-r): Kel Yamada, Steve Leber, Gary Clark; (Back row, l-r): Jeff Neil, Scott Pomeroy, Ken Mack, Jan Mathisen.

Outstanding Junior Member Award in 2018 and organizer and presenter of not one, but two symposia staged at the upcoming CNS Annual Meeting in Boston), and Christina Gurnett (Division Director at Wash U and faculty member with the CNCDP, shown below at the CNCDP retreat coincident with the 2018 CNS Annual Meeting in Chicago).

I will close with the biggest "What if?" of all: what would the future of child neurology and the CNS look like without all those in the current Wash U program pictured on the next page and posted on their website? What would their future, and so our future, look like without the training, teaching and practice skills modeled and passed on to them by Christina Gurnett (Division Chief), Soe Mar (Residency Program Director), Rejean Guerrero (Associate Residency Program Director) and Sarah Bauer Huang (Associate Program Director)? How can one begin to answer that unthinkably huge and overwhelming "What if?"

Thankfully, we don't have to.

Until Tuesday, September 7 (yes, friends, I am taking the Labor Day weekend off.)



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“X, Y, Z” is for Youth, Zeller, Zupanc and Zoghbi

And so we begin the downward slide backward through the alphabet counting down the days to the CNS Meeting in three weeks. After taking a few days off, I will need to compact a few letters and skip a few others, perhaps, but Boston awaits.

We have all grown up clumping “X, Y and Z” together, so why stop now? And people whose names begin with “Z” are accustomed, through years of schooling, to hearing their name called out last, a phenomenon that may have subtly contributed to the statistical improbability of 2 of the 11 recipients of the Arnold P. Gold Foundation Humanism in Medicine Award having a name that starts with “Z”: Robert Zeller (2015; shown below with Arnold Gold) and this year’s awardee, Mary Zupanc. They are used to seeing or putting other people ahead of themselves.

A classic example of this is captured in the 2015 award profile posted on the CNS website: “Dr. Zeller’s unceasing desire to provide for unrecognized needs is particularly exemplified by his reaction when he was told that one of his patients with epilepsy was not permitted to enroll in a summer camp. His reaction was to gather enough donors (not least himself), who together raised \$12,000,000 that enabled the building of “Camp For All” to serve the needs of children, adolescents, and adults with disabilities. Characteristically, Dr. Zeller not only raised the funds, but also played the critical role in selection of an architect and organization of the plans for the facilities that would best serve their needs. To date more than 100,000 individuals have benefited from this model facility.”



I will not steal any thunder from Bruce Cohen’s profile of Mary for the upcoming CNS Connections, or Ann Tilton’s introduction of Mary on September 29 when the Gold Award is presented to her at the Kenneth F. Swaiman Legacy Luncheon, but the choices and challenges involved in Mary putting others’ needs and interests ahead of her own comes up often in her life and career. I have had the great pleasure of knowing Mary since she first sat down and started fiddling with the keyboard of a grand piano in the atrium of the Hyatt Embarcadero in San Francisco at the Joint CNS-ICNA Meeting in 1994. She is my second favorite (Wisconsin) Badger, my daughter being #1 (neither confession comes easily for a lifelong Minnesotan). I wish I had a picture of the two of them in Vancouver in 2016, when Mary, a veteran marathon runner, spent ample time throughout the meeting advising Mekeia, who arrived stiff and sore 24 hours after completing her first marathon. My one regret about the timing of this year’s CNS meeting in Boston is that it comes a week too soon for Mary to run yet another Boston Marathon (in yet another COVID-induced scheduling quirk, the Marathon has been displaced from its traditional April/Patriot’s Day perch, to October). The same regret holds for another veteran runner honored this year, the 1st Martha Bridge Denckla Award Lecturer, Elizabeth Berry-Kravis.



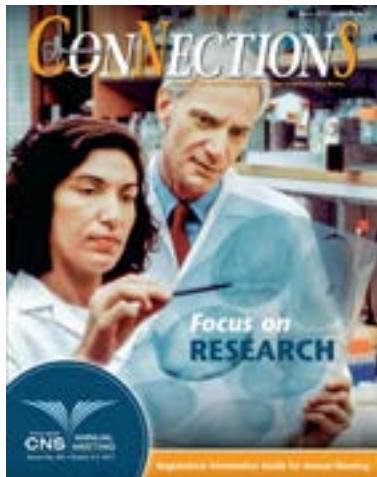
I don’t know if Huda Zoghbi is a runner. I can’t imagine where she would find the time. There is neither time nor space sufficient to even begin summarizing her contributions to neurogenetics and the Child Neurology Society. I would encourage you to go back to brief shout-outs in “C’ is for Canada” (what are the odds of her delivering both of her prestigious award lectures – the Young Investigator Award

21 Days to Boston

and the Bernard Sachs Award – in Canada?) and “F’ is for Fishman,” the latter including a link to a feature on her in the Summer 2017 CNS Connections posted on the CNS website.

What comes to mind with Huda now, as I transition to “Y’ is for Youth” is her role as a mentor and generational progenitor. As she noted when introducing her protégé, Jimmy Holder, Jr in 2015, before he delivered the Dodge Young Investigator Award Lecture, she is the intellectual granddaughter of Phil Dodge, having been mentored at Baylor by Dr. Dodge’s protégé at Washington University, Marvin Fishman. She noted the same 4th generation succession when introducing the 2020 Dodge YIA lecturer, Tuan-Hsiao Chao at last year’s virtual CNS-ICNA joint meeting, and again in a live-streamed conversation with Drs. Fishman and Chao moderated by Phil Pearl as part of the AAN Virtual Annual Meeting last spring.

Tuan is part of remarkable cadre of “next gen neurologists” that are revitalizing and reimagining the field of child neurology and, indeed, the Child Neurology Society itself. I can’t think of many better ways to start out talking about this emerging cadre than with the photo (right) of Tuan with this year’s winner of the Dodge Young Investigator Award, Monica Lemmon, from Duke University (shown with Lisa Emrick, Tuan’s colleague at Baylor). Both have benefitted from their involvement in the Child Neurology Career Development Project (CNCDP-K12), an NIH-funded program directed by Brad Schlaggar at Kennedy Krieger that holds its annual retreat on the front end of CNS Annual Meetings. This infusion of youthful talent and energy, coupled with the parallel programming just prior to CNS Annual Meetings of the Pellock Residents Seminar on Epilepsy, prompted me in 2018 to, perhaps unkindly, suggest to CNS Executive Committee members attending the CNS Annual Meeting in Chicago: “You may notice that 1-out-of-3 attendees this week walk faster than you do.”



I could go on for days writing about the many rising stars in the CNS who both amaze me by how much they have given back to the CNS already, and how much over the next 30, 40, even 50 years (it could happen), they may yet contribute, winning their share of Hower, Sachs and Denckla Awards along the way, serving on their share of Executive Committees as Councillors and Presidents alongside executive directors who will follow me. Those of you attending the September 30 Presidential Symposium Phil Pearl has organized, "The CNS at 50! Past, Present, and Future," will get a sampling of great things to come from presentations given by members of the Young Investigators Special Interest Group: Alexander Li Cohen (Developmental Cognitive Neuroscience), Darius Ebrahimi-Fahkari (Movement Disorders), Christopher Yuskaitis (Epilepsy Genetics), Verena Staedtke (Neuro-oncology), Giulia Benedetti (from Pellock Fellow to Faculty), and Bhooma Avaramuthan (Cerebral Palsy). You might also want to catch three conversations I videotaped with Alex, Darius and Chris in February 2020, and then email me or one of them if you are interested in joining the Young Investigators SIG.



21 Days to Boston



Creating the Early Investigators Special Interest Group (Recorded at Boston Children's Hospital)

[Click to watch video.](#)



Major Reasons Why I Went into Child Neurology (Recorded at Boston Children's Hospital)

[Click to watch video.](#)



Finding Mentors (Recorded at Boston Children's Hospital)

[Click to watch video.](#)

20 Days to Boston

“U” is for Updates

Are we still meeting in Boston?

Yes, absolutely. Only the city of Boston and/or the Commonwealth of Massachusetts can shut down the 50th/Golden Anniversary Meeting at the Hynes Convention Center at this point. Cases are rising in many parts of the country, and beginning to plateau in others. With 40-50% of our members within a day's drive of Boston, and this being the 50th/Golden Anniversary Meeting, I feel we need to hold on to the prospect of meeting in person as long as possible, hoping for movement in a positive direction a week or two before the meeting, prepared for the possibility there may not be. The virtual meeting platform will be fully ready for prime time the last week of September. Déjà vu all over again....

How many are registered as of September 9?

837 for Boston (888, including guests); 311 for Virtual.

What are the contingency plans?

Live in-Boston registrations can transfer to virtual registration any time (or vice versa) by contacting registration@childneurologysociety.org and referencing your confirmation #. If Boston/Hynes cancels, registration will automatically be assigned to the Virtual Meeting.

What basic protocols are in place for the meeting?

1. Masks will be mandatory in the convention center (speakers may remove their mask during presentation).
2. Vaccination is requested and, frankly, expected among our attendees, but there will be no active, across-the-board monitoring or enforcement related to proof of vaccination. See "V is for Vaccination (Proof of...) below.
3. Social distancing will prevail both by design and default (ie the # of likely attendees is 50 per cent below the originally projected 1800).

4. Cancelled: history-based scavenger hunt in exhibit hall and the 70s-theme for Friday reception; Reception is still happening; just "come as you are" and have a good time with great company, great food, and great music.

What deadlines apply to presenters?

1. **Posters.** PDF uploaded by September 8. See guidelines on CNS Website Annual Meeting page. <https://www.childneurologysociety.org/colleagues/network/cns.annual-meeting/>
2. **Speakers** (symposia, seminars, platforms):
...Presenting in Boston? Must upload and check in to Speaker Ready Room 24 hours before session begins.
...Presenting virtually from home/office? Zoom link will be provided to present live, in real-time from your computer.

What about alumni receptions?

Program chairs and coordinators: [click here to go to application portal \(SurveyMonkey\)](#). Limited rooms available Wednesday, Thursday, Friday nights at the Hynes. Will refer to Boston CVB to help find and book offsite venues.

Further Updates:

Check CNS Website. Updates will also be included in daily Countdown to Boston eConnections.

20 Days to Boston

“V” is for Vaccination (Proof of....)

I seem to have come full circle. In my “L is for LaCrosse” entry I played with the notion that 50 years ago my wilder 17-year-old self might conceivably have joined with friends, the sons and daughters of Mayo Clinic doctors, and using a fake ID to pass as an 18-year-old, taken a seat in the Holiday Inn Bar next to the “La Crosse 8” as they busily plotted a future association of child neurologists in September 1971. It’s a classic counterfactual history “What if?” moment. What if, say, we had disrupted that foundational meeting? Would we have unwittingly delayed momentum toward forming the CNS and holding its first meeting in Ann Arbor? Or, what if instead, 10 years later, Ken Swaiman walked into the outer office at the U of M Division of Pediatric Neurology on my first day on the job, looked me over quizzically and asked “Haven’t I seen you somewhere before?” I absolutely would not be writing this entry today.

What if the technology used to create fake IDs improved so much over the past 50 years that it might now be 50x easier to forge a proof of vaccination card getting me into a medical association meeting than it was creating a fake ID to drink beer in a Wisconsin bar in 1971? Too far-fetched? I don’t think so. And while that’s far from being the sole basis of my resistance to requiring proof of vaccination to get into the CNS Annual Meeting, it will serve as an entry point for laying out some of my reasons for not requiring proof of vaccination as entre into the Hynes Convention Center.

As it happens, “POV” is an acronym for both “Proof of Vaccination” and “Point of View,” a telling coincidence. For, in many respects, “Proof of Vaccination” is more of a perspective than it is an effective preventative measure. It won’t, as it turns out, fully keep you from being infected or even infecting others. Nor is it designed to. It’s designed to mitigate the serious outcomes that might present if you do get infected. It’s a security blanket that might help you sleep better at night, but it won’t keep you safe from all harm. Because there are so many other variables out there, so many other threats to your health and safety, some of which you can control, most of which you can’t.

If the CNS were meeting in a self-contained resort, as we did in Phoenix in 1997, or hoped to last year at the San Diego Marriott conference center and hotel, we might plausibly be able to control our environment enough to make mandatory vaccination a workable requirement rather than just a reasonable request for our meeting at the Hynes Convention Center in downtown Boston. But we are not alone in Boston; we are not even alone at the Hynes. Another group will be meeting on the front end of our meeting, whose policies and activities we have no control over. Nor do we have control over who enters the Hynes itself, whether from Boylston Street (one block away from where the bomb went off near the finish line of the 2013 Boston Marathon, for those clinging to illusions of 100% security), or the Prudential Center, a heavily trafficked skyway-level mall with dozens of shops and restaurants, connecting the Hynes to the Sheraton, the Marriott, and the Westin Hotel, among others. Attendees will be coming from those and other nearby hotels, none of which, I’m sure require proof of vaccination, and native Bostonians will be commuting from homes full of kids coming home from school.

You yourself will be coming to the meeting after having spent an hour or more in one or more airports and another 2-3 hours on an airplane, none of which require proof of vaccination. You may very well have, just the day before, seen unvaccinated patients, moved about in hospitals that are either considering or have begun newly implementing mandatory vaccination policies, but have not yet done so or have set deadlines falling weeks after the CNS Meeting ends. So why, I am asking, in all seriousness (“obtuseness,” you may say), the sudden, insistence by some on Proof of Vaccination to get into the CNS meeting? If we have no control over the far larger and more numerous threats to your health and safety before and after you enter the Hynes for the meeting each day, why pretend to do so within the meeting space itself? Because pretense is all it is. Your rational mind, the one that tells you “trust the science” knows this to be true. Meanwhile, the irrational fears, anger and anxieties we all have seen tick upward in the past 18 months wells

up inside of you, compelling you to cry out: "Do something!"

You know that cry. It's all too familiar. What do you do when a parent, holding a shaking or listless child in their arms, looks you in the eye and through gritted teeth cries, "Do something!"? Do you prescribe a drug or enroll them in a clinical trial you know won't help the child, but will at least offer visible evidence you are "doing something?" No, you don't. Nor will I in this particular situation prescribe a remedy to plausible fears about one's health and safety that might quell the fears but will do little or nothing to substantively address overall safety. We will all be in relatively highly secure environment just by virtue of the fact that 99 per cent of attendees are likely vaccinated (granting, of course, that is no guarantee against breakthrough infections; something two support staff for the meeting wrestled with in the past two weeks). Masks will be required in all areas of the Hynes, the CNS staff is fully vaccinated, and our vendors have policies, some including proof of vaccination or negative tests, that will be posted and available on the CNS website.

That is as good as we can practically do at this point, which is why we say vaccination is requested and expected, but not required; the latter term suggests levels of monitoring and enforcement we cannot honestly provide. I know several associations are scrambling to get something in place for meetings beginning 2-4 months from now, not 3 weeks. Nobody knows how they can vet companies charging exorbitant fees for these services based on no real track record, no viable data set by which to measure their ability to fully perform contracted services. And nothing less than "fully" will do. In which case, it really is just a security blanket, isn't it?

We have all dwelt too long in a pandemic-panicked world that has eroded nearly all our reserves of Keatsian "negative capability," that capability "of being in uncertainties, Mysteries, doubts, without any irritable reaching after fact & reason." There are too many uncertainties involved in holding a meeting in an urban environment beyond even the pretense of control. Pretending to shield oneself against all those uncertainties with a little piece of cardboard, and an easily forged one at that, will not do. All that one can do at this point is inventory individual risk thresholds; they will differ for each person based on as many variable considerations as there are variable and variants encompassing the Hynes, Boston, New England, and the entire web of airports from the Atlantic to the Pacific.

If, by not requiring Proof of Vaccination, I am preventing you from coming to Boston, I am truly, deeply sorry. Surely, by now, after 35 years, you know that. But I have, or rather, Sue Hussman has, provided you with an option: a virtual meeting platform that will deliver 90% of the CME content livestreamed from the Hynes Convention Center, the only threat to your safety being your family and the colleagues surrounding you daily. Anyone who wishes to may email registration@childneurologysociety.org to request their registration for the live meeting in Boston be converted to the virtual meeting. Those gathered in Boston will miss you. I will miss you. I wish it were otherwise.

19 Days to Boston

“T” is for Training Directors

When I was seven years old, I didn't just dream about growing up to be a major league baseball player, I knew in my heart, I could feel in my bones that I was bound to become one. My older brother had his doubts. And while I don't think he dreamed, even at age 11, about becoming a lawyer, I can see now, looking back, that his destiny seemed clearer and more certain than mine on that summer day in 1961 when he had me sign a piece of paper swearing I would someday play center field for the Minnesota Twins.

I'll save you the time and effort googling "Roger Larson + Hall of Fame" and tell you straight up it never happened. And never will, I ruefully decided a few years ago in my mid-5Os. Ruefully, and yet, without deep regret. That I save for other and later dreams, those that at least stood a chance of coming true, but somehow didn't. Like becoming a high school history teacher, or maybe a professor at some small liberal arts college. That too, I decided in my mid-5Os, was never going to happen.

Which may be why – envy being the easiest of the seven deadly sins to practice and perfect – the Training Director Award is the one I prize the most among those presented by the PECN and CNS at the annual meeting. I can and do sit through all the award lectures every year, listening to them the way I listen to French being spoken in Paris bistros, loving the sound of the words flowing fluidly, but without understanding more than the merest fragment of their meaning. Part of me wishes that the Training Director Awardees could give a lecture instead of a brief 3-5 minute acceptance speech, while another part of me is glad they don't. Because what these celebrated teachers and mentors do, daily and over a long period of time, is nothing short of magic and mystery, an intimate transfer of knowledge and wisdom that can no more be crystallized and conveyed on-stage from a podium in a darkened ballroom filled with 500 people than reading Willie Mays' stats on the



back of a baseball card can capture the wonder of that moment on September 29, 1954 when he made the greatest catch in baseball history. You had to be there.

Which is another reason why I so deeply prize the Training Director Award and those who receive it. It is presented on the basis of letters from those residents and colleagues who literally have "been there." And, having "been there," in the presence of pedagogical genius and generosity early in their career and life, when it really mattered, many of them are "here," as child neurologists gathered tribally at the CNS Annual Meeting to honor that year's recipient.

I can't do justice to any of the eight recipients. I envy those who can, and have. So without further ado, I will offer you a link to the full line-up of Training Director Award profiles posted on the CNS website (<https://www.childneurologysociety.org/calling/cns-awards/training-director/>), many written by colleagues, some by the 2015 awardee, Rob Rust. And I will encourage you to attend, or if you can't, watch live or by recorded playback on the virtual meeting platform, the Kenneth F. Swaiman Legacy Luncheon on September 29; the program will include presentation of the award to the 2021 recipient, Miya Asato, along with recognition of all past awardees: Harvey Singer (2013), Steve Leber (2014), Rob Rust (2015), David Uron (2016), Sid



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Gospe (2017), Bruce Shapiro (2018), and Karen Ballaban-Gil (2019).

(Note: no award was given in 2020, there being no equivalent award presented by our joint-meeting partner, the International Child Neurology Association).

But first, a final shout out and word of thanks, to Gary Clark who first proposed establishing this award and found funding for it, through its first seven years, from the Blue Bird Circle Clinic at Texas Children's Hospital.



18 Days to Boston

“S” is for Schor and Statues

An odd coupling on the face of it. And yet, not so odd when you stop to think about how central, how iconic even, Nina Felice Schor is within the narrative history of child neurology and the Child Neurology Society in the 21st century.

As Scientific Program Chair in charge of organizing the 2000 annual meeting in St. Louis and the 2001 meeting in Victoria during Mike Painter's presidency, she shaped the basic program contours that pertain to this day. As Secretary-treasurer from 2004-2010 she served on the Executive Committee during the presidencies of Jim Bale, Ann Tilton, John Bodensteiner and Donna Ferriero. She was President of the CNS from 2013-2015 when the CNS reached its \$1 million goal for endowing the Philip R. Dodge Young Investigator Award and the Child Neurology Foundation dusted itself off, got back on its feet and recommitted itself to pursuing a path toward effective, complimentary partnership with the CNS. She was honored in 2017 with presentation of the Hower Award and gave a memorable lecture following a near-equally memorable introduction by her twin sons, Jonathan and Stanford.

I hardly need retrace the career path in research, teaching, mentorship, and administration that took her from being Chief of the Division of Child Neurology in the Department of Pediatrics, and Associate Dean for Medical Student Research at the University of Pittsburgh, to Chair of the Department of Pediatrics and

Pediatrician-in-Chief at the University of Rochester Medical School, to her current position as Deputy Director of the NINDS. Many of you know her better as, or have worked with her more directly in her role as a Director of the American Board of Psychiatry and Neurology (ABPN) or lead chair of one of several key committees within the ANA, AAN, AMSPDC, SPR or various NIH study groups. All of that is well known. But, even better known, perhaps, are the personal, non-professional/non-CV entries that are equally, if not more remarkable relative to her peers: her incomparable character and incandescent charm; her thoughtful attentiveness and probing intelligence, her innate kindness and compassion. She is, some have said (myself included) both one of the brightest and nicest human beings on the planet. She is, well....“perfect,” many say; “she should have a statue erected in her honor.”

Nonsense, I say. Sheer nonsense. In an age more noted for tearing down statues than erecting them, we should pause before indulging in any kind of loose talk about erecting more statues. Particularly in this case. Because, I can tell you from long experience, Nina is not perfect.

Start with this: we used to have weekly noontime meetings by phone when she was CNS President. I can clearly recall three times when she kept me waiting, once for more than 5 minutes. And then there was that time she forgot to cc me on an email. Trifles, you say? OK, let's take it up a notch and ask a few harder questions about more substantive matters.



Longtime friend, Pat Crumrine (L) shares a laugh in Vancouver with Nina. The two friends ran against each other for CNS President in 2013 and are featured on the CNS in a great video conversation, “The Three Amigas”, with past-President, Ann Tilton.

[Click to view video.](#)



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"Nina makes everyone around her better," many say. Really? How would being willing to run through a wall for her, something many (including me) have said many times, make them "better"? Ask Chris Giza and the TBI specialists at UCLA what they think about that before answering.

"She's so focused and disciplined," others say, wishing they could emulate her. "Focused and disciplined"? She writes poetry, for crying out loud! She played in a klezmer band! And don't even get me started on the splendid grand piano in her house that she spends an awful lot of her time playing; beautifully, yes, but shouldn't she be reading case studies posted on some obscure Eastern European online journal? Where, one wonders, would the CNS be if other Presidents spent their time stroking the ivories? Wouldn't that time be better spent, say, on Capitol Hill meeting with fellow-physician, Rand Paul, working on meaningful vaccine and child healthcare legislation?

"She's a great judge of character and mentors her trainees and colleagues wisely and patiently." Uh huh. Mike Painter mentored her, counseling patience and humility that had her charting a 16-year path forward from scientific program chair in 2001 to CNS Executive Committee in 2004 to President in 2013 to Hower Award in 2017 and appointment as Deputy Director of NINDS the same year. Did she then turn around and provide the same wise and steadyng counsel to her Scientific Program Chair, Jon Mink? Hardly. Appointed program chair in 2013, Jon became CNS President in 2017 and Hower Awardee in

2021: an 8-year sprint covering the same ground in half the time. That's a lot of pressure. What does Nina suggest he do next? Drop the mike after finishing his Hower lecture on Saturday, pack the car, drive south and walk into Francis Collins' office at the NIH on Monday, muttering irritably, "I was hoping it would be bigger, but I guess this will do"?

"She is knowledgeable about CNS history, has no ego, and is sensitive to members' needs and interests." Oh, please. How sensitive was she as President in 2014 when the CNS met in Columbus, Ohio, triggering untold trauma among members from the University of Michigan in Ann Arbor, site of the 1st CNS Annual Meeting? Seven years and six consecutive losses later, I know of one Wolverine who continues to undergo serious therapy that includes having his picture taken in front of the Buckeye's stadium wearing a maize and blue "M" cap. Mike Painter was a proud Michigan alumni; maybe this is petty payback for having her wait twice as long as she needed to, apparently, to stockpile all those offices and accolades.

"She models work-life balance in ways I wish I could." People: we've already covered this. Remember the poetry and piano-plinking? While I hesitate to call anyone's parenting into question, I have to wonder how her twin sons became or remained so over-protected and insecure that when one enrolled on the opposite side of the country in the MD-PhD program at Stanford, the other enrolled in the MD-PhD program at UCSF, less than an hour's drive away.

"She's so respectful of her elders." That's not my impression. When she



and Donna Ferriero were asked by two elderly members to hang up their coats at an ANA Annual Meeting years ago, mistakenly assuming they were hotel staff rather than ANA members ("When did we start admitting women?"), did she dutifully do so, or did she merely gently point them in the right direction? What about the time an elderly gentleman approached her at a Yale Alumni gathering and asked what year her husband graduated, innocently unaware or in denial about Yale going coed in 1969. How tough would it have been to simply respond, "1975," and let him totter away, none the worse off for not realizing it was she who graduated Yale that year?

And why, when everyone else indulged Fred Plum's penchant for playing the role of intimidating elder sage, did she feel compelled to break protocol, calmly and confidently answering his query about what field she wanted to enter: "Child Neurology."? His grim riposte, "Young lady, you are entering neurology through the basement!" got her dander up, confirming her resolve to go into the still young, developing and underappreciated field. But, really, isn't 30 years an awful long time just to stubbornly prove a point? Is that

respectful? Or, more importantly, is that the kind of mature decision-making process residents and young attendings should be emulating? I don't think so. (Note: I am grateful she did. That anecdote inspired me to use as the working title of our growing collection of videotaped CNS Conversations on the website, "The Basement Tapes"; with a nod to Bob, of course).

So you see: she's not perfect. Not even close. And we shouldn't be talking about erecting a statue in her honor. She is brilliant and she is delightful, and I am grateful to call her a friend. But I'm in no rush to see her cast in bronze on some street corner in New Haven, Pittsburgh, Rochester or Bethesda, with graffiti sprayed all over its base, "Justice for Fred Plum!" or "Free Jon Mink!"

ADVICE, FUTURE, MENTORS AND MENTORING, RESEARCH
more: Videos | My Mentor: Lessons and Ideas for the Future of Research in Child Neurology



[Click to view video.](#)

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“R” is for Rob Rust

I knew when I began this series, running up and back down the alphabet, that there was no running away from the letter “R” and Rob Rust, no getting around wrestling with how much I miss him, how much I have missed the pleasure of his company the past several years as he and Betsy quietly adapt to the cruel loss of memory and cognition that, in his prime, few could come close to matching.

I last saw Rob in 2017, when Howard Goodkin kindly invited me to Charlottesville to attend the 1st Robert S. Rust Annual Endowed Lecture in Child Neurology, given by Joe Volpe. Rob’s brother was there as well, an historian and “last of a dying breed” himself as a well-traveled photographer for the Associated Press. capturing history as it happened for nearly a half-century.

It never occurred to me, a year earlier, in the spring of 2016, when Rob and I began tossing ideas back and forth for the 50th CNS Meeting while walking the grounds of the University of Virginia and Monticello, that he would not be available in the intervening five years to help shape and inform that upcoming milestone meeting. Rob was himself so central to CNS history, having served on the Executive Committee (2008-10), and been honored with presentation of the Hower Award in 2007 and the Training Director Award in 2015. He chaired the Archives Committee for decades, wrote nearly all the awards profiles from 1994 – 2016, and was the officially designated “CNS Historian”. Other than, perhaps,

Steve Ashwal (whose monumental 2nd edition of the Founders book, will be available both at the meeting and on-line afterward), no one could more thoroughly and enthrallingly capture and convey the essential history of child neurology and the Child Neurology Society than Rob. His not being with us in Boston leaves a huge, unfillable hole for me and for so many others, and makes it hard for me, in this moment, to write about him (doubly so after the passing last weekend of a dear friend to me and so many others in Boston and beyond, Theresa Trapilo, who attended and helped out with all but one CNS meeting from 1994 to last year’s virtual meeting, about whom I will write more later).

So, emotionally drained as I am at the moment, I will avail myself of the opportunity I took with Jack Pellock (“P is for Pellock”), to draw on an appreciation of Jack and Rob that I wrote for the Spring 2016 edition of CNS Connections. For those looking for more substance (all of you?), I highly recommend the richly insightful professional appreciation co-authored by Howard Goodkin and Phillip Pearl in the aforementioned Founders book, *Child Neurology: Its Origins, Founders Growth and Evolution*.

“In June 1968, the ABPN issued its first set of certificates in Neurology with Special Qualifications in Child Neurology (Charles Barlow received Certificate #1, Arnold Gold #6, Isabelle Rapin #9). Less than a year later, an ad agency in Richmond launched one of the most iconic tourism marketing campaigns of all-time with the tagline, “Virginia is for Lovers.”



The connection might not seem obvious at first glance, but had you been with me at Jack Pellock’s funeral in Richmond the third Saturday morning in May, or driven north to Charlottesville that afternoon to stroll around Monticello with Rob Rust, two weeks after he retired, you might have spotted it. As different as these two squires from the Commonwealth of Virginia were in temperament and appearance, both nurtured and generously shared with colleagues a vast wealth of knowledge in the unfolding mysteries of neurological development and disorders. Both richly personified Ray Bradbury’s oft-quoted credo: “Do what you love and love what you do.” And, both are, or were, not “merely” respected and revered, but genuinely and unabashedly loved by their colleagues, as witness Larry Morton’s wonderful tribute to Jack posted on the CNS website, and Phillip Pearl’s splendid profile of Rob Rust, published in the October 2015 CNS Connections in tandem with his receiving the Blue Bird Circle Training Director Award (also available on the website).



Jack touched on Rob Rust in the same conversation, rueing the fact that he had to leave the meeting early (but for the best of all reasons: his daughter's wedding) and would miss seeing Rob receive the Outstanding Training Director Award on Friday morning. "Rob had all of us thinking for years that being bald was somehow a marker of how bright you were," Jack remarked while playfully rubbing his chemo-smoothed pate, "Imagine my disappointment when I didn't just catch up with Rob, but blew by him, only to find out I still wasn't half as smart!"

If it were "simply" a matter of smarts, the word "awe" might not serve our purposes so well as, say, "envy" or "amazement." Where the word "awe" fits so well with Rob – as both word and acronym – is in its ability to suggest scope and scale, silence and reflection, a sense of humility and humanity, of being centered, soulful, and grounded. Of being as willing to listen as to speak. I am thinking here of some comments Rob made as a panelist addressing junior members at the 40th CNS Annual Meeting in Savannah in 2011.

"The one most important question to ask is right at the end of your history," Rob quietly asserts – "And what else?" – repeating the question after each halting, tentative response (from the parents); "And what else? And what else?" Finally, the parents may say, "Well, there's nothing else."

"But many times," Rob observes, "whether this is a first visit or the patient has been with you for many years, they may look at each other and say, 'We were thinking of getting a divorce,' or 'Should we put our child in an institution?' It takes that long

sometimes for that to come up. So if you can ask that 'What Else' question, you'll be doing everybody a favor."

Classic Rob. An almost zen-like sensitivity and core-consistency of character that marries the well-honed professional skills involved in listening to a patient with a lifelong personal disposition toward listening patiently...to everyone, thereby "Doing everybody a favor." And the lesson learned over time applies not solely to the clinical exam, but translates more broadly to the manner in which one approaches and adapts to parallel situations in one's own life and the lives of those one shares time and space with on a regular, even daily basis: medical students and residents beset with anxiety; colleagues besieged and burned out by a rapidly, almost chaotically changing set of professional and cultural guidelines, rules and expectations. And, above all, family members.

So, "AWE," then: "And What Else?" The question asked gathering patient histories is also the sine qua non of the professional calling Rob initially started out pursuing in his youth. When I visited Rob last fall in Charlottesville and got the two-hour "Grand Tour" of the most beautiful college campus in America, (including a lingering pause by the bench where he proposed to Betsy), we stood together in the small parking lot separating his current office from the building housing the History Department twenty yards away. "I guess I haven't made much progress in 40 years, have I?" he mused, wonderingly.

What struck me at that moment was how, one way or another, we seemed destined to meet in this very parking lot. As an

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undergraduate at the University of Minnesota, I leaned strongly toward going to graduate school in History at the University of Virginia; Rob may well have ended up being my graduate advisor. Instead, seduced by film, fiction and femmes fatales, then ensnared by a part-time job in Ken Swaiman's Division of Pediatric Neurology, I somehow found myself, thirty some years later, with the CNS. However improbable and indirect the route, Rob and I met and became friends. Through the years we have ended up sharing many conversations about American History – in Charlottesville, at Appomattox Courthouse, at Monticello, as well as at a couple dozen CNS meetings – that we might otherwise have had daily at UVA or yearly at AHA annual meetings. Either way, the general theme of those wide ranging conversations might still most usefully be encoded using a third acronym: "PLA," shorthand for "the Possibilities of Life in America."

What began for Rob as an academic career in History spent asking the question, "And What Else?" relative to "the Possibilities of Life in America," became instead a calling spent asking the same question of patients, parents and fellow pediatric neurologists: what are "the Possibilities of Life in America" for children with neurological diseases or disorders and how might they be improved upon? That question, or challenge, is not or need not be limited to America, of course; no more so, certainly, than the declarations of rights and freedoms issuing from the Sage of Monticello were or still are.

Three weeks before seeing Rob in Charlottesville, at a meeting of

the International Child Neurology Association board of directors in Amsterdam, I talked about "PLA" while presenting the CNS proposal to host a joint CNS-ICNA meeting in San Diego in 2020. Noting Rob's commitment to international child neurology – his multiple trips worldwide to deliver lectures, conduct clinics, and lead grand rounds, and his service on the ICNA Board of Directors – I suggested that once again, Rob was leading, training, and inspiring his colleagues in child neurology, young and old, by expanding the scope of "PLA" (the "Possibilities of Life in America") to "PLW" (the "Possibilities of Life in the World") for children, their families, and the community of child neurologists engaged in research, advocacy, and direct medical care on their behalf. I mentioned as well how easily, and appropriately Rob's signature "AWE" question might also lend itself to another variation on "PLW": the Possibility of Learning from (or with) the World, a possibility CNS members were increasingly ready and willing to embrace.

Louis Sullivan, the great American architect ("Father of Skyscrapers") once noted, "In a democracy there can be but one fundamental test of citizenship, namely: Are you using such gifts as you possess for or against the people?" In following their call to be child neurologists, Rob and Jack met and mastered that test with a sense of JOY ("Just Offer Yourself") and AWE, extending the Possibilities of Life in America to the World. Doing what they loved and loving what they do, they earned the respect, admiration – and love – of their colleagues and their communities."



16 Days to Boston

“P” is for Peter, Painter and Pennsylvania

I have been gently chided in otherwise warmly appreciative emails about my Countdown entries being a bit, well, “white menish”. I would not argue that point beyond saying, “yes, the Society’s early years seem suspiciously so, as well, don’t they?”

This is the material, these are the individuals I have to work with, after all. I am “white menish” and of a certain age myself. But, I try, whenever possible, to hint at possible arcs and transitions that may make my “Once upon a times” follow or point down paths that lead to different “And they lived happily ever afters” than the fairy tales and histories I grew up hearing and reading. As I have said several times before, this series is highly subjective: its casual reflections are emblematic, not encyclopedic.

Rarely does that need repeating more insistently than today, with “P is for Peter, Painter and Pennsylvania.” They don’t come much “whiter” or more “menish” than Peter Berman and Michael Painter, two lions from the early years of the CNS without whom the Society’s history might be told very differently, or might not even be told at all. One could no more recount the history of the CNS than one could chronicle that of the Department of Neurology at Children’s Hospital of Philadelphia (CHOP) or Children’s Hospital of Pittsburgh (CHP) without referencing these two. Both loom large, one on the eastern, seaboard side of Pennsylvania, the other on the western, mountain side of the state. I liked and respected them both immensely but I would suggest that while both are admittedly and unavoidably “white menish,” they are also – or were also – as extraordinarily different in personal style and sensitivities as they were extraordinary, in a more general, professional sense of accomplishments and stature. While Dr. Berman might sometimes talk to me about Art (OK, more like “lecture me,” but he was far better-versed in the visual arts than I). Dr. Painter would hold court on History, a more mutually embraced and evenly contested field of discourse, as he and I delighted in discovering and re-discovering over the years.



Peter Berman’s distinctive voice can be heard on audiotapes of the first CNS business meetings in 1972, clearing away the fog, outlining critically important considerations, and decisively throwing his weight behind forming a new professional association for child neurologists. That it took until 1991 for him to be elected CNS President surprises me now. That he would be so humble in looking back on his term in office doesn’t surprise me; he was always proud of, even a little in awe of finding himself sandwiched between his predecessor, Darryl De Vivo, and his successor, Joe Volpe. His steady helmsmanship during the nail-biting negotiations involved in pivoting successfully from the bombed out ballroom of the Vista hotel, adjoining the World Trade Center, in February 1993, to the Orlando Hilton later that fall was remarkable. No CNS President has encountered challenges approaching that until last year...and, again, this year; which should give you some sense of how considerable and consequential Phil Pearl’s contributions have been over the past two years of endless crisis and uncertainty.

When I consider Dr. Berman’s legacy, two of his earliest and most accomplished protégés come quickly to mind. The first, Barry Russman, served on the CNS Executive Committee from 1983-85 and was presented the CNS Lifetime Achievement Award in 2007. Among my favorite annual rites was listening to the two of them argue over who had attended the most CNS meetings, with Barry grudgingly admitting the one year he missed when, as President of the AACDPM, duty

16 Days to Boston

called him away. I highly recommend catching the two of them sharing memories on the CNS Conversations section of the website:

<https://www.childneurologysociety.org/video/drs-peter-berman-and.barry-russman/>

The second protégé of particular note is Amy Brooks-Kayal (pictured below), who received the Young Investigator Award in 1999, and later served as President of the American Epilepsy Society, an honor that pleased but in no way surprised Peter (the two of them are shown below with Ed Myer, from VCU; Dr. Myer was CNS board member from 1990-92).

Dr. Berman would be equally pleased to see his seat at the head of CHOP Neurology deftly assumed by Brenda Banwell, and would be equally unsurprised to find that two of the five Outstanding Junior Member Awards, and two of the four "Best of Show" poster presentations given in a session moderated by Doug Nordli at the CNS Meeting in Chicago in 2018 recognized work done by CHOP residents, Melissa Hutchinson and Sara Fridinger (shown above in the middle).



Mike Painter's best known protégés and partners in Pittsburgh come easily and quickly to mind as well. In much the same way that it would be hard to imagine the CNS without the signal contributions of Drs. Berman and Painter, it would be next-to-impossible to imagine the program in Pittsburgh or the CNS without the creative, nearly immeasurable contributions made by Pat Crumrine and Nina Schor. If part of Mike's compelling, if sometimes frustrating charm was his penchant for generating two brilliant ideas a



day along with one deeply fraught one, identifying and encouraging Pat and Nina's natural leadership qualities were among the most brilliant of those twice-daily lighting strikes of pure genius. And he would have been delighted to see Miya Asato receive this year's CNS-PECN Training Director Award. The residents at UPMC continue to consistently submit high-quality abstracts garnering high-profile junior member awards at the CNS annual meeting. And I don't know of any training program whose faculty and fellows seem to enjoy each other's company more than those from Pittsburgh; they always seem to bring some of the fizz that makes CNS Annual Meetings so fun and friendly. That, I think, is part of Mike's legacy too.

HISTORY, TRAINING PROGRAMS

[Home](#) | [Videos](#) | [University of Pittsburgh Medical Center - Pt 1](#)



University of Pittsburg Medical Center - Part 1

[Click to watch video.](#)

Mike served on the CNS Executive Committee from 1985-87, and later as PCN President before becoming CNS President in 1999. During his tenure, he and Ken Swaiman, then CNS Finance Committee chair, guided a proposal through to Board approval in 2000 establishing the Child Neurology Foundation. Mike later succeeded Dr. Swaiman as CNF President. I have previously expressed amazement at the statistical improbability of 2-of-11 Gold Awardees having last names starting with "Z": Robert Zeller and Mary Zupanc. How much more amazing is it, then, that 3-of-7 Child Neurology Foundation past-presidents should come from Pennsylvania? Mike's tenure was followed by Alan Percy, from Birmingham, AL, after which the crown returned to the Keystone State for two successive terms with Larry Brown (shown right-middle) with another estimable figure from the City of Brotherly Love, Agustin Legido, International Committee Chair, flanking Dr. Sam Gwer, the 2013 D'Souza International Fellow), and Bill Trescher, from the Penn State program in Hershey. Bill will be presenting important material in early October as part of a live CNS webinar organized by the RVU Task Force.

Mike and I did not always see eye-to-eye, and he sometimes seemed not to have heard me as he chased another newly hatched notion around the corner. But we always enjoyed each other's company and I delighted in hearing him unspool a new cache of Lincoln and Churchill quotes and anecdotes



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when we crossed paths at CNS and AAN meetings. I regretted upon first learning of Mike's declining health in early 2019, what I knew but would not admit to myself as, simultaneously, Rob Rust slipped quietly into the shadows in Virginia: the three of us, who had longed plan to get together "some" December for the Memorial Illumination at Antietam, would never make that trip.

So, I was truly touched when, in November 2019, Ira Bergman invited me to say a few words at Mike's memorial service at UPMC. I thought it a fitting homage to draw on Churchill, noting that what the British Prime Minister said of his most important World War II ally could be equally well said of Mike Painter: "Meeting Franklin Roosevelt was like opening your first bottle of champagne; knowing him was like drinking it."



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“O” is for Old Friends (and New)

If a picture is worth 10,000 words, a smile must certainly be worth 20K. The heartbeat of every CNS Annual Meeting is reuniting with old friends and meeting new ones. There's nothing more I can or should say that these photos can't say better.

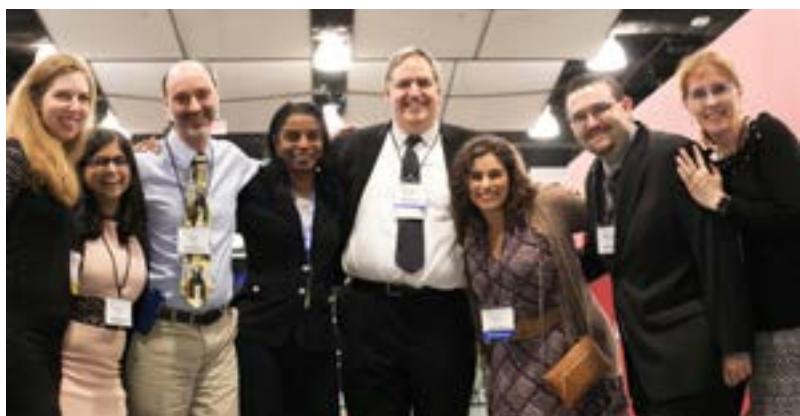


15 Days to Boston





15 Days to Boston



14 Days to Boston

“N” is for Next Up: Previews of Coming Attractions

We are now two weeks away from opening day of the 50th/Golden Anniversary CNS Meeting in Boston. The CNS Scientific Program Committee has put together a very strong and wide-ranging program under the direction of co-chairs Carl Stafstrom (shown below with 2018-19 Program Chair, Erika Augustine) and Yasmin Khakoo (shown below with 2002-03 Program Chair, Donna Ferriero).

All will be staged live in Boston, most will be live-streamed as well (the CNF Symposium, Humanism Breakfast, and Clinical Research Workshop will not live-stream, but will be available to registrants later as recorded videos).

The Fall 2021/Annual Meeting edition of CNS Connections will be posted next week on the CNS website with a detailed listing of the program, along with the traditional profiles of all award recipients.

Featured below are titles and links to brief videos of organizers outlining some of the highlights of their sessions.



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Awards Lectures



Martha Bridge Denckla Award Lecture: Disease Targeted Treatment Translation in Fragile X Syndrome and Neurodevelopmental Disabilities: The First Chapter

Dr. Elizabeth Berry-Kravis

[Click to watch video.](#)



Bernard Sachs Award Lecture: Gene Therapy Changing the Outcomes for Children with Neuromuscular Disease

Jerry Mendell, MD, PhD

[Click to watch video.](#)



Challenges and Opportunities

Dr. Monica Lemmon

[Click to watch video.](#)

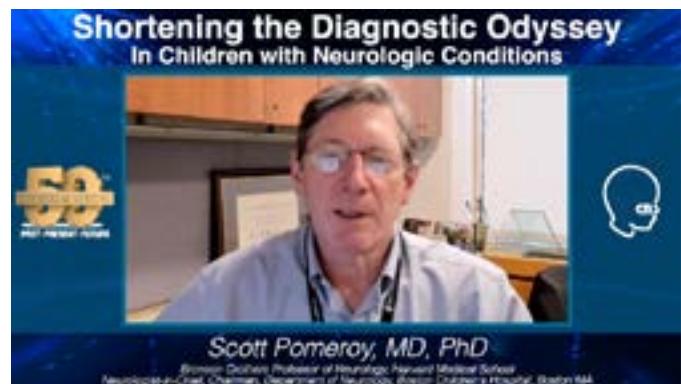


Hower Award Lecture: Mentors and Proteges: Standing on the Shoulders of Giants and Following Footsteps into the Future

Jonathan Mink, MD, PhD

[Click to watch video.](#)

Symposia & Workshops



**Symposium I:
CNF: Shortening the Diagnostic Odyssey in
Children with Neurologic Conditions**

Scott Pomeroy, MD, PhD

[Click to watch video.](#)



**SYMPORIUM III:
Neurological Manifestations and Long-Term
Sequela of Pediatric COVID-19 Infections**

Laura A. Malone, MD, PhD

[Click to watch video.](#)



**SYMPORIUM II:
PRESIDENTIAL SYMPOSIUM:
The CNS at 50! Past, Present, and Future**

Phillip Pearl, MD; President, CNS

[Click to watch video.](#)

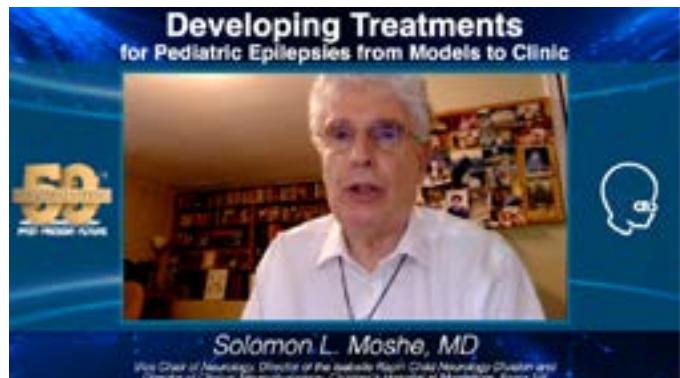


**SYMPORIUM IV:
Progress in Child Neurology through the
Lens of an NINDS Career Development Program**

Dr. Brad Schlaggar

[Click to watch video.](#)

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SYMPOSIUM V:
**Developing Treatments for Pediatric Epilepsies:
From Models to the Clinic**

Solomon L. Moshe, MD

[Click to watch video.](#)



SYMPOSIUM VII:
**Are We Poised for a Therapeutic
Revolution in Child Neurology?**

Louis Dang, MD, PhD

[Click to watch video.](#)



SYMPOSIUM VI:
**The Tiny Elephant in the Zoom Room:
Harnessing a Crisis to Recover, Maintain and
Enhance Career Development in Child Neurology**

Dr. Keith Van Haren

[Click to watch video.](#)



**CNS Clinical Research Annual Workshop:
2021 – Pediatric Neurology Clinical Trials –
Introduction to the Series**

Ariel Maia Lyons-Warren, MD, PhD

[Click to watch video.](#)

Seminars

PECN Previews

INNOVATION EDUCATION REPORT – THE PANDEMIC AND BEYOND

- Acquisition of best value in education through a global pandemic
- Virtual learning, teaching and patient care
- Acquisition of delivery and support in our learning programs with the new virtual world
- Recruitment support Virtual Neurology
- 2020 will see more focus in pediatric epileptology

Nancy Bass, MD
President of the Professors & Educators of Child Neurology
Program Director, Pediatric Neurology, UH Cleveland Medical Center, Cleveland OH

Professors & Educators of Child Neurology Meeting (CME)

Nancy Bass, MD; President, PECN

[Click to watch video.](#)

Updates in COVID-19 for the Pediatric Neurologist

COVID-19
CORONAVIRUS
Panic buying
Lockdown expand
Healthcare workers
Masks shortage
CDC
WHO
WHO
WHO

Grace Gombolay, MD
Pediatric Neuroimmunology, Emory University
Children's Healthcare of Atlanta, Atlanta GA

SEMINAR 3: The Brave New World of Pediatric Spinal Muscular Atrophy – Implications of Newborn Screening and Effective Treatment

Grace Gombolay, MD

[Click to watch video.](#)

Lessons Learned From Establishing an Adult Transition Clinic

Julia Frueh, MD
Child Neurology Resident
Boston Children's Hospital, Boston MA

SEMINAR 1: Lessons Learned from Establishing an Adult Transition Clinic

Julia Frueh, MD

[Click to watch video.](#)

The Brave New World of SMA

Erin Elizabeth Neil Knierbein, DO
Clinical Assistant Professor, Child Neurology, Neuromuscular Medicine
Pediatric Neurology Clinic, C.S. Mott Children's Hospital, Ann Arbor MI

SEMINAR 3: The Brave New World of Pediatric Spinal Muscular Atrophy – Implications of Newborn Screening and Effective Treatment

Erin Elizabeth Neil Knierbein, DO

[Click to watch video.](#)

14 Days to Boston



SEMINAR 4:
Neurologic Implications of
Youth Sports Participation

Sean Rose, MD

[Click to watch video.](#)



SEMINAR 6:
Medulloblastoma, New Clinical and
Translational Insights: The Path Forward

Dr. Roger Packer

[Click to watch video.](#)



SEMINAR 5:
CP to You is Not CP to Me –
Strategies for Mitigating Practice Variability
in Cerebral Palsy Care

Bhooma Aravamuthan, MD, DPhil

[Click to watch video.](#)



SEMINAR 7:
Disorders of Consciousness in Critically Ill Children:
Curing Coma for the Developing Brain

Mark Wainwright, MD, PhD

[Click to watch video.](#)

Seminars



SEMINAR 9:
NEURO-HUMANITIES:
**Neurologists and Neurology in Art,
Comedy, Poetry, and Music**

Dr. Phillip Pearl - Neuro Humanities

[Click to watch video.](#)

13 Days to Boston

“M” is for Minnesota Twins: Mack & Mink

I have never been partial to sequels (the lone exceptions being *Godfather II* and the *Thin Man* movies), but I knew, even before I finished writing the first “Minnesota Twins” entry (page 128) that there would have to be a second.

The subjects of this second entry can’t quite match the close connections between Ken Swaiman and Bruce Berg; those two “old lions,” both grew up in St. Paul, were undergraduates and medical students at the University of Minnesota a year or two apart, were both elected President of the CNS and the PCN, and were both honored with presentation of the Hower Award. But today’s set of quasi-twins come awfully close.

If I can come up with 10 non-genetic links between Ken Mack and Jon Mink without breaking a sweat, I’m guessing most of you, as trained neurologists, could spend two minutes scanning their CVs and come up with 20.

Minnesota

Let’s start with the easiest link: both Ken Mack and Jon Mink are closely linked to Minnesota. Ken left Madison, Wisconsin in 2001 to join the staff at the Mayo Clinic in Rochester, MN (Jon moved from St. Louis to Rochester, NY the same year). Jon grew up in Minneapolis and returns to Minnesota often to visit family and go camping and paddling in the Boundary Waters Canoe Area.

Stature

Both are notably imposing, both physically and professionally. Dr. Mack is an internationally recognized expert in pediatric headache, Dr. Mink is known in Tourettes and Movement Disorders circles worldwide.

Wash U

Both trained at Washington University in St. Louis. Ken was among the “young dudes” pictured in a previous feature on Wash U showing a remarkable cadre of seven young residents and fellows in 1987, four of whom went on to win the Young Investigator Award, including Scott Pomeroy (1989), Ken Mack (1991), Kel Yamada (1992) and Jeff Neil (1993). Jon is a few years younger and arrived at Wash U a few years later.

Special Interests

Both are associated with key “satellite” cohorts and activities not officially organized or sanctioned by the CNS, but subsidized by it, certainly, in recognition of their value to child neurologists in and outside of the CNS. Ken Mack teamed up with Steve Leber in 1994 to launch the ChildNeuro ListServe; while relatively dormant now, it served for many years as a hothouse germinating great ideas, consults, discussions and collaborations. In 1999, Jon Mink, Leon Dure and Harvey Singer organized and presented a hugely impactful symposium on movement disorders that soon thereafter spawned the Woodstock of CNS



SIGs; the BYOV Movement Disorders "film fest" on Wednesday evenings draws big crowds and sparks high energy, with 150-200 attendees bringing videos to show and offer for a lively Q&A exchange moderated by a panel of experts, which for many years, up until the past few, featured Drs. Mink, Singer and Dure. To use a fishing metaphor, if I had to pick one fly to use for hooking med students coming to the CNS on child neurology, it would be the Wednesday evening Movement Disorders meeting.

Teaching

Both Ken and Mink are well-recognized and multiply-rewarded teachers and mentors both within their institutions and within their broader, international subspecialty communities.

International Child Neurology Association

Both Ken and Jon have been very active in and seminally responsible for much of the growth and success of ICNA, including extended service by both on its Board of Directors. Ken is credited with revitalizing ICNA with his game-changing plan, adopted by the BOD, to eliminate membership fees in hopes of drawing members from the less affluent developing nations. Jon served as Chair of the Joint CNS-ICNA Scientific Program Committee in 2019-20, overseeing what turned out to be the highly successful 2020 Joint Virtual Meeting of the two organizations. That meeting's success was not, by any stretch, a sure thing; that it turned out to be is owing in no small part to the respect the international child neurology community has for Jon, compelling them to follow his lead in pivoting from San Diego to a virtual platform.

CNS Presidents

Both Dr. Mack and Mink served as Councillors on the CNS Executive Committee, Ken from 2005-07, Jon from 2007-09. Both were later elected CNS President, Ken serving from 2015-17, Jon succeeding him from 2017-19. Ken played a pivotal role in helping me make a successful bid to the ICNA BOD in 2016 to host a joint CNS-ICNA



[Click to watch video.](#)



13 Days to Boston

meeting in San Diego in 2020; one of the central selling points was an extension of the expanded outreach to junior members: the importance of providing a new, emerging generation with the opportunity to affordably attend an international child neurology meeting and establish networking relationships around the world that would strengthen both organizations, all for the ultimate benefit of children everywhere. Ken was also the key player effecting the transition, following Jack Pellock's passing in 2016, from the decades-old Pellock Epilepsy Seminars to a wholly planned and supported annual course in conjunction with the CNS Annual Meeting for child neurology and NDD residents in their final year of training.

Jon continued to build on the revitalized "youth movement" of the past decade, actively encouraging younger members to be involved in committees and SIGs. He is also almost singularly responsible for encouraging substantive diversity initiatives, out of which the current Leadership, Diversity, Equity and Inclusivity Task Force, chaired by Rujuta Bhatt Wilson has grown. This is not a newfound, passing interest with Jon; in 2013 he received an award from the University of Rochester for his work in establishing and fueling diversity efforts at the medical school. Similar movement in a more open and diverse direction was initiated during his two-year term as Chair of the CNS Nominating Committee.

Names and Games (of Thrones)

Perhaps this is a good time and place to take a break from the portentous and make brief mention of the more mundane and obvious: their names. "Mack and Mink" are so closely matched aurally and phonetically that, had they met earlier, they might have formed a thriving law firm or an early vaudeville act. They are, or were, in fact, two characters caught up in a three-character Presidential succession that almost has a "Game of Thrones" feel to it. Coming from Rochester, MN myself, I was very taken by the notion that the years 2013-19 will go down



in CNS history as "The Reign of Rochester," with Nina Schor (Rochester, NY) being succeeded by Ken Mack (Rochester, MN) followed by Jon Mink (Rochester, NY). I doubt anything like this has ever happened or will ever happen again in CNS annals, or in any association of any kind, for that matter.

Hower Award

Ken Mack was selected by the CNS Awards Committee to receive the Hower Award and present the Hower Lecture in 2020 in San Diego, an honor which, unfortunately, was accorded him virtually. Jon Mink is the recipient of the 2021 Hower Award and is slated to give his lecture, "Mentors and Protégés: Standing on the Shoulders of Giants and Following Footsteps into the Future" on Saturday morning, October 2. The crowd for that lecture will likely, and unfortunately, be about half of what it might normally be because of COVID. I use the word "unfortunately" when referring to Ken's virtual and Jon's hybrid presentations not only because it is unfortunate they will not receive the full effect of a roomful of peers giving them a "standing O," but because both of them have such unique gift for "commanding a room"; these are genuine missed historical moments. Both of them are powerful speaking presences. I very distinctly remember sitting in on Ken's headache lecture at the ICNA meeting in Amsterdam in 2016. Generally soft-spoken, but with a scarcely hidden, delightfully unaffected *joi de vivre* pulsing just under his skin, one doesn't expect him to be a dynamic speaker. And yet. When he took the podium, it was like magic. Expertly moving his hands for emphasis (his use of hand motions is as good as anyone I've watched at CNS meetings), he really seemed to weave a web that caught everyone up in the room for the full length of the lecture.

Conversely, in a smaller, vastly more intimate setting, I enjoyed the privilege of a front row seat at a mentor/med student session organized by Rujuta Bhatt a few years ago at the AAN Annual Meeting in Los Angeles. I sat next to Jon,



enthralled as I watched and listened to him charismatically connect with a steady stream of different students and residents, sharing stories about his side interest in woodworking taken up while he was a resident, asking probing questions that were personal but not intrusive, awakening a sense in each one overall that, "hey, I can talk to this guy; this guy remembers what it was like to be in his 20s, trying to figure out what he wanted to do with his life." Small wonder that his residents all seem so passionately devoted to him. How entralling was it? I put it a notch above the Dodgers game I was lucky enough to attend that evening with Jon and his Rochester and "green journal" colleague, Bob Gross.

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Minnesota Moments

Two personal Minnesota moments that I'll share with you, and then you can get back to your work. I remember driving down to Rochester to have lunch with Ken, Marc Patterson, and John Bodensteiner a few summers ago when Ken was CNS President, Marc was Scientific Program Chair, and John had not yet retired to Arizona. We dined in a new Mayo Clinic educational tower built on the very space my junior high school once occupied. If you know any one of the three, you'll know the conversation was lively and engaging. If you know all three of them, you'll have no trouble believing me when I say I laughed harder in that one hour than I did in any single full-day spent on that same spot almost 50 years earlier.

My second Minnesota moment is like a bookend to one of the first Countdown entries where I showed a picture from one of my sunset walks taken along the Mississippi River. My other sunset walks take me through the Macalester College campus and the adjoining Tangletown neighborhood to the west. Sometimes on that walk I pass by a plaque outside the science classroom building dedicated to Walter Mink, Jon's father. Two siblings and two of my best friends all went to Macalester in the early 70s and remember him well as being hugely popular among their peers, a veritable legend. (An alt-rock band formed by late 80s Mac alumni called themselves "Walt Mink" and made a small splash with their half-dozen CDs). On the plaque is embossed, "HIS INTELLECTUAL CURIOSITY, COMPASSION AND HUMOR WERE REFLECTED IN HIS TEACHING AND VALUED BY THOSE WHO KNEW HIM. HE NURTURED THE POSITIVE IN PEOPLE AS A TEACHER, ADVISOR, COLLEAGUE AND FRIEND."

You tell me: who (else) does that sound like?



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“L” is for Legacy Luncheon

Note: I apologize for the unannounced weekend hiatus. Too much going on with my “day job”. I’m told there is a meeting coming up, involving details, deadlines, etc.. Who knew?

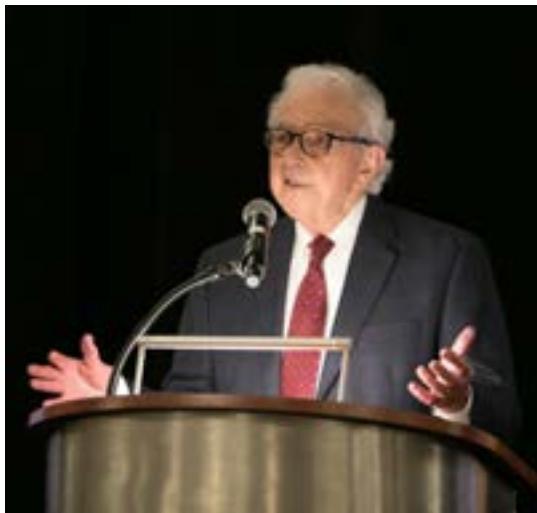
In his profile of one of this year’s two Brumback Lifetime Achievement Award recipients, Sid Gospe, published in the Fall CNS Connections to be posted on Wednesday, Jim Bale noted that Sid vividly recalls that as a child growing up in the Bay Area he attended one of the 1962 World Series games matching a San Francisco Giants team that included four future Hall of Fame players – William Mays, Willie McCovey, Juan Marichal and Orlando Cepeda – against a New York Yankees team that included three – Mickey Mantle, Yogi Berra and Whitey Ford. My guess is, that despite retirement, downsizing, and moving from Seattle to North Carolina in the last two years, Sid still has the ticket from that game. I mention that only to point what may be obvious to many, but overlooked by most: a ticket is a mere artifact, a visual and tactile reminder of an experience which, when held in memory, is still alive, still expressing itself, still being shared with, related to, passed on to others as a story....as a legacy.

The ticket itself is not itself the true legacy: the life, the blood and pulse and sensations aroused and satisfied in that moment and the life lived forward from that moment forward as experience to be valued, reflected on, and re-valued with new and evolving meaning and significance, that is the legacy. Similarly, the infamous

napkin saved from that 1971 meeting at the Holiday Inn in LaCrosse, listing Ken Swaiman and the “LaCrosse 8” along with a small handful of others who might support the founding of a new association of child neurologists, is not a legacy itself; it is an inert object that points in the direction of the fuller, truer, living legacy of lives lived in such a way such that one of them has the Legacy Luncheon named after him. Even more to the point, he trained a resident decades ago, Steve Ashwal, who put together a 2nd edition of the Founders book this year that will be signed by subjects and authors of those profiles after the luncheon. That is what legacy is, and does.

A second “napkin signer” and member of the “LaCrosse 8”, Ray Chun, played a powerful shaping role in the life of this year’s Gold Humanism Awardee, Mary Zupanc. And still another founder, David Clark, not listed on the napkin, but a decisive voice at the first business meeting in Ann Arbor urging those gathered to formally establish the CNS, recruited Robert Baumann, the other 2021 Lifetime Achievement Awardee, to come to the University of Kentucky, where he remained his entire career. Similarly, Mike Painter was influential in shaping the career of this year’s Training Director awardee, Miya Asato, shown below introducing the 2019 awardee, Bruce Shapiro, who mentored her and so many others, and through her, so many more.

Drs. Ashwal, Zupanc, Baumann and Asato are legatees, a part themselves of a legacy: the leaping flame passed from person to person, generation to generation. They are the planted seeds or replanted saplings watered from



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common sources that each grew into essentially similar, but splendidly different varieties of full-grown trees, each of them seeding several more in kind.

I will not be around in 25 years to celebrate the next milestone meeting of the CNS, recognizing the names of those officers and awardees who subsequently received and passed on the legacy we celebrate this year. Nor will many of you. But I'm guessing you might agree with me that in

scanning the room in Boston next week, looking at the youthful faces of those 50 and younger, we can identify many who are likely to be celebrated in the future in no small part because they felt it important for them to take the time to honor and uphold the meaning and value of legacy simply by being there.



Below you will find the agenda for the luncheon. If you have yet not purchased your ticket, I would urge you do so: tickets may not still be available on-site the day of the luncheon. If you are among those past officers and awardees being honored who did not sign up for the luncheon using the comp code sent to you via eConnections July 23, I would urge you recover that email and click the link to return to registration to modify your Registration: <https://www.badgeguys.com/reg/2021/cns/register.aspx>



Phillip L. Pearl MD, President

There will be numerous presentations during the Legacy Luncheon, but simply being in the room, filled with our founders in body and spirit, will be the professional thrill of a lifetime. If you are able to travel to Boston, you will not want to miss this event.

KENNETH F. SWAIMAN CNS LEGACY LUNCHEON

WEDNESDAY, SEPTEMBER 29

11:30 AM – 1:30 PM

Welcome and Introduction

Phillip L. Pearl, MD President, Child Neurology Society

Recognition of Past CNS Presidents

Recognition of Past CNS Secretary-treasurers and Councillors

Presentation of 2021 Arnold P. Gold Foundation Humanism in Medicine Award

- Mary L. Zupanc, MD, FAAN, FAAP

Recognition of Past Gold Humanism Award Recipients

Presentation of 2021 Roger & Mary Brumback Lifetime Achievement Awards

Robert J. Baumann, MD, FAAN

Sidney M. Gospe, Jr, MD, PhD

Recognition of Past Roger & Mary Brumback Lifetime Achievement Award Recipients

Recognition of Past Bernard Sachs Award Lecturers

Recognition of Past Hower Award Lecturers

Presentation of 2021 CNS/PECN Training Director Award

- Miya Asato, MD

Recognition of Past CNS/PECN Training Director Award Recipients

Recognition of Past Phillip R. Dodge Young Investigator Award Recipients

Recognition of Past Outstanding Junior Member Award Recipients

Presentation of 2021 Outstanding Junior Member Awards

- Rhandi Christensen, MD, PhD
- Darius Ebrahimi-Fakhari, MD, PhD
- Laura Gilbert, DO, MBA
- Hannah Wellman, MD

Presentation of Outstanding Junior Member Award (Post Graduate)

- Eric M. Chin, MD · Thiviya Selvanathan, MD FRCPC

Presentation of M. Richard Koenigsberger Scholarship Award

- Jennifer Keene, MD, MS, MBA

Presentation of Bhawan Garg High School Student Neuroscience Award

- Meagan Ryan, Ossining, NY

8 Days to Boston

“K, J, & H” is for Kennedy Krieger and Johns Hopkins

Today's entry will be brief, I hope, as most confessions of guilt or ignorance should be. How, you wonder – eyes wide and mouth hanging open (although, who would know – you're wearing a mask, right?) – could anything written, not just about one or the other, but about both Kennedy Krieger Institute and Johns Hopkins possibly be brief?

But, that's just the point: I don't know all that much about them. Or, more to the point, I don't honestly know the difference between them. (How, you wonder, could that possibly be?). Now, before you get on your high horse and start calling or texting past and present board members demanding to know how this appalling knowledge deficit could go undetected or unpunished – not just for years, but decades – let me pose that dreaded “He that is without sin....” question and see if you don't quietly put that stone (or iPhone) down and walk away.

I remember being amazed and appalled a few years back when one of the brightest child neurologists I know, having just given grand rounds at the University of Minnesota, told me he never realized the Mississippi River flowed between Minneapolis and St. Paul. Well, “duh!” I could have said, but didn't, quietly dropping the stone to my feet. Because we all have our own pockets of ignorance. Someone in New York might think you are an idiot if you confessed you didn't know the difference between Brooklyn and the Bronx, or worse: Uptown, Midtown and

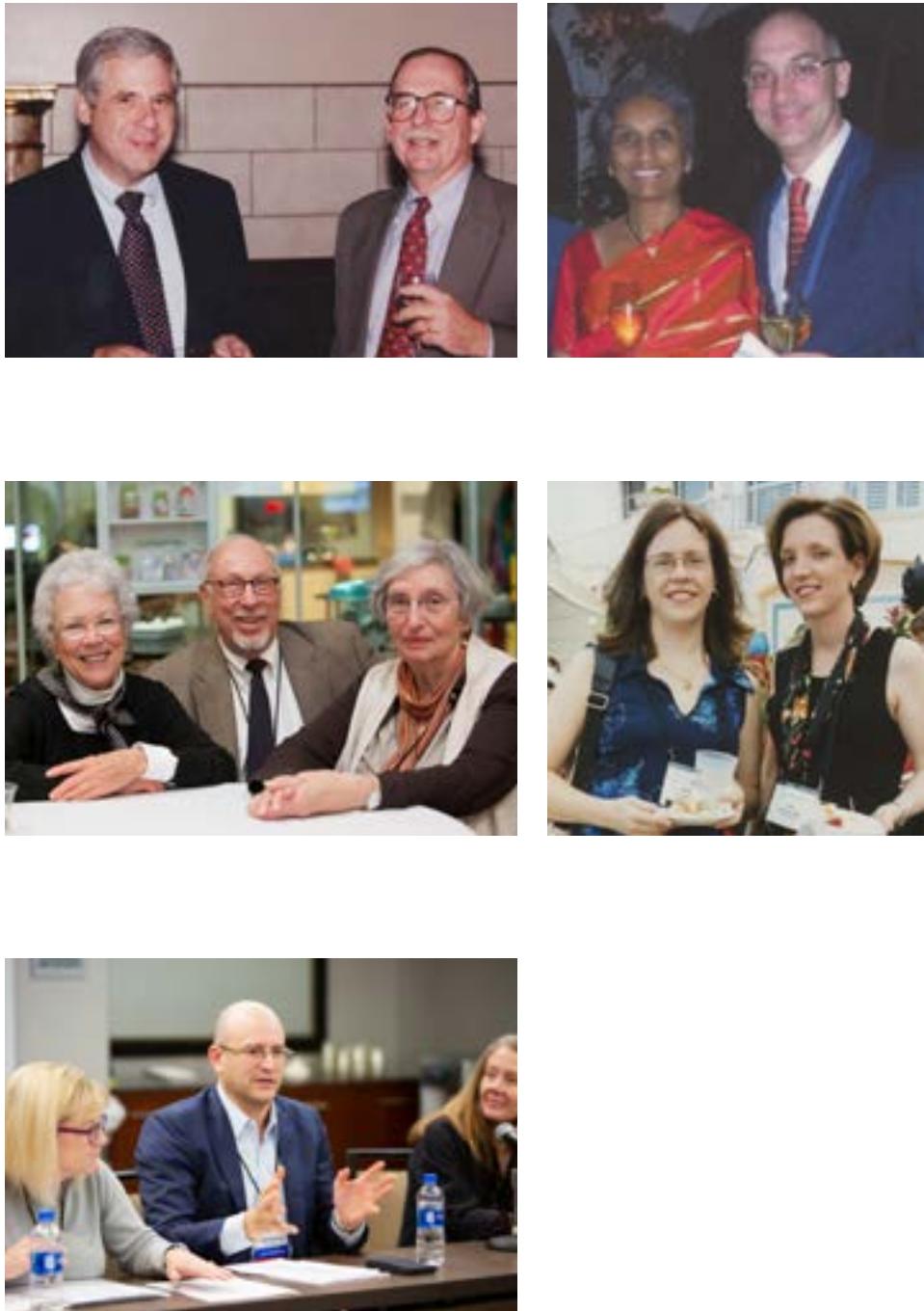
Downtown. Or, someone half my age might walk away muttering “OK, Boomer” if I shrugged my shoulders when asked “Which do you like more: Beyoncé or Rihanna?” They wouldn't even bother asking the obvious follow-up question: “Which is more like Kennedy Krieger and which is more like Hopkins?” Good thing, because I couldn't tell them. Could you?

On a good day I could recite in order the last three division chiefs at Hopkins: John Freeman, Harvey Singer, and Eric Kossoff. Same for Kennedy Krieger: Hugo Moser, Gary Goldstein and Brad Schlaggar. But ask me the bonus question, “Where does Guy McKhann fit into the picture?” and I couldn't answer. I could list which four from Baltimore won the Hower Award: Hugo Moser (1994), John Freeman (2004), Sakkubai Naidu (2010) and Harvey Singer (2016). And without breaking a sweat I could list the three who received the Sachs: Hugo Moser (1987), Martha Bridge Denckla (1997) and Michael Johnston (2008). I could tell you which four I might go to for wise counsel, noting their tenure as Councillors on the CNS Executive Committee: John Freeman (1979-81), Gary Goldstein (1987-89), Michael Johnston (1999-2001), Sakkubai Naidu (2009-11). And I can think of two I would trust to balance my checkbook: Harvey Singer, CNS Secretary-treasurer from 2010-2015, and Lori Jordan, the current Secretary-treasurer who, though now at Vanderbilt, trained at Hopkins...I think. Which is the point: ask me which of them goes with KKI and which with JHMI, and I'd probably guess wrong half the time.



So, rather than prolong this parade of ignorance, I'll post a few photos, noting in my defense that I have posted many featuring KKI/JHMI notables the past several weeks (Carl Stafstrom, Erika Augustine, Bruce Shapiro, and Miya Asato – both in the same picture, even, in yesterday's installment). And, as all of you know, far better than I, there have been dozens of photos featuring Kennedy Krieger or Hopkins alums (e.g. Alan Percy or Bernie Maria); I just didn't always mention it, either because I didn't know they were linked to either, or because I didn't know whether they were "Uptown or Downtown," "Beyoncé or Rhianna."

One small post-note: there are still two shout-outs to Kennedy Krieger yet to come with "D is for Denckla" and "C is for CNCDP," both drawing heavily on current KKI CEO, Brad Schlaggar's sizeable contributions. Stay tuned. Don't give up on me just yet.



7 Days to Boston

“I” is for International Child Neurology

Big topic for a single Countdown entry, so I can't really afford to waste time and space in self-indulgent rue. But how can I not, one more (last) time, take a backward glance at what might have been, as suggested by this picture of gloriously happy and expectant child neurologists caught on camera in front of the 2020 CNS-ICNA promo backdrop at the Charlotte meeting in 2019?

The Joint CNS-ICNA Meeting theme was “Sharing Knowledge, Sowing Friendships, Spreading Hope.” Not being able to realize that mission in-person in San Diego in 2020 was a blow, but not a fatal blow. True, no seeds were scattered and sown in the way that only person-to-person interaction allows, particularly among younger child neurologists experiencing their first international meeting. But knowledge was widely and effectively shared via the virtual platform and the ripple effect from that positive outcome continues to play out, as witness this year’s Humanism Breakfast focusing on Global Health that Nigel Bamford organized. The session includes several presenters who “lit up the screen” last fall with their virtual presentations: Archana Patel (Boston Children’s Hospital), Doug Postels (Children’s National Medical Center), Ed Trevathan (Vanderbilt), and Jorge Vidaurre (Nationwide Children’s Hospital, and Chair of the CNS International Affairs Committee). The breakfast is in-person only and sold-out, but it is being recorded and will be made available later this fall on the CNS website.

And what of Hope? Hope springs eternal, not least through the eyes and efforts of the aforementioned Jorge Vidaurre. If, as some have suggested, Huda Zoghbi is a credible candidate for someday booking a flight to Stockholm to receive the Nobel Prize in Medicine, Jorge’s indefatigable efforts worldwide, with the support of both ICNA and the CNS, put him on a trajectory



Jorge Vidaurre, Dave Clark, and Sandy Waran

that might someday have him boarding a plane to Oslo to receive the Nobel Peace Prize. Seriously. Take a look below at a mere sampling of activities in 2019 and 2020 had a hand in launching before the pandemic foreclosed all direct, on-the-ground activities and forced them on-line.

2019 Educational activities

2019 feb 24- 26	Ped/ Neurology Society El Salvador	San Miguel, El Salvador	Jorge Vidaurre, Roberto Caraballo	Jorge Vidaurre
2019 Feb 26- 28	Ped Society of El Salvador	San Salvador, El Salvador	Jorge Vidaurre, Roberto caraballo	Jorge Vidaurre
2019. March 25-30	Workshop Caribbean	Antigua and Barbuda	Dave Clarke	Nurse nutritionists suported by CNS/ICNA
2019 April 28-30	ICNA Board meeting ICNA educational meeting + Turkish	Antalya, Turkey	all board members	Haluk Topaloglu, Hasan Tekgul
2019 May 1- 3	Child neurology society	Dalaman, Turkey	Jo Wilmhurst, Ingrid Tein, Pratibha Singh, Michael Johnston, Hans Hartman, Lakshmi Nagarajan, Anaita hegde	Haluk Topaloglu, Hasan Tekgul
2019 April 10-14	Neurophysiology symposium+ EEG training	Kumasi, Ghana	Sam. Dzodzomenyo, Jorge Vidaurre, Keith Morgan	Charles Hammond, Justice Sylverken
2019 -Sept	ICNA educational meeting + PET	Luanda, Angola	Marillissa Guerreiro	Leite,
2019 -	World Federation of Neurology	Dubai,	Jo Wilmhurst, Ingrid Tein,Pratibha Singh	
2019 sept 19-21	National congress of Ped Neurology	Ecuador	Aicy Torres	Marcelo Roman, Aicy Torres, Jorge Vidaurre
2019 Nov	Workshop on Neuromuscular disroders	Dubai	Andre Urtebezi	

2020 approved and proposed educational activities

2020 Feb 25- March 8	Pakistan Child Neurology Program	Karachi, Lahore, Peshawar, Pakistan	Mubeen Rafay
	International Ped		
2020 - March 19-21	Neuroimmunology Meeting	Buenos Aires, Argentina	Silvia Tenenbaum,
	ICNA EB + Quito educational		Jorge, Elaine, Lieven, Jo, Edward, Lakshmi, Aicy, Richard, Haluk,
2020 - March 26-28	meeting	Quito, Ecuador	Vanessa
	Pan Arab Child Neurology		Ahmed Raouf, Biju Hamid, Anaita Hegde, Hans Hartmann, Chaney
2020 - April 9-11	conference	Alexandria, Egypt	Triki
	Baltic Congress of Ped		
2020- June 4-5	Neurology	St Petersburg, Russia	Adam Kirton
	El Salvador, Epilepsy Surgery	San Salvador, San Miguel, El	
2020 July 13-18	Program	Salvador,	Jorge Vidaurre, David Donahue, Angel Hernandez
	Mexico, Epilepsy Surgery		
2020 August 12-13	Symposium	Distrito Federal, Mexico	Jorge Vidaurre, Satya Gedela
	ICNA educational meeting		
2020- sept	+PET	Maputo, Mozambique	Marillissa Guerreiro
2020 - Oct 19-23	ICNC + CNS	San Diego, USA	all board
	Etiopia, Child Neurology		
2020 November?	Symposium	Etiopia, Mekelle University	Dave Clarke

7 Days to Boston



Exploring new programs CNS/ICNA

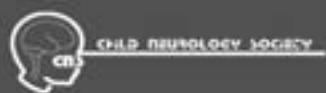
Building **infrastructure** in different **countries**

- ✓ Ghana
- ✓ Tanzania (Dar Es Salam)
- ✓ Caribbean

- ✓ Type of infrastructure:
- ✓ EEG laboratory
- ✓ Donation of EEG machines
- ✓ 13 machines donated by Emory. Transferred to Africa mainly Tanzania



New initiatives



CNS/ICNA supported first program lead by **nurse educators** and **midwives**. No MDs were supported

Education to primary care providers and schools in Antigua and Barbuda



Training of teachers and students

The COVID-19 pandemic slowed, but did not stop the committee's collaborative commitment and activity. Take a look at the report Jorge filed for the upcoming CNS Board Meeting:

None of the aforementioned activities involve Jorge's work alone. Far from it. His gift, his genius if you will, is bringing together a vast network of people in the child neurology community to creatively plan and dynamically and cooperatively enact meaningful, sustainable programming that will have real short-term and long-term impact around the globe. Witness two recent CNS.ICNA initiatives Jorge helped launch, with others taking the lead to bring the project to fruition: an on-line Child Neurology Neuromuscular Workshop led by Drs. Shahzad Zafar and Sharoon Qaiser, and a 4-month course in Pakistan planned and led by Mubeen Rafay, a member of the CNS International Committee from Toronto.

And then there is the Bernard D'Souza International Fellowship Award, something that was once the primary, or only, activity the International Committee was involved in, rather than one of many. Jorge has prevailed upon me over the years to double the number of Bernard D'Souza International Fellowship Awards. ("Prevailed" might be a stretch; it's never a matter of him pushing an agenda and the question is never "how can I say 'no'?", but, rather, caught up in his enthusiasm and unassailable record of past achievement, "how can I say anything but 'yes'?"). The D'Souza Fellowship Award was created in 1989 with the support of John Freeman and the Johns Hopkins program as a memorial

International Committee report 2021

The COVID 19 pandemic impacted significantly the activities planned by the international committee. As the pandemic evolved, travel restrictions were imposed in multiple countries and academic centers in the USA. Given these circumstances, the committee decided to use virtual platforms for all educational programs and outreach projects developed in 2021. Each country provided their own platform, and no budget was used.

Unexpectedly, the committee received an unexpected larger than usual number of requests to support national meetings and training modules. Most of these were important national meetings. Some activities were developed as part of collaborative efforts with ICNA.

This is the list of activities supported by our society:

Argentina : Annual Argentinian league against epilepsy meeting (LACE)

Ecuador: National meeting |

Colombia: National meeting

Peru: National pediatric society meeting (neurology section)

Chile: Latin America EEG course

El Salvador: International meeting

Mexico: Annual meeting of Mexican league against epilepsy

Pakistan: National meeting. This meeting evolved to include other countries in Asia

to their esteemed former resident and colleague who subsequently became chair of the Duke University program before his untimely passing in 1988. The award has been presented to 34 early/mid-career child neurologists from 24 different countries. No awards were presented in 2020, but four outstanding applicants were selected this year: Drs. Chaw Su (Malaysia), Sebunya Kabuye (Uganda), Alireza Tavasoli (Iran), and Paulinea Tejada (Chile). Final selections came too late for proper recognition in any meeting programs or publications finalized in August, but all will participate in the meeting virtually and we hope to feature their work in a zoom webinar this winter, as well as profile them in the Winter 2021 CNS

SATURDAY
8:00PM EST
9-11 AM EST

Workshop

Dr. Shahzad Zafar

Dr. Sharoon Qaiser

Supported By

The International Child Neurology Society
The International Child Neurology Association

7 Days to Boston

Connections. Hope being central to everything Jorge does as chair of the committee, he hopes we can resume "normal" programming of the D'Souza Fellowship in 2022, including live in-person participation in the CNS Annual Meeting followed by a stay of one or two weeks at a host institution with strong programming in the Fellows' area(s) of interest.

Promotional graphic for the 4-month Pediatric Neurology Course. It features a blue speech bubble containing text and logos for the International Faculty and supporting organizations. Below the main text are three smaller boxes detailing session topics and dates.

Pediatric Neurology Teaching Sessions By International Faculty Supported by CNS/ICNA & CHICH Lahore

4-month Pediatric neurology Course

- Topics: Neurophysiology & Neuroradiology Basics
- Format: Lectures, Workshops and Case Discussions
- Session Dates: September– December 2021
- Saturdays: 5:00– 8:00 pm Pakistan Standard Time
- Register at: <https://forms.gle/PPrb99eJ5uQHsQje8>
- Detail program with zoom link to follow. Please register ASAP

EMG, NCS, EP & Neuromuscular Sessions
September 11 & 25, 2021
Saturday, 5:00 – 8:00 pm PST

EEG, Epileptic Encephalopathies DRE & Ketogenic Diet Sessions
Oct 16, 30 & Nov 6 & 20, 2021
Saturday, 5:00 – 8:00 pm PST

Neuroradiology Sessions
December 11 & 18, 2021
Saturday, 5:00 – 8:00 pm PST



2013 D'Souza Fellow, Sam Gwer, from Kenya, with International Committee member, Doug Postels



2019 Fellow, Jitendra Kumar Sahu from India, with Ram Kairam



2017 Fellow, Charles Hammond, from Ghana, with 2015 Fellow, Edward Kija



2016 Fellow, Arushi Gahlot Saini, from India

“I” is also for Indian Pediatric Neurology Group



Competition between training programs is always stiff, if politely unspoken, over who has the most fun, the best spread of food or the finest music at their alumni reception.

When it comes to food and fun, none, however, hold a candle to the group of Indian pediatric neurologists who gather each year at the CNS meeting. It is a star-studded group, featuring multiple Hower, Lifetime Achievement, Outstanding Junior Member and, in recent years, D'Souza Fellowship

awardees, as well as numerous committee chairs and past, present or future CNS board members. Rank means nothing, cheerful camaraderie means everything. It would amount to nothing short of crude and pathetic pandering were I to churlishly suggest in closing, that while I have always hoped to be invited to one of their festive gatherings (who hasn't?), I never have been. I'm getting too old and too near the end of my tenure to worry about pride and propriety..... my email, if anyone is interested, is rblarson@childneurologysociety.org.

6 Days to Boston

“F” is for Child Neurology Foundation

“F” is also for “Friends.” I first met Amy Brin over coffee at an AAN meeting in Philadelphia back in 2013, before she became Executive Director of the Child Neurology Foundation. The coffee has never stopped flowing and the friendship has never stopped growing. Like a true friend, Amy has always put out the open offer, “Whatever I can do to help, let me know.” As the meeting draws closer and I find myself drowning in deadlines and details, I took her up on her offer, grateful for the extra time it buys me, but more importantly, knowing no one could tell this tale better than she (certainly not me). So, with your kind indulgence, Dear Reader, I will flip “G” and “F” and let Amy take it from here.

No walk down memory lane is complete without including memories shared with your favorite partners. One of the most distinct relationships CNS has shared in its first 50 years is the one with the Child Neurology Foundation (CNF). And for CNF, there is no greater relationship than the one we share with CNS.

Founded 30-years after CNS, CNF began its service to the child neurology community in 2001 through the leadership of Dr. Kenneth Swaiman. Dr. Swaiman saw the opportunity for greater philanthropic activity to help the child neurology profession and joined with titans like Stephen Ashwal, MD; Donna Ferriero, MD; Gary Goldstein, MD; John Pellock, MD; and Alan Percy, MD to set the course for this new endeavor. Under these pioneering leaders – and with partners like Dr. Roy Elterman of **Pediatric Epilepsy Research Foundation** – CNF began to provide research grants to early investigators. Like any “younger sibling,” CNF learned to crawl and then walk during these formative years... and struggled to find its identity, often “trying on” various roles with programs in disease awareness or medical student outreach. These “play periods” brought about confusion regarding CNF’s identity. What is CNF’s role in the child neurology sector? And



what is its relationship with CNS? In truth, by the time CNF reached its adolescence – year 13 of operating – it was in chaos, with great uncertainty and internal strife.

For all of us trained in Pediatrics, we are taught to offer reassurance and preach the importance of consistency, stability and order – especially in the time of change (i.e. adolescence). Enter W. Donald Shields, MD: the ultimate “parental figure” who was named CNF President in 2012. With Don at the helm, truth was seen, and truth was spoken. Difficult but revolutionary decisions were made that chartered a new course for CNF. Don’s vision signaled the critical need for a “hub” – a connective center – for the child neurology sector that would bring caregivers, physicians, allied health professionals, researchers and industry partners together for the first time. This center would be collaborative, with impeccable values anchored in stewardship and “doing the right thing first.” It would be innovative in its operations – utilizing for-profit business mechanisms to avoid falling victim to the typical fiscal and management lability seen in some non-profits. It would be courageous in tackling complex, gnarly problems that often reside in the shadows of our community yet are the very issues that impede both families and physicians from attaining/providing quality care.

The Child Neurology Foundation rebranded in 2015: to create a community of support. As true with any bold, decisive and needed act of leadership, Don's efforts were profoundly noticed by his child neurology colleagues, and immediately as well as in the years to come, his comrades in arms stepped up to serve the vision Don championed. CNF continues to be stewarded by some of the sector's most compassionate, daring and esteemed leaders: Jan Brunstrom, MD; Lawrence Brown, MD; Bruce Cohen, MD; Sidney Gospe, MD; Shaun Hussain, MD; Shafali Jeste, MD; Tom Langan, MD; Bennet Lavenstein, MD; Ken Mack, MD; Jonathan Mink, MD; Anup Patel, MD; Phillip Pearl, MD; Scott Perry, MD; Scott Pomeroy, MD; Nina Schor, MD; Ann Tilton, MD; William Trescher, MD; Amy Waldman, MD; and Mary Zupanc, MD. These CNS members have been part of CNF's Board of Directors alongside allied health professionals, business leaders and parent advocates for the past seven years. Together, their leadership provides a unified vision for how an organization can leverage multi-stakeholder expertise, insights and resources to strategically approach issues that affect the entire child neurology landscape. They operate from a position of unity: that we are all child neurology.

Through their deep commitment and excellence in leadership, these collaborators have rewritten the Rising Tide of CNF as the only patient-facing advocacy organization in the neurology space that was started by and actively governed by physicians. Today, CNF drives in the areas:

1. **Education** (patient and provider), including topics in **transition of care, shortening diagnostic odyssey, SUDEP, genetic testing, telehealth and behavior management**
2. **Support**, including **resource navigation, emotional support** for caregivers and **financial grants**
3. **Research**, including **grants** and investment technology to bring unique **clinical decision support system to child neurology**
4. **Advocacy**, federal, state and community levels



A photograph of a man in a suit holding a white card with handwritten text. The card reads: "My favorite thing about the child neurology community is... Connection to CNF! Help with Neurology conditions like Epilepsy, Cystic Fibrosis, etc." Below the text is the Child Neurology Foundation logo. The background shows a blue wall with the foundation's name and website. The text at the bottom of the image reads: "Child Neurology FOUNDATION Creating a Community of Support www.childneurologyfoundation.org #CNSMeeting2019 ZimZoomPhotoBooth | pw: CNF2019".

6 Days to Boston

And the results speak for themselves:

- Annually, serving hundreds of thousands of patients/ families
- Serving families in all 50 states and over 70 countries
- Working in over 90 disease states within the child neurology spectrum
- Developed over 100 patient education materials
- Providing \$250K in financial relief to families during 2020 COVID-19
- Providing \$4.1M in research grants to CNS members
- Annual hosting of symposium at CNS Convention with growing numbers of attendees (125 in 2015 to >350 in 2020)

As CNS celebrates its' 50th anniversary in 2021, CNF celebrates our 20th. Proud to have grown out of our awkward years of adolescence, we now stand confidently in our identity and in our revised mission statement: to serve as a collaborative center of education, resources, and support for children and their families living with neurologic conditions and facilitate connection with medical professionals who care for them.

We look to our Next 20!

years, grateful to serve beside our closest partner, CNS. We want to hear the child neurology profession's greatest challenges and needs and understand how we can be of service to you. We want to celebrate your gains. We want a brighter tomorrow for the child neurology profession: one that showcases the unique expertise you are distinctively trained to bring to our country's most vulnerable – our medically complex children. We envision a future where you have the resources and support you need to not feel burnt out or overwhelmed by the administrative requirements hitting your clinical practice. One where the research innovations that are driving evidence-based best practices towards new treatments and cures are able to be seamlessly absorbed into your craft. We, at the Child Neurology Foundation, see this future because it is only THIS future that allows our vision – that *all children living with neurologic conditions will reach their full potential* – to be realized.



Let us be clear, the Child Neurology Foundation is laser focused on grabbing that better tomorrow for all children and families living with a neurologic condition, BUT we can only do that when we are all working as one. We are here to support you, CNS, and we salute all your members – the newest, the most revered, the ones that have yet to make a CNS meeting, the ones who will share their expertise next week with us in Boston, the ones who are feeling burnt out, and the ones who know they belong. We are here for you. Let us know how we can help you in the care you provide to our community's children and their families.

We look forward to seeing you in Boston and toasting your 50th years strong!

Warmly and with great respect,
Amy E. Brin, MSN, MA, PCNS-BC
CNF Executive Director / CEO

www.childneurologyfoundation.org
Join our Newsletter!

5 Days to Boston

“G” is for Generations

Here's a chicken and egg question:
Was I drawn to characters Jimmy Stewart played in films of the 30s and 40s because of perceived parallels to the Child Neurology Society, or was it the other way around? Or, does it even matter, really?

I remember that for the longest time, before I really knew any of the CNS members, or they knew me, I would get through a tough day by quoting Stewart from his Oscar-winning performance as Macaulay Conner in *The Philadelphia Story*: “With the rich and mighty, always a little patience.” I don’t remember how or why that came up in conversation with Mike Painter, but it prompted a rebuttal in the form of one of his favorite – and my least favorite – lines: “You know, you have to take a vow of poverty to be a child neurologist.”

When the CNS met in Washington, DC in 2002, I drew on another classic Stewart film for the brochure and show look, framing everything as “Dr. Smith Goes to Washington.” To Mike Painter’s point, the character played by Jean Arthur, like so many in Frank Capra’s films, grew up in genteel poverty as the offspring of a doctor-father who cared more about taking care of his patients than taking their money. That same mix of low income and high ideals reached its apotheosis in Capra’s 1946 masterpiece, *It’s A Wonderful Life*. Stewart plays George Bailey, “the brightest of the bunch” growing up in Bedford Falls, NY, the boy most likely to succeed and most determined to “shake the dust of this crummy little town” off his feet and see the world. After which, he crows, “I’m gonna build airfields, I’m gonna build skyscrapers a hundred stories high, I’m gonna build bridges a mile long.”

As nearly every film-loving American of a certain age knows, he did none of those things. Instead, he stayed in Bedford Falls keeping the family business running through the Depression and World War II, and running himself headlong into depression and suicidal despair. One of the greatest film scenes of all time finds him at the dinner table with his father, Peter Bailey, hours



5 Days to Boston



before he passed away from a sudden stroke and George's grandiose dreams passed with him. When his father expressed hope that he might still change his mind and stay home to take over the business, he reflexively protests, "No, no I couldn't stand staying cooped up for the rest of my life in a shabby little office," then catches himself, and in a moment of pure heartbreak looks his dad in the face and says, "Pop, you want a shock? I think you're a great guy."

I think of that scene often when looking over the small, but growing list of child neurologists whose sons and daughters have followed in their footsteps. I have 8 names on my list; perhaps you know of more. The fathers – and they come from a day and age when, by and large, they were bound to be fathers – include Roger Brumback, Peter Camfield, Richard Friederich, Bill Gaillard, Kenneth Huff, Gordon Millichap, Doug Nordli, and Don Shields. The 2nd generation child neurologists have, in a sense, not only taken up their father's calling, but in a larger sense, now represent, albeit in loose confederation, a reboot of the original "Lacrosse 8" who founded the CNS. This new cohort of 8 child neurologists, four male and four female, are incomparably more connected and collaborative and are advancing toward a far vaster and more hopeful horizon made possible by breakthroughs in genetic research that their forbears never dreamed possible. The new cohort includes Audrey Brumback, Renee Shellhaas, Katie Friederich, Jonathan Gaillard, Hanalise Huff, John Millichap, Douglas Nordli III, and Justin Shields. Together, they will lead child neurology into the next 50 years. Who knows whether any might have children, a 3rd generation, who will follow them? If they do, one thing seems all but certain to me, knowing many of them as I do: for all the undoubtedly other, and possibly more lucrative options they might have chosen to pursue instead of pediatric neurology, they will each, in time, and deservedly so, be toasted as George Bailey was in *It's A Wonderful Life* as "the richest (person) in town!"



(Note: I try as much as possible, to shield members' children from exposure on the CNS website/internet. In one instance today, however, I have film footage of a father and daughter – Richard and Katie Friederich – that I find so compelling I can't help but post it and bid you enjoy it.

The screenshot shows the Child Neurology Society website. At the top, there is a navigation bar with links for MEMBERSHIP, COLLEGIAL, CAREERS, EDUCATION, and COMMUNITY. Below the navigation bar, a yellow banner features the text "HISTORY, MENTORS AND MENTORING". To the right of the banner, there is a sidebar titled "VIDEOS AND PODCAST LIBRARY" which lists categories such as "CNS Communications", "Members", "Families", "Training Programs", "Leadership", "Mentors and Mentoring", "Research", "Education", "Public Policy", and "Community Partners". The main content area displays a video player with two people, a man and a woman, sitting side-by-side. The video player has a play button and a progress bar.

Two Generations of Child Neurologists: Richard & Katie Friederich

[Click to watch video.](#)

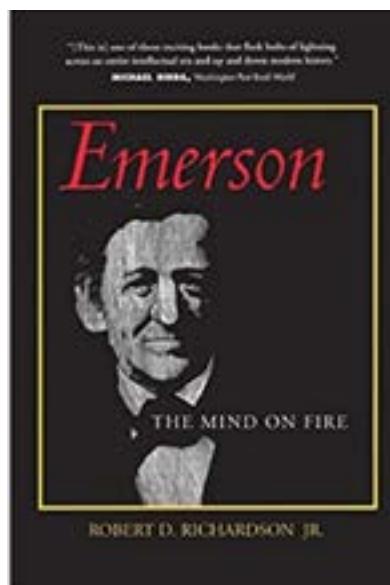
4 Days to Boston

“E” is for Emerson and Effort

I had known Phil Pearl for many years, but not well, having crossed paths and held passing conversations with him when he was on the CNS Executive Committee as a Councillor for the Northeast, and prior to that when he was President of the PCN and Chair of the CNS Awards Committee, although I didn't directly liaise with either at the time. I remember being taken by both his CNS Connections profile and later his introduction of Rob Rust in 2015 when Rob was presented the Blue Bird Circle Training Program Director Award at the CNS Annual Meeting.

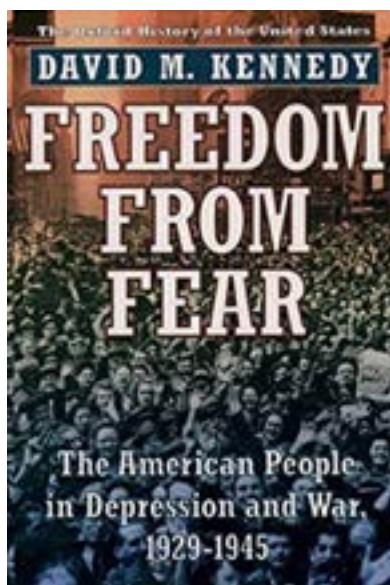
But it wasn't really until December of 2018, at a reception Ann Tilton hosted at her house for child neurologists attending the AES Annual Meeting in New Orleans, that I got my first glimmer of who he was and why, I felt sure, we might “click” when and if we ever had the chance to work together closely as, indeed, we have the past two years during his CNS presidency.

Phil was playing holiday tunes at the grand piano when I rounded the corner into the room and he looked up, flashing a smile and a look of such total delight that it prompted me to recall a line from Ralph Waldo Emerson about someone “carrying the look of holiday in his eye.” I didn't mention that to him then, or ever, that I can recall, so you can imagine my surprise the following summer when I flew to Boston to meet with Phil in his office to go over what he hoped to accomplish during his two-year term that would begin on the final day of the Charlotte meeting in October. Immediately as I walked in, right in the middle of his office bookshelf at eye level, my eyes fixed upon the title of a familiar and much prized book, Robert D. Richardson's magisterial biography, Emerson: The Mind on Fire. Pure coincidence? Sure. A harbinger of good things to come? I thought so, even though he hadn't yet read it, as it turns out (he did, however, this past summer).



I'm not suggesting some crude or clumsy congruence between Phil and the Sage of Concord, but there are Emersonian parallels and approximations to be found in Phil that, I think, carried him and the CNS through the past two years of rigor and trial. They certainly carried me through. For starters, consider the book's epigraph, taken from William James, whom Emerson first met when James was a baby in his crib being shown off proudly by William Sr at the house overlooking Washington Square in New York: "We measure ourselves by many standards. Our strength and intelligence, our wealth and even our good luck, are things which warm our heart and make us feel ourselves a match for life. But deeper than all such things and able to suffice unto itself without them is the sense of the amount of effort we can put forth...He who can make none is but a shadow, he who can make much is a hero."

I've used that quote each of the last two years when announcing the candidates for CNS members to consider in choosing who should represent them on the Executive Committee, charting a course forward for the Society and the field. If, as most agree, Emerson was the first apostle of American social and intellectual democracy, affirming his commitment to constructing democratic communities founded on faith in the inherent dignity of each individual, James was his most forceful interpreter in the succeeding generation; his American pragmatism focused on questions like "How can one be of practical use in the world? or "What shape might the fulfillment of individual purpose take that will make a difference?" Those are both lofty questions of calling and vocation, and more quotidian considerations child neurologists confront daily in individual practice settings, and institutionally through professional associations like the Child Neurology Society. Phil's announcement earlier this week of election results amplified that point, as he thanked and congratulated "all those who put themselves out there and ran in a national election held by a professional society...expressing an interest in serving," then adding, "We are proud of this process and appreciate everyone's commitment."



4 Days to Boston



Photo of "old" and "new" 2018-20 boards below, taken in Charlotte in October 2019)

The shift from Emerson's transcendentalism and James' pragmatism in the direction of politics is worth nothing. In a very real sense, Franklin Roosevelt's approach to the New Deal built on both philosophies, reflecting throughout the two philosophers' notably blithe lack of concern for logical consistency. Roosevelt kept coming up with new ideas and programs, searching for solutions to the Great Depression. It was telling, I thought, when early in his CNS presidency, coincident with the early days of the pandemic, Phil quoted from Roosevelt's first inaugural address delivered in 1932, "We have nothing to fear but fear itself," then proceeded with FDR-like energy and resolve to stoke fires and prod efforts within the CNS to respond to both the moral and practical needs of the moment. Although Phil, like Roosevelt, is not himself a founder, his time in office was, like Roosevelt's, a second founding of

sorts, a highly consequential reinterpretation and revitalization of the founders' original spirit and accomplishments.

I will not steal thunder from Phil's "State of the Union" presentation to be delivered on Thursday morning as part of the Presidential Symposium, but as he reviews the actions taken during his two-year term, listen for the echoes in this 21st century Harvard faculty member's address of the three Harvard alumni from the 19th and 20th centuries: Ralph Waldo Emerson, William James and Franklin Delano Roosevelt. And watch closely as, more than once while speaking at the podium, and several times more later in the week while seated at a keyboard, he carries in true Emersonian style "the look of holiday in his eye." He takes joy in expending effort and being useful. It was a true joy watching him work, and an even greater joy and honor to be a part of that work.

3 Days to Boston

“D” is for Denckla

I have previously noted in this countdown series the iconic status achieved by two women in the CNS: Isabelle Rapin and Nina Schor, or simply “Isabelle” and “Nina,” icons needing only one name.

There are likely several others who currently are, or very soon may be considered icons, although naming them might spark a more heated argument than you would think, with one notable exception: no one would dispute Martha Bridge Denckla’s qualifications.

I don’t really know Dr. Denckla personally, other than in passing, but child neurology is a small community, so I know many people who do, of course; many of them are, in fact, members of the child neurology community and the CNS primarily because of Martha (we’ll go with the iconic first name designation from here on). Ask any of them about her and you’d better take a seat; you’re going to be there for a while. Those who know her well, who were mentored by her and charted a career course inspired by her don’t merely speak highly of her; their voice quickly rises and their speech comes out in a mixed rush of reverence and enthusiasm. And then, a moment later, they relax, having communicated the first thing that comes to mind – her lofty professional stature – before unspooling a steady stream of warm praise about her generous gift for being both a wise and caring friend and mentor, always leavened by disarming ease and easy laughter.

At first blush all those qualifying as friends and mentees might blanch at the suggestion that we should maybe sell t-shirts at this year’s CNS meeting with Martha’s image hovering over the well-known quote, “Well-behaved women seldom make history.” While no one would suggest she is ill-mannered, no one would dispute she has made history. In a year that finds us both celebrating the founders and rueing their still, too-freshly felt absence, it’s wonderful to be able to not only celebrate Martha’s continued vital presence and active influence, but to recognize her role as, quite literally, a founder, having founded the field of child behavioral neurology. She is also making



history of a sort by being the first woman to have a individual award named after her; this year’s meeting will be highlighted on Thursday by presentation of the inaugural Martha B. Denckla Award Lecture by Elizabeth-Berry Kravis.

Let’s go back for a moment to that notion that “well-behaved women seldom make history.” I mean that only in a playful, suggestive sense. Most of our parents – most of us who are parents, for that matter – harbor doubts at one point or another about the sort of people we or our kids hang out with, worried that we or they will grow up to be “the wrong kind of person”. Hang out with giants and you might end up being a

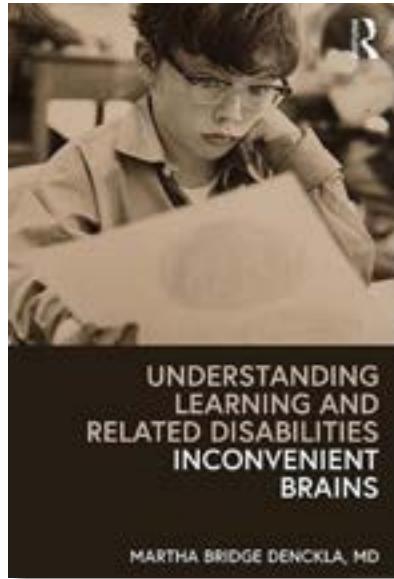
3 Days to Boston

giant yourself. Which is precisely what happened. Hanging out with the likes of Norman Geschwind early in her career, was no guarantee that Martha would find herself becoming later in life a giant in the field of child behavioral neurology, but it also shouldn't have surprised her, or anyone around her. Following Sid Carter's advice at the College of Physicians and Surgeons, Columbia University was not the best or surest way to settle into a comfortable life of clinical routine unruffled by breakthroughs in research or leading to challenging collaborations, like Martha's with neuropsychologist, Rita Rudel, exploring dyslexia and ADHD. But, what did she expect?

Our parents also tell us and we tell our kids to stay inside the fence and don't go wandering off. But Martha has climbed fences and wandered off in multiple directions throughout her career, spending what some might consider an inordinate amount of time with parents, educators and policymakers. Parental common sense says that kind of profligate wayfaring and indiscriminate boundary-crossing can only end badly, right? And how, one must ask, can dumbing things down or making complex scientific concepts and arguments seem simple be a good thing or model "good behavior"?

In a golden age of marketing monomania, where the value of everything is measured by money, where did she get the idea, who did she hang out with that told her it was OK to develop something as crude, simple, effective and non-lucrative as the Rapid Automatized Naming (RAN) test? Would a good scientist – would a well behaved woman scientist, no less – write a useful, approachable guide for parents like *Understanding Learning and Related Disabilities: Inconvenient Brains* when there are monographs to be published in peer reviewed journals? Of course not. (Her CV amply suggests one can do both).

In the end, it's a good thing Martha Denckla chose early on not to be a "good girl" or a "well behaved woman." She made history by making it possible through her pioneering work for generations of so-called under-achieving, slow learning children to come out of hiding and get the help they need to perhaps, in time, make some history themselves.



Elizabeth Berry-Kravis, MD, PhD is the winner of the first (2021) Martha B. Denckla Award.

2 Days to Boston

“C” is for CNS: Past, Present and Future

Seasoned jazz musician that he is, Phil Pearl seized upon the dominant theme of “CNS: Past, Present and Future” and riffed on it in the past year in such a way that all will be pleased and few should be surprised when he swings back to it in grand fashion on Thursday morning with the Presidential Symposium.

More on that in a moment, but first, as prelude, let me share this photo taken at the meeting in Phoenix in 1997.

Many of you will recognize on the left, Darryl De Vivo, CNS President from 1989-91. Others may recognize in the middle, Michael Cohen, CNS President from 1995-97. Some of the older, more astute, and/or Texas-trained child neurologists may even recognize the back of Marvin Fishman's head, having tried so often and for so long to catch up with him; Marvin was CNS President from 1987-89. All of you should recognize now, or will soon recognize the youngest member of that trio (or quartet), standing on the right: Bruce Cohen. Bruce's two-year term as CNS President begins this coming Friday, when he becomes the first CNS President to share the same last name as a previous President.

The image caught on film was taken in 1997 at a strategic retreat Mike Cohen organized on the front end of the 26th CNS Annual Meeting in Phoenix. The retreat's purpose was to plot a path forward for the CNS as it moved into its 2nd quarter-century as the primary association of child neurologists in the US and Canada. I can't help but be struck now by Bruce's presence at that meeting, standing alongside the then-CNS President, Mike Cohen, knowing as I do that he was elected by his peers to be the President charged with moving the Society into its 2nd half-century. Nor can I think of a person better matched to that moment. He is not, as he related to me in recent conversation, an academic-researcher of the same mold or stature of many past-CNS presidents. Although fully conversant with the needs and interests of academic researchers, he is one of the very few CNS thought leaders I have known who is deeply

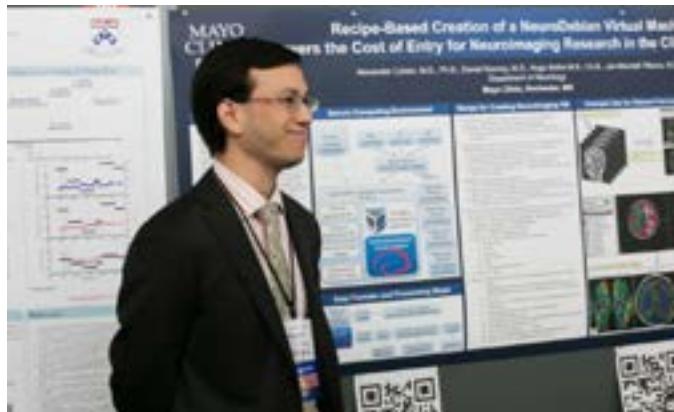


immersed in and sympathetic to the differing needs and interests of non-academic researchers in and outside of the CNS. As we enter a new era in healthcare economics that will impact child neurologists directly, maybe even direly in some ways, we are fortunate to have Bruce at the helm. Drawing on his long immersion in the micro and macroeconomic ecosystems child neurologists operate within, and leveraging his active and highly valued and influential participation in the AAN, Bruce is the right person in the right place at the right time to move the Child Neurology Society into its next 50 years, making it a more broadly and effectively inclusive and representative organization.

In an earlier entry I compared Phil Pearl's response to the crises and challenges confronting him in his two years as CNS President to FDR's innovative New Deal response to the Great Depression in the United States. Bruce's temperament and tool kit make him ideally suited to oversee an ensuing period of both consolidation and innovation. I am both confident and hopeful. And I am keenly aware, taking a second glance at that photo taken in Phoenix, that what I am seeing is the Past, Present and Future of Child Neurology.

2 Days to Boston

One final note in this vein: I don't want to doom Alexander Li Cohen with what some might misperceive as an early endorsement – and an unsolicited and probably unwanted one, at that – but after taping a conversation with Alex in early 2020 at Boston Children's Hospital, and in anticipation of his talk on Cognitive Neuroscience as part of "The Future" segment of Phil's Presidential Symposium, I can't help thinking there may someday be a 3rd Cohen elected CNS President.



"C" is also for CNCDP-K12

Having mentioned Alex Cohen, who has participated in and benefitted from CNCDP programming, and being mindful that the 2nd day of the CNCDP retreat is now in full swing, how can I not give them a quick shout-out when talking about the future of child neurology and the CNS? Rather than steal any thunder from Brad Schlaggar's Friday morning symposium, "Progress in Child Neurology Through the Lens of an NINDS Career Development Program: CNCDP, Past, Present and Future," I will both offer you quick pics of some of the CNCDP Executive Committee ("the old guard") and the younger, free-spirited scholars they mentor, and urge you attend on Friday morning.



1 Day to Boston

“B” is for “Bale, Barry, Bodensteiner & Brumback

Like all those unfortunate make-up artists and sound editors who, through the years, have found themselves onstage at the Academy Awards thanking everyone who showed them a moment's kindness only to hear the director below strike up the band signaling "time's up," I feel stressed coming to the next-to-last entry of the Countdown, knowing that for every well-intended nod in the direction of a Bhooma, Bennett or Bill there lurks the unintended neglect of a Bamford, Bass, Baram or Buchhalter.

That's not a bad hook, actually, for today's entry, because for three of today's four featured stars, riffing on Hollywood's Biggest Night feels natural and easy. Especially with the first star: Jim Bale.

Perhaps I should explain. In the summer of 2003, just after Jim Bale was chosen President-elect, with a two-year term that would make him the President overseeing the 2004 and 2005 annual meetings, Mary Currey and I were still searching for a site for the 2005 meeting. We had settled on LA, but hadn't quite nailed down which of two hotels to choose: the Century Plaza or the Renaissance Hollywood? The latter was located next door to the Kodak (now Dolby) Theater, the new "permanent home" of the Academy Awards when it opened in 2001. It was the chance of a lifetime, really: too good to be true, too big to pass up.

But we did. And for no better reason than that neither of us could quite get our heads around putting the humble, genial, soft-spoken Kid from Kalamazoo in the penthouse Presidential Suite with its dazzling view of the iconic Hollywood sign and a glass-domed ceiling open for all the world to see (or at least that part of the world that could afford hilltop mansions with high-powered telescopes, or a private helicopter). True, he had come a long way in life in classic All-American fashion: after a brief trek east to earn undergrad and medical degrees in Ann Arbor, the young man went west first to train, then to reign in



Two of my favorite "Mountain Men": Jim Bale (Wasatch and Oquirrh Mountains of Utah) and Alan Seay (Rocky Mountains of Colorado)

1 Day to Boston

Utah, with a solid stint in Iowa sandwiched in between. But LA? And Hollywood? The last leg of that archetypal westward journey didn't quite fit; the leap from Salt Lake City peds clinic to a penthouse suite on Hollywood Boulevard was just not his schtick.

Looking back, I wonder if maybe we thought too small. Maybe we should have dreamed bigger, as any casting director worth his Porsche would have, knowing at a glance how ga-ga America would be at the sight of this good looking doctor with the great voice sashaying around hospital stage sets surrounded by his bigscreen-worthy 2005 Board members all dressed up in white lab coats and powder blue scrubs. Sadly, we'll never know. By taking a pass on the Renaissance and signing with the Century Plaza, we denied O. Carter Snead III, Alan Percy and Mustafa Sahin the chance to receive the Sachs, Hower and Dodge awards on the same stage Clint Eastwood, Kate Blanchett and Morgan Freeman received their Oscars a few months earlier. We robbed Doug Nordli, Leon Dure and Marc Patterson of the chance to be discovered in time to replace Clooney, Pitt and Damon in Ocean's Thirteen. And the fabulous leading lady roles Donna Ferriero, Nina Schor and Ann Tilton might have filled? They all went to Meryl Streep. I was OK with Jim Bale not going Hollywood, though, as he is himself, I'm sure: staying married to Martha, having kids go off to serve in the Peace Corp then return to raise grandkids to join Jim on the ski slopes (but without all those pesky paparazzi swarming about). A Penthouse President's Suite overlooking the bright lights of Hollywood doesn't hold a candle to that.

The truth is, It really was a star-studded ensemble:

- Leon Dure, Program Chair during Alan Percy's presidency for the 1998 and 1999 meetings, Councillor (2004-06), PCN President and longtime member of the Movement Disorder Power Trio along with Harvey Singer and Jon Mink
- Nina Schor, Mike Painter's Program Chair for the 2000 and 2001 meetings and, later, Secretary-treasurer (2004-10), President (2013-15), and 2017 Hower Awardee



- Marc Patterson, Ken Mack's Program Chair for the 2016 and 2017 meetings, Councillor (2003-05), and JCN Editor
- Donna Ferriero, Steve Ashwal's Chair for the 2002 and 2003 meetings, Councillor (2004-06), President (2009-11) and Sachs Lecturer (2006)
- Doug Nordli, Councillor (2003-05), frequent faculty member presenting as part of Jack Pellock's resident seminar on epilepsy, father to a 2nd generation bow-tied child neurologist (Douglas Nordli III, MD)
- Ann Tilton, Councillor (1996-98), Secretary-treasurer (2003-04), President (2005-07), Hower Awardee (2012) and President of the Child Neurology Foundation

One would never suspect, looking at this 2005 BOD photo, with nary a "B" to be found, other than "Bale," that this modest Son of the Midwest had a bizarre coastal culture fetish for all things "B". But the evidence seems clear and undeniable. Jim's primary mentors were "Pat Bray, Richard Barringer and William Bell. The two child neurologists I, and many others, associate him with most closely in Iowa? Dan Bonthius and John Bodensteiner (although, to be fair, while both Drs. Bale and Bodensteiner are strongly linked to Iowa, they were never there at the same time; John went to medical school at the University of Iowa years before Jim got his first faculty appointment in Iowa City). And the rising star Jim mentored in Utah? Josh Bonkowsky (same initials even; kinda creepy).

“B” is for Barry

It's no surprise, then, that the Scientific Program Committee Chair that Jim chose to oversee the 2004 and 2005 meetings in Ottawa and Los Angeles would also be a “B”: “Barry”, aka Barry Kosofsky. Which brings us back to Hollywood again: no director could have done any better casting a program chair for a meeting in LA than Barry, with his cinemix of Warren Beatty's glamour and Jack Nicholson's roguish charm.

I could spend the next several hours regaling you with “BarryTales.” I’m guessing many of you have 2 or 3 as good or better than mine, however, so I’ll limit myself to four:

- October 2005, onboard a chartered bus wandering aimlessly on LA freeways, forlornly hoping to find its way to the BelAir resort, site of that year’s CNS Presidential Appreciation Reception. Tensions are rising and things are about to get ugly: we’re already 30 minutes late and a past-president seated across the aisle from me is ready to blow. Up pops Barry from his front row seat, waving his arms and shouting “OK! Everybody join in: “...a three-hour tour!” After leading a busload of child neurologists in singing the “Gilligan’s Island” theme song twice, Barry pivoted toward the besieged bus driver and guided him safely to the BelAir.
- April 2008, Wrigley Field, Chicago. Playing hooky from the AAN Annual Meeting with Sue Hussman, Zack Grinspan, and Barry we happily endure a kaleidoscope of wind, snow, rain and sun. Two rows ahead of us a gaggle of 10-year-old girls celebrating a birthday party are falling over each other laughing at Barry as he leads the fans in PG-rated cheers for the Cubs. Suddenly, a foul ball comes our way, directly into the waiting hands of....who else? Barry promptly presents it to the birthday girl, leaving her, her friends, and assorted moms to vie for who has the biggest crush on this crazy guy in a Red Sox hat.
- October 2013, Austin, TX. It’s Halloween. We’re in Austin, TX (“Keep Austin Weird”). Meanwhile, 1,000 miles away, the Boston Red Sox have gone on a pedal-to-the-metal testosterone bender growing bushy beards enroute to another World Series championship. And the biggest, baddest, bawdiest BoSox fan is fully-costumed and on the loose....
- February 2018. It’s -10 degrees in St. Paul the night before the Patriots-Eagles Super Bowl across the river in Minneapolis. I’m with Barry at what was a quiet, respectable sold-out restaurant that his wife, Debbie, back in New York, managed to get us into at the last minute. Within minutes Barry has



Barry with Mary Currey in 2005, shortly before the infamous “Three Hour Tour”



Barry, with longtime friend from his Boston days, Cathy Chapman



While this photo opp (photo bomb?) might not make Phyllis Sher or Ken Swaiman’s Top 100 list of career highlights, it did provide a few laughs at the 2013 meeting in Austin.

1 Day to Boston

taken over the place, leading everyone in cheers and the frenzied calisthenics involved in being human alphabets spelling "Go Pats!" When I tell a particularly ripe and rowdy fan the guy in the Gronk jersey is a doctor, he rasps back at me: "Yeah? Which show? I don't watch a lot of TV?"

There are other BarryTales, of course, plenty of them. Some are more serious and humane, like those with Barry and Debbie taking my daughter out for dinner and looking out for her after she moved to Brooklyn. Or the time we were both in Boston and he invited me to join him at his son, David's house for my first (and only) Shabbat; rarely have I felt so touched and honored. Added bonus: the rabbi and his wife brought their baby and I got to watch the "real" Barry as he gently calmed and sweetly played with him, beaming the whole time. It was true highlight reel material.

And where does one even begin ticking off the many contributions Barry has made to the CNS? Included on this long list would be past Scientific Program Chair, Research Committee Chair, Councillor on the Executive Committee (2011-13), and partner, with Brad Schlaggar in piloting the NIH-funded, Kennedy Krieger hosted Child Neurology Career Development Program (CNCDP-K12) that is the seedbed of progress in scientific research, leadership within the CNS, and hope for generations of children.



CNCDP-K12's dynamic duo: Barry Kosofsky and Brad Schlaggar



Boardroom Barry, during his years on the Executive Committee with fellow Councillor, Vinodh Narayanan (above) and chairing a CNS Research Committee meeting (below).



“B” is for Bodensteiner

I mentioned John Bodensteiner earlier, how he and Jim Bale were both linked in my mind with Iowa.

The reason why is probably due to a prolonged, raucous exchange of Minnesota-Iowa jokes the three of us engaged in for Ann Tilton's benefit at a dinner Deborah Hirtz hosted for the CNS Board some 20+ years ago when the spring board meetings were held in DC. John may be even less “Hollywood” than Jim, and yet, there's that voice: his rich, baritone voice is reminiscent of Hollywood legend, Gregory Peck. And then there is John's golf game: a scratch golfer, in his prime, he might have made more money outdriving and putting Hollywood's best on LA's well-manicured greens. Fortunately for you, me, the CNS, AAN, ABPN, JCN and thousands of patients, some now collecting Social Security, he stuck with medicine.

There is no face, or voice, I have welcomed seeing and hearing at CNS and AAN meetings more over the years than John's. There are very few, maybe none, that I have seen more often. Which is a roundabout way of noting how generously John has lent his time, talent and wisdom to neurology and child neurology over the years, seemingly without pause or end: in addition to being a Councillor on the CNS Executive Committee from 1994-96, President-elect/President/Past-President from 2006-10, and Hower Awardee in 2013, he has served on multiple association and editorial boards and currently serves as Board Chair of the American Board of Psychiatry and Neurology (ABPN) Executive Committee. Thanks to the proximity of the Minnesota Twins to the CNS National Office (his twin grandchildren, not the baseball team or the aforementioned Swaiman-Berg or Mack-Mink duos), the CNS staff and I have enjoyed multiple visits and meals through the years and have had the pleasure of getting to know his soft-spoken, sweet-souled wife, Donna.



Enjoying a few Iowa jokes: John Bodensteiner & Jim Bale



(L-R), Marc Patterson, Roger Larson, John Bodensteiner, Max Wiznitzer



(L-R) John & Donna Bodensteiner, Steve Roach

1 Day to Boston

And finally, “B” is for Brumback

How can the curtain possibly come down on “B” without acknowledging the Brumbacks?

Few members, certainly few with last names starting with “B”, have had as much impact on the Society’s first 50 years as Roger Brumback. Few will have as much impact on the next 50 years, as his daughter, Audrey. I can’t begin to do justice to either of them. Out of due respect and humility, I won’t even try. I will refer you, instead, to the wonderful tribute to Roger and Mary Brumback written by their good friend, Steve Roach in 2013, and the profile he wrote four years later of their daughter, Audrey, on the occasion of her receiving the 2017 Philip R. Dodge Young Investigator Award. (Both are on the CNS website “Calling” section): <https://www.childneurologysociety.org/calling/>

I have to add one final memory in closing; my fondest memory, really, of the 2008 CNS Meeting in Santa Clara. I was on my way out the door on Saturday afternoon, heading to Stanford with my then 15-year-old daughter, Mekea, when we chanced across Roger and Mary in the hotel lobby. Roger enthusiastically regaled us with stories of nature hikes he and Mary had taken in the area, next to which Palo Alto’s charms paled miserably, he assured us. Although unpersuaded at the time, I like to think Roger’s infectious enthusiasm got through to Mekea and may account for the many weekend hikes north of NYC she and her boyfriend have enjoyed together the last three years. When I mentioned that 2008 lobby meeting to Mekea a year or so ago, it didn’t register with her at first who that “funny, animated guy” urging her to give up her fashionable shoes for hiking boots was. When I told her it was “Audrey’s dad,” her face brightened, Audrey being one of her favorite (and one of my favorite) child neurologists.



Roger Brumback & John Bodensteiner



April Levin & Audrey Brumback

0 Days to Boston

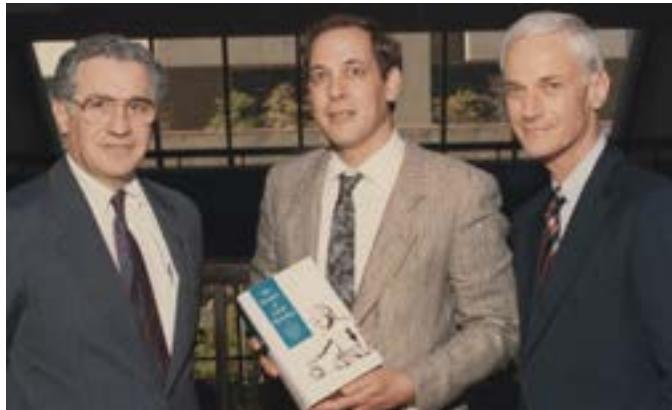
“A” is for Ashwal and Ann

Describing today’s final Countdown to Boston entry as “Saving the Best for Last” would be misleading – there are far too many contenders for me to feel comfortable making that claim. It may, however, stand up as a case of saving the most obvious for last.

Who, after all, could plausibly make a case on the eve of the Child Neurology Society’s 50th Anniversary Meeting in Boston, and the 50th full year of Society activities to follow, for anyone other than Steve Ashwal to be the final featured lead?

Certainly not the 125 meeting attendees picking up a copy of *Child Neurology: Its Origins, Founders, Growth and Evolution*. Nor the additional 125 members ordering a shipped copy of the 2nd, significantly updated and expanded edition of the original Founders book that Steve also edited back in 1990. And certainly not the 2,500 remaining CNS members who might mistakenly think they don’t want – make that need – a copy of this 1,000 page compendium of beautifully written profiles bursting at the seams with incredible insights and information. ([Click here to order a member-discounted copy online through Elsevier](#)).

Who, other than Steve, could have edited the first edition? Who but Steve had the magic mix of vision, wisdom, insight, command of content, love of language, drive, discipline and breathtaking chutzpah to see this massive project through from conception to completion in two years? I have often said (half-kiddingly) that there are less than a dozen neurologists who know how to spell “deadlines,” and only three that can consistently meet them. Steve qualifies as one of those three and seems perpetually – and genuinely – surprised to discover there are not more like him. It is one of his many undeniable charms. He is as serenely kind, warm and generous personally as he is detail-oriented and demanding professionally. I remember listening by phone to Ken Swaiman commenting (not complaining) with



Darryl DeVivo, Stephen Ashwal, Marvin Fishman (1990)



Stephen Ashwal (2021)

0 Days to Boston

faux exasperation about Steve's near-daily onslaught of suggestions, corrections and solicitations. He chuckled appreciatively when I responded with faux innocence, "Gee, I wonder who trained him?"

I would be hard-pressed to name anyone, other than Steve's training director at the University of Minnesota, who has left his fingerprints on more parts of the Society's past than Steve. Listing three committees he has NOT served on before, during, and after the 10 years he served on the Executive Committee would be a good Trivial Pursuit question. Like Washington frequently departing from and returning to Mount Vernon to serve his country, Steve repeatedly came and went from the program he chaired at Loma Linda to serve on the CNS BOD as Councillor (1988-90), Secretary-treasurer (1993-97), and President-elect/President/Past-President (2000-2004). He was also the first editor of the CNS Newsletter (before it was refashioned as CNS Connections), served on the BOD of the Child Neurology Foundation, and received the CNS Hower Award in 2008. And then there are the latter editions (soon to be seven) of Swaiman's *Pediatric Neurology: Principles and Practice*. Unlike Washington, who did, in fact, retire, I don't foresee reading a "Farewell Address" by Steve anytime soon. For that, we can all be grateful.



Kenneth Swaiman, Phyllis Sher, Eileen Ashwal, Stephen Ashwal (2017)



2003-04 Executive Committee:

Seated (L-R): Julie Parke, James Bale, Stephen Ashwal, Ann Tilton

Standing (L-R): Harvey Singer (PCN), Ken Swaiman (CNF), Michael Noetzel, Roy Elterman, Carl Crosley

“A” is also for Ann

I can no more name a favorite CNS President than I can unambiguously identify a single, favorite annual meeting. I prize them all.

But, I will say, as someone who grew up in the shadow of the Mayo Clinic and has worked with pediatric neurologists for four decades, that there is no doctor I adore more than Ann Tilton. Which hardly makes me special. There are, I’m sure, hundreds of AAN and CNS members young and old, male and female who would say the same thing, and thousands of past and present patients, parents and caregivers that would eagerly add their name to that list.

I first met Ann at a CNS meeting in the early 90s (Atlanta, 1992?). Peter Berman introduced his pregnant protogee to me in a manner that would no longer pass muster: “This is Ann Tilton. She’s going to be CNS President someday...if she ever stops having babies.” I don’t know which of her four kids was present in utero that day. I do know that all four of her babies have grown into full-splendored adulthood, all graduating from the University of Virginia (her husband, Greg’s alma mater), with two of them adding extra sheen by majoring in American Studies (as I did). One of them became a welcome friend to my daughter, Mekeia, when she first moved to Brooklyn. Ann herself has been something of a mother-hen to Mekeia checking in on and looking out for her through the years. She has also, both personally and professionally, been a mother-hen of sorts to many, many younger child neurologists. Many of those who have grown into leadership



John Bodensteiner, Ann Tilton, Alan Percy, Jane Lane (2019)



Ann Tilton and Erika Augustine talk about the AAN ELF program

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roles in the CNS in recent years – Erika Augustine and Rujuta Bhatt Wilson spring quickly to mind – have done so thanks to Ann's tireless efforts promoting the Emerging Leadership Forum (ELF) at the AAN to the benefit of both organizations. I used to wonder, looking at Ann and Nina Schor, Pat Crumrine, Donna Ferriero and a handful of others from that generation, "where is the next cohort going to come from that will throw themselves so wisely and willingly into the work that needs to be done within the CNS and in partnership with other organizations?" I don't wonder anymore, thanks in no small part to Ann. I only wish I was younger and could watch that remarkable emerging cohort grow into those roles, create new roles and realities, and be rewarded for their commitment and effort.

Ann's overall contributions to the child neurology community rival Steve Ashwal's, noted above: Councillor (1996–98), Secretary-treasurer (2003–04), President-elect/President/Past-President (2004–08). One would need all the letters of the alphabet to list the acronyms of organizations Ann has worked with on behalf of child neurologists (start with AAN, ABPN, ACGME, AACPDM....). She also served on the original Child Neurology Foundation BOD and later served a three-year term as CNF President, co-steering the Foundation through a remarkably productive and promising renaissance with its phenomenally gifted Executive Directory, Amy Brin (another "A," who I also adore).

Had anyone else been CNS President in 2007 when I wrestled with the knotty question of whether it might be time to leave the CNS for another job (or, even gamble my family's fortunes returning to writing and/or going to seminary), I would not be tapping out the final



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Amy Brin, Roger Larson, Ann Tilton (2018)

Countdown to Boston installment today. In the end, there was simply no way I could walk out on Ann and leave her hanging. That's the nobler spin on why I stayed with CNS. A less lofty explanation would involve revisiting a painful episode in Ann's past: the Friday evening reception at the 2006 Annual Meeting in Pittsburgh when, at my suggestion, we experimented with moving presentation of the lifetime achievement awards from their traditional morning slot to dinner on Friday evening. As President, Ann gamely tried to tame or shame a crowd of 600 prattling pediatric neurologists into respectful silence – or at least a muted roar – while Lifetime Achievement Awardees Ray Chun and Barry Russman were introduced and gave their acceptance speeches. It was a lost cause. No one heard a word from the stage. Half of those gathered may not even have been aware anyone was onstage.

I've had my share of bad ideas over the years. That may have been the worst. Walking out on Ann after that debacle would have left me feeling like a hit-and-run driver. So, I stayed on. For another 15 years – long enough for Ann and Barry to forgive and forget, and almost long enough for me to feel only slight regret and remorse at leaving. And while "walking out" on Bruce Cohen, one of the kindest and most honorable people I know, doesn't feel any easier or better than walking out on Ann would have in 2007, the sad, sobering truth is that I am older now and more mindful of how many steps I might still have left to me, and how far and in what directions they might take me. And so, my friends, a final "A": "Adieu!".



Ann with two CNS-PECN Training Director Awardees: David Urion (2016) and Miya Asato (2021). Some may find it curious that I did not write about David in the Countdown to Boston. The reason is simple: Failure of Nerve. As I once told CNS photographer, Suzanne Shaff, "While I genuinely like and greatly respect most child neurologists, David I revere." Maybe someday, after I retire I'll be capable of writing about, or maybe even co-author something with him.....



Ann Tilton & Barry Russman on stage in 2006

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