



NEWSLETTER



Au revoir, Pittsburgh... Bonjour, Quebec!

Gary D. Clark, MD, Chair
CNS Meeting Planning and Scientific Selection Committee



Reviews of the 2006 Annual Meeting in Pittsburgh are in and, to no one's surprise, they were "all over the place" (e.g. "In general, outstanding!"...."This year a bit less than I've come to expect."....

"I thought that this year was a step above what I've seen in recent years."). Which is precisely as it should be. Seasoned veterans of the CNS Scientific Selection Committee recognize that as diverse as the feedback was this (and all previous) years, we as a society are equally diverse in our professional orientations and interests: 55% of attendees describe themselves as "academic clinical", 30% "private practice," 10% "academic research," and 5% "hospital-based." Our committee recognizes that the challenge that we face yearly is to attempt to meet the varied and changing needs of all members of our society. We are especially grateful for comments such as "this one met my needs for scientific interest and clinical practice." That, in a nutshell, is our aim.

While it is certainly true that the Society "houses" a host of different aims and interests, we are, nonetheless, part of an (easily?) identifiable "collective consciousness" and generally tend to think in certain ways despite our diversity. For instance, we tend to order similar tests

for our patients with developmental disorders and are guided by our outstanding practice parameters. We eagerly seek knowledge and want to know why a disease has certain manifestations. We don't shy away from new genetic knowledge, and we quickly incorporate such knowledge into our practices. That is why the meeting is designed to push the envelope, to provide up-to-date reviews and to allow the incorporation of new insights into practice. We want the meeting to be provocative and to be forward thinking, because we are a collective in evolution.

Among the very highest marks given out for this past year's symposia were those awarded "The Future of Therapy in Child Neurology," arranged by Evan Snyder of the Burnham Institute. Each talk was simply outstanding. It was extremely gratifying to see that we have such forward thinkers as members and friends of our Society, and while much of what was discussed in this symposium may never be realized clinically, the audience felt that the future of therapy in child neurology was bright. One criticism was "why did we place such an outstanding symposium on the last day of the meeting when so many

Continued on page eight

In This Issue

- 2 Letter from the President
- 3 CNS Annual Meeting Preview
- 8 CNS Announcements
- 10 Legislative Affairs Committee Update
- 11 Personnel Registry

CHILD NEUROLOGY SOCIETY

From the President



Ann Tilton, MD
CNS President

One of the virtues of a society our size is the relative ease and openness of communication it allows. The detailed responses given by CNS members to two recent surveys on the CNS website—the 2006 Annual Meeting/CME survey and the Long Range Planning Committee Survey—yielded a treasure trove of insights into the present configuration and future needs of the Society and the subspecialty it represents.

Of the 230 members responding on-line in November to the Long Range Planning Survey, roughly 60 per cent characterized their primary practice environment as academic, 30 per cent indicated they were in private practice, and 10 per cent checked “other” (most were retired). That 60/30 split closely mirrored the 65/35 split registered in the Annual Meeting survey the previous month. There was a near-unanimous endorsement of the need to have a Long Range Planning Committee, with a solid majority indicating committee members should be appointed by the CNS Executive Committee for a minimum five-year term. Our greatest opportunity was perceived to be strengthened ties with academic pediatrics and neurology, our greatest strength the perceived need for our unique services, and our greatest weakness—in virtually direct tension with that perceived need—is our inability to capture revenue. Outgoing Executive Committee members Leon Dure and Donna Ferriero have agreed to co-chair the reconstituted LRP Committee, focusing their energies on the three issues identified in the survey as being most critical: 1) Workforce, 2) Education, and 3) Training.

One added bonus of the CME and LRP surveys was the overwhelming number of members indicating a willingness to be a part of the solution to the challenges identified by serving on one or more CNS Committees. Newly reconstituted committees will be posted on the CNS website and the roster of those expressing interest in serving will be regularly updated as, year-by-year, members are rotated on and off each committee with an eye toward maintaining a regular infusion of fresh insights and energy while also ensuring continuity and longterm focus on coordinating committee initiatives in the broader interests serving the Society’s mission.

Looking ahead to October, the newly reconstituted and renamed Meeting Planning and Scientific Selection Committee reviewed 26 outstanding symposia proposals submitted by CNS Members for the fall meeting, from which three morning and two afternoon symposia were selected, as well as nine breakfast seminars. Responding to years of survey feedback suggesting the meeting is becoming frenetically overscheduled, the committee has trimmed the afternoon schedule to a single symposium each afternoon and created a window of opportunity from 3:00 – 6:00 pm Friday afternoon with no scheduled sessions, thus allowing delegates to schedule Special Interest Group or Alumni Meetings or kick back and enjoy the autumnal delight of walking around Quebec City.

Watch for meeting updates on the CNS website in the coming months: this one promises to be very special.



EDITOR

John Bodensteiner, MD

MANAGING EDITORS

Mary Currey
Roger Larson

CORRESPONDENCE

Child Neurology Society
1000 West Cty Rd. E, Suite 290
St. Paul, MN 55126
Tel: 651/486-9447 ■ Fax: 651/486-9436
nationaloffice@childneurologysociety.org
www.childneurologysociety.org

Printed in St. Paul, MN
Published Quarterly



Printed on Recycled Paper
50% Post Consumer Waste
50% Recycled Fibers



Proposed Agenda and Format for the 2007 Neurobiology of Disease in Children Symposium

CNS 36th Annual Meeting

Québec City, October 10th, 2007

Note: This proposed program has not yet been submitted for ACCME review and subsequent approval for CME credit. Once approved, this session and all annual meeting sessions will be printed/posted and distributed in June.

7:30 AM – 5:30 PM
**NEUROBIOLOGY OF DISEASE IN
CHILDREN SYMPOSIUM**

Tumors of the Central Nervous System
Supported by the National Institutes of Health (NIH grant 2 R13 NS40925-01), the Child Neurology Society and the Pediatric Brain Tumor Foundation.

7:30 AM – 7:45 AM
Welcome and Statement of Goals
*Bernard L. Maria, MD, MBA, PI of NDC
Medical University of South Carolina
Charleston, SC*

Biomedical Research in CNS Tumors
*Story Landis, PhD, Director of NINDS
Bethesda, MD*

7:45 AM – 10:15 AM
CLINICAL ASPECTS OF CNS TUMORS
*Moderator: Roger J. Packer, MD
Children's National Medical Center
Washington, DC*

7:45 AM – 8:15 AM
**Accomplishments and Ongoing
Challenges**
*Roger J. Packer, MD
Children's National Medical Center
Washington, DC*

8:15 AM – 8:45 AM
Advances and Limitations of Imaging
*Gilbert Vezina, MD
Children's National Medical Center
Washington, DC*

8:45 AM – 9:30 AM
Initial Management
***Surgery:** James Rutka, MD, PhD, FRCSC,
FACS, FAAP, University of Toronto, Toronto,
Ontario
Radiotherapy: Larry Kun, MD, St. Jude
Children's Research Hospital, Memphis, TN
Chemotherapy: Amar Gajjar, MD, St. Jude
Children's Research Hospital, Memphis, TN*

9:30 AM – 10:00 AM
Preventing Late Effects
*Bartlett Moore, PhD
MD Anderson Cancer Center
Houston, TX*

10:00 AM – 10:15 AM
Question and Answer Session

10:15 AM – 10:30 AM
BREAK

10:30 AM – 12:35 PM
**MOLECULAR MECHANISMS IN
CNS TUMORS**
*Moderator: Ian Pollack, MD
University of Pittsburgh
Pittsburgh, PA*

10:30 AM – 11:00 AM
Stem Cell Hypothesis in Pediatric CNS Tumors
Robert Wechsler-Reya, PhD
Duke University Medical Center
Durham, NC

11:00 AM – 11:30 AM
Molecular Mechanisms in Embryonal Tumors
Richard Gilbertson, MD, PhD
St. Jude Children's Research Hospital
Memphis, TN

11:30 AM – 12:00 AM
Animal Models for Mechanistic and Preclinical Studies
Eric Holland, MD, PhD
Memorial Sloan Kettering Cancer Center
New York, NY
and
C. David James, PhD
University of California San Francisco
San Francisco, CA

12:00 AM – 12:20 PM
Implications for Translational Research
Ian Pollack, MD
University of Pittsburgh
Pittsburgh, PA

12:20 AM – 12:35 AM
Question and Answer Session

12:35 PM – 1:35 PM
LUNCH

1:35 PM – 3:20 PM
CONTROVERSIES AND UNANSWERED QUESTIONS
Moderator: David H. Gutmann, MD, PhD
Washington University
St. Louis, MO

1:35 PM – 1:55 PM
Low Grade Gliomas
David H. Gutmann, MD, PhD
Washington University
St. Louis, MO

1:55 PM – 2:15 PM
Aggressive Infantile Embryonal Tumors
Tobey MacDonald, MD
Children's National Medical Center
Washington, DC

2:15 PM – 2:35 PM
Cutting-Edge in Ependymomas
Thomas E. Merchant, DO, PhD
St. Jude Children's Research Hospital
Memphis, TN

2:35 PM – 2:55 PM
Pontine and Spinal Cord Gliomas: Neuraxis of Evil
Bernard L. Maria, MD, MBA
Medical University of South Carolina
Charleston, SC

2:55 PM – 3:20 PM
Question and Answer Session (Coffee and Snacks in Room)
Executive Summary for the Day
Abhijit Guha, MD, MSc, FRCSC
University of Toronto
Toronto, Ontario

3:20 PM – 5:00 PM
FUTURE DIRECTIONS
Moderators: Jane Fountain, PhD,
NINDS Program Director, NCI (CTEP)
Program Director

3:20 PM – 3:35 PM
Search for Active Compounds
Jeremy Rich, MD
Duke University Medical center
Durham, NC

3:35 PM – 3:50 PM
Novel Delivery Strategies
Russell Lonser, MD
National Institutes of Health
Bethesda, MD

3:50 PM – 4:50 PM
Panel Discussion:
Jeffrey C. Allen, MD, New York University
Medical Center, New York, NY
Susan Blaney, MD, Texas Children's Cancer
Center, Houston, TX
Nalin Gupta, MD/PhD, University of
California San Francisco, San Francisco, CA
Scott Pomeroy, MD, PhD, Children's Hospital,
Boston, MA
Michael D. Taylor, MD, PhD, Hospital for
Sick Children, Toronto, Canada

4:50 PM – 5:00 PM
Closing Comments
Bernard L. Maria, MD, MBA, PI of NDC
Jane Fountain, PhD, NINDS Program Director
Mike Traynor, PBTF of the US

IN MEMORIAM

Hugo Moser, MD



We Remember Hugo

Michael V. Johnston, MD and Gary W. Goldstein, MD

Dr. Hugo Moser, one of the world's most eminent and gracious neurologists, who was famous for his pioneering research on adrenoleukodystrophy (ALD) and related peroxisomal disorders, died at Johns Hopkins Hospital in Baltimore on January 20, 2007 at age 82. He was University Professor of Neurology and Pediatrics at Johns Hopkins University School of Medicine and Director of the Neurogenetics Department at the Kennedy Krieger Institute. It was our good fortune and pleasure to work closely with him for more than 18 years. When we arrived at the Institute, he had already served as its President for more than a decade and had reached an age when many people are considering retirement. However, we soon learned that he was only at mid-career in terms of his major contributions to pediatric neurology research.

Dr. Moser was born in Bern, Switzerland in 1924 and spent his early years in Berlin where his father was an art dealer and his mother was an actress. The family fled Nazi Germany in 1933 for Holland, and in 1940 they moved across Europe and then to Cuba before they obtained visas to reach New York. After attending Harvard College and Columbia Medical School, he became an Assistant in Medicine at Peter Bent Brigham Hospital in 1950 followed by a residency in Neurology at Massachusetts General Hospital. His training was interrupted by service in the US Army during the Korean War. In 1976 he moved from his position as Professor of Neurology at Harvard Medical School and Massachusetts General Hospital to Baltimore to lead the John F. Kennedy Institute, which later became the Kennedy Krieger Institute. With his wife, Ann, he

established a world renowned research program at the Institute on the causes of mental retardation, initially focusing on new evidence that blood levels of very long chain fatty acids are elevated in ALD. Research on the childhood cerebral form of this disorder along with related disorders of the peroxisome and attempts to treat and prevent these disorders became his passion for the next 30 years.

By every ordinary criteria of academe, he was a fantastic success, with hundreds of papers in excellent journals and decades-long, multi-million dollar funding from NIH. The laboratory methods that he and Ann developed for diagnosis of peroxisomal disorders became the international standard, and mailing instructions for sending samples to their laboratory at Kennedy Krieger can be found in hospitals throughout the world. His work put the institute on the map as a leading center for translational neuroscience research. However, one additional accomplishment set him apart from virtually every other pediatric neurologist and the vast majority of physicians: his portrayal in a major motion picture. Peter Ustinov starred as Professor Nikolais, a character fashioned after Dr. Moser, in the 1992 movie "Lorenzo's Oil" about a 5 year old boy suddenly stricken by ALD. The boy's parents, Augusto and Michaela Odone, were played by Nick Nolte and Susan Sarandon. The movie portrayed the parents' struggle to have the medical profession take seriously a non-standard therapy based on olive and rapeseed oils. Although Dr. Moser was not fond of the movie because he felt it portrayed him as a somewhat detached academic who demanded a controlled trial, he eventually

Continued on page six

IN MEMORIAM

Dr. Hugo Moser

WE REMEMBER HUGO, continued from page 5

did publish evidence that Lorenzo's oil benefits patients in the early stages of ALD and the Odone's credited him with keeping an open mind. Recently, Dr. Moser assisted Mr. Odone with his own recovery from a major illness while he was hospitalized at Hopkins, and both men were later featured in a front page story with a color picture together in the Wall Street Journal.

Dr. Moser was a charismatic lecturer and teacher and an enthusiastic member of the Child Neurology Society and the International Child Neurology Association, and other major neurological organizations. He loved to travel the globe spreading the word about his research, although in recent years he was hampered by myasthenia gravis making it necessary for him to use a walker. This did not seem to slow him down, although his wife Ann began to go along to look after him. After he returned from one of his trips, there would be phone calls, letters and emails from young people who had been inspired by his lectures and who wanted to come to Baltimore to work with his group. Occasionally we were surprised when someone would call from the airport to tell us that they had arrived to work with him. Many of these young people did join his laboratory over the years, and became co-authors on his publications as well as leading investigators in their own right. Many also needed a place to stay and lived for weeks to years with him and Ann in their big house in the Roland Park section of Baltimore.

What we liked most about him was his warm, self-effacing manner, his enthusiasm and the opportunity to learn from him about his latest discovery or idea for new research. He was always generous and accessible to students, residents and faculty, and enjoyed hearing about new research ideas. He thanked you for sharing ideas with him, and made you feel that he valued your opinion. When he was working on a new idea or project, he would sometimes appear at your office door, his voice literally shaking

with excitement. He was a self-confessed workaholic who remained vigorous working 12 hour days until the last few months of his life. We often saw his car in the parking lot when we arrived in the morning and it was still there when we went home. Just prior to major surgery for cancer last fall, we found him in his hospital room in the Halsted building at Hopkins working feverishly to meet an NIH grant deadline. He and Ann developed a new method that would allow all newborn infants to be screened for ALD, and he wanted to be sure that the project would be considered for funding even if his surgery did not go well. He had a prolonged recovery from his surgery but by early January he was back home listening to the opera and reading the New York Times, vividly recalling his adventures with modern hospital care. As usual, he had bounced back from adversity, and he seemed indestructible. We were genuinely surprised and greatly saddened when he succumbed two weeks later.

Several years ago his portrait was painted and has been hanging in the front of the lobby at the Institute so that it is the first thing we see when coming to work each morning. It is a good likeness of him, and shows him with a cheerful face and rosy cheeks. He is smiling and looks excited and quite pleased, perhaps as he was when he had solved a problem, got a good score on a grant, or thought he had discovered a new way to help patients and families with ALD. In addition to all that he has given us as a legacy, this is how we will remember Hugo.

A memorial service for the family was held in early February in Massachusetts and another one is being planned here in Baltimore. Cards and letters can be sent to Mrs. Ann Moser care of the Kennedy Krieger Institute, 707 North Broadway, Suite 500, Baltimore, MD 21205.

IN MEMORIAM

Joseph Farrell Pasternak, MD



by Joseph Mantovani, MD

Joseph Farrell Pasternak, Head of the Division of Pediatric Neurology at Evanston Northwestern Hospital and Associate Professor of Pediatrics and Neurology at Northwestern University Medical School died at home on December 5, 2006 at age 57 after a five year battle with pancreatic cancer. He is survived by his wife and clinical and research partner, Barbara Trommer, M.D. and two daughters, Emily and Rebecca.

A native of Des Moines, Iowa, Joe received his undergraduate degree in mathematics from the University of Iowa in 1971 and his M.D. from Washington University School of Medicine in 1975 where he won virtually all of the academic awards. Due to an unexpected vacancy and Joe's remarkable academic and clinical abilities, he entered our internship group at St Louis Children's Hospital in April of 1975, three months ahead of his scheduled medical school graduation. He completed his residencies in pediatrics and neurology and fellowship in child neurology as a "Golden Boy" in the Dodge/Prensky training program at Washington University (personal communication, Walter Allan, M.D.). During his training, he was an influential collaborator with Dr Joseph Volpe in the early days of neonatal neurology and published other important clinical observations.

In his last year of fellowship in St. Louis, Joe met Barbara, who was interviewing for a child neurology position. With characteristic directness, the two of them pursued a long-distance courtship, married, and in 1979 moved to Wilmette, Illinois where Joe became the first Head of Child Neurology at Evanston Hospital (now Evanston-Northwestern Medical Center [ENH]), and Barbara completed her three-year fellowship

in child neurology at Children's Memorial in Chicago before joining Joe at ENH. The two of them worked side-by-side until his final days to build and sustain a premiere child neurology division with commitments to clinical care, neurological education and basic neuroscience research resulting in over 50 publications.

In Wilmette, Becky and Emily followed apace, and the Pasternak-Trommer household blossomed into a close-knit, child-centered haven for all of them. As a frequent visitor I always felt genuine warmth and hospitality, but couldn't escape the sense that Joe was happiest when it was just the four of them. He was a devoted father who doted on his girls and their accomplishments, and he and Barbara had a wonderful partnership including a life-long love affair, complementary professional interests and a shared affection for the arts, literature and the luxury of good conversation around the dinner table.

From the time I met him in St Louis, Joe was recognized for his extraordinary intellectual acuity and range of medical knowledge. Always analytical and self-critical, his views on child neurology practice never failed to entertain and enlighten. He believed that caring for children was important work but understood the foibles and contradictions intrinsic to that enterprise better than most. Although Joe will be justifiably remembered for his seminal contributions to the clinical and scientific understanding of neurology, it was his understated style and gentle skepticism, his genuine humility informed by a wry and worldly perspective, and his native kindness and generosity that made him a wonderful husband and father, an exemplary physician and an inspiring friend. We will miss him greatly.

INTERNATIONAL AFFAIRS COMMITTEE

Nursing Research Grant 2007

The Child Neurology Foundation will be offering a nursing research grant for up to \$2500 for ACNN members this year. Applications and information can be obtained from Irene Elliott, ACNN Chair of Research at Irene.Elliott@sickkids.ca. Deadline for submission to ACNN: June 1, 2007

ACNN Travel Grant

ACNN gratefully acknowledges the Child Neurology Society contribution of Travel Grants for ACNN members. Two Travel Grants (\$500.00 per grant) are available to current ACNN members. The deadline for application is May 31, 2007. For information please contact ACNN President Ricki Hobdell at (215) 427-5113 (w).

Bernard D'Souza International Fellowship Award

The Child Neurology Society is now accepting applications for the 2007 Bernard D'Souza International Fellowship Award, which will sponsor all expenses for a child neurologist from a developing country to attend the 36th Annual Meeting of the CNS to be held in Quebec City, PQ, Canada October 10-13, 2007. This will be preceded, or followed, by a visit to a selected training program in North America. The purpose of the award is to promote child neurology in developing countries.

Applicants must have trained in a developing country, should be practicing child neurology in an academic environment in a developing country and should be prepared to present a

scientific paper in English. Preference will be shown to applicants less than age 45 years.

The deadline for receipt of applications for the award is May 1, 2007. The application and complete selection criteria can be obtained by contacting:

Elizabeth Berry-Kravis, MD, PhD
Chair, International Affairs Committee
Child Neurology Society
Rush University Medical Center
1725 W Harrison, Suite 718
Chicago, IL 60612
Elizabeth_M_Berry-Kravis@rush.edu

AU REVOIR, PITTSBURGH...BONJOUR, QUEBEC!, continued from page 1

people cannot attend?" To address that criticism, I would remind Society members that our meeting ends at 12:00 noon on Saturday, and that this committee does not plan substandard symposia. Please plan to stay through the end of the annual meeting; our committee will not disappoint you and neither will Quebec City.

So, as members of the Meeting Planning and Scientific Selection Committee plan next year's meeting (the revised nomenclature reflects a broadened mission and vision), we have altered the planning process and have asked for more input from the society. The committee reviewed an

impressive set of 26 symposia proposals submitted on-line by CNS members, from which fourteen were chosen for presentation in Quebec. By the time the April 4 abstract submission deadline comes around, much of the rest of the meeting content will be determined. We recognize our diversity, our collective thinking and our unique quest for knowledge, and we will strive to design a meeting that will meet the needs of all members of the Child Neurology Society. Our hope is that you leave the meeting remarking to yourself and others (bilingually, of course!) "this was one 'je me souviens!'" Don't forget that you need passports if coming from the US.

LEGISLATIVE AFFAIRS COMMITTEE REPORT

Bennett Lavenstein, MD, Chair

In this column in the past we have reviewed the activities of the CNS LAC. As we enter the new year with a new Congress we should address the future in view of the outcome of the fall elections. Before addressing any specifics it is important to remind the membership that the CNS, along with ANA and the AAN, sponsors the Ken Viste Neurology Public Policy Fellowship. To date we have not had a child neurologist avail themselves of this opportunity to spend a year in Washington working with a Congressman, Senator, congressional staffs and/or their respective committees to understand and participate in the drafting and passage of legislation at the federal level. Both Dr. Deborah Hirtz and I, who serve on the selection committee, would encourage individuals to explore this unique opportunity which is detailed at the AAN website, let us know and apply by October 15th if this is of interest.

With regard to the future, the composition of many Congressional committees has changed and clearly the chairmanships have rotated. In specific areas that politically impact child neurology, and children's health issues, new leadership has emerged providing opportunity to contact and speak with many in the House and Senate. Committees that ultimately set the course and determine outcomes include the Appropriations Committee, HELP Committee (Health Education Labor and Pension) Finance, Energy and Commerce Committee, and Ways and Means Committee. These committees in fact handle many issues on our agenda including Universal New Born Screening, Respite Care, Best Pharmaceuticals and Devices Practice Act, Medicare, Medicaid, Stem Cell research, and Child

Neurology workforce issues. We continue to participate with the HHS Committee on Universal Newborn Screening as criteria are defined to suggest the appropriate disorders and mechanisms to implement this nationally. We thank Senator Norm Coleman for his ongoing support of our requests for funds for the CNS workforce study and for the ability to collect the data that was most recently acquired under this grant by Dr. Jim Bale. We will continue to explore avenues that might be appropriate in maximizing the recruitment of bright individuals into child neurology. We continue to partner with the AAP on many common areas including access to specialty care, support for NIH funding, and reauthorization of the Children's Health Act. It has been a great source of pride that Dr. Martina Bebin was a Robert Wood Johnson fellow and spent over one year on Capitol Hill participating in legislative activities and that Dr. Eileen Ouellette has continued her interest with our committee despite her duties as president of the AAP this past year. Special thanks to Dr. Suresh Kotagal and his Minnesota delegation for all they do on quick notice representing our interests in child neurology. We welcome Dr. Patricia Duffner with her special expertise to our committee and her participation along with all the others who joined us in Pittsburgh at the annual meeting. Suggestions have been made that we continue with advocacy activities that involve parent groups/organizations and hope that we will meet with shared success in 2007. As I write the concluding words, I note that the House today just passed a bill for stem cell research! Please feel free to contact any of our committee members or myself with any ideas or suggestions that will continue to foster our success this year.