## TOGETHER-APART Virtual 2020

OCTOBER 12-23, 2020





#### The 2020 CNS Scientific Program

The CNS Scientific Program is designed by and is primarily intended for child neurologists and professionals in other fields of study related to neurologic and developmental disorders in children and adolescents. "As a result of attending this meeting the physician will be better able to care for children with neurological disease through an understanding of recent advances in neuroscience, neuro-diagnostics and therapeutics relevant to child neurology."

#### **Accreditation Statement**

This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint providership of the Minnesota Medical Association and Child Neurology Society. The Minnesota Medical Association (MMA) is accredited by the ACCME to provide continuing medical education for physicians.

#### **CME Statement**

The Minnesota Medical Association designates this live activity for a maximum of 100.25 AMA PRA Category 1 Credit(s)™.

Physicians should claim only the credit commensurate with the extent of their participation in the activity.









16th International Child Neurology Congress 49th Annual Child Neurology Society Meeting



#### YOU ARE INVITED!

- 22 Jo Wilmshurst, MB, BS, MD; President of the ICNA
- 23 Phillip L. Pearl, MD; President, Child Neurology Society



#### 10 THINGS

**24** • To Know Before You Go (to your computer)



#### **SCHEDULE**

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TOGETHER-APART virtual2020

OCTOBER 12-23, 2020

#### You Are Invited!





On behalf of the International Child Neurology Association, it is my great pleasure to welcome you to the 16th International Child Neurology Congress being held October 12-23, 2020 in collaboration with the Child Neurology Society. Due to the COVID-19 pandemic, this will be the first virtual ICNC. Our congress theme is "Sharing Knowledge, Sowing Friendships, Spreading Hope". The additional theme Together•Apart Virtual 2020 is the perfect concept for this congress. The ICNCs have truly set the stage as the key forum which provides the very latest and most relevant updates on child neurologic disorders from a global perspective. Speakers from across the six major geographic regions will present at the congress. The scientific program will feature internationally recognized experts, including themes of "Developmental and Epileptic Encephalopathies: What we know and what we do not know" (Nicola Specchio/Pritchard Award); "Update in Pediatric Neurometabolic Disorders 2020" (Lance Rodan/Linda de Meirleir Neurometabolic Award); "The Global Burden of Paediatric Neurological Disorders" (Charles Newton/Frank Ford Award) and "Dietary Therapies for Epilepsy in Low Resource Settings: Challenges and Success" (Suvasini Sharma/Sheila Wallace Award).

We are keen to hear from members of the ICNA and CNS community and hope you successfully submitted your proposals. Following the successful framework of previous congresses, the globally representative scientific committee, chaired by Prof Jonathan Mink, have selected the most innovative proposals to ensure a rich and diverse program guaranteeing that all delegates will leave inspired and with knowledge gained.

There will be opportunity for the newly established Council of the Future Leaders of ICNA (FLICNA), comprised of outstanding, regionally nominated senior child neurology residents, fellows and junior faculty to meet virtually and discuss strategy, as well as how the ICNA can support junior child neurologists. To promote access from clinicians based in low and low-middle income countries the registration rate has been significantly reduced. Based on popular demand there will be a strong educational program inclusive of master classes and teaching courses.

There will also be an opportunity for different child neurology subspecialty special interest groups to meet virtually. The networking opportunities building international collaborations is a key theme for the ICNA and the 2020 ICNC-CNS congress will be an ideal opportunity to pursue this. The congress promotes connecting clinicians involved in the phenotyping of unique clinical populations afflicted with specific neurological diseases with researchers in state-of-the-art research laboratories.

Please join us for a scientifically stimulating ICNC2020 program. We look forward to meeting virtually new colleagues and engaging with old friends. Following on from the COVID-19 pandemic, I hope that we can learn from the experience and identify new and positive ways to support each other and promote the health of children with neurologic disease.

On behalf of the ICNA board Jo Wilmshurst, MB, BS, MD President of the ICNA





My fellow CNS and ICNA members, this Welcome Letter has undergone too many versions to anticipate anything at all but an unconventional meeting. But we will have a great meeting; Roger Larson guarantees it! Seriously, he and the CNS National Office are working so hard, with a great vendor and platform, to give us a superb conference, and in concert with the international crowd to boot. I am so pleased to co-host this conference with Jo Wilmshurst from ICNA and Jon Mink as chair of the Scientific Planning Committee. So many have worked so hard to coordinate these efforts; please plan to attend the sessions, which will now be spread out over two weeks, lest anyone has to sit in front of a screen and concentrate in aliquots as you would by sitting in a beautiful conference center in sunny San Diego!

This meeting has been years in the planning, but in Churchillian fashion, the best-laid plans of mice and men often go awry. In any case, we will still feature plenty of networking opportunities (Networking Lounges, Happy Hours and roundtable discussions), the Pellock Epilepsy Course for graduating child neurology residents, a Neurobiology of Disease symposium on head injury, and a scientific program replete with plenary award lectures, symposia, platform & poster presentations, Meet-the-Expert sessions, and workshops. The symposia span neuroimmunology, epilepsy, stroke, neuro-oncology, neuro-infectious disease, neuromuscular, movement disorders, neonatal neurology, behavioral neurology, neurogenetic-metabolic, neonatal neurology, neuro-opthalmology, and more. There is something for everyone, including a combination of practical knowledge and research advances, along with international representation that has been carefully integrated into the program. The organization of the meeting has been meticulous, but we are very busy trying to have all the material pre-recorded in time for uniformly high technical quality.

A highlight coming at the end of Week 1 will be the annual Child Neurology Foundation's symposium, this year focusing on the diagnostic odyssey so familiar to us and our patients in the process of genetic diagnosis, symposia. We will also offer a very special series of evening programs in both Week 1 and Week 2. I so much enjoy experiencing other cultures when attending international conferences. Please join me in our novel course on AMERICAN CREATIVITY, INGENUITY, and DIVERSITY. We are going to demonstrate how the diversity that makes up American society has led to magnificent creativity and ingenuity in the arts, and I will be joined by my colleague and local bard, David Urion MD, past President of the Professors of Child Neurology, in an exploration of the literary works that help illustrate this aspect of American humanities. I will also be joined by colleagues from the Berklee School of Music here in Boston, drawing upon the diversity and expertise of their faculty, so that I will have a chance to play the music presented in the program with some of the greatest performing musicians in the world today. I'm delighted to share the joy of watching and listening to this incredible combo perform from your front row seat in front of the computer screen!

Phillip L. Pearl, MD
President, Child Neurology Society
William G. Lennox Chair, Boston Children's Hospital
Professor of Neurology, Harvard Medical School
Institute of Music and Health, Berklee College of Music

# 10. THIS 5 To Know Before You Go

(TO YOUR COMPUTER)

### REGISTRATION FEES: What's Included

Delegates paying registration fees (listed p55) will be eligible for:

- All Open CME courses listed in this prospectus
  - Neurobiology of Disease in Children (NDC): Traumatic Brain Injury requires payment of an additional course fee
- Special Interest Group meetings: Week 1; dates & times to be listed in late September
- Industry-Sponsored CME seminars and/or product theaters Week 1 & 2; dates & times to be listed in late September
- Up to 100.25 CME credits. To earn credit, delegate must attend the full session & click link at the end of the session to answer a CME question. CME credits will be totaled and a certificate issued beginning December
  - Participation certificates (not good for validating CME credits earned) will be available immediately upon completing a course.
  - Because sessions are available On-Demand through March 2021, delegates paying registration fee may be able to earn needed CME credits for two years (2020 and 2021; # of credits will be based on when courses are completed).
  - Special thanks to the ABPN for a generous grant making it possible for non-CNS/ICNA members certified neurologists to attend at member rates.

## JUNIOR MEMBERS

Four Junior Member seminars have been scheduled in Week 1 for CNS & ICNA Junior Members and medical students to attend.

#### LIVE SESSIONS (OCTOBER 12-23, 2020)

All sessions listed will be shown "live" once. Each session will begin **promptly** at the scheduled time, serially showing pre-recorded lectures. A live Question and Answer period will follow each set of pre-recorded lectures with Session Chairs and available presenters providing audible response to questions selected by a moderator from among those submitted in a side text/chatbox during the lectures.

## ON DEMAND SESSIONS (NOVEMBER 2020 - MARCH 2021)

All live sessions will be recorded and most will be offered On Demand (24/7) via the virtual meeting platform November 15, 2020 thru March 31, 2021.

To Access
Sessions
On Demand thru
March 2021,
You must be
registered by
October 23



49th Annual Child Neurology Society Meeting

## POSTERS & VIDEO-POSTERS

More than 550 posters (pdf files) and 100 video poster presentations (PPT presentations) will be available On Demand (24/7) during both Week 1 and Week 2, and On Demand through March 2021.

Posters & Video-Posters will be available beginning Thursday, October 15.

## INDUSTRY-SPONSORED CME SEMINARS AND/OR PRODUCT THEATERS

These will be listed along with all ICNA-CNS CME session in the "Sessions" listings of the virtual meeting platform. A complete listing also appears on the page.

NOTE: Industry-sponsored sessions were designed and are staged in complete independence of the CNS-ICNA meeting. A fee is paid to CNS & ICNA to link to external websites on which these sessions are hosted; no endorsement of products, research or positions is implied by provision of this paid service.

## SPONSORS & EXHIBITORS

This meeting would not be possible - this year especially - without the financial support and participation of our corporate and non-profit partners. Show your appreciation by visiting Sponsor & Exhibitor microsites (booths) available during both Week 1 and Week 2, and On Demand thru December 31, 2020.

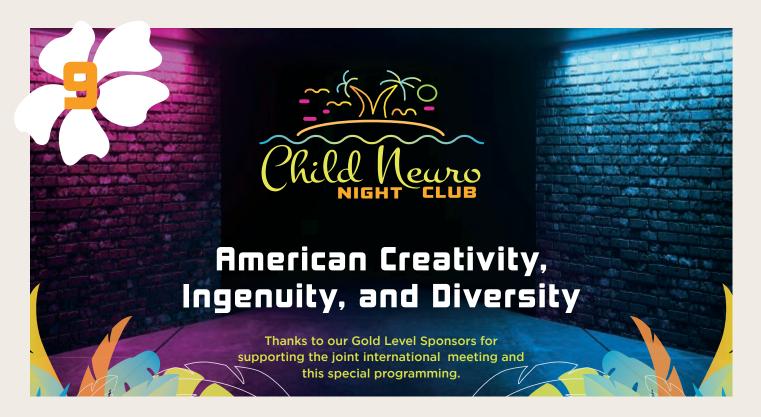
Sponsors & Exhibitors will be available beginning Wednesday, October 14.

### NETWORKING

- Special Interest Group Meetings.
  - Nine 90-minute Special Interest Group (SIG) Meetings are scheduled during Week 1. Each may be followed by multiple pre-scheduled or spontaneously scheduled roundtable meetings involving up to 6 delegates at a time (signing up for wait list is an option).
- Networking Lounge & Roundtables
   Roundtables enabling up to 6 people to gather at a time to discuss anything and everything!
- "Hello World!"

When first logging in, delegates will be asked to

- Check up to 7 "Areas of Interest" (tags) to help Al link you to others sharing your interests
- Introduce yourself with uploaded photo, brief bio, and brief video greeting



I am pleased to announce the development of a special educational/entertainment program, *American Creativity, Ingenuity, and Diversity*, offered to our colleagues from around the world by the CNS as the host association and country for this year's International Child Neurology Congress. This program was originally created earlier this year in response to the pandemic and social unrest

in our society, as a means to reflect on how diversity has enriched our culture and created great American art forms. The curriculum is formatted as presentations in words and music, and is done collaboratively between David Urion MD, the Charles Barlow Chair for Neurology Education at Boston Children's Hospital (and local bard at Harvard Medical School) and myself. This was initiated



during weekly town hall meetings in our neurology department, during which we found that all department members, from the medical and nursing staff to technical, administrative, and others gravitated and found meaning and solace. If you have the opportunity to partake of the program, you will note that it is organized into ten segments, each described briefly below. We invite you to watch one segment each night - whenever and wherever in the world it is nighttime for you leading off your virtual "Happy Hour" networking with colleagues old and new. Those of you who still have a full week blocked off from when we originally hoped and planned to be together in San Diego may choose instead to binge watch the entire series Netflix-style. Either way, I hope you enjoy it.

#### **PROGRAM OVERVIEW:**

Literary reading: Weather, by Claudia Rankine – commissioned by NY Times Book Review just after the killing of George Floyd in Minneapolis.

Musical selection: How High the Moon, composed by Morgan Lewis (music) and Nancy Hamilton (lyrics), and recorded by Benny Goodman (clarinetist) in 1940, rewritten as Ornithology by Master Alto Saxophonist Charlie Parker ("Father of Bebop") in 1946.

**2.** Literary reading: Allegiance, by William Stafford (poet laureate, conscientious objector) and Those Winter Sundays by Robert Hayden (protégé of Auden, African American US Poet Laureate).

Musical selection: American Song Book Standard It Could Happen to You (Jimmy van Heusen 1943) rewritten by African American Bebop Tenor Saxophonist Dexter Gordon as Fried Bananas (1969)

**3.** Literary reading: Shoulders, by Naomi Shihab Nye (Arab -American poet who writes of connections across cultures)

Musical selection: What Is This Thing Called Love? (Cole Porter 1929) rewritten by African American Pianist, Composer, and Arranger Tadd Dameron as Hot House 1945. **4.** Literary reading: Excerpt from The Plague, by Albert Camus, and WE THE PEOPLE, poem by Maya Angelou that was placed on the spacecraft Voyager at the suggestion of Carl Sagan

Musical selection: Les feuilles mortes (1945 Hungarian-French composer Joseph Kosma) rewritten as Autumn Leaves, as recorded by American trumpeter Miles Davis on Blues and Ballad album, featured soloist on Kind of Blue (#1 selling jazz album in the world) 1959

**5.** Literary reading: Psalm, by Wislawa Szymborska, Nobel laureate (leaky boundaries; 'Only what is human can be truly foreign')

Musical selection: A Night in Tunisia (1942) John Birks "Dizzy" Gillespie ("Godfather of Latin Jazz")

**5.** Literary reading: To be of Use by Marge Piercy

Musical selection: Nostalgia in Times Square 1959, African American Jazz Master on Creativity, bassist Charles Mingus, dies of ALS 1979, defined American music as: "what we play, that belongs with the people who have a feeling of freedom and like to play together without discrimination."

**7.** "Es war beschreibt", David Urion story of a home visit

Musical selection: My Favorite Things from The Sound of Music (1959), the last work of the prodigious Broadway writing duo Richard Rodgers and Oscar Hammerstein, as interpreted in the iconic recording of saxophonist John Coltrane (1961)

**8.** Literary reading: Excerpt from "Sonny's Blues", short story by James Baldwin (1959), African American poet writing of life in Harlem

Musical selection: When Sunny Gets Blue (1959)

**9.** Literary reading: *The Dakini* Speaks, by Jennifer Welwood (on impermanence)

**Musical selection:** Waltz for Debby (1956) Bill Evans, giant American pianist (& personal favorite)

ID. Band Finale: Caravan (Edward Kennedy "Duke" Ellington 1936), composer of the Far East Suite (note the alternating African safari sound/rhythms with straight ahead American jazz using blues form of sequential perfect 4ths)

With pleasure, let me share the members of this CNS Band Event, all of whom have toured internationally with the leading active jazz musicians in the world today.

Jacques Bart-Schwarz – tenor sax, Professor of Music, Reeds Department, Berklee College of Music, native of Guadeloupe, blends Caribbean music with jazz

Yoron Israel – drums, Chair and Professor, Percussion Department, Berklee College of Music, #3 album on national jazz charts 2004

Dan Fox - bass, Arlington-Boston Jazz Festival, Boston Jazz Ambassador to Cuba, alumnus, Berklee College of Music

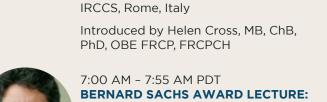


## PLENARY/AWARD LECTURES





6:00 AM - 6:55 AM PDT
JOHN STOBO PRITCHARD
AWARD LECTURE:
Developmental and Epileptic
Encephalopathies: What We Know
and What We Do Not Know
Nicola Specchio, MD, PhD,
Bambino Gesu' Children's Hospital,
IRCCS, Rome, Italy





Introduced by William Dobyns, MD





6:00 AM - 6:55 AM PDT

SHEILA WALLACE AWARD LECTURE:

Dietary Therapies for Epilepsy
in Low Resource Settings:

Challenges and Successes

Suvasimi Sharma, MD, DM;

Lady Hardinge Medical College and

Associated Kalawati Saran

Children's Hospital, New Delhi, India

Introduced by Pratibha Singhi, MBBS, MD, FIAP, FNAMS

Introduced by Huda Zoghbi, MD





**THURSDAY, OCTOBER 22** 

6:00 AM - 6:55 AM PDT
LINDA DE MEIRLEIR
NEUROMETABOLIC
AWARD LECTURE:
Update in Pediatric
Neurometabolic Disorders 2020
Lance Rodan, MD, FRCP(C);
Boston Children's Hospital,
Harvard Medical School,
Boston, Massachusetts, USA

Introduced by Ingrid Tein, MD

7:00 AM - 7:55 AM PDT HOWER AWARD LECTURE: Migraine, Vertigo and Dizziness Kenneth J. Mack, MD, PhD; Mayo Clinic, Rochester, MN, USA Introduced by Paul Youssef, MD





6:00 AM - 6:55 AM PDT
FRANK FORD AWARD LECTURE:
The Global Burden of Paediatric
Neurological Disorders
Charles Newton, MD;
University of Oxford, Oxford,
United Kingdom, KEMRI-Wellcome
Trust Collaborative Programme,
Kilifi, Kenya

Introduced by Jo M. Wilmshurst, MD, BS, MD

## PARTNERS IN CARE



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16th International Child Neurology Congress
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#### ALL TIMES SHOWN: PACIFIC DAYLIGHT TIME

#### Monday, October 12

2:15 PM - 4:30 PM
PROFESSORS OF CHILD
NEUROLOGY (PCN):
CLINICIAN TRAINING AND
ASSESSMENT

This session is limited to members of the Professors of Child Neurology (PCN) and the Program Coordinators of Child Neurology (PCCN) and is offered as Part II of the PCN Annual Business Meeting. The recorded lectures listed are available for general viewing, but Live Q&A will not be included on the meeting platform.

#### Organizer:

Tim Lotze, MD; President, PCN; Baylor College of Medicine, Texas Children's Hospital, Houston, Texas, USA

#### Child Neurology in the 21st Century: More than the Sum of our RVUs

Mary L. Zupanc, MD; CHOC Neurosciences Institute, University of California-Irvine; CHOC-Children's Hospital of Orange County, Orange, California, USA

#### Creating a Clinical Educator Track for Your Trainees

James Reese, Jr., MD, MPH, MA, FAAN; University of New Mexico, Albuquerque, New Mexico, USA

#### **Course Description:**

The Professors of Child Neurology is attended by Residency Program Directors, Division Chiefs, and Program Coordinators who are members of the organization. The session includes two parts. The first part provides updates regarding organizational business, national involvement efforts of members, and updates from affiliated groups to include the AAP Section of Neurology. The second part of the meeting provides CME on selected topics which include a discussion of the current practice of child neurology in the era of productivity metrics and development of a clinician educator track for residents.

#### **Learning Objectives:**

- Identify opportunities to educate residents regarding productivity metrics in clinical medicine.
- Describe strategies for developing a clinical educator curriculum for residents seeking an academic career.

#### **Impact Statements:**

- Attendees of the meeting will receive a comprehensive update on the current state of residency training.
- identify opportunities for ongoing program development at their own institution.

#### Learning Objectives and Impact Statement

All Learning Objective statements listed for each session should be read as responses to the following: 'As a result of this educational session, participants will be able to:'

All Impact Statements listed for each session should be read as responses to the following: 'This educational session helped me to identify changes I could make in my practice related to:'

#### **Tuesday, October 13**

1:00 PM - 3:15 PM

MEET THE EXPERTS:

EXPERIMENTAL THERAPEUTICS:

Gene Therapy for Childhood

Neurological Disorders

#### **Course Description:**

Participants will gain an understanding of the rapidly evolving landscape of gene therapy for neurological disorders of childhood. We will discuss the basic principles of gene vector development and delivery, and describe specific diseases for which gene therapy is currently approved for clinical use or available as an experimental treatment in clinical trials. Finally, we will discuss challenges facing gene therapy development, including cost and worldwide accessibility.

#### **Learning Objectives:**

- Understand the principles of gene therapy development and delivery.
- 2. Be able to describe how different gene therapy strategies can be used to treat specific neurologic diseases in children.

#### **Impact Statements:**

- 1. Recognizing genetic disorders that are amenable to treatment with gene therapy.
- Identifying opportunities for patients with rare diseases to participate in clinical trials of experimental therapies.

#### Organizer:

Toni Pearson, MBBS; Washington University School of Medicine, St. Louis, Missouri, USA Targeting the Central Nervous System: Experiences with Gene Therapy for AADC Deficiency Toni Pearson, MBBS

#### Gene Therapy Primer

Barry Byrne, MD, PhD; Child Health Research Institute, University of Florida, Gainesville, Florida, USA

#### Experiences with Gene Therapy for Childhood Neuromuscular Disorders

Diana Bharucha-Goebel, MD; Children's National Hospital & National Institutes of Health, Washington, DC, USA

Panel Discussion - Present and Future Challenges in the Development of Universally Accessible New Therapies for Ultra-Rare Diseases

Carsten G. Bönnemann, MD; National Institute of Neurological Disorders and Stroke, Bethesda, Maryland, USA

#### 3:30 PM - 5:45 PM

WORKSHOP: NEUROPSYCHIATRY/ MOVEMENT DISORDERS: Practical Management of Functional Neurologic Diseases in Children

#### **Course Description:**

Attendees to this symposium will gain knowledge and expertise in the recognition of children with functional neurologic disorders (FND), particularly those manifesting as non-epileptic seizures and movement disorders.

Additionally, participants will learn how to communicate a diagnosis to patients and families, as well as how to develop a plan of care and treatment that results in a lessening of disability and a resumption of normal participation for the child.

#### **Learning Objectives:**

- Appropriately consider the place of functional neurologic disorders in the context of pediatric disorders of movement and pediatric paroxysmal disorders.
- 2. Effectively explain the diagnosis of functional neurologic disorders to families and children
- 3. Develop and implement appropriate treatment plans for children with functional neurological disorders and their families as a result of this educational session.

#### **Impact Statements:**

- Accurately and confidently diagnosing functional neurological disorders in children.
- 2. Communication with families and children about functional neurological disorders.
- 3. The creation of effective treatment and management plans for children with functional neurological disorders.

#### Organizer:

Leon Dure, MD; University of Alabama at Birmingham, Birmingham, Alabama, USA

TOGETHER-APART VIRTUAI2020

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#### Tuesday, October 13 · continued

Psychogenic Non-Epileptic Seizures in a Pediatric Patient Leon Dure, MD

Functional Neurologic Disorder Presenting as a Movement Disorder in a Pediatric Patient

Shekeeb Mohammad, MD, FRACP, PhD; The Children's Hospital at Westmead, Sydney, NSW, Australia

Practical Treatment and Management of Functional Neurological Disorders in Pediatric Patients

Aaron D. Fobian, PhD; University of Alabama at Birmingham, Birmingham, Alabama, USA

6:00 PM - 8:15 PM

MEET THE EXPERTS: ETHICS: COSTLY DRUGS AND HEALTHCARE - ETHICS AND VALUE PERSPECTIVES FROM DIFFERENT HEALTHCARE SYSTEMS

#### Course Description:

Healthcare is expensive in all countries and availability is often limited by affordability. The development of new ultra-expensive, first-in-class specialty biopharmaceuticals for rare neurological diseases exacerbates the health care affordability problem. The objective of this symposium is to discuss the ethical challenges and practical approaches to the rising cost of prescription drugs and healthcare in different healthcare systems.

#### **Learning Objectives:**

- Understand why exorbitant drug pricing poses direct challenges for distributive justice, which is concerned with the fair distribution of benefits and burdens across society.
- 2. Understand why costly treatments inevitably lead to some type of "rationing" such as limitations of access (lack of insurance coverage), cost (excessive out-of-pocket expenses), or long wait times.

#### **Impact Statements:**

- Understanding the ethical challenges of rising costs in all healthcare systems.
- Explaining to patients how healthcare affordability may affect access to certain new treatments now and in the future.

#### Organizer:

William D. Graf, MD, FAAP, FAAN; Connecticut Children's, Farmington, Connecticut, USA

Growing Disparities in International Healthcare - Ethical Perspectives on the Availability Versus Affordability Crisis William D. Graf, MD, FAAP, FAAN

Costly Drugs and Healthcare -Challenges for Distributive Justice and the Inevitability of Rationing Amy Y. Tsou, MD, MSc; ECRI Institute, Michael J Crescenz VA Medical Center, Philadelphia, Pennsylvania, USA

The Economization of Healthcare in Germany - Lessons for a Sciencebased, Patient-centered and Needs-orientated Care

Klaus-Peter Zimmer, MD PhD; UKGM, Standort Gießen / Justus-Liebig-Universität; Gießen, Germany

Rising Prescription Drug Costs in Canadian Healthcare – The Implementation of National Pharmacare

Michael Shevell, MDCM, FRCP, FCAHS; McGill University, Montreal Children's Hospital, Montreal, Quebec, Canada 6:00 PM - 8:15 PM
MEET THE EXPERTS:
NEUROIMMUNOLOGY:
Para-infections and Seronegative
Autoimmune Encephalitis
in Children: Updates and
Controversies

#### Course Description:

Encephalitis in children are most frequently infectious, parainfectious or autoimmune in etiology. CSF profile, next generation sequencing, and neuroimaging, can help differentiate infectious versus autoimmune causes in some cases, but the etiology remains uncertain in more than half of the patients. Even when autoimmune encephalitis (AE) is greatly suspected, CSF antibodies are encountered in less than 50% of the cases. Furthermore, viruses can trigger autoimmune responses. Thus, differentiating infectious versus parainfectious and seronegative AE are common challenges encountered in clinical practice, and treatment strategies frequently overlap.

In this symposium we will dive into the parainfectious phenomenon through 2 examples: the pathophysiology of ADEM and the post-herpetic NMDA R ab encephalitis. We will also discuss controversies regarding management of seronegative AE and the escalation of immune therapy.

#### **Learning Objectives:**

- Acquire tools to help differentiating infectious versus non-infectious AE in the clinical practice.
- 2. Acknowledge the diagnostic challenges and controversies in the management of encephalitis in children and determine which encephalitic processes may benefit from escalation in immune therapy.

#### **Impact Statements:**

- 1. Adequate management of Acute Encephalitis in children.
- 2. Appropriate use of immunotherapy in Seronegative autoimmune encephalitis.

#### Organizer:

Cristina Fernandez-Carbonell, MD; Cohen's Children Medical Center, Lake Success, New York, USA

Introduction: Infectious,
Parainfectious and Autoimmune
Encephalitis. Challenges in
Clinical Practice
Cristina Fernandez-Carbonell, MD

Parainfectious Encephalitis and ADEM. Updates and Controversies Silvia Tenembaum, MD; National Paediatric Hospital

Dr. Juan P. Garrahan, Buenos Aires, Argentina

#### Postviral Autoimmune Encephalitis: The Case of Post-Herpetic NMDAR Antibody Encephalitis

Thaís Armangue, MD, PhD; IDIBAPS-Hospital Clinic, University of Barcelona, Sant Joan de Déu Children's Hospital, University of Barcelona, Barcelona, Spain

#### Seronegative Autoimmune Encephalitis. Updates and Controversies

Russell Dale, MRCP, PhD; Children's Hospital at Westmead, University of Sydney, Sydney, NSW, Australia 6:00 PM - 8:15 PM
SEMINAR: EPILEPSY:
Don't Ask Don't Tell, or Full
Disclosure? Discussing SUDEP
with Patients and Families in the
Global Community

#### **Course Description:**

In spite of uniform parental desire for information, consistent SUDEP counseling is not happening in our pediatric neurology practices globally. This session highlights the important cultural barriers that prevent child neurologists from discussing SUDEP by providing information on the incidence and frequency of mortality in pediatric epilepsy patients, as well as our current understanding of the phathophysiology of SUDEP. This will be followed by a panel of experts throughout the globe who will describe the unique cultural beliefs that affect discussing SUDEP and mortality in his/her region.

#### **Learning Objectives:**

- Gain a better understanding of the frequency and potential pathophysiology of SUDEP in pediatric epilepsy patients
- Recognize differences in cultural practices regarding discussing SUDEP and mortality in pediatric epilepsy patients

#### **Impact Statements:**

- Understanding the parental desire for SUDEP and epilepsy mortality counseling
- Identifying potential cultural barriers that prevent the participant from discussing SUDEP and epilepsy-related mortality in his/her practice

#### Organizer:

Katherine Nickels, MD, FAES, FAAN; Mayo Clinic College of Medicine, Rochester, Minnesota, USA

How Common is the Nightmare? Global Frequency and Causes of Mortality in Pediatric Epilepsy Elizabeth Donner, MD, MSc, FRCPC; The Hospital for Sick Children, University of Toronto, Toronto, Ontario, Canada

#### What is our Current Understanding of SUDEP in Pediatrics

Omar Abdel-Mannan, MRCPCH, MA, Great Ormond Street Hospital for Children, London, UK

#### **Panel Discussion**

- Jeffrey Buchhalter, MD, PhD; University of Calgary, Calgary, Alberta, Canada
- J Helen Cross MB, ChB, PhD, OBE FRCP, FRCPCH; UCL Great Ormond Street Institute of Child Health, London, UK
- Manjari Tripathi, DM; All India Institute of Medical Sciences, Delhi, India
- Viviana Venegas, MD;
   Advanced Center of Epilepsy,
   Clinica Alemana de Santiago,
   Institute of Neurosurgery,
   Santiago, Chile



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#### Wednesday, October 14

8:00 AM - 10:15 AM

#### SEMINAR:

NEUROINFECTIOUS DISEASE: Measles Vaccination - Current Situation and Consequences -A Global Perspective

#### **Course Description:**

- Repercussions of the present trends in measles vaccination due to increasing exemptors – short & long term effects on the developed and developing world.
- Efforts required on the part of the Child Neurology fraternity to help with the drive for regional and eventually global eradication. Lessons from Smallpox and Polio.
- Latest understanding into the neuro-immunology of the measles virus, highlighting the role of research options in the treatment and or cure of SSPE.

#### **Learning Objectives:**

- 1. Know the present status of measles with a global perspective. How the present drop in immunization is going to affect the clinical scenario today & in the future, along with their role in the eradication process.
- Understand the neuroimmunology of the measles virus – understanding present and future research in the treatment and cure for SSPE.

#### **Impact Statements:**

- Understand the implications of drop in measles vaccination? – the immediate and long term picture. How this knowledge will help to convince patients to immunize their children? How can each of us help in the measles eradication process
- Understanding of the neuroimmunology of the measles virus.
   Understanding different research options in SSPE, with the hope of a cure or treatment in the near future.

#### Organizer:

Anaita Udwadia-Hegde, MD, MRCPCH; Jaslok Hospital & Research Centre, SRCC NH Children's Hospital, Wadia Children's Hospital, Mumbai, India

#### Co-Organizer:

Pauline Samia, MBchB, MMed Peds, MPhil; Aga Khan University, Nairobi, Kenya

#### Impact of the Measles Outbreak -A Global Perspective

Kristen A. Feemster, MD, MPH, MSPHR; Children's Hospital of Philadelphia, Philadelphia, Pennsylvania, USA

#### Measles Eradication -Where do we Stand

Anaita Udwadia-Hegde, MD, MRCPCH

Why Can't we Eradicate Measles -Data from the Developing World Pauline Samia, MBchB, MMed Peds, MPhil

Newer Understanding of the Immunological Basis of Measles & SSPE Banu Anlar MD:

Banu Anlar, MD; Hacettepe University, Ankara, Turkey

8:00 AM - 10:15 AM
SEMINAR: STROKE:
Pediatric Stroke in the
Era of Advanced Genetics

#### **Course Description:**

The adverse health and economic impacts of pediatric arterial ischemic stroke are increasingly appreciated. Mechanisms underlying childhood arterial ischemic stroke (AIS) are heterogeneous and poorly understood but critical for the development of targeted interventions. Cerebral vasculopathies are one of the major causes of pediatric stroke. Genetic discoveries are being increasingly recognized as an important cause of many cerebral vasculopathies. This symposium will highlight the role of advanced genetic analysis in pediatric cerebrovascular diseases, focusing on the common and currently known genes and molecular pathways involved in genetic cerebral vasculopathies.

The role of vascular smooth muscle cell dysfunction will be highlighted, as well as the role of endothelial cell dysfunction in small vessel diseases. Current approaches for the genetic evaluation and its implementation in pediatric stroke based on a clinical and radiologicaldriven approach will be discussed, using a pattern-recognition approach. Existing challenges in the provision of accurate definition and phenotyping of patients with vasculopathies in order to facilitate future genotypephenotype correlations and identify novel associations and disease mechanisms will be highlighted along with potential ways for enhancing gene discoveries in this developing field.

#### **Learning Objectives:**

- Identify specific clinical as well as radiological phenotypes associated with common and newly described monogenic disorders related to pediatric stroke
- Understand the basic concepts of cellular and molecular pathways involved in genetic medium to large cerebral stenoocclusive arteriopathies and small vessel diseases.

#### **Impact Statements:**

- Identify clinical and radiological patterns of recently discovered genetic cerebral vasculopathies including arteriopathies and small-vessel diseases.
- 2. Understand the basic pathophysiological concepts involved in pediatric cerebral vasculopathies

#### Introduction: An Overview of the Genetic Landscape of Pediatric Stroke

Moran Hausman-Kedem, MD; Pediatric Neurology Institute, Dana-Dwek Children's Hospital, Tel-Aviv Sourasky Medical Center, Tel Aviv, Israel

Mechanistic Insights from Monogenic Causes of Cerebrovascular Diseases Vijeya Ganesan MD; UCL Great Ormond Street Institute of Child Health, London, UK

Fits and Misfits: Radiographic Approach to Genetic Diagnosis in Stroke

Nomazulu Dlamini, MBBS, MRCPCH, MSc (Lon), PhD; The Hospital for Sick Children and University of Toronto, Toronto, Ontario, Canada

Clinical Management and Future Perspectives of Genetic Cerebrovascular Diseases

Patricia L. Musolino, MD, PhD; Massachusetts General Hospital, Harvard Medical School, Boston, Massachusetts, USA 10:00 AM - 12:15 PM WORKSHOP: EPILEPSY: PEDIATRIC EPILEPSY SURGERY: When, by Whom, and What to Expect?

#### **Course Description:**

Epilepsy surgery is a highly successful treatment option for children with focal and lesional epilepsy. Despite its excellent seizure outcomes and cognitive benefits, surgery is still underutilized and a large treatment gap remains between geographical regions worldwide. This symposium aims to increase the awareness of epilepsy surgery, inform the audience about novel insights in surgical indications, timing, seizureand cognitive outcomes, and their determinants. We will present the newly defined ILAE criteria for different levels of care in pediatric epilepsy surgery centers and address minimum requirements for surgical procedures in the context of the existing treatment gap.

#### **Learning Objectives:**

- Identify candidates for epilepsy surgery and counsel children and parents about its expected seizure- and cognitive outcomes
- 2. Name the two levels of care for pediatric epilepsy surgery centers and the main requirements to establish such centers

## TOGETHER-APART VIRTUAI2020

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#### Wednesday, October 14 · continued

#### **Impact Statements:**

- Indications for referral of children with epilepsy for presurgical evaluation
- 2. Counselling of patients and their parents about expected outcomes of epilepsy surgery

#### Organizer:

Prof. Dr. Kees P.J. Braun, University Medical Center Utrecht, UMCU Brain Center, Utrecht, Netherlands Epilepsy Surgery in Children: Indications and Seizure-outcome Prof. Dr. Kees P.J. Braun

Cognitive and Behavioural
Outcome after Epilepsy Surgery
J Helen Cross MB, ChB, PhD, OBE
FRCP, FRCPCH; UCL
Great Ormond Street
Institute of Child Health,
London UK

Criteria for Pediatric Epilepsy Surgery Centers; What about the Treatment Gap? William D. Gaillard, MD; Children's National Medical Center, Washington, DC, USA

10:30 AM - 12:45 AM
SEMINAR: NEUROGENETICS:
Recent Advances in the Etiologies
and Mechanisms Underlying
Common Brain Malformations

#### **Course Description:**

- Understand recent advances in the genetic causes and mechanisms underlying common brain malformations, focusing on polymicrogyria, lissencephaly and cortical dysplasia.
- 2. Understand the imaging and phenotypic spectrum for the common genetic causes of common brain malformations.
- 3. Understand how advances in genetics have led to a better understanding of seizure generation in focal cortical dysplasia.

#### **Learning Objectives:**

- Identify the most common genetic causes of lissencephaly, polymicrogyria and cortical dysplasia.
- Determine the most appropriate genetic workup for children with lissencephaly, polymicrogyria and cortical dysplasia following review of clinical and imaging features.

#### **Impact Statements:**

- Recognising the imaging features of different brain malformations.
- 2. Understanding the most likely genetic causes of lissencephaly, polymicrogyria and cortical.

#### Organizer:

Rick Leventer, FRACP, PhD; The Royal Children's Hospital Melbourne, Parkville, Victoria, Australia

#### Co-Organizer:

William Dobyns, MD; University of Washington, Seattle, Washington, USA

Cortical Dysplasia: Linking Genes to Seizure Generation
Rick Leventer FRACP, PhD

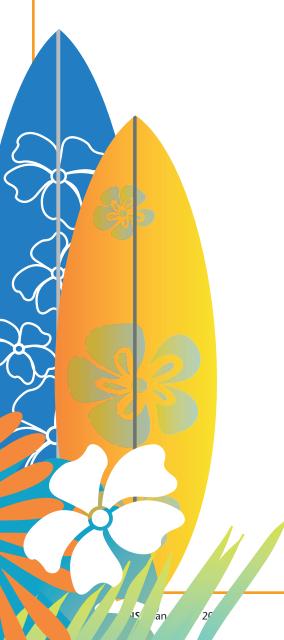
Lissencephaly: Novel Clinical and Molecular Insights
Nataliya Di Donato, MD,

Institute for Clinical Genetics, TU Dresden, Dresden, Germany

Polymicrogyria: A Clinical and Genetically Heterogenous Malformation

Anna C. Jansen, MD, PhD, Peditiatric Neurology Unit, UZ Brussel, Brussels, Belgium

**Conclusion & Future Directions**William Dobyns, MD



1:00 PM - 3:15 PM

#### **SEMINAR: NEUROIMMUNOLOGY:** A New Era for Patients with NMOSD, including Children

#### **Course Description:**

- To learn current diagnostic criteria for NMO/NMOSD
- To know updated information on the diagnostic biomarkers and appropriate laboratory techniques
- To learn current rescue therapies for acute events, and introducing novel relapse prevention strategies for patients with **NMOSD**

#### **Learning Objectives:**

- 1. Learn new clinical and neuroimaging diagnostic criteria for NMO/NMOSD and corresponding biomarkers
- 2. Receive updated information on current rescue therapies for severe acute CNS events, and learn on relapse prevention strategies, including novel immunosuppressive drugs.

#### **Impact Statements:**

- 1. The appropriate diagnosis of **NMOSD**
- 2. The relevant data about treatment options that should be considered for the correct treatment of acute events and relapse prevention with immunosuppression in children.

#### Organizer:

Silvia N. Tenembaum, MD; National Pediatric Hospital Dr. Juan P. Garrahan, Buenos Aires, Argentina

#### Co-Organizer:

E. Ann Yeh, MD, MA, FRCPC; Hospital for Sick Children, University of Toronto, Toronto, Ontario, Canada

Introduction: Current Diagnostic Criteria of Neuromyelitis Optica Spectrum Disorders (NMOSD)

Silvia N. Tenembaum, MD

#### Diagnostic Biomarkers of NMOSD: AQP4-IgG and MOG-IgG

Thais Armangue, MD, PhD; IDIBAPS-Hospital Clinic. University of Barcelona, Sant Joan de Déu Children's Hospital, University of Barcelona, Barcelona, Spain

#### Current Preventive Treatment Strategies for NMOSD

E. Ann Yeh, MD, MA, FRCPC

New Era on Preventive Treatment of NMOSD: Recently Approved and Investigational Agents

Tanuja Chitnis MD, FAAN; Harvard Medical School, Boston, Massachusetts, USA

#### Treatment of Acute Clinical Events

Andrea Savransky, MD; National Pediatric Hospital Dr. J. P. Garrahan. Buenos Aires, Argentina

#### 6:00 PM - 8:15 PM

#### JUNIOR MEMBER SEMINAR: **Becoming a Physician Scientist** in Pediatric Neurology

#### Course Description:

How do we conduct a good research and write a good scientific paper? We will approach this universal question through three specific talks: "Common faults editors see", "What PhD brings to research" and "Research outside a medical center". This symposium is aimed to help young physicians embark on their research journey.

#### Learning Objectives:

- 1. Learn the common pearls and pitfalls in writing a good manuscript.
- 2. Better plan their medical research career path, especially for those in their early stages.

#### **Impact Statements:**

- 1. Improve skills to write a scientific paper.
- 2. Better plan one's medical research career path.

#### Organizer:

Chang-Chun Wu, MD; Department of Pediatrics, Taipei City Hospital, Taipei, Taiwan

#### Co-Organizer:

Hiroya Nishida, MD; Tokyo Metropolitan Institute of Medical Science, Tokyo, Japan

#### What are the Common Faults Editors See?

Jonathan W. Mink, MD, PhD; University of Rochester, Rochester, New York, USA

#### What PhD Brings to our Research and Clinical Work?

Pratibha Singhi, MBBS, MD, FIAP, FNAMS; Medanta, The Medicity, Gurgaon, Haryana, India

#### Suggestions on Research Outside a Medical Center

Takeru Honda, PhD; Tokyo Metropolitan Institute of Medical Science, Tokyo, Japan



16th International Child Neurology Congress
49th Annual Child Neurology Society Meeting

#### **Thursday, October 15**

10:30 AM - 12:45 PM
WORKSHOP: GLOBAL
NEUROLOGY: Training to
Bridge the Gap in Global
Access to Child Neurology Care

#### **Course Description:**

The participants will gain specific knowledge about barriers to access to child neurology care in diverse settings, with an emphasis on South America and Sub-Saharan Africa. They will learn about socioeconomic, geographic, and infrastructure barriers that continue to limit access to care. They will acquire knowledge about three specific settings where training programs are bridging these gaps in access to child neurology care.

#### Learning Objectives:

- Understand some of the socioeconomic, geographic, and infrastructure barriers that continue to limit access to child neurology care globally
- 2. Become aware of a variety of approaches to training to overcome those barriers.

#### **Impact Statements:**

- How to design educational and training programs to sustainably improve access to child neurology care in diverse settings
- 2. How to participate in educational and training programs that increase access to child neurology care in low to moderate resource settings.

#### Organizer:

Alex R. Paciorkowski, MD; University of Rochester Medical Center, Rochester, New York, USA

#### Child Neurology in Brazil, a Model and Challenges

Helio van der Linden, Jr., MD; Instituto de Neurologia de Goiânia, Goiânia, Goiás, Brazil

#### Breaking New Ground in Zambia -First Child Neurology Trainees

Nfwama Kawatu, MD; University Teaching Hospitals, Children's Hospital, Lusaka, Zambia

#### Innovative Child Neurology Curriculum in Ecuador

Kevin Shapiro, MD, PhD; Cortica Healthcare, Los Angeles, California, USA

## 1:00 PM - 3:15 PM JUNIOR MEMBER SEMINAR: Nurturing the Global Pipeline of Academic Child Neurologists

#### **Course Description:**

There is an ever-growing gap between the need for clinical Child Neurology and Neurodevelopmental Disabilities services and the number of trained practitioners throughout the world. In this setting, nurturing and encouraging trainees and junior faculty towards an academic career path is a constant, but necessary, enterprise to ensure that clinically focused research in our field continues to scale as well. This seminar will discuss the current challenges and opportunities for training the next generation of Child Neurology physicianscientists both within the US and globally. There is an evergrowing gap between the need for clinical Child Neurology and Neurodevelopmental Disabilities services and the number of trained practitioners throughout the world. In this setting, nurturing and encouraging trainees and junior faculty towards an academic career path is a constant, but necessary, enterprise to ensure that clinically focused research in our field continues to scale as well. This seminar will discuss the current challenges and opportunities for training the next generation of Child Neurology physicianscientists both within the US and globally.

#### **Learning Objectives:**

- Understand and educate others about the training and funding mechanisms available to support trainees and junior faculty interested in an academic Child Neurology career path.
- Be aware of the research and service delivery priorities for expanding Child Neurology access globally in addition to training more practitioners.

#### **Impact Statements:**

- Encouraging trainees and junior faculty to pursue academic career paths.
- Prioritizing lines of research and training that are globally applicable.

#### Organizer:

Alexander Li Cohen, MD, PhD; Boston Children's Hospital, Boston, Massachusetts, USA

The NIH Perspective on the Child Neurology Physician-Scientist Workforce Adam L. Hartman, MD, FAAP,

FANA, FAES; National Institute of Neurological Disorders & Stroke Neuroscience Center, Rockville, Maryland USA

#### Building a More Diverse Pediatric Research Community

Erika Augustine, MD, MS; University of Rochester Medical Center, Rochester, New York, USA

Growing a Global(ly Capable)
Pediatric Neurology Workforce
Jo M. Wilmshurst, MB, BS, MD,

Red Cross War Memorial Children's Hospital, University of Cape Town, Cape Town, Western Cape, South Africa 3:30 PM - 5:45 PM

## MEET THE EXPERTS: BEHAVIORAL NEUROLOGY: Management of Behavior in Children with Neurodevelopmental Disorders

#### **Course Description:**

Pediatric Neurologists now care for more children and adolescents with neurodevelopmental disabilities as the prevalence increases worldwide. The neurobehavioral care of these children is especially challenging. This Meet the Experts session will address some of the common behavioral management issues through case-based presentations of children with neurodevelopmental disorders including Autism, Tuberous Sclerosis, Fetal Alcohol Syndrome and other intellectual disabilities and Phelan McDermid Syndrome. The Experts will discuss management of problems such as irritability, behavior issues in a child with epilepsy, Attention and executive function challenges and sleep.

#### **Learning Objectives:**

- Treat four common behavior challenges in children with NDD's including irritability, anxiety, attention and sleep.
- Understand some of the behavior challenges in children with autism, tuberous sclerosis complex, fetal alcohol syndrome, and Phelan McDermid Syndrome, their shared characteristics across disorders but also unique challenges.

#### **Impact Statements:**

- Identifying behaviors in minimally verbal children and NDD
- 2. Treatment of behaviors in children with NDD.

#### Organizer:

Ann M. Neumeyer, MD; Massachusetts General Hospital, Boston, Massachusetts, USA

#### Moderator:

Sarah Spence, MD PhD, Boston Children's Hospital, Boston, Massachusetts, USA

Case 1: Behavior Changes and Anxiety in a Child with Tuberous Sclerosis Complex Shafali Spurling Jeste, MD; UCLA David Geffen School of Medicine, Los Angeles, California, USA

Case 2: Behavior Changes and Irritability in a Child with Autism Spectrum Disorder Evdokia Anagnostou, MD; University of Toronto, Bloorview Research Institute,

Holland Bloorview Kids Rehabilitation Hospital, Toronto, Ontario, Canada

Case 3: Identifying and Treating Executive Function and Inattention in a Child with Fetal Alcohol Syndrome Kirsten A. Donald MD, PhD, University of Cape Town, Cape Town, South Africa

Case 4: Behavior Changes and Sleep in a Child with Phelan McDermid Syndrome

Ann M. Neumeyer, MD; Massachusetts General Hospital, Boston, Massachusetts, USA

TOGETHER APPRIT

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#### Thursday, October 15 · continued

6:00 PM - 8:15 PM

MEET THE EXPERTS:

NEUROMETABOLIC DISORDERS:

Unravelling the Complexity

of Treatable Neurometabolic

Disorders: A Case-based Session

#### **Course Description:**

Inborn errors of metabolism (IEM) are individually rare but collectively they form a major group of treatable disorders in children. Affected children manifest with neurological and psychiatric symptoms that overlap more common conditions, and delayed diagnosis is not uncommon. Enhancing knowledge and understanding of these conditions will help neurologists establish early diagnosis. Unravelling

the complexity of treatable neurometabolic disorders will enhance knowledge and impact outcomes through appropriate multidisciplinary management. This symposium will focus on the approach and management of patients with treatable neurometabolic disorders, IEM associated with hyperammonemia, pediatric neurotransmitter disorders, cerebral creatine deficiency syndromes and treatable IEMs associated epilepsies.

#### **Learning Objectives:**

- 1. Understand key metabolic pathways involved in the biosynthesis of essential neurotransmitters, the clinical presentations and the role of the laboratory in diagnosis of primary defects in neurotransmitter metabolism
- 2. Identify biochemical abnormalities and the clinical consequences in primary hyperammonemic disorders, their diagnoses and management
- Identify the clinical phenotypes, diagnose various subtypes and optimize the management of inherited cerebral creatine deficiency syndromes
- Identify the phenotype and diagnose treatable metabolic causes of epilepsy in children and adolescents.

#### **Impact Statements:**

 Timely recognition, utilization of appropriate biochemical and genetics testing to establish early diagnosis and improve outcomes in the four groups of metabolic disorders discussed through appropriate therapeutic interventions  Enhancing collaboration and establishing networks in the global pediatric neurology community dedicated to improve the outcomes of children affected by neurometabolic disorders.

#### Organizer:

Asuri N. Prasad, MBBS, MD, FRCPC, FRCPEdin, FAES; Schulich School of Medicine and Dentistry Western University, London, Ontario, Canada

Primary Disorders of Neurotransmitter Metabolism: Challenges in Diagnosis & Management

Asuri N. Prasad, MBBS, MD, FRCPC, FRCPEdin, FAES

Primary Hyperammonemic Disorders: Neurological Implications, Current Diagnosis and Management Strategies Bindu Parayil Sankaran MD, DM, FRACP, PhD; Children Hospital at Westmead NSW, Sydney, Australia

Epilepsies Associated with IEM Annapurna Poduri, MD, MPH; Boston Children's Hospital, Harvard Medical School, Boston, Massachusetts, USA

Cerebral Creatine Deficiency Syndromes – An Underdiagnosed Entity: Clinical Aspects and Management

Sangeetha Yoganathan, MD, DNB, DM; Christian Medical College, Tamil Nadu, India





16th International Child Neurology Congress
49th Annual Child Neurology Society Meeting

#### Friday, October 16

8:00 AM - 10:15 AM

MEET THE EXPERTS:

NEURO-CUTANEOUS DISORDERS:

IN SPANISH: Neurocutaneous

Syndrome Iberoamerican Network

#### **Course Description:**

The aim of the Iberoamerican network is to implement an international collaboration where healthcare professionals (pediatric epileptologists, pediatric neurologist, geneticists, neurosurgeons, pediatricians, psychologists, nurses, etc.), affected families and caregivers from different countries share their field of expertise, knowledge and experiences. A platform enables sharing and empowers families.

The main objective of the symposium is to emphasize the importance of early diagnosis, adequate treatment and precise follow-up in the more prevalent Neurocutaneous Diseases.

#### **Learning Objectives:**

- Learn about the spectrum of clinical presentation, importance of early diagnosis, adequate treatment and accurate follow up.
- 2. Have a clear understanding of the benefits of having a multidisciplinary team for the treatment and surveillance of patients and their families.

#### **Impact Statements:**

- 1. The use of appropriate diagnostic and treatment algorithms concerning the management of these patients.
- 2. The development of a multidisciplinary approach.

#### Organizer:

Federico Jose Ramos, MD; Sant Joan de Déu Hospital, Barcelona, Spain

#### Introduction

Federico Jose Ramos, MD

Update on mTOR Inhibition as Treatment for Neurological Tuberous Sclerosis Complex (TSC) Manifestations

Lorena Lechuga-Becerra, MD; Sofia Salud, Mexico City, Mexico

Early Management and Strategies for the Treatment of Epilepsy Associated with Sturge Weber Syndrome

Bolívar Quito-Betancourt MD; Hospital Monte Sinai, Cuenca, Ecuador

Neurocognitive Problems and Impact of Individualized Neuropsychological Intervention for Children with Neurofibromatosis Type 1 (NF1) Alba Parra Checa, MSc; Sant Joan de Déu Hospital, Barcelona, Spain

TOGETHER-APART VIRTUAL 2020

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#### Friday, October 16 · continued

10:30 AM - 12:45 PM
SEMINAR: HEADACHE:
IN SPANISH: Migraine in Children
and Adolescents - Diagnosis,
Management and Treatment

#### **Course Description:**

This seminar about Migraine in Children and Adolescents. addressed in Spanish, will allow participants to learn and/or review the diagnostic criteria, epidemiology, therapeutic modalities, economic impact and quality of life data regarding Migraine in the Pediatric population in The Americas. Through lecture format and case presentation, participants will learn and/or review therapeutic modalities for migraine, including cognitive behavioral therapy (CBT), acute medications, preventive medications, "natural" treatments and neuromodulation. Participants will learn about "ointments, concoctions and potions" and will learn perspectives related to the level of scientific evidence for each therap. Participants will learn about health habit modification, accommodations in school, exercise, meditation and psychiatric comorbidities for patients with migraine. In addition, participants will learn about the similarities and differences in the practice of pediatric neurology (US vs Canada vs Latin America), as it relates to the regional, cultural and social norms, as well as the resources available to each demographic.

#### Learning Objectives:

- Know the diagnostic criteria, epidemiology, therapeutic modalities, economic impact and quality of life data regarding Migraine in the Pediatric population in The Americas.
- 2. Know the importance of health habit modification, accommodations in school, exercise, meditation and addressing psychiatric comorbidities for pediatric patients with migraine.

#### **Impact Statements:**

- Implementing a comprehensive plan for the management of migraine in the pediatric population that includes pharmacological as well as nonpharmacological therapies.
- Implementing actions that will address reintegration to school and management of psychiatric comorbidities in patients with migraine.

#### Organizer:

Clarimar Borrero-Mejias, MD; Barrow Neurological Institute at Phoenix Children's Hospital, University of Arizona – COM- Phoenix, Phoenix, Arizona, USA

Migraine: Diagnosis,
Epidemiology and Burden of
Disease in The Americas
Edith Alva Moncayo MD;
President of Mexican Councile of
Neurology and Pediatric Neurology
in Medical Center La Raza IMSS,
México

#### Migraine Therapies: Medications and Beyond

Denia Ramirez-Montealegre MD, MPH, PhD; The University of Tennessee Medical Center Knoxville, Tennessee, USA

Migraine: Habits, School, Mind and Mood Clarimar Borrero-Mejias, MD 10:30 AM - 12:45 PM

#### **SEMINAR: NEUROINFLAMMATION: Interferonopathies**

#### **Course Description:**

The objectives are to be able to consider interferonopathies in the appropriate context of progressive or static encephalopathies, to learn about their pathogenesis, and possibilities of treatment.

#### **Learning Objectives:**

- Think of a particular group of disorders with variable age of onset and severity, but typical constellation of symptoms.
- 2. Start the work-up or where to refer if needed.

#### **Impact Statements:**

- This session allowed me to consider a hereditary disorder in the differential diagnosis of intrauterine infections, cerebral calcifications, or hereditary paraparesis.
- 2. I will include recessive interferon pathway disorders in any child with slowly progressive or static neurological deficits, particularly when more than one offspring is affected in the family albeit at different degrees.

#### Organizer:

Banu Anlar, MD; Hacettepe University, Ankara, Turkey

Case Presentations Illustrating the Clinical Spectrum Banu Anlar, MD

#### Molecular Pathogenesis and Treatment Targets

Adeline Vanderver, MD; Children's Hospital of Philadelphia, Philadelphia, Pennsylvania, USA

#### Monogenic Interferonopathies with Non-Aicardi Goutieres Phenotype

Raphaela Goldbach-Mansky MD, MHS; Laboratory of NIAID/NIH, Bethesda, Maryland, USA

**Discussion & Questions** 

#### 10:30 AM - 12:45 PM **SEMINAR: NEONATAL NEUROLOGY: The Value of Magnetic Resonance Imaging**

in the Newborn

#### Course Description:

The participant will gain knowledge regarding the appropriate use of MRI in the neonatal period under a variety of conditions. In particular, the parent and clinician perspectives will be highlighted so as to inform the decision-making process.

#### **Learning Objectives:**

- 1. Make an informed decision about when to obtain an MRI in the newborn period.
- 2. Understand what MRI offers in conditions such as neonatal stroke, hypoxic-ischemic encephalopathy, congenital heart disease and extreme prematurity.

#### **Impact Statements:**

- 1. When to order MRI in the newborn.
- 2. The need for MRI in the preterm newborn and the appropriate time to get it.

#### Organizer:

Donna M. Ferriero, MD, MS; UCSF Weill Institute for Neurosciences. San Francisco, California, USA

#### Tailor Made Prediction of Neonatal Stroke

Linda S. de Vries, MD, PhD; University Medical Center Utrecht, the Netherlands

Congenital Heart Disease and Brain MRI: The Heart of the Matter

Steven Paul Miller, MDCM, MAS, FRCPC: The Hospital for Sick Children, The University of Toronto, Toronto, Ontario, Canada

#### Preterm MRI - Is it Immature Information?

Terrie Inder, MBChB, MD: Brigham and Women's Hospital, Boston, Massachusetts, USA

MRI after Therapeutic Hypothermia - Are there Cool Findings

Donna M. Ferriero, MD, MS

#### **Questions & Answers**

10:30 AM - 12:45 PM **MEET THE EXPERTS: NEUROMUSCULAR:** The Many Faces of Pediatric Neuromuscular Diseases: Cases. **Approaches, Pearls and Challenges** 

#### **Course Description:**

Neuromuscular diseases encompass a heterogenous group of disorders which may be genetically determined, genetic or acquired, congenital or later onset, acute or chronic, and progressive, static or intermitted. Specific therapies are emerging for an increasing number of diseases with promising results for genetically determined diseases of the neuromuscular system, including spinal muscular atrophy, Duchenne muscular dystrophy and treatable myopathies, but also for acquired conditions. The entry point for any directed therapy however is an accurate diagnosis.

The aim of this 'Meet the Experts' session for the Junior Members of ICNA, non-member trainees and anyone interested is to discuss selected case presentations from different age groups and patient populations, reflecting daily practice from different sites and resources in an interactive way, with a focus on the various tools we have to achieve a diagnosis. These are ranging from the purely clinical, the extended phenotype (imaging and electrodiagnostics), biopsy, to genetic and genomic investigations.

Educational objectives for the symposium are three fold:

- 1. Review clinical clues from a detailed history and points on the physical examination and discuss when to consider a neuromuscular disease
- 2. Teach how to integrate clinical phenotype, and/or imaging and histology, as well as genetic tools to arrive at a diagnosis
- 3. How to confirm or refute a suspicious but not yet diagnostic genotype, based on careful iterative clinical analysis

#### Learning Objectives:

- 1. Approach to most common neuromuscular presentations including early-onset muscle diseases, and recognize various important phenotypes in the pediatric age group using clinical, extended clinical, and basic laboratory clues
- 2. Learn to fully characterize the patient to create a differential diagnostic list of diagnostic possibilities based on the patient presentation and exambased localization according to anatomic region and systems involved, and combine traditional and modern diagnostic testing and consider management strategies including proactive treatment opportunities

#### Friday, October 16 · continued

#### **Impact Statements:**

- Awareness of the many different presentations in the pediatric neuromuscular field and recognition of patients in whom a neuromuscular specialist should be referred in the 'Pediatric Neurology' practice
- 2. Recognition of most common clinical phenotypes, individualized clinical and laboratory approaches, molecular diagnostic tests, and management strategies including genetic counseling in the pediatric neuromuscular disorders field

#### Organizer:

Göknur Haliloğlu, MD; Hacettepe University Children's Hospital, Ankara, Turkey

#### Case Presentations

Göknur Haliloğlu, MD

Carsten G. Bönnemann, MD; National Institute of Neurological Disorders and Stroke, Bethesda, Maryland, USA

#### 1:00 PM - 3:15 PM

#### WORKSHOP: EPILEPSY/GENERAL CHILD NEUROLOGY: Telehealth - A Means to Global Outreach

#### Course Description:

This workshop will bring together a panel of experts to review wide ranging applications of telemedicine technologies and provide resources to an international audience to implement programs, collaborate with experts and colleagues and develop virtual outreach capability. This session will address resources for Child Neurologists, opportunities to empower primary care providers to increase their confidence, and self-efficacy in co-managing common neurological conditions and partner with specialists in Pediatric Neurology care.

#### **Learning Objectives:**

- Understand the range of applications of Telemedicine Technologies
- 2. Avail of resources to connect with programs for increasing physician capacity for managing neurological conditions

#### **Impact Statements:**

- Recognizing applications of telemedicine as a plausible, attractive and cost-effective option to foster regional as well as international collaboration in patient care and education
- 2. Improving capacity of referring physicians in increasing self-efficacy and confidence in comanaging neurological disorders

#### Organizer:

Sucheta Joshi, MD, MS; Michigan Medicine, Ann Arbor, Michigan, USA

#### Co-Organizer:

Charuta Joshi, MBBS; Children's Hospital Colorado, Anchutz Medical Campus, Aurora, Colorado, USA

Act Local, Reach Global: The Impact of Telementoring through Project ECHO Sucheta Joshi, MD, MS

#### The Guatemala-Colorado Child Neurology Telemedicine Experience

Diana Walleigh, MD; Children's Hospital Colorado, Anchutz Medical Campus, Aurora, Colorado, USA

Guillermo Bolaños Ventura, MD; Center for Human Development, FUNSALUD, Center for Global Health, Retalhuleu, Guatemala

Child Neurology Telehealth Special Interest Group: Current Landscape and Future Directions Charuta Joshi, MBBS 3:30 PM - 5:45 PM
JUNIOR MEMBER SEMINAR:
International Clinical Research
Consortia in Child Neurology:

#### Course Description:

Get Involved!

The main objectives of this session are to demonstrate the benefit and need for international pediatric clinical trial consortia and how to engage with international clinical research consortia in child neurology. Content is geared to both "site" or local principal investigators (PIs) and consortium PIs, regardless of geographic location. Perspectives from consortium PIs, site/local PIs, and institutions will be presented.

#### **Learning Objectives:**

- Gain a better understanding of the benefit and need for international pediatric clinical trial consortia.
- Join and support an ongoing an international clinical research consortium in child neurology.

#### **Impact Statements:**

- Joining and supporting an international clinical research consortium in child neurology.
- Seeking institutional and financial support for an international clinical research consortium in child neurology.

#### Organizer:

Adam L. Hartman, MD, FAAP, FANA, FAES; National Institute of Neurological Disorders & Stroke Neuroscience Center, Rockville, Maryland USA

#### Introduction

Adam L. Hartman, MD, FAAP, FANA, FAES

#### IPSS: Collaboration on Pediatric Stroke in 25 Countries

Heather J. Fullerton, MD, MAS; University of California, San Francisco, San Francisco, California, USA The Institutional Perspective on International Research Consortia Edwin Trevathan, MD, MPH; Vanderbilt University Medical Center, Nashville, Tennessee, USA

Understanding the Etiology and Pathogenesis of Nodding Syndrome in Eastern Africa Richard Idro, MMED, PhD; Makerere University, Kampala, Uganda

#### Question & Answer

3:30 PM - 5:45 PM
CHILD NEUROLOGY
FOUNDATION SYMPOSIUM:
Shortening the Diagnostic
Odyssey in Children with
Neurologic Conditions

#### **Course Description:**

This symposium will bring together medical professionals, families and advocates from around the world to discuss ways to shorten the diagnostic odyssey in children with neurologic conditions. On average, it takes five years to diagnose a rare disease. This is frustrating for both family and healthcare providers as it is critical, and sometimes lifesaving, to get to a diagnosis and begin making informed decisions about next steps in care for the child. During this session, participants will receive an overview of the current perspective, of families and professionals, on the challenges of getting to a diagnosis. The symposium will include speakers who share information on both low-tech and high-tech tools to accelerate the diagnostic journey. Participants will discuss the available tests and screens as well as how to best access and utilize these tools. We will also share information on best collaborate with families during the diagnostic process.

#### Two Learning Objectives:

- Identify the different types of tools available for diagnosing children with neurologic differences.
- Identify the key elements of collaborating with families and mobilizing energy to use resources effectively.

#### Two Impact Statements:

- Developing a more effective protocol to utilize the appropriate tests and screeners for children in search of a diagnosis.
- 2. Improving communication and collaboration with families to shorten the diagnostic journey.

#### Organizer:

Child Neurology Foundation Scott L. Pomeroy, MD, PhD; Harvard Medical School, Boston Children's Hospital, Boston, Massachusetts, USA

Welcome and Assessment Results Scott L. Pomeroy, MD, PhD;

Harvard Medical School, Boston Children's Hospital, Boston, Massachusetts, USA

#### Family Perspective/Hope for Diagnosis and Possibly Precision Treatment

E. Gay Grossman, Patient Advocate, Co-Founder ADCY5.org, San Diego, California, USA

Family Support Through Multidisciplinary Programs/Genetic Counseling Beth Rosen Sheidley, MS, CGC; Boston Children's Hospital, Boston, Massachusetts, USA Historical view of the evaluation of neurologic disorders. The impact of genetic progress and shift in diagnostic approach to genetics viewed from the perspective of neuromuscular disorders; solving the unsolved, implications for treatment.

James Dowling, MD, PhD; Hospital for Sick Children, Toronto, Ontario, Canada

How to address disorders where the differential diagnosis includes genetic and non-genetic causes, from the perspective of epilepsy. Role of imaging, role of genetics, progress and shift in diagnostic approach, evolving implications for treatment, role of community engagement.

Ingrid E. Scheffer, AO, MBBS; The University of Melbourne, Austin Health and Royal Children's Hospital, Heidelberg, Victoria, Australia

Rare Neurological Diseases -Taking an Undiagnosed Diseases Network Model

#### Panel Discussion

- James Dowling, MD, PhD
- E. Gay Grossman, Patient Advocate
- Annapurna Poduri, MD, MPH; Boston Children's Hospital, Harvard Medical School, Boston, Massachusetts, USA
- Scott L. Pomeroy, MD, PhD
- Ingrid E. Scheffer, AO, MBBS
- · Beth Rosen Sheidley, MS, CGC

#### Close

Scott L. Pomeroy, MD, PhD; Harvard Medical School, Boston Children's Hospital, Boston, Massachusetts, USA

#### Friday, October 16 · continued

3:30 PM - 5:45 PM
MEET THE EXPERTS:
MOVEMENT DISORDERS:
Tics, Stereotypies, and Their
Look-a-Likes - Understanding and
Managing Repetitive Movements

#### **Course Description:**

This Meet the Experts Interest Group session will address tics, stereotypies, psychogenic mimics, and similar-appearing movements. The presenters will share their clinical experience on use of key diagnostic features from home videos and in-person neurological evaluations in order to distinguish challenging cases. They will also share the latest research and neurobiological advances regarding the pathophysiology and treatment of these conditions.

#### **Learning Objectives:**

- Use clinical skills to accurately distinguish tics and stereotypies from "mimics" including drug-induced and functional movement disorders.
- 2. Discuss recent advances in understanding of neurobiology of tics, stereotypies, and functional movement disorders.

#### **Impact Statements:**

- More accurate diagnosis based on phenomenology without medical diagnostic testing
- 2. Implementation of treatment strategies starting with effective communication of diagnoses and treatment options to caregivers

#### Organizer:

Donald L. Gilbert, MD, MS; Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, USA

Mimics - Functional (Psychogenic), Drug-induced, and Otherwise Donald L. Gilbert, MD, MS

#### Stereotypy Phenomenology and Pathophysiology

Harvey S. Singer MD; Johns Hopkins Medicine, Kennedy Krieger Institute, Baltimore, Maryland, USA

#### Tic Phenomenology and Pathophysiology

Russell Dale, MRCP, PhD; Children's Hospital at Westmead, University of Sydney, Sydney, NSW, Australia

## 6:00 PM - 8:15 PM JUNIOR MEMBER SEMINAR: Choosing Your Career Track Academic, Private Practice, and NGOs

#### Course Description:

This session will discuss diverse choices in building a career post-training in child neurology. Three different career paths will be discussed:

- Academic/research careers how to interact with chairs, apply for jobs, negotiate time for research or education
- Private practice how to find a good practice, tips towards starting your clinical career and negotiating for dedicated time for your clinical interests
- 3. NGO and governmental jobs (i.e. CDC) how to pursue a non-traditional career path and interact with multiple governmental associations and industry resources outside of the traditional clinical setting.

These sessions include speakers that are early career investigators at the NIH, public health officials working for the department of defense, and physicians in private practice. Speakers will discuss options available for junior child neurologists in building bridges to various research funding entities, carving out a subspecialty interest within a group practice, as well as pursuing governmental careers in the translation of scientific advances to the field.

#### **Learning Objectives:**

- 1. Identify distinct career options following training.
- 2. Successfully transition into a long career role that best suits their career needs.

#### Impact Statements:

- 1. Pursue as a child neurology attending.
- Identify clear steps to continue on my career trajectory and achieve my long-term career goals.

#### Organizer:

Payal Patel, MD; Seattle Children's Hospital, Seattle, Washington, USA

#### The Academic Track

Naila Makhani, MD, MPH; Yale University, New Haven, Connecticut, USA

#### The Private Practice Track

Doug Smith, MD; Minnesota Epilepsy Group, St. Paul, Minnesota, USA

#### The Off-the-Beaten-Path Track, Working in Government

Ana-Claire Meyer, MD, MHSH; US Army Medical Research and Development Command, Fort Detrick, Maryland, USA



## CREATING HOPE THROUGH INNOVATION

At Eisai, everything we do is guided by a simple principle: patients and their families come first. We spend time with them. We listen and we learn about their lives, their desires and their greatest needs. We call this human health care or hhc, giving first thoughts to patients and their families and helping increase the benefits health care provides.

Our *hhc* mission is what drives us to discover innovative solutions and therapies that help address unmet needs within the communities that we seek to serve.

Eisai is proud to support the 2020 CNS-ICNA Conjoint Meeting.

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16th International Child Neurology Congress
49th Annual Child Neurology Society Meeting

#### Monday, October 19

7:00 AM - 3:30 PM

SYMPOSIUM I: NEUROBIOLOGY OF DISEASE IN CHILDREN (NDC): Traumatic Brain Injury (TBI)

#### Course Description:

Traumatic brain injury (TBI) takes an enormous toll on the developing nervous system. NDC 2020 will focus on the topic including a description of clinical features, pathogenesis and its management, as well as identifying future research directions. TBI not only contributes to high levels of childhood mortality but also considerable morbidity demanding the expertise of child neurologists at diagnosis and in follow-up, impacting learning and well-being.

#### Learning Objectives:

- To recognize the spectrum of clinical presentations and complications arising from traumatic brain injury in children.
- To learn of latest developments in the field and how best to manage resulting neurological complications

#### **Impact Statements:**

- To have a deeper understanding of key concepts that enables cutting edge management in one's practice soon after injury and in follow-up.
- 2. To serve as an advocate for prevention of TBI and to educate others about emerging concepts in care and management.

#### Organizer:

Bernard L. Maria, MD, MBA, Goryeb Children's Hospital, Morristown, New Jersey, USA

Supported by the National Institutes of Health (NIH grant 5R13NSO40925-21), and the Child Neurology Society



7:00 AM - 7:15 AM
OPENING COMMENTS/
INTRODUCTION

Bernard L. Maria, MD, MBA

7:15 AM - 9:15 AM
SESSION I:
Clinical Aspects and Diagnosis

#### Moderator:

Christopher C. Giza, MD; UCLA - Mattel Children's Hospital, Los Angeles, California, USA 7:15 AM - 7:25 AM

OVERVIEW OF

CLINICAL ASPECTS

Christopher C. Giza, MD

Christopher C. Olza, MD

7:25 AM - 7:50 AM
EPIDEMIOLOGY OF PEDIATRIC TBI

Alcy R. Torres, MD; Boston University School of Medicine, Boston Medical Center, Boston, Massachusetts, USA

7:50 AM - 8:15 AM
SEVERE TBI AND NEUROCRITICAL
CARE MONITORING

Mark Wainwright, MD, PhD; Seattle Children's Hospital, University of Washington, Seattle, Washington, USA

8:15 AM - 8:40 AM
SIDELINE ASSESSMENT OF
CONCUSSION IN SPORT

Javier Cárdenas, MD; Barrow Concussion & Brain Injury Center, Barrow Neurological Institute, Phoenix, Arizona, USA

8:40 AM - 9:05 AM
CLINICAL EVALUATION OF
PEDIATRIC CONCUSSION
AND MILD TBI

Sean Rose, MD; Nationwide Children's Hospital, Columbus, Ohio, USA 9:05 AM - 9:15 AM **QUESTION AND ANSWER SESSION** 

**BREAK** 

9:30 AM - 11:20 AM **SESSION II: PATHOGENESIS** 

Co-Director and Moderator: Mayumi Prins, PhD; Brain Injury Research Center, University of California Los Angeles, Los Angeles, California, USA

9:30 AM - 9:55 AM **OVERVIEW OF PATHOBIOLOGY OF TBI** Mayuni Prins, PhD

9:55 AM - 10:20 AM

**SEX DIFFERENCES IN TBI** Meervo Choe. MD: UCLA Mattel Children's Hospital, Los Angeles, California, USA

10:20 AM - 10:45 AM **ADVANCED NEUROIMAGING IN TBI** 

Emily Dennis, PhD; University of Utah, School of Medicine, Salt Lake City, Utah, USA

10:45 AM - 11:10 AM **GENETIC AND MOLECULAR** MARKERS FOR TBI Christopher C. Giza, MD

11:10 AM - 11:20 AM **QUESTION AND ANSWER SESSION** 

**BREAK** 

12:25 PM - 3:00 PM **SESSION III:** TREATMENT AND MANAGEMENT

Co-Director and Moderator: Lucia Braga, Neuroscientist, PhD; SARAH Network of Rehabilitation Hospitals, Brasilia, Brazil

12:25 PM - 12:50 PM POST-TRAUMATIC SEIZURES. **BIOMARKERS, AND EPILEPSY** 

Adam Numis, MD: UCSF-Benioff Children's Hospital, University of California San Francisco. San Francisco, California, USA

**POST-TRAUMATIC HEADACHE AND MIGRAINE** 

Heidi K. Blume, MD, MPH; Seattle Children's Hospital, University of Washington. Seattle, Washington, USA

1:15 PM - 1:40 PM **EXERCISE AND CONCUSSION** John Leddy, MD; Jacobs School of Medicine, Buffalo, New York, USA

1:40 PM - 2:05 PM REHABILITATION FROM PEDIATRIC MODERATE-SEVERE

Lucia Braga, Neuroscientist, PhD; SARAH Network of Rehabilitation Hospitals, Brasilia, Brazil

2:05 PM - 2:30 PM TRANSCRANIAL STIMULATION **AND RECOVERY** 

Karen M. Barlow, MBChB, MRCPCH(UK), FRACP; University of Queensland, Brisbane, QLD, Australia

2:30 PM - 2:55 PM SPORTS AND RECREATION IN CHILDREN WITH **NEURODEVELOPMENTAL DISORDERS** 

Ruiuta B. Wilson, MD: **UCLA David Geffen** School of Medicine, Los Angeles, California, USA

2:55 PM - 3:25 PM **SESSION IV: FUTURE DIRECTIONS & QUESTION AND ANSWER SESSION** 

Moderator: Bernard L. Maria, MD, MBA

Panelist: • Christopher C. Giza, MD

Mayumi Prins, PhD

Karen Barlow, MBChB,

MRCPCH(UK), FRACP

Lucia Braga, Neuroscientist, PhD

NINDS or NCI Program Officer

3:25 PM - 3:30 PM **CLOSING COMMENTS** Bernard L. Maria, MD, MBA

TOGETHER APART rtual2020

OCTOBER 12-23, 2020



16th International Child Neurology Congress
49th Annual Child Neurology Society Meeting

#### **Tuesday, October 20**

6:00 AM - 6:55 AM
JOHN STOBO PRITCHARD
AWARD LECTURE:
Developmental and Epileptic
Encephalopathies: What We Know
and What We Do Not Know
Nicola Specchio, MD, PhD,
Bambino Gesu' Children's Hospital,
IRCCS, Rome, Italy

#### **Course Description:**

To review the evolution of the concept of Epileptic Encephalopathy (EE) during the course of past years and analyze how the current definition might impact on both clinical practice and research. Developmental delay in children with epilepsy could be the expression of the etiology, consequence of intense epileptiform activity (seizures and EEG abnormalities). or due to the combination of both factors. Therefore, the current ILAE classification identified three electro-clinical entities that are those of Developmental Encephalopathy, Epileptic Encephalopathy, and Developmental and Epileptic Encephalopathy (DEE). Many biological pathways could be involved in the pathogenesis of DEEs. DNA repair, transcriptional regulation, axon myelination, metabolite and ion transport, and

peroxisomal function could all be involved in DEE. Also, epilepsy and epileptiform discharges might impact on cognition via several mechanisms, although they are not fully understood. The correct and early identification of a etiology in DEE might increase the chances of a targeted treatment regimen. Interfering with neurobiological processes of the disease will be the most successful way in order to improve both the cognitive disturbances and epilepsy that are the key features of DEE.

#### **Learning Objectives:**

- Correctly define early onset severe epilepsies distinguishing conditions where epilepsy and epileptiform abnormalities are responsible for the cognitive decline from conditions where the etiology is the major player in the cognitive dysfunctions.
- Be updated regarding new neurobiological process of genetic origin which are responsible of developmental and epileptic encephalopathy.

#### **Impact Statements:**

- Diagnoses different types of developmental and epileptic encephalopathy
- 2. Improve their knowledge on specific etiologies and targeted therapies in developmental and epileptic encephalopathies

## 7:00 AM - 7:55 AM BERNARD SACHS AWARD LECTURE: Genes as a Window into the Developing Brain

Joseph G. Gleeson, MD; University of California San Diego, Rady Children's Institute for Genomic Medicine, San Diego, California, USA

#### **Course Description:**

Discuss causes of childhood neurological conditions including intellectual disability, autism spectrum disorder and brain dysplasia. Focus on developing an approach towards genetic investigation based upon clinical presentation and family history and developing pathways towards new treatments.

#### **Learning Objectives:**

- Differentiate between dominant, recessive, de novo, somatic, and complex modes of inheritance.
- Understand differences between gene testing strategies and their power to detect genetic mutations that can determine underlying signs and symptoms.

#### **Impact Statements:**

- Approaches and limitations in evaluating children with neurodevelopmental disease for underlying genetic causes to enable more definitive genetic diagnoses,
- 2. Approaches to selecting targeted therapies for specific mutations using antisense oligonucleotides.

10:30 AM - 12:45 PM SYMPOSIUM: NEUROIMMUNOLOGY: International Consensus Opinions in Opsoclonus-Myoclonus-Ataxia Syndrome

#### **Course Description:**

The objectives of this symposium on opsoclonus-myoclonus-ataxia syndrome (OMAS) are to provide participants with up-to-date consensus opinions from a collaborative international OMAS study group. Attendees will learn current epidemiology, diagnostic criteria, biological mechanisms of disease, optimal treatment, and long-term outcomes.

#### Learning Objectives:

- Explain cardinal presenting features, ratings scales, and the clinical course of opsoclonusmyoclonus-ataxia syndrome (OMAS)
- Apply common evaluation and treatment practices for patients with OMAS

#### Impact Statements:

- The recognition and initial evaluation of children with opsoclonus-myoclonus-ataxia syndrome.
- 2. The use of immunomodulatory agents in the early course of and long-term follow-up of opsoclonus-myoclonus-ataxia syndrome.

#### Organizer:

Tim Lotze, MD; Baylor College of Medicine, Texas Children's Hospital, Houston, Texas, USA

#### Introduction:

Tim Lotze, MD

Consensus Recommendations for the Evaluation and Treatment of Opsoclonus-Myoclonus-Ataxia Syndrome

Mark Gorman, MD, Boston Children's Hospital, Boston, Massachusetts, USA

Recognized Etiologies and Emerging Biomarkers in Opsoclonus-Myoclonus-Ataxia Syndrome

Russell Dale, MRCP, PhD; Children's Hospital at Westmead, University of Sydney, Sydney, NSW, Australia Cardinal Presenting Features,
Rating Scales, and the Clinical
Course of OpsoclonusMyoclonus-Ataxia Syndrome
Ming Lim, MD, PhD;
Evelina London Children's Hospital,
King's Health Partners Academic
Health Science Centre,
London, United Kingdom

Short and Long-term
Neurodevelopmental Outcomes
in Opsoclonus-MyoclonusAtaxia Syndrome
Wendy G. Mitchell MD;
Keck School of Medicine,
Children's Hospital Los Angeles,
Los Angeles, California, USA

TOGETHER-APART VIRTUAL 2020

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#### Tuesday, October 20 · continued

10:30 AM - 12:45 PM
SYMPOSIUM: STROKE:
PEDIATRIC STROKE:
Hot Topics, Global Challenges

#### **Course Description:**

Our aim is to provide practical updates and strategies to address the most pressing and controversial issues related to pediatric stroke. A focus on infectious/ inflammatory mechanisms and acute management will emphasize practical clinical issues combined with distinct but universal considerations of mechanism. Speakers will be experts within an emerging childhood cerebrovascular disease global network and will address the challenges of stroke management in resource-limited settings.

#### **Learning Objectives:**

- Approach the acute management of a child with stroke with confidence based on modern evidence-based best clinical practice, and
- 2. Appreciate the possible roles of specific infections and inflammation in the pathogenesis of childhood arterial ischemic stroke and resultant treatment implications.

#### **Impact Statements:**

- 1. Evaluating children for infectious causes of stroke.
- 2. Offering children hyperacute stroke therapy.

#### Organizer:

Adam Kirton, MD; University of Calgary, Calgary, Alberta, Canada

Acute Stroke Management in Children: An Overview with a Global Perspective

Mark MacKay, MBBS, PhD; Royal Children's Hospital, Melbourne, Australia Pilipino Perspective on Pediatric Stroke: Differences in Etiologies and Management Marilyn Tan, MD, FCNSP, FPNA, FPPS; University of the Philippines, Philippine General Hospital, Manila, Philippines

African Perspective on Pediatric Stroke: Stroke in Children with HIV Alvin Ndondo, MBChB, FCPaed (SA); Red Cross War Memorial Children's Hospital, University of Cape Town, Cape Town, Western Cape Province, South Africa

Infectious Mechanisms of Childhood Arterial Ischemic S troke: Overview and Update on New Global Efforts

Heather J. Fullerton, MD, MAS; University of California, San Francisco, San Francisco, California, USA

1:00 PM - 3:15 PM SYMPOSIUM: NEURO-ONCOLOGY: PEDIATRIC MIXED NEURONAL-GLIAL TUMORS: New Classifications, Molecular Understandings and Targeted Therapy

#### **Course Description:**

Pediatric mixed neuronal-glial tumors are an increasingly recognized subtype of childhood brain tumors (BTs), frequently causing seizures. The most recent WHO classification of pediatric BTs identifies 13 different neuronalglial tumor types. Over the past decades there has been an explosion of knowledge concerning their molecular makeup, with the majority having distinct molecular signatures. This session will review the clinical, radiographic, histopathologic and molecular aspects of neuronal-glial BTs and closely aligned low-grade gliomas and summarize new data concerning the effectiveness of novel molecular targeted approaches.

#### **Learning Objectives:**

- To inform attendees of the new understandings of the molecular constitution of pediatric neuronal-glial BTs and closely aligned pediatric gliomas, so as to better direct therapies.
- 2. To summarize the potential molecular therapies available for pediatric neuronal-glial BTs and how such therapy can dramatically affect outcome; the potential toxicities of these new agents will also be discussed.

#### **Impact Statements:**

- Understand the molecular differences between the different subtypes of pediatric low-grade neuronal-glial tumors and how these differences affect management and prognosis
- 2. Understand the potential new therapies available for these lesions, the indications for molecular-targeted therapy and the common side effects of such treatment.

#### Organizer:

Roger J. Packer, MD; Children's National Hospital, Washington, DC, USA

Neuroradiographic Features of Pediatric Neuronal-Glial Tumors Gilbert Vézina, MD, FACR; Children's National Hospital, Washington, DC, USA

Classification of Pediatric
Mixed Neuronal-Glial Tumors
Brent Orr, MD, PhD;
St. Jude's Children's
Research Hospital,
Memphis, Tennessee, USA

Histologic and Histoimmunologic

Molecular Classification and Resultant Therapeutic Implications of Pediatric Mixed Neuronal-Glial Tumors David T. W. Jones, PhD; Hopp Children's Cancer Center,

Heidelberg, Germany

New Understandings and Molecular-Targeted Therapies for Pediatric Neuronal-Glial Tumors Roger J. Packer, MD

3:30 PM - 5:45 PM

SYMPOSIUM:

NEUROMUSCULAR DISEASE:

Advances in Pediatric

Charcot-Marie-Tooth Disease

#### **Course Description:**

Charcot-Marie-Tooth disease (CMT) is a heterogenous group of peripheral nerve diseases and it is the most prevalent genetic neuromuscular disease caused by mutations in more than one hundred various genes. The onset of disease often falls into the pediatric age group and may lead to significant disability. The Symposium will provide many updates regarding the causes of CMT, and will discuss validated assessment tools as well as new therapeutic approaches:

- The genetic basis of various forms of CMTs including novel rare forms will be presented.
   A rational strategy for genetic testing will be provided.
- 2. New developments in standardized clinical evaluation tools (CMPTPeds, CMTInf) will be discussed. These tools are employed for natural history data collection in pediatric CMT and they may serve as outcome measures in emerging treatment trials.

- 3. Electrophysiology evaluation continues to be important in differential diagnosis of various CMTs from other types of neuropathies, moreover some parameters like CMAP may serve as biomarkers in clinical trial. Quantitative muscle MRI techniques are emerging as potential biomarkers along with some other biological measurements.
- 4. In vitro disease models and transgenic animal research are aimed at understanding the molecular pathology of CMTs leading to developments of new therapeutic targets.

#### **Learning Objectives:**

 Learn about the genetic causes of CMT and acquire validated evaluation tools that can be used neuromuscular clinics.

#### **Impact Statements:**

 Will help the audience to learn about proper diagnostic strategies, which could make their neuromuscular practice more efficient. Employing the validated functional assessment tools will make the long term progression of CMT more accurate to assess.

#### Organizer:

Gyula Acsadi MD, PhD; Connecticut Children's Medical Center, University of Connecticut School of Medicine, Farmington, Connecticut, USA Introduction to Charcot-Marie-Tooth Disease (CMT) Gyula Acsadi MD, PhD

#### Genetic Basis of Charcot-Marie-Tooth Disease (CMT)

Shawna Feely, MS, LGC; University of Iowa Hospitals & Clinics, Iowa City, Iowa, USA

#### Validated Assessment Tools in Natural History for CMT

Timothy Estilow OTR/L; The Children's Hospital of Philadelphia, Philadelphia, Pennsylvania, USA

#### Electrophysiology and Biomarkers

Richard A. Lewis, MD; Cedars-Sinai Medical Center, Los Angeles, California, USA

#### Molecular Basis of CMTs and Cellular Drug Targets

Mario Saporta, MD, PhD, MBA, FAAN, University of Miami, Miami, Florida, USA

#### Tuesday, October 20 · continued

3:30 PM - 5:45 PM SYMPOSIUM: NEONATAL SEIZURES: Practical Approaches to Classification, Diagnosis and Management

#### **Course Description:**

The educational objective of this symposium is to present key findings from the International League Against Epilepsy's Task Force on the Classification, Diagnosis and Treatment of Neonatal Seizures. Speakers will emphasize key concepts and management strategies that can be applied across a variety of practice settings, including resource-limited locations.

#### **Learning Objectives:**

- Accurately diagnose and classify neonatal seizures using clinical signs, amplitude-integrated EEG and conventional EEG, and assign a level of certainty to their diagnosis.
- 2. Apply current evidence to optimally manage neonatal seizures across a wide range of practice settings.

#### **Learner Outcomes:**

This education workshop helped me to identify changes I could make in my practice related to:

- Recognizing when to suspect neonatal seizures and how to confirm the diagnosis using available resources.
- 2. Managing neonatal seizures in an evidence-based fashion.

#### Organizer:

Courtney J. Wusthoff, MD; Stanford University, Stanford, California, USA

Definition and Classification of Neonatal Seizures: Insights from the ILAE Task Force Ronit Pressler, MD, PhD; Great Ormond Street Hospital for Children, London, UK Diagnosis of Neonatal Seizures by Clinical Signs, Amplitude-Integrated EEG and Conventional EEG

Cecil D. Hahn, MD, MPH; The Hospital for Sick Children, University of Toronto, Toronto, Ontario, Canada

#### Treatment of Neonatal Seizures Informed by Current Evidence

Hans Hartmann, MD; Hannover Medical School, Clinic for Pediatric Kidney, Liver and Metabolic Diseases, Hannover, Germany

### Management of Neonatal Seizures in Resource-Limited Settings

Jo M. Wilmshurst, MB, BS, MD, Red Cross War Memorial Children's Hospital, University of Cape Town, Cape Town, Western Cape, South Africa

## 6:00 PM - 8:15 PM SYMPOSIUM: NEUROINFECTIOUS DISEASE: Tropical Infections of the CNS:

#### **Course Description:**

A Worldwide Problem

Globalization, communications, and technology, have improved the mobility of populations around the world. Infectious diseases previously limited to specific geographic areas are n longer restricted to their geographic location or origin. Due to immigration and the popularity of international travel, patients affected by infectious diseases including malaria, tuberculosis, zika, dengue, chikungunya, and Ebola can be found anywhere in the world. These infections may have devastating consequences for both individuals and society, especially if clinicians are not aware of them and do not consider them in their differential diagnosis. Important advances have been made in both diagnosis and treatment of many of these infectious diseases. In this symposium we will:

- An update in clinical care, diagnosis and research in some of the most frequent and lethal infection diseases affecting CNS, like TB and Malaria,
- Discuss the acute neurological manifestations associated with Arbovirus infections,
- Understand implementation challenges for clinical trials conducted in Low and Middle Income Countries investigating new therapeutic modalities for tropical central nervous system infectious diseases

#### **Learning Objectives:**

- 1. To learn to identify some of the most common tropical neurological infectious diseases and how to establish the proper, diagnosis and treatment.
- To learn about the neurological manifestations of acute infections for arbovirus.

#### **Impact Statements:**

- This educational session helped me to identify changes I could make in my practice related to identify some of the most common tropical neurological infectious diseases and how to establish the proper, diagnosis and treatment.
- 2. This educational session helped me to identify changes I could make in my practice related to learn about the neurological manifestations of acute infections for arbovirus.

#### Organizer:

Maria Teresa Acosta, MD; National Human Genome Research Institute, National Institutes of Health, Bethesda, Maryland, USA

#### Co-Organizer:

Alfredo Cerisola, MD; University of the Republic, Uruguay

## CNS Tuberculosis: Recent Concepts in Diagnosis and Treatment

Pratibha Singhi MBBS, MD, FIAP, FNAMS; Medanta, The Medicity, Gurgaon, Haryana, India, Post Graduate Institute of Medical Education and Research Chandigarh, India

## Cerebral Malaria: Recent Concepts in Diagnosis and Treatment

Charles Newton, MD; University of Oxford, Oxford, United Kingdom, KEMRI-Wellcome Trust Collaborative Programme, Kilifi, Kenya

#### Dengue, Zika and Chickungunya: Acute Neuroinfections

Marco T. Medina, Chevalier, FAAN; National Autonomous University of Honduras, Tegucigalpa, Honduras

#### Clinical Trials in Tropical Infections: Challenges and Successes

Douglas G. Postels, MD, MS; Children's National Medical Center, George Washington University, Washington, DC, USA 6:00 PM - 8:15 PM

SYMPOSIUM: MOVEMENT
DISORDERS: Lessons from
Tourette Syndrome - Better
Understanding of the
Development of the Child Brain

#### **Course Description:**

Lessons learned from this symposium about Tourette syndrome include comorbid disorders sometimes being more impairing than tics alone and how to avoid time-wasting and disappointed regimens. This symposium will give audience a better understanding of the development of the child brain. Changing life style may help a lot. Otherwise, deep brain stimulation may improve those refractory patients.

#### **Learning Objectives:**

- Learn the whole scope of clinical manifestations of Tourette syndrome (TS), not just tics alone.
- Apply non-pharmacological and pharmacological managements appropriately, and the role of deep brain stimulation in refractory TS.

#### **Impact Statements:**

- 1. Try non-pharmacological management and appropriate medicine for children with Tourette syndrome; and deep brain stimulation perhaps another choice for refractory patients.
- 2. Avoid many irrelevant alternatives.

#### Organizer:

Huei-Shyong Wang, MD; Chang Gung Children's Hospital, Chang Gung University, Taoyuan, Taiwan Beneath the Tip of the Iceberg: Comorbidities of Tourette Syndrome Jennifer Vermilion, MD, University of Rochester,

Non-Pharmacological Management: Anti-Boring Lifestyles for Children with Tourette Syndrome Huei-Shyong Wang, MD

Rochester, New York, USA

Pharmacological Therapy for Tourette Syndrome: What Medicines Can Do and Cannot Do Yoshiko Nomura, MD PhD; Yoshiko Nomura Neurological Clinic for Children, Tokyo, Japan

Deep Brain Stimulation in Tourette Syndrome Jonathan W. Mink, MD, PhD; University of Rochester, Rochester, New York, USA

#### Tuesday, October 20 · continued

6:00 PM - 8:15 PM
SYMPOSIUM: EPILEPSY:
Infantile Spasms - Current
Management - A Global
Perspective; The Way Forward

#### **Course Description:**

This symposium will deal with an important epileptic encephalopathy ie Infantile Spams. Even Infantile Spasms constitute the commonest devastating infantile epilepsy worldwide, there is a wide variability in their etiology, clinical spectrum, and diagnostic and management protocols across the world. Despite some large clinical trials, several challenges and uncertainties continue to exist. There is lack of consensus even among experts as to what exactly constitutes hypsarrhythmia, and the certainty with which one can diagnose infantile spasms. Also, there are several unanswered questions not only whether ACTH or oral steroids should be used, but also regarding the doses, dosing, tapering, and duration of ACTH therapy and whether synthetic and natural ACTH should be used. Similar questions also exist regarding the use of Vigabatrin, other antiepileptics, special diets and even surgery for the control of IS. In this symposium, experts from across the globe will try to address these issues in light of the current scientific evidence and present the state of art information on the subject, with a global perspective. Some new drugs in pipeline and newer ways to conduct clinical trials will also be discussed. Since children with

infantile spasms are managed not only by child neurologists, but also by paediatricians and adult neurologists in many parts of the world, this topic is relevant for all. It is hoped that it would provide current information with an international perspective and opportunities for collaborative research.

#### Learning Objectives:

- Make a correct diagnosis and plan a rational evaluation of a child with suspected infantile spasms
- Make evidence based, rational choices for the management of Infantile Spasms, keeping in mind a global perspective.

#### **Impact Statements:**

- Making an early and correct diagnosis in a child with suspected infantile spasms.
- Formulating appropriate management protocols for children with infantile spasms.

#### Organizer:

Pratibha Singhi MBBS, MD, FIAP, FNAMS; Medanta,

The Medicity, Gurgaon, Haryana, India, Post Graduate Institute of Medical Education and Research, Chandigarh, India Infantile Spasms: Peculiarities and Challenges in Resource Limited Countries; Role of ACTH, Steroids, and Other Antiepileptic Drugs Pratibha Singhi, MBBS, MD, FIAP, FNAMS

Evaluation of Infantile Spasms -Role of Genetics; Approach to a Child with IS in Japan Shinichi Hirose, MD, PhD; Fukuoka University, Fukuoka, Japan

Diagnosis and Management of Infantile Spasms in the USA – New Drugs in the Pipeline; What is the Way Forward? Shaun Hussain, MD, MS; University of California Los Angeles, Los Angeles, California, USA

Infantile Spasms - Concepts and Differential Diagnosis; the European Approach Towards Management Alexis Arzimanoglou, MD; University Hospitals of Lyon, Lyon, France and Children's Hospital San Juan de Dios, Barcelona, Spain





16th International Child Neurology Congress
49th Annual Child Neurology Society Meeting

#### Wednesday, October 21

6:00 AM - 6:55 AM
SHEILA WALLACE
AWARD LECTURE:
Dietary Therapies for Epilepsy
in Low Resource Settings:
Challenges and Successes
Suvasini Sharma, MD, DM;
Lady Hardinge Medical College
and Associated Kalawati
Saran Children's Hospital,
New Delhi, India

#### Course Description:

I have been working in the field of Dietary therapies of childhood epilepsy for the last 15 years. I will share my experience with the use of ketogenic diets and its modifications in India. I work in a low resource setting, and in a cultural mileau which is very unfamiliar with ketogenic diet. In this talk, I will discuss the challenges faced by pediatric neurologists and parents who wish to use the diet in children with refractory epilepsy; and how we have used simple low cost innovations to overcome these challenges. We have evolved from the use of the classic ketogenic diet to the flexible use of the modified Atkins diet, which we have demonstrated to be efficacious in randomized controlled trials.

#### **Learning Objectives:**

- Understand the problems faced in low resource settings, for prescribing and administering dietary therapies for refractory childhood epilepsy.
- Learn strategies for low cost delivery of the diet in resource constrained and underpriviledged populations.

#### **Impact Statements:**

- Consider and offer the option of ketogenic diet if medically indicated, even in low socioeconomic populations, if the caregivers are motivated.
- Use simple and flexible approaches to the use of the ketogenic diet for low resource settings

7:00 AM - 7:55 AM
PHILIP R. DODGE
YOUNG INVESTIGATOR
AWARD LECTURE:
The Impact of Serendipity:
From "Rare" Neurodevelopmental
Disorders to Common Insights
Hsiao-Tuan Chao, MD, PhD;
Baylor College of Medicine,
Houston, Texas, USA

#### **Course Description:**

Discuss genetic, cellular, and neural circuit mechanisms underlying neurodevelopmental conditions characterized by autism, intellectual disability, and epilepsy. Focus on integrating multidisciplinary approaches in model organisms including fruit flies and mice with genetic investigation based on clinical findings.

#### **Learning Objectives:**

- Recognize how the identification and study of the genetic underpinnings of "rare" disorders can uncover biological pathways shared with more common conditions.
- Understand the application of functional studies in fruit fly and mouse model organisms and their power to reveal pathogenic gene alterations and underlying disease mechanisms.

#### **Impact Statements:**

- Approaches and limitations in the evaluation, diagnosis, and prognosis of children with neurodevelopmental disorders.
- Approaches to identifying genetic etiologies underlying neurodevelopmental disorders.

10:30 AM - 12:45 PM

SYMPOSIUM: NEUROGENETICS: Current Status of Developmental Encephalopathies: Rett Syndrome, MECP2 Duplication Disorder, CDKL5 Deficiency Disorder, and FOXG1 Disorder

#### **Course Description:**

- To understand the recent advances in the developmental encephalopathies, namely, Rett syndrome, MECP2 Duplication Disorder, CDKL5 Deficiency Disorder and FOXG1 Disorder through comparison of the important similarities and critical differentiating features of this expanding group of neurodevelopmental disorders;
- To understand the phenotypegenotype relationships that characterize each disorder; and
- To promote the existing and emerging clinical trials that offer the potential for diseasemodifying or curative promise.

#### **Learning Objectives:**

- 1. To understand the recent advances in the developmental encephalopathies, namely, Rett syndrome, MECP2 Duplication Disorder, CDKL5 Deficiency Disorder and FOXG1 Disorder through comparison of the important similarities and critical differentiating features of this expanding group of neurodevelopmental disorders including clinical trajectories and phenotype-genotype correlations
- Understand the current strategies and challenges to develop and promote clinical trials that offer the potential for disease-modifying or curative therapeutics.

#### **Impact Statements:**

- Evaluation, diagnosis, and management of these developmental encephalopathies including directing these children to clinical centers focusing on these disorders.
- 2. Educate and advocate for parents and other caregivers regarding the therapeutic opportunities available or under development for these developmental encephalopathies.

#### Organizer:

Alan Percy, MD; University of Alabama at Birmingham, Birmingham, Alabama, USA

Rett Syndrome: Current Status and Therapeutic Considerations Jeffrey L. Neul, MD, PhD; Vanderbilt Kennedy Center, Nashville, Tennessee, USA MECP2 Duplication Disorder: Understanding the Developmental Trajectory and Potential Therapies Sarika U. Peters, PhD; Vanderbilt University Medical Center Nashville, Tennessee, USA

Recent Progress in Genotype-Phenotype Correlations in FOXG1 Disorder Knut Brockmann, MD; Interdisciplinary Pediatric Center for Children with Developmental Disabilities and Severe Chronic Disorders Children's Hospital, University Medical Center, University of Göttingen, Göttingen, Germany

Comparison of the Core Features of the Developmental Encephalopathies from the Rett Natural History Study Eric Marsh, MD, PhD; Children's Hospital of Philadelphia, Perelman School of Medicine at the University of Pennsylvania, Philadelphia, Pennsylvania, USA

TOGETHER-APART VIRTUAL 2020

OCTOBER 12-23, 2020

#### Wednesday, October 21 · continued

10:30 AM - 12:45 PM
SYMPOSIUM:
NEUROIMMUNOLOGY:
Cutting Edge Technology in
Neuroinflammation: Advancing
Science and Increasing Capacity in
Low and Middle-income Countries

#### **Course Description:**

This symposium will provide an overview of advanced technologies, such as metagenomic nextgeneration sequencing, phage display and enhanced virome sequencing, to identify evidence of infection or autoantibodies in patients with neuroinflammation such as infectious encephalitis (IE) and autoimmune encephalitis (AE). We will also discuss the high mortality and morbidity of IE and AE in low and middleincome countries (LMIC) and potential application of these technologies as well as capacity building in LMIC. Upon completion of this symposium, participants will become familiar with new technologies for pathogen and antibody discovery; understand the impact of infectious and autoimmune encephalitis in LMIC and potential usage of technology to advance science, to save brains and to build capacity in LMIC.

#### **Learning Objectives:**

- To understand cutting edge technologies which can detect pathogens directly by sequencing-based approaches and indirectly with comprehensive serology assays, along with autoantibody discovery in patients with noninfectious encephalitis.
- 2. To understand the impact of infectious and autoimmune encephalitis in LMIC and possible ways to build research capacity in LMIC

#### **Impact Statements:**

- Understanding advanced technologies in diagnosing neuroinflammatory diseases
- Potential involvement in the global health and capacity building process

#### Organizer:

Soe Mar, MD; St. Louis Children's Hospital, Washington University School of Medicine, St. Louis, Missouri, USA

**Technologies in LMIC, Advancing Science and Increasing Capacity** Soe Mar, MD

Decoding Neuroinflammation with Metagenomics and Phage Display Michael Wilson, M.D, MAS; UCSF Well Institute for Neurosciences School of Medicine, San Francisco, California, USA

Detecting Hidden Virus with Enhanced Human Virome Sequencing Kristine Wylie, PhD; Washington University School of Medicine, St. Louis, Missouri, USA

The Impact of Infectious and Autoimmune Encephalitis in LMIC Aye Mya Min Aye, MB.BS, M.Med.Sc; Yangon Children's Hospital, Yangon, Myanmar 1:00 PM - 3:15 PM
SYMPOSIUM: COGNITIVEBEHAVIORAL NEUROLOGY:
The Molecular & Cellular Basis
of Developmental Cognitive &
Behavioral Disorders

#### **Course Description:**

- The overall educational objective of this symposium is to expose child neurologists to cutting-edge insights into the developmental roots of pediatric neurological disorders, particularly those influencing cognition, language, and behavior.
- Many disorders in child neurology - particularly those that are manifest by cognitive and behavioral dysfunction, the failure to reach developmental milestones, dysmorphisms, and congenital epilepsies - are attributable to fundamental aberrations during cerebrogenesis, whether genetic or acquired. To that extent, a child neurologist might actually be viewed as a "translational developmental biologist". Newer insights and tools in cell and molecular biology (e.g., human induced pluripotent stem cells, genome editing, organoids, whole genome sequencing, single cell 'omics, epigenetic modeling, live cell imaging, high-throughput high content screening, etc.), have increased our ability to understand both normal cerebrogenic processes and the types of abnormalities that might occur in those processes which might produce the disorders we, as child neurologists, treat. Although many of these insights are so new that they have not yet yielded concrete treatments, they certainly have started to suggest ways to diagnose and

- stratify patients early and to offer potential drug targets. This symposium seeks to discuss some of the cuttingedge research that might yield a better understanding of the cellular and molecular basis of some categories in this class of disorders.
- The format for each of the 4 representative categories below will be as follows: (1) a 5 min. introduction to the clinical entity; (2) a 20 min. synopsis of some of the cutting-edge molecular and cellular research and/or modeling ongoing in that entity; (3) a 5 min. conclusion by the first speaker with an emphasis on the therapeutic implications of the new scientific insights.

#### **Learning Objectives:**

- Understand how and why a particular clinical entity emerged as an aberration of normal developmental processes
- 2. Envision where future diagnostic and therapeutic options may lie.

#### **Impact Statements:**

- Counseling patients and their families with regard to the cause of a disorder and the likelihood of it's being observed in future offspring or future generations
- 2. Explaining to families where the cutting-edge scientific understanding (based on the latest cellular and genetic techniques) lies for a particular disorder and what novel diagnostic and therapeutic options may lie ahead based on these understandings (new early tests, new drugs, new rehab strategies, etc.)

#### Co-Organizers:

Evan Y. Snyder MD, PhD, FAAP; Sanford Burnham Prebys Medical Discovery Institute, UC San Diego School of Medicine, San Diego, California, USA

Doris Trauner MD; UC San Diego, La Jolla, California, USA

#### Introduction

Doris Trauner MD

#### Genetic Epilepsy Syndromes

Annapurna Poduri, MD, MPH; Boston Children's Hospital, Harvard Medical School, Boston, Massachusetts, USA

Joseph G. Gleeson, MD; University of California San Diego, Rady Children's Institute for Genomic Medicine, San Diego, California, USA

#### Autism

Adi Aran, MD, Shaare Zedek Medical Center, Hebrew University, Jerusalem, Israel

Alysson R. Muotri, PhD; UC San Diego School of Medicine, San Diego, California, USA

#### Neuropsychiatric Disorders

Shafali Jeste, MD; David Geffen School of Medicine, University of California, Los Angeles, California, USA

Evan Y. Snyder MD, PhD, FAAP

#### 1:00 PM - 3:15 PM SYMPOSIUM: SLEEP: Integrating Pediatric Sleep Medicine into Child Neurology

#### **Course Description:**

Better understanding of various sleep disorders encountered in the child neurology practice, how to read the sleep study report that will be generated by the sleep physician and sent to the referring child neurologist, what treatment options are available for these sleep disorders including insomnia, and finally, when these patient should be referred to a sleep physician.

#### **Learning Objectives:**

- Incorporate better screening questions and order appropriate diagnostic tests in their evaluation of children in child neurology clinics to assess and confirm the underlying sleep disorder.
- Initiate management strategies to treat the underlying sleep disorder

#### **Impact Statements:**

- Diagnose and manage comorbid or primary sleep problems in child neurology
- 2. Appropriate referral to sleep physician

#### Organizer:

Sanjeev V. Kothare, MD, FAAN, FAASM; Cohen Children's Medical Center, Lake Success, New York, USA

#### Wednesday, October 21 · continued

Evaluation of Nocturnal Events: Seizures, Parasomnias and More Sanjeev V. Kothare, MD, FAAN, FAASM

Evaluation of a Sleepy Child Joseph Kaleyias, MD, PhD; East Sussex Healthcare NHS Trust, Eastbourne, East Sussex, England, UK

Evaluation of Sleep in Neurodevelopmental Disorders Joanna Wrede, MD; Seattle Children's Hospital, University of Washington, Seattle, Washington, USA

#### Sleep Pharmacology in Pediatric Insomnia

Ann Marie Morse, DO; Geisinger Commonwealth School of Medicine, Geisinger, Commonwealth School of Medicine, Geisinger Medical Center, Janet Weis Children's Hospital, Danville, Pennsylvania, USA

3:30 PM - 5:45 PM

#### SYMPOSIUM: CEREBRAL PALSY: An Open Discussion on the Definition of Cerebral Palsy

#### **Course Description:**

Participants will gain an awareness of the historical evolution of the definition of cerebral palsy including the current (2007) consensus definition. Potential amplification and clarification of this definition suggesting continuity will be presented from the perspectives of epidemiology, genomics, health care limitations, rehabilitation and the lifespan. This will frame an open discussion with parental input about what challenges may lie ahead in any modification of the established definition.

#### **Learning Objectives:**

- Identify potential challenges to the current definition of cerebral palsy from a variety of perspectives
- Identify more clearly children with and without cerebral palsy and those that that do not fit clearly into an either-or dichotomy

#### **Impact Statements:**

- To accurately diagnosing cerebral palsy
- Counselling families about what a diagnosis of cerebral means and does not mean for their child

#### Organizer:

Michael Shevell, MDCM, FRCP, FCAHS; McGill University, Montreal Children's Hospital, Montreal, Quebec, Canada

The History of the Definition of Cerebral Palsy & Epidemiologic Considerations Michael Shevell, MDCM, FRCP, FCAHS

The Emergence of Genomics in Cerebral Palsy and Its Potential Impact on Definition Michael Kruer MD; Barrow Neurological Institute, Phoenix Children's Hospital, Phoenix, Arizona, USA

Low Resource Settings and Defining Cerebral Palsy Gulam Khandakar, MBBS, MPH, DCH, PhD, FAFPHM; Central Queensland Hospital and Health Service, Rockhampton, Australia

Rehabilitation, Lifespan, ICF Considerations in Defining Cerebral Palsy Annette Majnemer OT, PhD; McGill University, Montreal, Quebec, Canada 3:30 PM - 5:45 PM SYMPOSIUM: EPILEPSY: Epilepsy and Psychiatric Comorbidities

#### **Course Description:**

This educational symposium has the objective to review the main psychiatric and behaviour disorders in children with epilepsy. Importantly, the symposium will focus on the difficulties of diagnosis and optimal management of ADHD, anxiety and depression in children with epilepsy.

#### **Learning Objectives:**

- Understand the difficulties and the auxiliary tests for the diagnosis of ADHD, depression and anxiety in children with epilepsy;
- Understand the optimal management of psychiatric and behaviour disorders in children with epilepsy.

#### **Impact Statements:**

- The diagnosis of ADHD, depression and anxiety in children with epilepsy.
- The optimal management of ADHD, depression and anxiety in children with epilepsy.

#### Organizer:

Ana Carolina Coan, MD, PhD, Campinas University - UNICAMP, Campinas, SP, Brazil

Epilepsy in Children -Beyond Seizure Control Marilisa Guerreiro, MD, PhD, Campinas University, Campinas, Brazil How to Differentiate ADHD from its Mimics in Children with Epilepsy? Stéphane Auvin, MD, PhD, Hôpital Universitaire Robert-Debré, Université de Paris, Paris, France

Depression and Anxiety in Children with Epilepsy -How to Improve the Diagnosis? Kette Valente, MD, PhD, University of São Paulo, São Paulo, Brazil

Management of Psychiatric and Behavior Disorders in Children with Epilepsy Kirsten A. Donald MD, PhD, University of Cape Town, Cape Town, South Africa

6:00 PM - 8:15 PM
SYMPOSIUM:
GLOBAL NEUROLOGY:
Global Challenges and
Opportunities in Inpatient
Child Neurology

#### **Course Description:**

The objective of this symposium is to highlight and understand the reasons behind the differences in management of commonly encountered pediatric neurological conditions across the globe. Discussants from three diverse settings (a resource-intense US academic medical center. a managed care non-North American but developed academic center setting, and a developing nation with limited resources) will compare and contrast their approach to three common acute neurologic conditions: status epilepticus, anti-NMDA receptor encephalitis, and stroke. After each discussant comments on the evaluation, diagnosis, and management of each condition, the panel will have an open discussion to identify themes and practices that can be improved, barriers that could be overcome from a healthcare systems perspective and shared and implemented across international settings. The discussion will highlight the need for development of global networks and collaborations to systematically harmonize clinical care pathways as well inform the potential for research opportunities in common acute pediatric neurologic conditions.

#### **Learning Objectives:**

- Explore and understand the approach to workup and treatment of three common acute neurologic conditions in each of the following settings:
   Resource-intense academic medical center,
   a managed care non-North American but developed academic center setting,
   and
   Developing
   Nation with limited resources
- Conceptualize how to provide high-quality, research-informed care depending on the resources available in each individual's setting.

#### **Impact Statements:**

- 1. The resources I have available to investigate, diagnose and manage status epilepticus.
- The resources I have available to investigate, diagnose and manage anti-NMDA receptor encephalitis.
- The resources I have available to investigate, diagnose and manage acute arterial ischemic stroke.

#### Organizer:

Mahendra Moharir MD, MSc, FRACP; University of Toronto, The Hospital for Sick Children, Toronto, Ontario, Canada

Acute Pediatric Neurology in the Inpatient Setting across the Globe - Can One Size Fit All? Mahendra Moharir MD, MSc, FRACP

Acute Inpatient Pediatric
Neurology - The North American
Academic Practice Perspective
Craig A. Press, MD, PhD;
Children's Hospital of Colorado,
University of Colorado School
of Medicine,
Aurora, Colorado, USA

Acute Inpatient Pediatric Neurology - The Australian Managed Care Approach Mark MacKay, MBBS, PhD; Royal Children's Hospital, Melbourne, Australia

Acute Inpatient Pediatric
Neurology in the Developing
World - Advancing Care
with Limited Resources
Vrajesh Udani, MD;
Hinduja National Hospital &
Medical Research Centre,
Mumbai, India

Panel Discussion and Q & A

#### Wednesday, October 21 · continued

6:00 PM - 8:15 PM SYMPOSIUM: EPILEPSY: Ketogenic Diets in Child Neurology - A Tale of 100 Years: What Does the Future Hold?

#### Course Description:

As ketogenic diet completes a century of its use in child neurology, this symposium proposal will summarize the current and future perspectives of the use of ketogenic diet and its variants in epilepsy and other neurological disorders in children. The symposium will cover the recently published International consensus guidelines, the use of the diet in genetic and metabolic epilepsies, use in neurological disorders other than epilepsy, and new insights into the mechanism of action of the diet and implications for clinical utilization. The speakers include Dr Eric Kossoff (USA), Dr Helen Cross (UK), Dr Hoon-Chul Kang (South Korea) and Dr Suvasini Sharma (India). As ketogenic diet completes a century of its use in child neurology, this symposium proposal will summarize the current and future perspectives of the use

of ketogenic diet and its variants in epilepsy and other neurological disorders in children. The symposium will cover the recently published International consensus guidelines, the use of the diet in genetic and metabolic epilepsies, use in neurological disorders other than epilepsy, and new insights into the mechanism of action of the diet and implications for clinical utilization.

#### **Learning Objectives:**

- Be aware of the recent international consensus guidelines on the use of KD, and its uses in metabolic and genetic epilepsies and non-epilepsy neurodevelopmental conditions in children.
- 2. Understand the current thinking on the mechanisms of action of the diet, and how we can potentially use this to optimize patient outcomes.

#### **Impact Statements:**

- Early identification of childhood neurological conditions which are likely to respond to the ketogenic diet.
- Awareness of the new International consensus guidelines for the use of ketogenic diet in children with epilepsy.

#### Organizer:

Suvasini Sharma, MD, DM; Lady Hardinge Medical College and Associated Kalawati Saran Children's Hospital, New Delhi, India

#### Dietary Therapy at a Century: From Popularity to Obscurity and Back Again

Eric H. W. Kossoff, MD; Johns Hopkins Hospital, Baltimore, Maryland, USA

#### Ketogenic Diet in Genetic and Metabolic Epilepsies Puneet Jain, MD, DM; The Hospital for Sick Children Toronto, Ontario, Canada

New Insights into the Mechanisms of Action and Implications for Utilization Helen Cross, MB, ChB, PhD; University College London, Great Ormond Street Institute of Child Health, London, UK

Non-epilepsy Uses and Other Benefits of the Ketogenic Diet Suvasini Sharma, MD, DM





No-cost genetic testing to help ensure families can make informed decisions about their child's health

#### PTC THERAPEUTICS AND INVITAE

have partnered to provide no-cost genetic testing and counseling for individuals with symptoms of cerebral palsy (CP) with unknown etiology or suspected neurotransmitter diseases, such as Aromatic L-amino Acid Decarboxylase (AADC) deficiency.

#### Through PTC Pinpoint, patients can get:



#### No-cost genetic testing

- Neurotransmitter disorders panel
- CP spectrum disorders panel<sup>a</sup>



Genetic counseling post testing



Family follow-up testing for relatives of those with confirmed or likely pathogenic variants

#### <sup>a</sup>Program eligibility

This program is available in the US and Canada for individuals with symptoms suggestive of cerebral palsy in the absence of risk factors for an acquired brain injury.







To learn more or order a no-cost genetic test for CP spectrum or neurotransmitter disorders, visit:

invitae.com/en/PTC-Pinpoint-CP-Spectrum

or

invitae.com/en/PTC-Pinpoint >



16th International Child Neurology Congress
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#### Thursday, October 22

6:00 AM - 6:55 AM
LINDA DE MEIRLEIR
NEUROMETABOLIC
AWARD LECTURE:
Update in Pediatric
Neurometabolic Disorders 2020
Lance Rodan, MD, FRCP(C):

Lance Rodan, MD, FRCP(C); Boston Children's Hospital, Harvard Medical School, Boston, Massachusetts, USA

#### **Course Description:**

- Discussion of metabolic disease discovery in the post-genomic era: what are the tools we have?
- Discussion of metabolic pathway analysis in the discovery of future disease modifying therapies.
- Illustrative examples, through review of recently described neurometabolic disorders, including a novel disorder of cerebral folate metabolism and a disorder of polyamine metabolism, among others.

#### **Learning Objectives:**

- Identify a number of recently described neurometabolic disorders
- Become familiar with currently available clinical tests that can aid in the diagnosis of rare neurometabolic disorders

#### **Impact Statements:**

- The recognition of neurometabolic disorders
- 2. The interpretation of metabolic test results

7:00 AM - 7:55 AM **HOWER AWARD LECTURE: Migraine, Vertigo, and Dizziness**Kenneth J. Mack, MD, PhD;

Mayo Clinic,

Rochester, Minnesota, USA

#### **Course Description:**

This session will help attendees to identify changes they could make in their practice related to addressing the multiple target symptoms of migraine, which include dizziness and vertigo.

#### **Learning Objectives:**

- 1. Better organize the components of the migraine attack
- Understand the multiple forms of vertigo and dizziness that patients experience

#### **Impact Statements:**

 Addressing the multiple target symptoms of migraine, which include dizziness and vertigo

#### 10:30 AM - 12:45 PM SYMPOSIUM: NEONATAL NEUROLOGY: Neurodevelopmental Outcomes in Congenital Heart Disease: From Fetal Pathogenesis to Prevention

#### **Course Description:**

This symposium will bring participants up-to-date on the critical role of fetal risk factors for neurodevelopmental disabilities arising from congenital heart disease including the key contributions of chronic fetal hypoxemia and maternal-fetal stress. Emerging insights from fetal and neonatal human imaging and experimental models will define the impact of fetal hypoxemia on brain growth and neuronal dysmaturation. We will explore emerging potential interventions ranging from maternal-fetal hyperoxygenation to early life environmental enrichment.

#### Learning Objectives:

- Recognize the spectrum of neurodevelopmental disabilities associated with various forms of congenital heart disease and their key fetal and neonatal neuroimaging findings.
- Recognize the relative impact of pre- and postnatal factors, including maternal-fetal stress and chronic in utero hypoxemia on long-term neurodevelopmental outcomes associated with various forms of congenital heart disease

#### **Impact Statements:**

- Counselling parents on risks for adverse neurodevelopmental outcomes associated with various forms of congenital heart disease.
- The indications and interpretation of fetal or neonatal imaging for patients with various forms of congenital heart disease.

#### Organizer:

Stephen A. Back, MD, PhD, Oregon Health & Science University, Portland, Oregon, USA

Pathogenetic Mechanisms of Hypoxia-mediated Cerebral Dysmaturation Stephen A. Back, MD, PhD

Fetal Oxygenation in Utero of Human Fetuses with Congenital Heart Disease Mette Høj Lauridsen, MD, PhD; Aarhus University Hospital, Aarhus, Denmark

Advanced Brain Imaging – From Fetus to Neonate with Congenital Heart Disease Serena J. Counsell, PhD; King's College London, London, UK

Where to Next: Potential Interventions from the Fetus to the Environment Steven Paul Miller, MDCM, MAS, FRCPC; The Hospital for Sick Children, The University of Toronto, Toronto, Ontario, Canada 10:30 AM - 12:45 PM SYMPOSIUM: NEURODEVELOPMENTAL DISORDERS:

IN SPANISH: Beyond

Pharmacological Treatment for Neurodevelopmental Disorders: What Parents and Physicians Want to Know About the Available Options

#### Course Description:

Neurodevelopmental disorders such as ADHD, ASD and learning disabilities are the most common cause of consultation in Pediatric Neurology in all countries. While pharmacological treatment has been extensively studied, in some conditions like ADHD, the access to stimulant medications in many countries is very limited and with very selective options. In addition, the high cost of medications makes them of inaccessible for many populations around the world. In other conditions, like ASD and LD. the benefits of medications are more controversial. Nonpharmacological and alternative interventions have been used extensively around the world without clear evidence of the benefits that they can provide to patients and families. Some of these alternative interventions are more expensive and have side effects that are often not disclosed. Parents have strongly advocated for research to demonstrate the

real impact of those interventions. In this symposium we aim:

- To present an update on therapeutic alternatives, beyond pharmacological interventions, for treating neurodevelopmental disorders like ADHD, ASD and learning disabilities
- To discuss the evidence base available about the benefits of those interventions
- To present a clinical model for the care of neurodevelopmental disorders that can be adapted by practitioners, worldwide.

#### **Learning Objectives:**

- Learn how to evaluate and recommend common nonpharmacological interventions and technology aids as part of the treatment of patients with neurodevelopmental disorders.
- 2. Learn how to develop programs to provide comprehensive evaluation and treatment for patients with neurodevelopmental conditions that decrease the long-term impact on their mental and physical health as they grow up.

#### **Impact Statements:**

- The use of some common nonpharmacological interventions and alternative therapies in Neurodevelopment disorders, especially Autism.
- 2. How to coordinate chronic and long-term care for patients with neurodevelopment disorders, especially ADHD.

TOGETHER-APART VIRTUAI2020

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#### Thursday, October 22 · continued

#### Organizer:

Maria Teresa Acosta, MD; National Human Genome Research Institute, National Institutes of Health, Bethesda, Maryland, USA

#### Co-Organizer:

Gabriel Gonzalez Rabelino, University of the Republic of Uruguay, Pereira Rossell Hospital, Montevideo, Uruguay

Why to Treat ADHD as a Chronic Medical Condition: Impact of a Health Care Model and Long-Term Outcomes Maria Teresa Acosta, MD

Alternative Therapies and Non-Pharmacological Treatment in Autism: What Parents Would Like to Know Víctor Ruggieri, MD; Hospital de Pediatría J. P. Garrahan,

Buenos Aires, Argentina

Advances in the Use of Technology and Virtual Reality for the Diagnosis and Treatment of ASD and Other Neurodevelopmental Disorders Fernando Mulas Delgado, MD, PhD; Instituto Valenciano de Neurología Pediátrica, Valencia, Spain

Treatment of
Neurodevelopmental Disorders
without Geographic Barriers
Manuel Vides-Rosales, MD MS;
Centro Medico Escalon,
San Salvador, San Salvador,
El Salvador

1:00 PM - 3:15 PM

SYMPOSIUM: ETHICS:
HUMANISM IN CHILD

NEUROLOGY: The Time is Now!

#### **Course Description:**

Goal: The primary goal of this symposium is to increase global awareness about the importance of humanism in child neurology for our patients and for ourselves.

#### **Secondary Goals:**

- Recognize the humanistic needs of our patients with neurological disorders
- Understand how to live a humanistic professional life while facing many challenges
- Learn what humanism means in every continent and country throughout the world

#### Learning Objectives:

- 1. Understand the importance of humanism in child neurology
- 2. Understand what humanism means in different global settings

#### **Impact Statements:**

- Being more aware and supportive of the humanism of my patients and their families and more responsive to them
- 2. Being more sensitive to the different meanings of humanism in my patients who come from various cultural backgrounds

#### Organizer:

David L. Coulter, MD; Harvard Medical School, Boston Children's Hospital, Boston, Massachusetts, USA

## Definitions and History of Humanism

Alcy R. Torres, MD; Boston University School of Medicine, Boston Medical Center, Boston, Massachusetts, USA Obstacles to Practice Humanism in Child Neurology in Global Health Ornella Ciccone; MD, DTM&H, MMED; University Teaching Hospital, Lusaka, Zambia

#### Neurology and Longevity: A Critical Care Pediatrician's Perspective

Kam Lun Ellis Hon; MBBS, MD, FAAP, FCCM, The Hong Kong Children's Hospital, Hong Kong

The Time is Now! Humanism as the Global Bedrock of Child Neurology David L. Coulter, MD

1:00 PM - 3:15 PM
SYMPOSIUM: HEADACHE:
Migraine Management in 2020:
New Options for Treatment
and How to Incorporate Recent
Guidelines and Novel Treatments
in Clinical Practice

#### **Course Description:**

This session will cover recent developments in migraine management. Dr. Lewis and Dr. Oakley will review new medications (including anti-GCRP medications) and neuromodulatory devices designed for the acute and preventive treatment of migraine. Speakers will discuss the mechanisms of action, evidence of efficacy, potential side effects, and pediatric specific issues for these novel treatments. Dr. Guidetti will review recently published guidelines for the treatment of pediatric migraine and discuss how to integrate these recommendations into the clinical practice treating youth with chronic migraine. He will also consider similarities and differences between European and US migraine treatment so we can each learn from others' experience. Together these topics will enhance participants' ability to manage episodic and chronic migraine in clinical practice.

#### **Learning Objectives:**

- Understand the role of CGRP in migraine and how anti-CGRP medications may be used to treat migraine.
- 2. Understand and describe the role of neuromodulation in the management of migraine and how these devices may be used to treat migraine in the pediatric population.
- 3. Discuss how the new AAN guidelines on the treatment of pediatric migraine can be applied to clinical practice.

#### **Impact Statements:**

- 1. The management of chronic migraine in pediatrics.
- 2. Acute or abortive treatment of migraine in pediatrics.

#### Organizer:

Heidi K. Blume, MD, MPH; Seattle Children's Hospital, University of Washington, Seattle, Washington, USA

Novel Medications for the Treatment of Migraine: Anti-GGRP Therapies and Other Medications in the Migraine Pipeline

Kara Stuart Lewis, MD, FAHS, FAAN; Barrow Neurological Institute at Phoenix Children's Hospital, Phoenix, Arizona, USA

Neuromodulation for Migraine: What is the Role for Devices in the Treatment of Childhood Migraine? Christopher B. Oakley, MD; Johns Hopkins Hospital, Baltimore, Maryland, USA New Guidelines for Treatment of Pediatric Migraine: How to Apply These Recommendations and Novel Treatments to Manage Chronic Migraine in Clinical Practice Vincenzo Guidetti, MD; University of Rome "La Sapienza," Rome, Italy

# 3:30 PM - 5:45 PM SYMPOSIUM: NEUROMUSCULAR DISEASE: Gene Transfer for Children: What We Know Now

#### Course Description:

The promise of gene therapy is now a reality for several neuromuscular conditions. This symposium will address four educational objectives including 1)to understand treatment implementation for commercially available gene transfer 2) to understand the status of ongoing clinical trials in Spinal Muscular Atrophy, X-linked myotubular myopathy, Duchenne and limb girdle muscular dystrophy; 3) to understand future gene therapy for other neuromuscular disorders and 4) to understand the critical role of Newborn screening if gene therapy is to succeed.

#### **Learning Objectives:**

- Understand the current status of approved, ongoing, and future clinical gene transfer trials for children with neuromuscular disorders.
- 2. Understand the role of the Newborn Screening in the translation of these clinical trials to implementation across all populations.

#### **Impact Statements:**

- Understanding the treatment and care of a child before, during and after gene transfer and the role of Newborn screening as therapies are approved.
- 2. Understanding and describing risk/benefit considerations of gene replacement therapy in a non-progressive muscle disease such as X-linked myotubular myopathy.

#### Organizer:

Anne M. Connolly, MD, FAAN; Nationwide Children's Hospital, The Ohio State University College of Medicine, Columbus, Ohio, USA

Gene Therapy for SMA and DMD: Where are we Now? Anne M. Connolly, MD, FAAN

Gene Replacement Therapy in X-linked Myotubular Myopathy Nancy L. Kuntz, MD, FAAN; Ann & Robert H Lurie Children's Hospital of Chicago, Chicago, Illinois, USA

Is Gene Replacement a Viable Option for my Favorite Disease? Katherine D. Mathews, MD; University of Iowa Carver College of Medicine, Iowa City, Iowa, USA

Newborn Screening in the Era of Gene Therapy Margie Ream, MD, PhD; Nationwide Children's Hospital, Columbus, Ohio, USA

#### Thursday, October 22 · continued

3:30 PM - 5:45 PM **SYMPOSIUM: EPILEPSY:**  *IN SPANISH:* Pediatric Epilepsy. When Drugs Don't Work

#### **Course Description:**

To present current data on drug resistant epilepsy and therapeutic options when pharmacological treatment is not a choice. This program will explore latest information about pediatric epilepsy surgery. Speaker from Cleveland Clinic, a center with extensive expertise in surgical epilepsy will present available surgical techniques and outcomes. This will be followed by a discussion about the challenges experienced in Latin America for the creation of surgical programs.

Finally, the symposia will address current therapeutic options for children with drug resistant epilepsy, when surgery is not an option. Target audience: Latin America and Spanish speaking countries, with the goal to raise awareness about importance of developing alternative therapies (including surgery) for children with drug resistance epilepsy. Dr. Vanegas, from Mexico has been a leader and advocate in the initiative of creating surgical centers in Latin America and is a representative of ILAE (International League against Epilepsy). This symposium is also intended to educate audience about need to develop such programs in poor resource regions.

#### **Learning Objectives:**

- As a result of this educational session, participants will be able to: learn relevant data about pediatric drug refractory epilepsy and understand that medications are not the best option.
- 2. As a result of this educational session, participants will be able to learn about importance of creating epilepsy surgery programs in Latin America to care for children with drug refractory epilepsy and alternative options when surgery is not a possibility

#### **Impact Statements:**

- This educational session helped me to identify changes I could make in my practice related to patients who present to my clinic with drug refractory epilepsy
- 2. This educational session helped me to identify changes I could make in my practice related to referral for epilepsy surgery evaluation in children with drug refractory epilepsy, who are appropriate candidates

#### Organizer:

Jorge Vidaurre, MD; Nationwide Children's Hospital, The Ohio State University, Columbus, Ohio, USA

Elia M. Pestana-Knight, DO; Cleveland Clinic Epilepsy Center, Cleveland, Ohio, USA

#### Co-Organizer:

Mario A. Genel Castillo, MD; Clinica de Epilepsia, Hospital de Salud Mental, Tijuana B.C., Mexico

#### Introduction

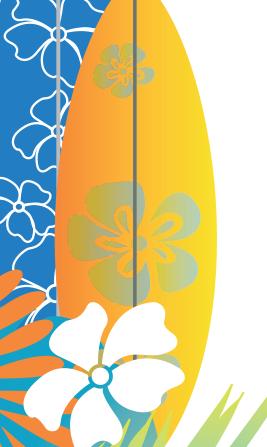
Jorge Vidaurre, MD

Pediatric Epilepsy Surgery in the Stereo EEG Era. Cleveland Clinic Experience Elia M. Pestana-Knight, DO

Epidemiology of Drug Resistant Epilepsy. Data You Should Know. What to Tell our Families? Loreto Ríos-Pohl, MD; Clínica Integral de Epilepsia Infanto-Juvenil (CIEI), Santiago, Chile

Establishing Epilepsy
Surgical Programs in
Low-income Countries.
The Latin America Experience
Mario A. Alonso Vanegas MD, FAES;
Internacional Epilepsy Surgery
Center, HMG-Coyoacán Hospital,
México City, México

Drug Refractory Epilepsy.
When Surgery is not an Option
Juan Carlos Perez-Poveda, MD;
Pontificia Universidad Javeriana,
Hospital Universitario San Ignacio,
Fundacion Hospital Pediatrico,
Bogotá, D. C., Colombia



6:00 PM - 8:15 PM

#### **SYMPOSIUM:**

NEURO-METABOLIC DISORDERS: Vitamin Responsive Conditions in Child Neurology: What's New?

#### **Course Description:**

Vitamin responsive conditions are a "must know" area for every child neurologist, as vitamin treatments are simple, inexpensive and safe treatments for a host of neurological conditions. Child neurologists need to be able to promptly recognize and treat these entities. In this session, the speakers will discuss the latest developments in vitamin responsive epilepsies, encephalopathies, movement disorders and neuromuscular conditions. The four speakers will be Dr Ingrid Tein (Canada), Dr Haluk Topaloglu (Turkey), Dr Naveen Sankhyan (India) and Dr Suvasini Sharma (India). Dr Tein's lecture will be focused on vitamin responsive early infantile epileptic encephalopathies with special reference to pyridoxine dependent epilepsy and related disorders. The current guidelines on recognition and treatment of these conditions as well as the new genetic conditions now recognized to causing pyridoxine dependent epilepsy will be discussed. Dr Topaloglu will discuss riboflavin responsive conditions with special emphasis on riboflavin transporter deficiency. The recent advances in clinical and genetic diagnosis and treatment strategies for riboflavin responsive disorders will be discussed.

Dr Sankhyan will be discussing inherited and acquired neurological disorders responsive to vitamin B12 and Folate treatment. There will be a special focus on infantile tremor syndrome, an interesting condition characterized by infantile onset neuroregression, tremors, skin and hair changes, which responds very well to vitamin B12 therapy. Dr Sharma will cover the recognition, diagnosis and management of inborn errors of metabolism which respond to thiamine and biotin supplementation with special focus on the recently described biotin and thiamine responsive basal ganglia disease, caused by mutations in the SLC19A3 gene. Acquired neurological disorders caused by thiamine deficiency, such as Wernicke encephalopathy will also be discussed.

#### **Learning Objectives:**

- Recognize common as well as rare and newly described vitamin responsive conditions in child neurology.
- Understand the diagnostic approach and treatment strategies.

#### **Impact Statements:**

- 1. Trial of high dose riboflavin supplementation unexplained progressive peripheral and cranial neuropathies and neuronopathies
- 2. Vitamin trials in unexplained refractory seizures in young infants, and high dose vitamin trials in acute metabolic decompensations.

#### Organizer:

Suvasini Sharma, MD, DM; Lady Hardinge Medical College and Associated Kalawati Saran Children's Hospital, New Delhi, India

Thiamine and Biotin Responsive Disorders Suvasini Sharma, MD, DM

#### Pyridoxine Dependent Epilepsy and Related Disorders: Recent Advances

Ingrid Tein, MD; The Hospital for Sick Children, University of Toronto, Toronto, Ontario, Canada

Riboflavin Responsive Disorders Haluk Topaloğlu, MD; Hacettepe Children's Hospital, Ankara, Turkey

## Vitamin B12 and Folate Responsive Disorders

Naveen Sankhyan, MD, DM; Post Graduate Institute of Medical education and Research, Chandigarh, India

#### Thursday, October 22 · continued

6:00 PM - 8:15 PM SYMPOSIUM: GLOBAL NEUROLOGY: Pediatric Neurology. A Global Perspective

#### **Course Description:**

To educate audience about the global situation of pediatric neurology, using data and statistics from the World Health Organization (WHO).The program brings international leaders and speakers with extensive experience in international outreach/collaborative projects directed to reduce gap in medical knowledge and access to neurological care. The symposium will educate audience about importance of collaborative efforts between medical societies (including CNS), to support local efforts in low income countries.

The panel of speakers (which includes current president of the international Child Neurology Association and past president of the international League against Epilepsy) will share their wide experience working with poorresource regions in Africa and other poor-resource regions and will educate audience with potential solutions to improve access to neurological care for children living in these areas.

#### **Learning Objectives:**

- Learn about the global situation of pediatric neurology and understand the situation of pediatric neurology practice in low income countries.
- Learn about importance of collaborative international projects directed to improve education and clinical care in low income countries.

#### **Impact Statements:**

- Learning about the global situation of pediatric neurology and becoming more active in supporting international educational programs
- 2. Recognizing importance of t international outreach programs directed to improve pediatric neurological care, and finding ways to collaborate, as a CNS member

#### Organizer:

Jorge Vidaurre, MD; Nationwide Children's Hospital, The Ohio State University, Columbus, Ohio, USA

#### Co-Organizer:

Agustin Legido, MD, PHD, MBA; Philadelphia, Pennsylvania, USA Introduction: A Global Perspective of Child Neurology Agustin Legido, MD, PHD, MBA

Jorge Vidaurre, MD

#### Child Neurology in Africa. Narrowing the Gap in Access to Medical Care

Jo M. Wilmshurst, MB, BS, MD, Red Cross War Memorial Children's Hospital, University of Cape Town, Cape Town, Western Cape, South Africa

Yes. There are Global Disparities in Epilepsy Care. Can we do Something? Solomon L. Moshé, MD; Albert Einstein College of Medicine, Montefiore Medical Center, Bronx, New York, USA

Practicing Pediatric Neurology in Poor Resource Regions. Importance of Collaborative Efforts Arushi G. Saini, MD, DM; Postgraduate Institute of Medical Education and Research (PGIMER), Chandigarh, India





## Connecting with patients

At UCB, everything we do starts with a simple question: "How will this create value for people living with severe diseases?"

UCB is proud to support the Child Neurology Society. We are committed to advancing research to improve the lives of people living with epilepsy and finding solutions to help patients live at their ideal.

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16th International Child Neurology Congress
49th Annual Child Neurology Society Meeting

#### Friday, October 23

6:00 AM - 6:55 AM

#### FRANK FORD AWARD LECTURE: The Global Burden of Paediatric Neurological Disorders

Charles Newton, MD; University of Oxford, Oxford, United Kingdom, KEMRI-Wellcome Trust Collaborative Programme, Kilifi, Kenya

#### **Course Description:**

An invited lecture that assess the global burden of Pediatric Neurology Disorders, discussing disability adjusted life years

#### Learning Objectives:

- Meaning of the Disability
   Adjusted Life Years in terms of
   Global Burden of Diseases
- Identify the neurological complications of diseases usually associated with low income countries and immigrant populations

#### **Impact Statements:**

- Make Pediatric Neurologists more aware of neurological conditions in low income countries and immigrant populations
- Introduce cultural awareness of neurological conditions in the immigrant populations.

10:30 AM - 12:45 PM
SYMPOSIUM:
TRAUMATIC BRAIN INJURY:
New Advances in Management,
Treatment and Rehabilitation

#### Course Description:

Each year, TBI causes a substantial number of deaths and leads to life-long disability for many children around the world. Every year, 830,000 children die from unintentional or "accidental" injuries and TBI represents about 30%. 2270 children die every day as a result of an unintentional injury and the vast majority of these injuries occur in low-income and middle-income countries.

Child injuries are a growing global public health problem. They are a significant area of concern from the age of one year. Among older children they represent almost half of the deaths. The effects of a TBI can vary significantly, but individuals with a moderate or severe TBI may have long-term or life-long effects from the injury. A severe TBI not only impacts the life of an individual and their family, but it also has a large societal and economic toll. The lifetime economic cost of TBI, including direct and indirect medical costs. was estimated to be approximately \$76.5 billion in 2010 is the US only.

Additionally, the cost of fatal TBIs and TBIs requiring hospitalization, many of which are severe, account for approximately 90% of total TBI medical costs. Falls are one of the leading causes of TBI-related ED

visits, hospitalizations, and deaths, and recent data shows that ver 25% of fall-related TBIs were among the youngest (0-4 years).

Goal: The main objective of this symposium is to increase awareness about importance of practicing humanism in child neurology not only for our patients but for ourselves.

#### Secondary Goals:

- Recognize the humanistic needs of our patients with neurological diseases
- Understand how to live a humanistic professional life facing so many challenges
- 3. Be familiar with difficult situations and how to solve them in current times and different areas of the world.

#### Learning Objectives:

- Recognize the symptoms
   of patients with mild or
   severe Traumatic Brain Injury
   and design comprehensive
   therapeutic plans for each group
   according to their needs
- Implement timely, appropriate supportive critical care, neurological therapy and rehabilitation for patients with traumatic brain injury

#### **Impact Statements:**

- Diagnosis and management of children with mild or severe traumatic brain injury
- 2. Rehabilitation of children with traumatic brain injury with long term sequelae

#### Organizer & Moderator:

Christopher C. Giza, MD; UCLA - Mattel Children's Hospital, Los Angeles, California, USA

#### Co-Organizer:

Alcy Torres, MD; Boston University School of Medicine, Boston Medical Center, Boston, Massachusetts, USA

Basic Science and Translational Research Relating to Pediatric TBI Christopher C. Giza, MD

**Pediatric Concussion and Mild TBI**Alcy Torres, MD

Severe TBI: Evaluation and Managing of Children in the ICU Biju Hameed, MRCPI, MRCPCH, PhD; Great Ormond Street Hospital for Children, London, England, UK

Innovative and Practical Methods of Rehabilitation

Lucia Braga, Neuroscientist, PhD; SARAH Network of Rehabilitation Hospitals, Brasilia, Brazil

10:30 AM - 12:45 PM
SYMPOSIUM:
NEUROMETABOLIC DISORDERS:
Novel Advanced Treatment in
Neurogenetic Disorders

#### **Course Description:**

The aim of this symposium is to present novel treatments for neurogenetic disorders, which will enhance our understanding of the future potential for treatment of a range of neurogenetic conditions.

#### **Learning Objectives:**

- Learn the pathogenic mechanisms of some important neurogenetic and neurometabolic diseases in children.
- Gain knowledge about recent advances in novel treatments for some important neurogenetic and neurometabolic diseases.

#### **Impact Statements:**

- The recognition of clinical features of certain rare neurogenetic and neurometabolic diseases.
- Knowledge about recent advances in the treatment of neurogenetic and neurometabolic diseases.

#### Organizer:

Wang-Tso Lee, MD, PhD, National Taiwan University Children's Hospital, Taipei, Taiwan

Recent Advances in SSADH Deficiency, a Disorder of GABA Metabolism

Phillip L. Pearl, MD; Boston Children's Hospital, Harvard Medical School, Boston, Massachusetts, USA

Recent Advance in Possible Probiotic Treatment for Neurogenetic Disorders Wang-Tso Lee, MD, PhD

St. Louis, Missouri, USA

Gene Therapy for AADC Deficiency and other Neurogenetic Disorders Toni Pearson, MBBS, Washington University School of Medicine,

Recent Advance in Targeted Treatment in Children with NCLs Nicola Specchio, MD, PhD, Bambino Gesu' Children's Hospital, IRCCS, Rome, Italy 1:00 PM - 3:15 PM
SYMPOSIUM:
NEUROIMMUNOLOGY: MOG
Antibody Associated
Neurological Disease An Update for the Clinician

#### **Course Description:**

This symposium's objective is to update the child neurology community on the emerging and rapidly expanding spectrum of MOG AB associated neurological disease. This would be predominantly clinician-centric and would help the participants in getting updated information on the diagnostic and therapeutic challenges the clinician faces in taking care of this newly described inflammatory demyelination disorder (IDD) of the central nervous system with myriad presentations.

#### **Learning Objectives:**

- Identify the different clinical situations where one should consider MOG antibody associated neurological diseases in the clinic and in the ICU.
- 2. Familiarize themselves with the imaging features that distinguish MOG AB associated IDDs from AQP-4 associated NMOSD and from MS and learn how to differentiate these different syndromes
- 3. Learn about the challenges of the detection of MOG ABs and also gat an overview of how these antibodies cause disease.
- 4. Decide the why, when and how to manage these disorders n the acute stage and in the long-term.
- 5. Give long-term prognosis to parents about risk of relapse and any persisting deficits expected.

TOGETHER-APART VIRTUAL 2020

OCTOBER 12-23, 2020

#### Friday, October 23 · continued

#### **Impact Statements:**

- Diagnosis and differential diagnosis of MOG – associated Neurological Disorders
- Treatment strategies in the different MOG associated disorders.

#### Organizer:

Vrajesh Udani, MD; Hinduja Hospital & Medical Research Centre, Mumbai, India

Overview of the MOG Antibody Associated IDDs and Challenges in Laboratory Diagnosis Vrajesh Udani, MD

Clinical and Imaging Features of the MOG Associated IDDs Russell Dale, MRCP, PhD; Children's Hospital at Westmead, University of Sydney, Sydney, NSW, Australia

#### Update on Current Management Strategies and Outcome in the MOG Associated IDDs

Yael Hacohen, MD; Great Ormond Street Hospital for Children, London, United Kingdom

#### Panel Discussion -Case Scenarios

Neelu Desai, MD, DNB; PD Hinduja Hospital & Medical Research Centre, Mumbai, India 1:00 PM - 3:15 PM SYMPOSIUM: GLOBAL NEUROLOGY: Integration of Global Health and Child Neurology: Perspectives and Successful Partnerships Around the World

#### **Course Description:**

In this symposium, we highlight the ways for participants to successfully partner with institutions around the world in order to integrate global health into child neurology practices. The objectives include:

- Discuss various mechanisms and levels of involvement possible for child neurologists, including opportunities for those in training and early career phases,
- Identifying mechanisms
   of involvement for child
   neurologists based in
   higher resourced settings to
   partner with civil and NGO
   organizations in the developing
   world with a primary
   educational or clinical focus,
- 3. Understand the perspectives of researchers in the developing world in order to build successful research collaborations, and 4. Providing an example of approaching research in global child neurology, including mechanisms for funding and partnership.

#### **Learning Objectives:**

- Identify opportunities for getting involved in global child neurology
- 2. Understand the core components of successful global research collaborations, including engagement, support for researchers in the developing world, and funding strategies

#### **Impact Statements:**

- Various mechanisms of involvement to provide effective support for child neurology practices in lower resource regions through global partnerships
- Developing strategies to establish successful partnerships in the developing world for research collaborations

#### Organizer:

Archana A. Patel, MD, MPH; Harvard Medical School, Boston Children's Hospital, Boston, Massachusetts, USA

Integrating Global Health in a Child Neurology Career Archana A. Patel, MD, MPH

How to Get Started - Clinical and Educational Opportunities in Global Child Neurology Douglas G. Postels, MD, MS; Children's National Medical Center, George Washington University, Washington, DC, USA

Building a Research
Collaboration- Considerations
and Perspectives
of Researchers from LMIC
Pauline Samia, Mphil;
Aga Khan University,
East Africa, Nairobi, Kenya

Building a Research
Collaboration- Considerations for
Funding and an Example from
the US and Nigeria
Edwin Trevathan, MD, MPH;
Vanderbilt University

Medical Center.

Nashville, Tennessee, USA





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UT Health Austin

Pediatric Neurosciences at Dell Children's

Variantyx



## **Schedule at a Glance**

#### **ALL TIMES PACIFIC DAYLIGHT TIME**

Monday, October 12, 2020				
On Demand (24/7)	Welcome: Jo Wilmshurst, President, ICNA			
On Demand (24/7)	Welcome: Phillip Pearl, President, CNS			
On Demand (24/7)	Welcome: Jonathan Mink, Chair, Joint CNS-ICNA Program Planning Committee			
1:00 PM - 2:00 PM	Professors of Child Neurology (PCN): Part 1: Annual Business Meeting (Private Zoom Meeting)			
2:15 PM - 4:30 PM	Professors of Child Neurology (PCN): Part II: Education Session (Private Zoom Meeting)			
2:30 PM - 4:00 PM	Cerebral Palsy SIG			
4:30 PM - 6:00 PM	Telemedicine SIG			
4:30 PM - 6:00 PM	Neurodevelopmental Disorders SIG			
On Demand (24/7)	Child Neuro Night Club: American Creativity, Ingenuity and Diversity (Jazz & Spoken Word)			
Tuesday, October 1	3, 2020			
11:30 AM - 12:30 PM	Industry Sponsored Product Theater: Spinal Muscular Atrophy (Genentech)			
1:00 PM - 2:00 PM	Industry Sponsored Educational Seminar: Patient Identification, Evaluation, and Management - Addressing Multiple Challenges in Neurodegenerative Lysosomal Storage Diseases (Takeda)			
1:00 PM - 3:00 PM	Meet the Experts: Experimental Therapeutics; Gene Therapy for Childhood Neurological Disorders			
3:00 PM - 4:30 PM	Education SIG			
3:30 PM - 5:30 PM	Workshop: Neuropsychiatry/Movement Disorders: Practical Management of Functional Neurologic Diseases in Children			
6:00 PM - 8:00 PM	Meet the Experts: Ethics: Costly Drugs and Healthcare – Ethics and Value Perspectives from Different Healthcare Systems			
6:00 PM - 8:00 PM	Meet the Experts: Neuroimmunology: Parainfections and Seronegative Autoimmune Encephalitis in Children: Updates and Controversies			
6:00 PM - 8:00 PM	Seminar: Epilepsy: Don't Ask Don't Tell, or Full Disclosure? Discussing SUDEP with Patients and Families in the Global Community			
On Demand (24/7)	Child Neuro Night Club: American Creativity, Ingenuity and Diversity (Jazz & Spoken Word)			

## Schedule at a Glance

#### **ALL TIMES PACIFIC DAYLIGHT TIME**

Wednesday, October 14, 2020				
8:00 AM - 10:00 AM	Seminar: Neuroinfectious Disease: Measles Vaccination – Current Situation and Consequences – A Global Perspective			
8:00 AM - 10:00 AM	Seminar: Stroke: Pediatric Stroke in the Era of Advanced Genetics			
10:00 AM - 12:00 PM	Workshop: Epilepsy: Pediatric Epilepsy Surgery: When, by Whom, and What to Expect?			
10:30 AM - 12:30 PM	Seminar: Neurogenetics: Recent Advances in the Etiologies and Mechanisms Underlying Common Brain Malformations			
12:30 PM - 1:30 PM	Industry Sponsored Educational Seminar: Distinguishing Pediatric Movement Disorders: Uncovering AADC Deficiency (PTCBio)			
1:00 PM - 3:00 PM	Seminar 4: Neuroimmunology: A New Era for Patients with NMOSD, including Children			
3:00 PM - 4:30 PM	Early Stage Investigator SIG			
3:00 PM - 4:30 PM	Neurogenetics SIG			
4:00 PM - 6:00 PM	Industry Sponsored CME Seminar: SMA Horizons: What is the Future of SMA Management? (Genentech)			
6:00 PM - 8:00 PM	Junior Member Seminar: Becoming a Physician Scientist in Pediatric Neurology			
On Demand (24/7)	Child Neuro Night Club: American Creativity, Ingenuity and Diversity (Jazz & Spoken Word)			
Thursday, October 1	15, 2020			
10:30 AM - 11:30 AM	Industry Sponsored Product Theater: Spinal Muscular Atrophy (Avexis)			
10:30 AM - 12:30 PM	Workshop: Global Neurology: Training to Bridge the Gap in Global Access to Child Neurology Care			
12:30 PM - 2:00 PM	Peds Demyelinating Disease SIG			
12:30 PM - 2:30 PM	Industry Sponsored CME Seminar: Developmental and Epileptic Encephalopathies (Zogenix)			
1:00 PM - 3:00 PM	Junior Member Seminar: Nurturing the Global Pipeline of Academic Child Neurologists			
3:30 PM - 5:30 PM	Meet the Experts: Behavioral Neurology: Management of Behavior in Children with Neurodevelopmental Disorders			
6:00 PM - 8:00 PM	Meet the Experts: Neurometabolic Disorders: Unravelling the Complexity of Treatable Neurometabolic Disorders: A Case-based Session			
On Demand (24/7)	Posters & Video Posters			
On Demand (24/7)	Child Neuro Night Club: American Creativity, Ingenuity and Diversity (Jazz & Spoken Word)			

#### **ALL TIMES PACIFIC DAYLIGHT TIME**

Friday, October 16, 2020				
8:00 AM - 10:00 AM	Meet the Experts: Neuro-Cutaneous Disorders <i>(In Spanish)</i> : Neurocutaneous Syndrome Iberoamerican Network			
10:00 AM - 11:00 AM	Industry Sponsored Product Theater: The Evolving Role of Early Pediatric Care for Spinal Muscular Atrophy (SMA) and a Treatment for Presymptomatic and Early-onset SMA (Biogen)			
10:30 AM - 12:30 PM	Seminar: Headache <i>(In Spanish)</i> : Migraine in Children and Adolescents - Diagnosis, Management and Treatment			
10:30 AM - 12:30 PM	Seminar: Neuroinflammation: Interferonopathies			
10:30 AM - 12:30 PM	Seminar: Neonatal Neurology: The Value of Magnetic Resonance Imaging in the Newborn			
10:30 AM - 12:30 PM	Meet the Experts: Neuromuscular: The Many Faces of Pediatric Neuromuscular Diseases: Cases, Approaches, Pearls and Challenges			
12:30 PM - 2:00 PM	Neuro-Oncology SIG			
12:30 PM - 2:00 PM	Neonatal Neurology SIG			
1:00 PM - 3:00 PM	Workshop: Epilepsy/General Child Neurology: Telehealth - A Means to Global Outreach			
3:30 PM - 5:30 PM	Junior Member Seminar: International Clinical Research Consortia in Child Neurology: Get Involved!			
3:30 PM - 5:30 PM	Child Neurology Foundation: Shortening the Diagnostic Odyssey in Children with Neurologic Conditions			
3:30 PM - 5:30 PM	Meet the Experts: Movement Disorders: Tics, Stereotypies, and their Look-a-Likes - Understanding and Managing Repetitive Movements			
6:00 PM - 8:00 PM	Junior Member Seminar: Choosing your Career Track - Academic, Private Practice, and NGOs			
On Demand (24/7)	Posters & Video Posters			
On Demand (24/7)	Child Neuro Night Club: American Creativity, Ingenuity and Diversity (Jazz & Spoken Word)			
Monday, October 19	), 2020			
7:00 AM - 3:30 PM	Neurobiology of Disease in Children Symposium: Traumatic Brain Injury (TBI)			
12:30 PM - 1:30 PM	Industry Sponsored Educational Seminar: Distinguishing Pediatric Movement Disorders: Uncovering AADC Deficiency (PTCBio)			
2:30 PM - 4:00 PM	Cerebral Palsy SIG			
5:00 PM - 6:00 PM	Industry Sponsored Product Theater: Spinal Muscular Atrophy (Genentech)			
On Demand (24/7)	Posters & Video Posters			
On Demand (24/7)	Child Neuro Night Club: American Creativity, Ingenuity and Diversity (Jazz & Spoken Word)			

## **Schedule at a Glance**

#### **ALL TIMES PACIFIC DAYLIGHT TIME**

Tuesday, October 20, 2020				
6:00 AM - 6:55 AM	JOHN STOBO PRITCHARD AWARD LECTURE: Nicola Specchio, MD, PhD, Bambino Gesu' Children's Hospital, IRCCS, Rome, Italy: Developmental and Epileptic Encephalopathies: What We Know and What We Do Not Know			
7:00 AM - 7:55 AM	BERNARD SACHS AWARD LECTURE: Joseph G. Gleeson, MD; University of California San Diego, Rady Children's Institute for Genomic Medicine, San Diego, CA, USA: Genes as a Window into the Developing Brain			
8:00 AM - 9:00 AM	Industry Sponsored Educational Seminar: Progressive Pathways: Recent Recommendations and Emerging Therapies for Treatment of Tumors Associated with Neurofibromatosis Type 1 in Children (AstraZeneca)			
10:30 AM - 11:30 AM	Industry Sponsored Product Theater: Spinal Muscular Atrophy (Avexis)			
10:30 AM - 12:30 PM	SYMPOSIUM: NEUROIMMUNOLOGY: International Consensus Opinions in Opsoclonus-Myoclonus-Ataxia Syndrome			
10:30 AM - 12:30 PM	SYMPOSIUM: STROKE: Pediatric Stroke: Hot Topics, Global Challenges			
1:00 PM - 2:00 PM	Industry Sponsored Educational Seminar: Patient Identification, Evaluation, and Management - Addressing Multiple Challenges in Neurodegenerative Lysosomal Storage Diseases (Takeda)			
1:00 PM - 3:00 PM	SYMPOSIUM: NEURO-ONCOLOGY: Pediatric Mixed Neuronal-Glial Tumors: New Classifications, Molecular Understandings and Targeted Therapy			
3:30 PM - 5:30 PM	SYMPOSIUM: NEUROMUSCULAR DISEASE: Advances in Pediatric Charcot-Marie-Tooth Disease			
3:30 PM - 5:30 PM	SYMPOSIUM: NEONATAL SEIZURES: Practical Approaches to Classification, Diagnosis and Management			
6:00 PM - 8:00 PM	SYMPOSIUM: EPILEPSY: Infantile Spasms - Current Management - A Global Perspective; The Way Forward			
6:00 PM - 8:00 PM	SYMPOSIUM: NEUROINFECTIOUS DISEASE: Tropical Infections of the CNS: A Worldwide Problem			
6:00 PM - 8:00 PM	SYMPOSIUM: MOVEMENT DISORDERS: Lessons from Tourette Syndrome - Better Understanding of Development of the Child Brain			
On Demand (24/7)	Posters & Video Posters			
On Demand (24/7)	Child Neuro Night Club: American Creativity, Ingenuity and Diversity (Jazz & Spoken Word)			

#### **ALL TIMES PACIFIC DAYLIGHT TIME**

15 Minutes Q&A Will be Added to Each CME Session (other than plenary/award lectures - no Q&A)

Wednesday, October 21, 2020				
6:00 AM - 6:55 AM	SHEILA WALLACE AWARD LECTURE: Suvasini Sharma, MD, DM; Lady Hardinge Medical College and Associated Kalawati Saran Children's Hospital, New Delhi, India: Dietary Therapies for Epilepsy in Low Resource Settings: Challenges and Successes			
7:00 AM - 7:55 AM	PHILIP R. DODGE YOUNG INVESTIGATOR AWARD LECTURE: Hsiao-Tuan Chao, MD, PhD; Baylor College of Medicine, Houston, TX, USA: The Impact of Serendipity: From "Rare" Neurodevelopmental Disorders to Common Insights			
8:00 AM - 10:00 AM	Industry Sponsored CME Seminar: SMA Horizons: What is the Future of SMA Management? (Genentech)			
10:30 AM - 12:30 PM	SYMPOSIUM: NEUROGENETICS: Current Status of Developmental Encephalopathies: Rett Syndrome, MECP2 Duplication Disorder, CDKL5 Deficiency Disorder, and FOXG1 Disorder			
10:30 AM - 12:30 PM	SYMPOSIUM: NEUROIMMUNOLOGY: Cutting Edge Technology in Neuroinflammation: Advancing Science and Increasing Capacity in Low and Middle-income Countries			
12:30 PM - 2:30 PM	Industry Sponsored CME Seminar: Developmental and Epileptic Encephalopathies (Zogenix)			
1:00 PM - 3:00 PM	SYMPOSIUM: COGNITIVE-BEHAVIORAL NEUROLOGY: The Molecular & Cellular Basis of Developmental Cognitive & Behavioral Disorders			
1:00 PM - 3:00 PM	SYMPOSIUM: SLEEP: Integrating Pediatric Sleep Medicine into Child Neurology			
3:30 PM - 5:30 PM	SYMPOSIUM: CEREBRAL PALSY: An Open Discussion on the Definition of Cerebral Palsy			
3:30 PM - 5:30 PM	SYMPOSIUM: EPILEPSY: Epilepsy and Psychiatric Comorbidities			
6:00 PM - 8:00 PM	SYMPOSIUM: GLOBAL NEUROLOGY: Global Challenges and Opportunities in Inpatient Child Neurology			
6:00 PM - 8:00 PM	SYMPOSIUM: EPILEPSY: Ketogenic Diets in Child Neurology - A Tale of 100 Years: What Does the Future Hold?			
On Demand (24/7)	Posters & Video Posters			
On Demand (24/7)	Child Neuro Night Club: American Creativity, Ingenuity and Diversity (Jazz & Spoken Word)			

#### **SPECIAL INTEREST GROUP MEETINGS**

Monday, October 12

Cerebral Palsy: 2:30 pm - 4:00 pm Telemedicine: 4:30 pm - 6:00 pm

Neurodevelopmental Disorders: 4:30 pm - 6:00 pm

**Tuesday, October 13** Education: 3:00 pm - 4:30 pm Wednesday, October 14

Early Stage Investigator: 3:00 pm - 4:30 pm

Neurogenetics: 3:00 pm - 4:30 pm

Thursday, October 15

Peds Demyelinating Disease: 12:30 pm - 2:00 pm

Friday, October 16

Neuro-Oncology: 12:30 pm - 2:00 pm Neonatal Neurology: 12:30 pm - 2:00 pm

## **Schedule at a Glance**

#### **ALL TIMES PACIFIC DAYLIGHT TIME**

Thursday Octobor	22 2020		
Thursday, October 2			
6:00 AM - 6:55 AM	LINDA DE MEIRLEIR NEUROMETABOLIC AWARD LECTURE: Lance Rodan, MD, FRCP(C); Boston Children's Hospital, Harvard Medical School, Boston, MA, USA: Update in Pediatric Neurometabolic Disorders 2020		
7:00 AM - 7:55 AM	HOWER AWARD LECTURE: Kenneth J. Mack, MD, PhD; Mayo Clinic, Rochester, MN, USA: Migraine, Vertigo, and Dizziness		
10:00 AM - 11:00 AM	Industry Sponsored Product Theater: The Evolving Role of Early Pediatric Care for Spinal Muscular Atrophy (SMA) and a Treatment for Presymptomatic and Early-onset SMA (Biogen)		
10:30 AM - 12:30 PM	SYMPOSIUM: NEONATAL NEUROLOGY: Neurodevelopmental Outcomes in Congenital Heart Disease: From Fetal Pathogenesis to Prevention		
10:30 AM - 12:30 PM	SYMPOSIUM: NEURODEVELOPMENTAL DISORDERS:  IN SPANISH: Beyond Pharmacological Treatment for Neurodevelopmental Disorders:  What Parents and Physicians Want to Know About the Available Options		
1:00 PM - 3:00 PM	SYMPOSIUM: ETHICS: Humanism in Child Neurology: The Time is Now!		
	SYMPOSIUM: HEADACHE: Migraine Management in 2020: New Options for Treatment and How to Incorporate Recent Guidelines and Novel Treatments in Clinical Practice		
3:30 PM - 5:30 PM	SYMPOSIUM: NEUROMUSCULAR DISEASE: Gene Transfer for Children: What We Know Now		
3:30 PM - 5:30 PM	SYMPOSIUM: EPILEPSY: <i>IN SPANISH:</i> Pediatric Epilepsy. When Drugs Don't Work		
6:00 PM - 8:00 PM	SYMPOSIUM: NEURO-METABOLIC DISORDERS: Vitamin Responsive Conditions in Child Neurology: Whats New?		
6:00 PM - 8:00 PM	SYMPOSIUM: GLOBAL NEUROLOGY: Pediatric Neurology. A Global Perspective		
On Demand (24/7)	Posters & Video Posters		
On Demand (24/7)	Child Neuro Night Club: American Creativity, Ingenuity and Diversity (Jazz & Spoken Word)		
Friday, October 23,	2020		
6:00 AM - 6:55 AM	FRANK FORD AWARD LECTURE: Charles Newton, MD; University of Oxford, Oxford, United Kingdom, KEMRI-Wellcome Trust Collaborative Programme, Kilifi, Kenya The Global Burden of Paediatric Neurological Disorders		
10:30 AM - 12:30 PM	SYMPOSIUM: TRAUMATIC BRAIN INJURY: New Advances in Management, Treatment and Rehabilitation		
10:30 AM - 12:30 PM	SYMPOSIUM: NEUROMETABOLIC DISORDERS: Novel Advanced Treatment in Neurogenetic Disorders		
1:00 PM - 3:00 PM	SYMPOSIUM: NEUROIMMUNOLOGY: MOG Antibody Associated Neurological Disease - An Update for the Clinician		
1:00 PM - 3:00 PM	SYMPOSIUM: GLOBAL NEUROLOGY: Integration of Global Health and Child Neurology: Perspectives and Successful Partnerships Around the World		
On Demand (24/7)	Posters & Video Posters		
On Demand (24/7)	Child Neuro Night Club: American Creativity, Ingenuity and Diversity (Jazz & Spoken Word)		



## Registration

**REGISTRATION FEES** admit delegate to all Live Open Sessions, Live SIG Meetings, and On-Demand ePoster and Video-Poster Sessions. Junior Members also admitted to Junior Member Sessions. NDC: Traumatic Brain Injury requires additional course fee.

#### PLUS....

**REGISTRATION FEE** good for all recorded sessions available On-Demand November 2020 - March 2021.

## CLICK HERE TO REGISTER

or go to https://www.badgeguys. com/reg/2020/cnsv/ register.aspx

CATEGORIES	REGISTRATION FEE	NDC COURSE FEE (ADDITIONAL - OPTIONAL
ICNA High Income	\$500	\$60
ICNA Member Upper Middle Income	\$300	\$35
ICNA Member Lower Middle Income	\$100	\$25
ICNA Member Lower Income	\$75	\$25
ICNA Junior Member	\$50	\$25
CNS Active Member (Dues paid by 7/31)	\$500	\$60
CNS Active Member (late or unpaid dues)	\$600	\$60
CNS Emeritus Member	\$100	\$60
CNS Junior Member	\$50	\$25
Medical Student/Resident	\$50	\$25
Non-CNS Member/Non-ICNA Member	\$750	\$60
Non-CNS Member and Non-ICNA Member - ABPN Certified *	\$600	\$60

<sup>\*</sup>ABPN Certified neurologists who are not CNS or ICNA members are eligible to register at CNS Active Member rates thanks to a grant from the American Board of Psychiatry and Neurology (ABPN)



# Industry-Sponsored Seminars & Product Theaters

Links provided on CNS 2020 Meeting Page: https://www.childneurologysociety.org/meetings/future-cns-annual-meetings

#### **PRODUCT THEATER:**

#### **Spinal Muscular Atrophy**

Tuesday, October 13, 11:30 AM - 12:30 PM Monday, October 19, 5:00 PM - 6:00 PM



#### **CME SEMINAR:**

#### **Developmental and Epileptic Encephalopathies**

(Miller Medical Communications with funding from Zogenix)

Thursday, October 15, 12:30 PM - 2:30 PM Wednesday, October 21, 12:30 PM - 2:30 PM

Developmental Epileptic Encephalopathies encompass an array of devastating conditions marked by treatment-resistant seizures and significant comorbid neurodevelopmental challenges for which there continues to be a high unmet need. As part of those neurodevelopmental challenges, many children clinically present with autistic tendencies and traits. This symposium will cover the latest understanding of these behavioral challenges; including genetic correlates, clinical characteristics and behavior management strategies.

#### **Educational Objectives:**

- Discuss the epidemiology, clinical presentation, and burden of autistic spectrum disorder (ASD) in epileptic encephalopathies (EE);
- Analyze the key neuroanatomical and molecular determinants that regulate the complexities of behavior associate with epilepsy and EE;
- 3. Examine the relationship between seizure frequency and executive functions, such as behavior, emotion, and cognition;
- 4. Discuss current and emerging behavioral and pharmacologic management approaches for the treatment of ASD in EE.

(This program is supported by an independent educational grant from Zogenix, Inc.)

#### ZOGENIX

#### **EDUCATIONAL SEMINAR:**

Patient Identification, Evaluation, and Management - Addressing Multiple Challenges in Neurodegenerative Lysosomal Storage Diseases

Tuesday, October 13, 1:00 PM - 2:00 PM Tuesday, October 20, 1:00 PM - 2:00 PM

Lysosomal storage diseases (LSDs) are a group of over 70 diseases that are characterized by lysosomal dysfunction, most of which are inherited as autosomal recessive traits. These disorders are individually rare but collectively affect 1 in 5,000 live births. LSDs typically present in infancy and childhood, although adult-onset forms also occur. Since LSDs are caused by systematic enzyme deficiencies, they often present with severe neurological symptoms. Diseases like Gaucher disease, mucopolysaccharidosis type II (MPS II), and metachromatic leukodystrophy (MLD) present with major neurological symptoms. Currently, the mechanisms for these neurological disease manifestations are not fully understood and present a diagnostic odyssey and major management challenges. Although these diseases are distinct with respect to pathology and clinical characteristics, there are important similarities in the unmet needs for these conditions. Some of these include substantial variability in patient phenotypes and associated prognoses; the need for biomarkers to support both patient identification and establishment of prognosis; improved early diagnosis including newborn screening to support earlier intervention; and a requirement for treatment approaches that address CNS pathology. Discussion of these unmet needs and a critical review of the manner in which they are now and will be addressed is important and timely; and it is the basis for the proposed symposium.

The product theatre will be presented in the following three sections:

- 1. Neurodegenerative consequences of Gaucher disease across the spectrum of patient phenotypes;
- Predicting, assessing, and addressing cognitive dysfunction in MLD;
- 3. MPS II: Meeting needs for prognosis and monitoring



#### **CME SEMINAR:**

#### **SMA Horizons:**

#### What is the future of SMA management?

(France Foundation with funding from Genentech)

Wednesday, October 14, 4:00 PM - 6:00 PM Wednesday, OCtober 21, 8:00 AM - 10:00 AM

Spinal muscular atrophy (SMA) is the leading genetic cause of infant death. There are currently 2 approved life-saving therapies, with approval of a third treatment anticipated by summer. Treatment early in the disease course is crucial to preventing irreversible neuromuscular damage. However, diagnosis is often missed and/or delayed because of insufficient awareness of SMA among clinicians and families, and because the clinical presentation may appear similar to that of other diseases. The expanding landscape of SMA treatments necessitates the need for education that provides real-life, timely solutions based on the most current evidence and expert recommendations. This session will feature world-renowned SMA clinical experts Dr. Claudia Chiriboga, Dr. Perry Shieh, and Dr. Julie Parsons. They will explain the SMA disease process, describe mechanisms of action of FDAapproved and emerging therapies, and highlight the importance and impact of newborn screening efforts in the United States. Videos of a patient's journey through recent SMA clinical trials will be interspersed throughout the session to illustrate real-world experiences of patients and families, support clinical relevance of interventions discussed, and engage learners. In addition, patient vignettes will be used to highlight various approaches to SMA management. Faculty will describe clinical trial findings and experiences with approved and emerging therapies and discuss how new treatments have impacted clinical care.

The session will conclude with an opportunity for questions from the audience. At the conclusion of this program, the learners will be able to:

- Review pathology, genetics, and epidemiology of SMA:
- 2. Explain the importance of genetic testing;
- 3. Discuss newborn screening and its importance in early diagnosis
- 4. Evaluate new and emerging therapies for SMA.

(This program is supported by an independent educational grant from Genentech, Inc.)



#### **EDUCATIONAL SEMINAR:**

## **Distinguishing Pediatric Movement Disorders: Uncovering AADC Deficiency** (PTC Therapeautics)

Wednesday, October 14, 12:30 PM - 2:00 PM Monday, October 19, 12:30 PM - 2:00 PM

Pediatric movement disorders can result from a variety of pathologies, including errors of metabolism, autoimmune processes, neurodegenerative and neurogenetic diseases, and others. Aromatic L-amino decarboxylase (AADC) deficiency is a rare, inherited disorder of neurotransmitter synthesis that presents early in life and can have debilitating effects on quality of life. Due to similarities in clinical presentation with other conditions (eg, cerebral palsy or epilepsy), patients with AADC deficiency are often undiagnosed or misdiagnosed. A differential diagnosis from other pediatric movement disorders is therefore critical to identify AADC deficiency and ensure optimal patient management. Understanding the clinical features, appropriate patient assessment methods and diagnostic approaches is key in this process. The objectives of this symposium are to provide an overview of pediatric movement disorders that may clinically resemble AADC deficiency, provide an overview of key clinical features, diagnostic tests, and screening methods for patients with suspected AADC deficiency, share clinical experience with regard to diagnosis of AADC deficiency in patients who initially presented with symptoms resembling those of certain pediatric movement disorders, review current management options for AADC deficiency, and provide a balanced overview of available information regarding treatments in development.

#### Faculty will:

- provide an overview of pediatric movement disorders and highlight AADC deficiency as a movement disorder including etiology, key clinical features, and diagnostic methods,
- review case studies and provide an overview of approaches to distinguishing and identifying AADC deficiency in these patients by highlighting key decision points along the patient journey and the testing methods that resulted in an accurate diagnosis of AADC deficiency, and
- 3. review current management options for AADC deficiency and provide a balanced overview of treatments in development for AADC deficiency, highlighting the importance of early and accurate diagnosis in order to provide appropriate disease management. The session will close with a group discussion designed to reinforce the key learning objectives and address questions from the audience.

(This program is supported by an independent educational grant from PTC Therapeutics)



#### Links provided on CNS 2020 Meeting Page:

https://www.childneurologysociety.org/meetings/future-cns-annual-meetings

#### **CME SEMINAR:**

#### **Progressive Pathways:**

Recent Recommendations and Emerging Therapies for Treatment of Tumors Associated With Neurofibromatosis Type 1 in Children

(PeerView w/ funding from AstraZeneca)

Tuesday, October 20, 8:00 AM - 9:AM

PeerView's latest MasterClass and Practicum satellite symposium will feature an expert review of:

- Treatment recommendations, including diagnostic criteria, current management paradigms, and challenges in the care of NF-1 and NF-1-associated tumors in children;
- 2. Insight into the expanding landscape of targeted therapies for NF-1-associated tumors;
- 3. Practical guidance on effectively and safely incorporating these strategies and new therapies.

After participating in the activity, learners are expected to be better able to:

- 1. Describe fundamental aspects of NF-1 etiology, pathophysiology, and clinical presentation as they relate to pediatric patients;
- Summarize current recommendations for NF-1 diagnosis and treatment of NF-1-associated tumors in pediatric patients;
- 3. Evaluate recent evidence regarding the role of emerging therapies in the treatment of NF-1- associated tumors in pediatric patients, including agents that affect the RAS/MAPK pathway;
- 4. Assess options for patient-centered treatment of PNs and other NF-1-associated tumors in pediatric patients.

(This program is supported by an independent educational grant from AstraZeneca)



#### PRODUCT THEATER:

Advancing Our Understanding of Gene Therapy in SMA: From Clinical Trials to Real-World Experience

Thursday, October 15, 10:30 AM - 11:30 AM Tuesday, October 20, 10:30 AM - 11:30 AM



#### PRODUCT THEATER:

The Evolving Role of Early Pediatric Care for Spinal Muscular Atrophy (SMA) and a Treatment for Presymptomatic and Early-onset SMA

Friday, October 16, 10:00 AM - 11:00 AM Thursday, October 22, 10:00 AM - 11:00 AM





## Sponsor/Exhibitors

#### **Aeglea BioTherapeutics**

Aeglea BioTherapeutics is a clinical-stage biotechnology company redefining the potential of human enzyme therapeutics to benefit people with rare and other high burden diseases. Aeglea's lead product candidate, pegzilarginase, is currently being investigated in a pivotal Phase 3 clinical trial for the treatment of Arginase 1 Deficiency.

#### **Aquestive Therapeutics**

Aquestive Therapeutics is a leader in developing and delivering medications via our proprietary PharmFilm® technology. We've created a robust, proprietary CNS portfolio. Our innovations in oral drug delivery aim to improve the treatment experience for patients with epilepsy and their caregivers.

## Association of Child Neurology Nurses (ACNN)

The Association of Child Neurology Nurses is an international non-profit organization of nurses and other health care professionals who promote excellence in child neurology nursing practice. The ACNN provides educational opportunities at national and regional conferences, nursing excellence awards, research support, newsletters, and online membership contacts for networking. Additional information and how to join can be found at www.acnn.org.

#### **GOLD SPONSOR**

#### AveXis, Inc.

Avexis is dedicated to developing and commercializing gene therapies for patients and families devastated by rare and life-threatening neurological genetic diseases. Our initial gene therapy for spinal muscular atrophy (SMA) has been approved in the United State, Japan and The European Union.



#### SILVER SPONSOR

#### **AstraZeneca (NO BOOTH)**

AstraZeneca is a global, science-led biopharmaceutical company that focuses on the discovery, development and commercialization of prescription medicines, primarily for the treatment of diseases in three therapy areas – Oncology, Cardiovascular, Renal & Metabolism and Respiratory. For more information, please visit www.astrazeneca-us.com and follow us on Twitter @AstraZenecaUS.



#### **AveXis Medical Affairs**

AveXis is dedicated to developing and commercializing gene therapies for patients and families devastated by rare and life-threatening neurological genetic diseases. Learn more at www.avexis.com. For medical information, please contact us at www.avexismedinfo.com or 1-833-828-3947.

#### SILVER SPONSOR

#### **Biocodex**

BIOCODEX is a family-owned multinational pharmaceutical company founded in France in 1953, with proven expertise in treatments for the central nervous system. As the maker of DIACOMIT® (stiripentol), we are dedicated to providing education and support to healthcare providers, affected individuals, and their families.



#### **Exhibitor/Sponsors**

#### **GOLD SPONSOR**

#### **Biogen (NO BOOTH)**

At Biogen, our mission is clear: we are pioneers in neuroscience. Biogen discovers, develops and delivers worldwide innovative therapies for people living with serious neurological and neurodegenerative diseases as well as related therapeutic adjacencies.



#### **BioMarin Pharmaceutical Inc.**

BioMarin is a world leader in developing and commercializing innovative therapies for rare diseases driven by genetic causes. With a 20-year history, BioMarin remains steadfast to its original mission – to bring new treatments to market that will make a big impact on small patient populations. Visit www.biomarin.com to learn more.

#### SILVER SPONSOR

#### **Cannabinoid Clinical**

Cannabinoid Clinical is a web-based platform to provide evidenced-based cannabinoid information to multi-disciplinary audience. Among the education resources is Covering Cannabinoids, a quarterly newsletter written to provide healthcare providers, payers, and policymakers timely information on scientific facts, trends, and regulations to help you make informed decisions. Sign up to receive this newsletter directly by email or read past issues by clicking the link: https://www.cannabinoidclinical.com/covering-cannabinoids



#### **GOLD SPONSOR**

#### Eisai Inc.

As the U.S. pharmaceutical subsidiary of Tokyo-based Eisai Co., Ltd., we are a fully integrated global business with two commercial focus areas: oncology and neurology (dementia-related diseases and neurodegenerative diseases). To learn more about Eisai Inc., please visit us at www.eisai.com/US.



## **European Paediatric Neurology Society (EPNS)**

A society for physicians with a research or clinical interest in Paediatric Neurology.

#### SILVER SPONSOR

#### bluebird bio (NO BOOTH)

At bluebird, our goal is to recode the science, the system – and even the status quo – for life. Powered by multiple labs, in-house lentiviral vector manufacturing capabilities and future drug product production, we push ourselves to find answers for the people who need them by exploring the cutting-edge spectrum of gene therapy.



#### SILVER SPONSOR

#### **Child Neurology Foundation**

The Child Neurology Foundation serves as a collaborative center of education and support for children living with neurologic conditions and their families. CNF's expanding network of patients and caregivers, advocates and partners, researchers and clinicians is here so no child will ever have to walk alone.



#### **GOLD SPONSOR**

#### Genentech

Genentech is a biotechnology company dedicated to pursuing groundbreaking science to discover and develop medicines for people with serious and life-threatening diseases. Our transformational discoveries include the first targeted antibody for cancer and the first medicine for primary progressive multiple sclerosis.

Genentech

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#### **GOLD SPONSOR**

#### **Greenwich Biosciences, Inc.**

Greenwich Biosciences is focused on discovering, developing, and commercializing novel therapeutics from its proprietary cannabinoid product platform. It is our passion and purpose to continually seek solutions that transform the lives of those living with rare and severe neurological diseases. or additional information, please visit www.GreenwichBiosciences.com. For more information about our product, please visit www.GBmedicine.com



#### Invitae

Invitae's mission is to bring comprehensive genetic information into mainstream medical practice to improve the quality of healthcare for billions of people. Our goal is to aggregate most of the world's genetic tests into a single service with higher quality, faster turnaround time and lower prices. Visit www.invitae.com.

#### Lineagen

Since 2010, Lineagen has developed and provided highly optimized genetic testing services for children with autism spectrum disorder and other neurodevelopmental disabilities. Lineagen's genetic tests, which are all validated and collected by cheek swab, include FirstStepDxPLUS chromosomal microarray, fragile X syndrome testing, epilepsy panel testing, whole exome and whole genome sequencing, and pharmacogenomic testing.

#### LivaNova

As pioneers of the VNS (Vagus Nerve Stimulation) Therapy® system, we continue to advance medical device solutions for people affected by treatment-resistant epilepsy. We strive to help where it really counts, where it truly matters the most. Sharp, responsive and effective – at LivaNova we serve health and improve lives. Day by day. Life by life.

#### Marinus Pharmaceuticals, Inc.

Marinus Pharmaceuticals is a clinical stage biopharmaceutical company committed to improving the lives of patients suffering from rare seizure disorders. Marinus is dedicated to the development of ganaxolone, offering a new mechanism of action for the potential treatment of adult and pediatric patient populations with CNS disorders.

## National Institute of Neurological Disorders and Stroke (NINDS)

The National Institute of Neurological Disorders and Stroke (NINDS) (www.ninds.nih.gov), part of the National Institutes of Health (NIH), provides information about research funding and free publications for patients and their families on neurological disorders. Home of the free Migraine Trainer<sup>TM</sup> app: https://www.ninds.nih.gov/sites/default/files/ninds\_migraine\_trainer\_flyer\_508c.pdf. Disorder information: https://www.ninds.nih.gov/Disorders. NINDS publications catalog: https://catalog.ninds.nih.gov/.

#### SILVER SPONSOR

#### Neurelis, Inc.

Neurelis, Inc. is an innovation-driven neuroscience company focused on the development and commercialization of product candidates for unmet medical needs in epilepsy and the broader central nervous system (CNS) market. Neurelis has reached a milestone in patient care with its first FDA-approved treatment. For more information, please visit http://www.neurelis.com.



#### **Origin Biosciences**

Origin Biosciences, a subsidiary of BridgeBio Pharma, is a biotechnology company focused on developing and commercializing a treatment for Molybdenum Cofactor Deficiency (MoCD) Type A. Together with patients and physicians, the company aims to bring a safe, effective treatment for MoCD Type A to market as quickly as possible.

#### **Orphazyme Medical Affairs**

Orphazyme is pioneering the Heat-Shock Protein response to develop innovative therapies for neurodegenerative orphan diseases. Arimoclomol, our lead candidate, is in development for four diseases: Niemann-Pick disease Type C (NPC), Gaucher Disease, sporadic Inclusion Body Myositis (sIBM), and Amyotrophic Lateral Sclerosis (ALS). For more information, visit www.orphazyme.com, LinkedIn or Twitter.

#### **Exhibitor/Sponsors**

#### Parent Project Muscular Dystrophy

Parent Project Muscular Dystrophy fights to end Duchenne. We accelerate research, raise our voices to impact policy, demand optimal care for every family, and strive to ensure access to approved therapies. Our Decode Duchenne program provides free genetic testing (diagnostic and carrier) for families living in the US or Canada.

#### Pediatric Epilepsy Research Foundation (PERF) (NO BOOTH)

The Pediatric Epilepsy Research Foundation (PERF) was established in 2004 as a not-for-profit foundation to support research in pediatric epilepsy and other pediatric neurologic conditions. PERF is proud to support this year's 5th Annual CNS John M. "Jack" Pellock Residents Seminar on Epilepsy for PGY5 and PGY6 trainees as part of a 5-year, \$50K/year unrestricted educational grant.

#### **GOLD SPONSOR**

#### **PTC Therapeutics**

PTC is a science-driven, global biopharmaceutical company focused on the discovery, development and commercialization of clinically differentiated medicines that provide benefits to patients with rare disorders. PTC's ability to globally commercialize products is the foundation that drives investment in a robust and diversified pipeline of transformative medicines and our mission to provide access to best-inclass treatments for patients who have an unmet medical need. To learn more about PTC, please visit us at www.ptcbio. com and follow us on Facebook, on Twitter at @PTCBio, and on LinkedIn.



#### RosmanSearch

RosmanSearch is a Neurosurgery, Neurology and APP recruitment firm. We place quality providers with quality practices nationwide. We are the only search firm with dedicated teams specializing in neuroscience. Our mission is to be the best, the most expert, and the one that is known for quality – every time!

#### **Saint Francis Health System**

Warren Clinic, a part of Saint Francis Health System, is looking to add a BC or BE Pediatric Neurologist to our group. This physician will be joining Oklahoma's largest health system, which was ranked by Forbes as a Best-in-State Employer in 2019.

#### **Sanford Health**

Sanford Health, one of the largest health systems in the United States, is dedicated to the integrated delivery of health care, genomic medicine, senior care and services, global clinics, research and affordable insurance. Headquartered in Sioux Falls, South Dakota, the organization includes 44 hospitals, 1,400 physicians and more than 200 Good Samaritan Society senior care locations in 26 states and 9 countries. Nearly \$1 billion in gifts from philanthropist Denny Sanford have transformed how Sanford Health improves the human condition. For information, visit sanfordhealth.org or Sanford Health News.

#### **Sarepta Therapeutics**

Our Products & Pipeline: Working urgently to bring therapies to those who need them.

At Sarepta, we are working with urgency to develop breakthrough therapies to treat genetic diseases. Currently, we have more than 40 investigational therapies in various stages of development – many already in late-stage clinical trials. In many cases, development is being accelerated by our gene therapy engine, which potentially provides a more efficient model for drug design.



#### St. Luke's University Health Network

St. Luke's University Health Network (SLUHN) is a fully integrated, regional, non-profit network of more than 16,000 employees providing services at 12 hospitals and 300+ outpatient sites.

To learn more, please visit www.slhn.org

#### **Tourette Association of America**

The Tourette Association of America is dedicated to making life better for all individuals affected by Tourette and Tic Disorders. The only nationwide organization serving this community, the Association works to raise awareness, fund research and provide on-going support through its network of 31 Chapters, 83 Support Groups and 18 Centers of Excellence.

## **UT Health Austin Pediatric Neurosciences at Dell Children's**

UT Health Austin Pediatric Neurosciences at Dell Children's provides world-class medical care for children with disorders of the central nervous system. The center is committed to interdisciplinary care promoting health-related quality of life through family-centered treatment, multidisciplinary collaborations, and interinstitutional partnerships. Including clinical academics and research-driven protocols with UT Austin.

#### **GOLD SPONSOR**

#### Takeda (NO BOOTH)

For over 200 years, Takeda has remained committed to bringing better health and a brighter future to people around the world by focusing on four therapeutic areas: Oncology, Rare Diseases, Neuroscience, and Gastroenterology (GI). Our neuroscience therapeutic area is driven by the immense unmet need of patients suffering from neurological diseases and current therapies include Major Depressive Disorder (MDD), Attention-Deficit Hyperactivity Disorder (ADHD), and Binge Eating Disorder (B.E.D.). In addition to this, Takeda also has a strong legacy in developing treatments for rare genetic and metabolic diseases, including Lysosomal Storage Disorders (LSDs) with visceral and neurological manifestations, which have a debilitating impact on patients, many of whom are diagnosed in early childhood. Our current portfolio for LSDs in the United States includes therapies for Gaucher Disease and MPS II (Hunter Syndrome). For more information on our pipeline and areas of focus please visit https://www.takeda.com/what-we-do/.



#### **GOLD SPONSOR**

## **Upsher-Smith Laboratories, LLC**

Upsher-Smith Laboratories, LLC is a trusted U.S. pharmaceutical company striving to improve the health and lives of patients through an unwavering commitment to high-quality products and sustainable growth. We seek to deliver the best value for our stakeholders and do more good for our customers. For more information, visit www.upshersmith.com.



#### **Variantyx**

We are a CLIA/CAP accredited genomic diagnostic lab that specializes in testing for rare inherited and neurological disorders. All of our tests, ranging from single gene to comprehensive genome-wide tests, are performed on a WGS-backbone methodology that uniquely detects all major types of genetic variation including small sequence changes, structural variants, mitochondrial variants and tandem repeat expansions. We provide the flexibility to test only the genes that you want to, with the option to reflex up to a comprehensive genome-wide test as part of the same test order.

#### GOLD SPONSOR

#### Zogenix

Zogenix is a global pharmaceutical company passionate about taking on the complex challenges of developing therapies with the potential to transform the lives of rare disease patients and their families.

ZOGENIX

# TOGETHER-APART Virtua 2020

OCTOBER 12-23, 2020



16th International Child Neurology Congress
49th Annual Child Neurology Society Meeting

Sharing Knowledge
Sowing Friendships • Spreading Hope

## **Want CME Credit?**

Complete CME survey online immediately after the meeting: October 23-November 2