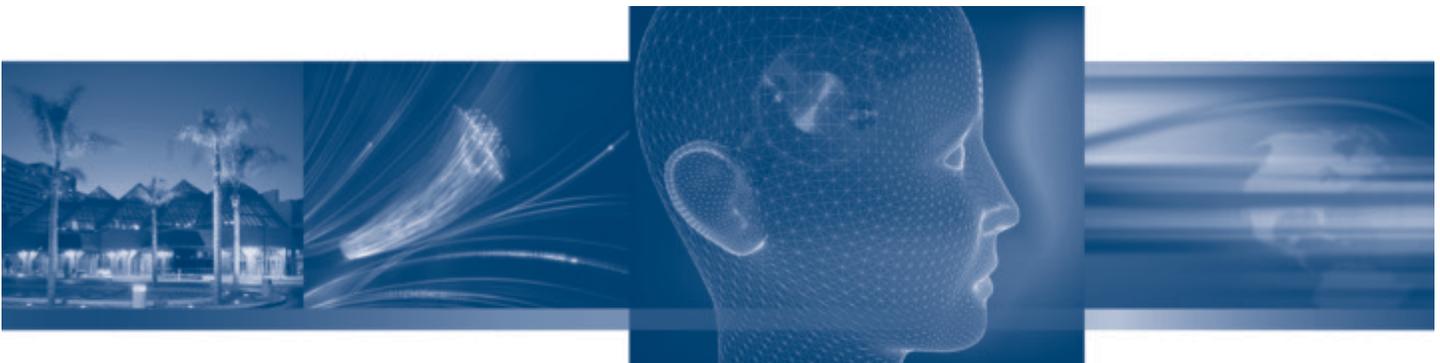




# NEWSLETTER

## REVIEWING SANTA CLARA, Previewing Louisville



In years to come, the 37th Annual Meeting of the Child Neurology Society will be remembered for three things: the excitement surrounding Barack Obama's election as President of the United States the night before the meeting opened; the energy and excitement generated by a record-setting 950 registrants feasting on a four-day serving of consistently well-crafted, well-executed symposia and seminars; and the notable lack of excitement to be found outside the convention center. Say what you will about Santa Clara, it knows how to keep attendees well rested and undistracted in a way that San Francisco, Boston and New Orleans never could. And while that might not always be desirable – once every 37 years seems about right – the ho-hum hub of Silicon Valley proved to be the perfect setting for showcasing an impressive line-up of sessions selected by Scientific Program Chair, Vinodh

Narayanan and his committee from among the 23 proposals submitted by CNS members on-line the previous winter. Proof of the program's excellence was evident in the scores and comments registered in the post-meeting CME survey – the highest set of scores ever tendered.

In most years, a composite average score of 4.2 out of a perfect 5 might set two or three of the symposia and, perhaps, another two or three breakfast seminars a head above the rest; this year, all nine breakfast seminars easily eclipsed that mark and three out of the five symposia followed suit, with a fourth just missing (at 4.19). Leading the honor roll of highly regarded sessions were Saturday's Neonatal Seizures and Neuroprotection symposium, the all-day Wednesday Neurobiology of Disease in Children Symposium on Cerebral Palsy, and Thursday

*Continued on page three*

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# CHILD NEUROLOGY SOCIETY

## From the President



John Bodensteiner, MD  
CNS President

As we move past the holidays, the Super Bowl and Presidents Day, I think a few reflections on the 37th annual CNS meeting in Santa Clara are in order. First of all, it was the largest meeting the CNS has ever had. We had over 950 registrants this year (the previous record was 875 at the 2006 meeting in Pittsburgh). Secondly, I think it is appropriate to thank Dr. Narayanan and his committee for the design and content of the program. I thought it was very informative, interesting and entertaining. The symposia were cogent and coherent as well. That certainly took a lot of work and time on the part of the committee and particularly the chairman. Third, I thought the venue was good. There was room enough for the posters and displays and they were close enough to the meeting rooms to be attended by everybody. I hope the increased emphasis on the posters was appreciated but we are always interested in constructive suggestions on how to do it better. I think it was considerate of the Santa Clara folks to avoid too many distractions in the immediate area so as to allow the attendees to focus on the meeting.

One of the issues that became apparent is that only about one half of the child neurologists passing Part II of the ABPN Examination have joined the CNS. This is a particularly distressing fact since with the implementation of the "Match" the number of child neurologists in training has almost tripled. If you know of junior child neurologists, in training or just finished training, please encourage them to join the CNS as the greater percentage of child neurologists represented, the stronger the voice of the organization. Thanks to a \$25,000 unrestricted educational grant from Questcor Pharmaceuticals, Inc., the 2009 meeting in Louisville will feature discounted registration fees for all Junior

Members of the CNS (\$50 discounts) and free registration for all Junior Members presenting papers or posters as the first author. I think perhaps increasing the numbers of young members will also insure that the issues addressed by the CNS leadership and Committees reflect the concerns of the membership. In this vein, I would suggest that any members who wish to participate on committees of the organization send your name to the national office. As each of the committees begins to define the terms of the members and develop mechanisms for regular and orderly turnover among the committee members, new members will be chosen largely from the list of those who have expressed a willingness to participate.

As you may remember, we had two eulogies at the Santa Clara meeting, for Krystyna Wisniewski and Bill DeMyer, and one of the lifetime achievement awardees, Niels Low, was also a posthumous award. Most of you know by now also that Dr. John Menkes has recently died. We are fortunate to have reflections written by long-time friends of all three of our colleagues appear in this issue. It may be instructive to remember those who have made many important contributions to our specialty in this small way. The fact that many of the many of the "old guard" are retiring makes the influx of the new trainees even more important if our subspecialty is to survive and prosper in the future.

Finally, a word of thanks to the many members submitting an impressive 41 symposia proposals for the 2009 Annual Meeting in Louisville. The quantity, quality and variety of submissions was truly remarkable and bodes very well for a scientific program in October that, against all odds, may surpass the excellence of last year's program in Santa Clara.



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## PREVIEWING LOUISVILLE, continued from page one

morning's Presidential Symposium on Ion Channelopathies. While the breakfast seminars were uniformly well-regarded, the top three scores went to sessions on The Future of Epilepsy Therapeutics (organized by Jong Rho, MD and supported by a grant from Ortho-McNeil Neurologics), Mitochondrial Disease (organized by Sumit Parikh, MD), and the ACNN-organized session on Telephone Triage (see page 14 for an update on the project). Individuals receiving notably high scores and rave reviews (i.e., cited as among the "meeting highlights") included Drs. Joseph Volpe, Peter Goadsby, Michael Johnston (Sachs Lecture), Frances Jensen and Renee Shelhaas.

Committee and Special Interest Group meetings continued to grow in numbers and energy and efforts are underway to carry the momentum from the meeting over onto the CNS website with workspaces for each committee and SIG featuring threaded discussion and document sharing functionality to encourage collaborative continuity.

Attendance by Junior Members of the CNS surged this year with, again, gratifying growth in numbers and energy being evident in the Junior Member Career Development Workshop organized by Meredith Golomb, MD (funded, in part, by an unrestricted educational grant from Questcor Pharmaceuticals, Inc.).

Finally, in the exhibit hall housing a record number of exhibitors and scientific posters, the Electronic Communication Committee, fronted by Drs. Mickey Segal, Steve Leber, and chair, Barry Kosofsky, hosted a demonstration booth showcasing the newly developed Case Studies section on the CNS website.

And so it goes: Santa Clara, perhaps the least memorable locale ever, played host to one of the most memorable, and certainly most successful, CNS Annual Meetings to date. A tough act for the 38th Annual Meeting in Louisville to top. But in the hometown of Churchill Downs and the Kentucky Derby, the smart money is betting that will happen. "With a year's experience under his belt and 41 symposia proposals to choose from, Vinodh Narayanan – riding his 25-member committee – is looking very strong out of the starting gate!" As well he should: Louisville, with its splendid museums and restaurants will prove to be a much more formidable competitor vying for his audience's attention. Watch for program updates on the CNS website and in the Spring newsletter. Registration material will be mailed out and posted on-line shortly after Memorial Day (hotel reservation link to the Marriott will go up in early May). And abstracts? That race has already begun, with the finish line just around the corner on April 7.

Go to [www.childneurologysociety.org](http://www.childneurologysociety.org) and submit an abstract. Remember: deadline is April 7.



REVIEWING SANTA CLARA, continued from page three



Drs. Mark Nespeca & Francis Filloux



(L-R): Drs. Isabelle Rapin, Max Wiznitzer, Sakkubai Naidu



San Francisco's Finest: Dr. Bruce Berg, 6th President of the CNS (1977-78) & CNS President-Elect Donna Ferriero



(L-R): Drs. Carl Crosley, Nina Schor, Leslie Morrison

Lifetime Achievement Awardee, Dr. Cesare Lombroso, and his protégé, Dr. Gregory Holmes



Bernard D'Souza International Fellowship Awardee, Dr. Ike Lagunju (from Ibadan, Nigeria) and her husband



CNS Executive Committee: (Seated, L-R): Drs. Donna Ferriero, John Bodensteiner, Nina Schor; (Standing, L-R): Drs. Jonathan Mink, Steven Leber, Wendy Mitchell, Robert Rust



Drs. Jin Hahn and Catherine Chapman



Drs. Harvey Singer & Robert Baumann



(L-R): Drs. Manikum Moodley, Michael Shevell, Barry Russman, and Annette Majnemer

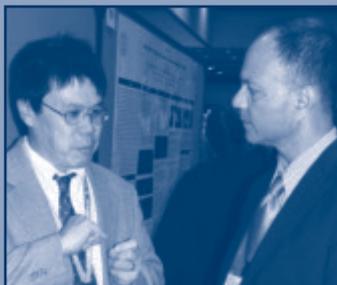


(L-R): Drs. Peter Berman, Dean Timmons, Michael Painter and Jean Holowach-Thurston (foreground) congratulate Dr. Stephen Ashwal following his Hower Award Lecture

Mary Margaret Low (wife) and Roger Low (son) accepted the Lifetime Achievement Award on behalf of Dr. Niels Low. Dr. Low passed away the previous year.



University of Michigan colleagues Drs. Renee Shelhaas and Steve Leber



Drs. David Hsu and Raj Sheth



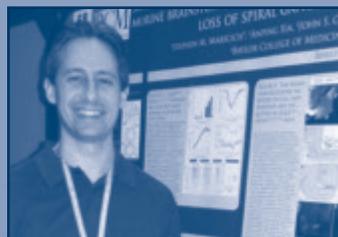
2008-09 CNS Scientific Program Chair, Dr. Vinodh Narayanan



Dona Bodensteiner & CNS President, Dr. John Bodensteiner



Dr. E. Anne Yeh



Dr. Stephen Marich

University of Rochester colleagues Dr. Jennifer Kwon and Amy Vierhile, RN, recipient of the 2006 ACNN Claire Chee Award for Excellence



Dr. Elizabeth Wells

(L-R): Drs. Frances Jensen, William Gaillard, Edward "Rusty" Novotny



2008

## AWARDS COMMITTEE

## CNS Awards Committee

## Bernard D'Souza International Fellowship Award

The Child Neurology Society is now accepting applications for the 2009 Bernard D'Souza International Fellowship Award, which will sponsor all expenses for a child neurologist from a developing country to attend the 38th Annual Meeting of the CNS to be held October 14-17, 2009 in Louisville, KY. 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, 2009. 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



CHILD NEUROLOGY SOCIETY

## Call for Abstracts

## 38th Annual Meeting

October 14-17, 2009  
Louisville Marriott Hotel  
Louisville, Kentucky

## On-Line

Submission Only  
Submit February 15 -  
April 7, 2009

Submission Deadline:  
April 7, 2009

For more information contact the CNS National Office at (651) 486-9447 or e-mail: nationaloffice@childneurologysociety.org

## Child Neurology Society International Visiting Professor Award

Applications are now being accepted for the 2009 International Visiting Professor Award for the Child Neurology Society (CNS).

The Objective of the award is to promote the discipline of child neurology in countries in which the existence of a child neurology sub-specialty is just beginning to emerge. Applications should come from active members of the CNS. Qualifications for the award should include:

- An established academic clinical reputation, as judged by the members of the CNS International Affairs Committee
- An area of clinical or academic expertise which would be of benefit to the host institution
- An ability and willingness to accommodate to the culture and conditions of the host country

The CNS will provide \$2,000 to defray travel expenses. Lodging expenses will be covered by the local authorities.

There are different avenues for selection of the host country. Applicants may arrange this, with the approval of the committee, or the committee can arrange a venue that the awardee finds suitable.

The deadline for receipt of applications is March 31, 2009. Applicants should submit a curriculum vitae and a letter describing the location to which they plan to travel, what they plan to accomplish during the visit, why this is of benefit, and information as to whether there is a plan for the host institution to accommodate the applicant. For further details please contact:

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

## AWARDS COMMITTEE

## CNS Awards Committee

2009 Philip R. Dodge Young  
Investigator Award

The Child Neurology Society announces an award for basic or clinical research by promising young investigators who are members of the Society. Applications will be judged on the basis of originality, scientific merit, succinctness and relevance. The recipient of the award will receive a grant-in-aid of \$20,000 and will be invited to present

their work at the 38th Annual Meeting of the Child Neurology Society, October 14-17, 2009 in Louisville, KY.

The deadline for receipt of applications is March 12, 2009. Go to Annual Meeting page of CNS Website for details.

### CHILD NEUROLOGY SOCIETY ANNOUNCES \$25K "Future Leaders Program" Grant from Questcor Pharmaceuticals, Inc.

The Child Neurology Society has received a \$25K grant from Questcor Pharmaceuticals, Inc. in support of the "Future Leaders Program" at the 38th Annual CNS Meeting held October 14-17, 2009 in Louisville, KY.

Program features include:

#### ■ Four Outstanding Junior Member Awards

- Awards are given to first/primary authors of the four top-ranked abstracts submitted by eligible Junior Members of the CNS.
- Junior Members of the Child Neurology Society enrolled in a three-year child neurology training program as of the April 7, 2009 abstract deadline are eligible.
- Award includes airfare and hotel as well as waived meeting registration fee
- Presentation of award (plaque) is made at the CNS Annual Business Meeting

#### ■ Waived Meeting Registration for ALL Junior Members in training whose abstracts are accepted for presentation (a minimum \$275 value).

- Junior Members of the Child Neurology Society enrolled in a three-year child neurology training program as of the April 7, 2009 abstract deadline are eligible.
- Must be first/primary author of accepted abstract

#### ■ \$50 Registration Fee discount for all Junior Members in training attending the meeting

#### ■ Reserved Registration for Friday *Junior Member Career Development Seminar*

## UPDATE:

# Practice Committee

## Vigabatrin Passes FDA Advisory Committee Vote

BY ERIC KOSSOFF, MD

On January 7th and 8th, 2009, the FDA Peripheral and Central Nervous System Drugs Advisory Committee met at the Hilton Washington DC in Rockville, Maryland. The purpose of this meeting was to decide if the committee would recommend vigabatrin for approval in the United States, with the indication discussed on January 8th being infantile spasms. As many child neurologists are no doubt aware, vigabatrin is not licensed in the United States for infantile spasms, but is available throughout much of the rest of world. Parents of children with infantile spasms, especially those with tuberous sclerosis complex, have had to obtain vigabatrin from Canada, Mexico, or elsewhere if prescribed.

I had the pleasure and honor to represent the Child Neurology Society at the afternoon “open hearing session” of this meeting. During this approximately 1-hour session, speakers were given a maximum of 3 minutes to present their opinions about this indication for vigabatrin. I was one of about 20 speakers, including Dr. Jeff Buchhalter (representing the Epilepsy Foundation), Dr. Elizabeth Thiele (J. Kiffin Penry Minifellowship), Dr. Steven Schachter (American Epilepsy Society), Dr. Joyce Cramer (Epilepsy Therapy Development Project), and others, including several parents of children with tuberous sclerosis complex representing the Tuberous Sclerosis Alliance.

Speaking on behalf of the CNS, and its President, Dr. John Bodensteiner, I highlighted the tremendous difficulty our membership has at this time in treating infantile spasms, a devastating disorder with potential long-term developmental

impact. As child neurologists in the United States primarily use corticosteroids (ACTH and prednisolone) first-line due to their “probably effective” designation by the 2004 joint Child Neurology Society and American Academy of Neurology Practice Parameter, and vigabatrin was deemed “possibly effective” (yet not available), our choices are limited. There is clearly an unmet clinical need and vigabatrin appears to have a role. Despite risks, the Child Neurology Society supported its approval and availability for United States child neurologists to have it as an option. I closed by thanking the FDA for their thorough and comprehensive review to keep our drugs safe.

At the end of the long day’s testimony, the FDA panel voted 23-0 in favor of recommending the FDA approve vigabatrin for infantile spasms. This was clearly a victory for child neurologists and their patients in the United States. I was impressed especially by the large number of child neurologists present at this meeting – at least 20 by my count in a room of approximately 120. Other than those at the open hearing session, Drs. Jack Pellock, Jim Wheless, and Don Shields gave scientific presentations earlier in the day. Several other child neurologists were invited FDA advisory committee members for this vote. All of us had traveled to Washington despite busy schedules for this important day of advocacy, which demonstrated to me personally what an important influence on health care policy we have as child neurologists.

## CHILD NEUROLOGY SOCIETY In Memoriam



1930-2008

### KRYSZYNA E. WIŚNIEWSKI, MD, PHD

**K**rystyna Wiśniewski, a long-time colleague and friend, passed away May 30, 2008, from complications of endometrial cancer, and her death caused an irreplaceable loss for her family, friends, child neurology and the whole scientific community. She was born in Poland, and there graduated from the Medical School in Gdansk, completed a residency in pediatrics, a fellowship in neuropathology, and was awarded a Ph.D. degree by the Polish Academy of Sciences in Warsaw in 1965.

In 1967 she came to the United States with her two sons to join her husband, Henry.

Between 1970 and 1974, she completed residencies in pediatrics and pediatric neurology in the Bronx, New York, and at the same time worked as a neuropathologist at the Albert Einstein College of Medicine, Bronx, New York.

After two years' sabbatical in England, Newcastle upon Tyne, she returned to the United States in 1976 and assumed the position of Associate Director of Clinical Services, and Head of Pediatric Neuropathology/Ultrastructural Laboratory at the New York State Institute for Basic Research in Developmental Disabilities, Staten Island, New York. She also worked part-time as an attending child neurologist at the Downstate Medical Center, Brooklyn, New York, and resigned from that position only a few months before her death. She was a devoted physician and an excellent teacher with vast knowledge in neuropathology of childhood neurodegenerative disorders.

In her research, she focused on Down syndrome and Batten disease and made many contributions to a better understanding of their pathogenesis as well as their treatment. She was instrumental in the development of the first therapies for children with Batten disease, i.e., stem cell and gene therapy. Her research led to over 200 publications, including 30 book chapters and two books.

She was an extraordinary woman and a friend to many of us who were lucky to know her. Throughout her life she simultaneously played numerous roles and excelled at every one of them. It is amazing to think that one person could be an ultimate mother, researcher, teacher and physician all at the same time. Krystyna and her late husband, Henry, contributed to preserve Polish-American cultural heritage. Also, they created the Wiśniewski Neuroscience Foundation for young Polish scientists that will continue to support the work of exceptional Polish scientists.

With the death of Krystyna, we have lost not only a neuropathologist and child neurologist who significantly advanced our knowledge of Batten disease and Down syndrome, but also an unforgettable friend.

*by Maria Gieron-Korthals, MD*

## CHILD NEUROLOGY SOCIETY In Memoriam



### JOHN HANS MENKES, MD

On 22 November 2008 in Los Angeles, California, one month short of his 80th birthday, the world of paediatric neurology lost an icon and one its contemporary fathers, and the World at large lost a true Renaissance Man – physician; scientist; playwright; philosopher; connoisseur of good literature, art, music and food; humanist and liberal thinker who deplored discrimination, intolerance, prejudices and false values of all types. The life he lived was as interesting and inspiring as were his contributions to paediatric neurology and his understanding of the world around him, both medical and social. He succumbed to colonic carcinoma and complications of chemotherapy.

John Menkes was born in 1928 in Vienna, Austria; he faced years of discrimination and racism for being Jewish. In 1939, just days before Germany initiated World War II in Europe, John and his parents were fortunate to be able to go to Ireland, where John attended school. The rest of his family that remained in Austria perished. He eventually immigrated to the U.S. and graduated high school in California. He earned a B.S. and M.S. degree in organic chemistry at the University of Southern California and attended medical school at Johns Hopkins University in Baltimore. During his internship he clinically described maple syrup urine disease and later biochemically defined the disease in another patient while a paediatric resident at Johns Hopkins University.

In 1957 he began a paediatric neurology fellowship at the New York Neurological Institute of Columbia University under the direction of Sidney Carter and H. Houston Merritt. He continued biochemical studies as

well and described a form of tyrosinosis and X-linked kinky hair disease, later to bear his eponym and initiating a lifelong interest in disorders of copper metabolism. Returning to Johns Hopkins, he pursued more clinical training in paediatric neurology under the tutelage of David Clark. In 1966 he was offered a faculty appointment at UCLA to establish the first Division of Paediatric Neurology on the U.S. West Coast, where he recruited many prominent researchers. There he spent the rest of his long career, actively practicing, taking call on the paediatric neurology service, teaching and also maintaining a small private practice until almost the end of his life despite a chronic terminal illness and with “emeritus” status since 1989..

John was an ideal role model for younger colleagues and trainees. His patience and firm but gentle manner with patients were legendary. He was always smiling and never angry. Despite what he and his family had suffered at the hands of a Nazi Austrian government in his childhood, when offered his Austrian citizenship back more than a half-century later, he graciously accepted it to become a dual U.S. and Austrian citizen and he even accepted an invitation to lecture at the University of Vienna Medical Faculty, to demonstrate that old wounds must heal and that the present generation not be blamed for sins of the previous, even if they were direct descendents. Such was the generosity and lack of resentfulness of this man.

I first met John Menkes in Toronto in 1975, at the first congress of the new International Child Neurology Association (ICNA). We became close friends and colleagues despite our generation gap. It was a great personal

honour to be invited by John in 1998 to co-edit the 6th edition of his textbook and subsequent editions; an even greater honour was John's friendship. John was always more concerned about the feelings and opportunities of others than about his own sentiments. He celebrated the successes of others, especially those of his colleagues and trainees, rather than feeling jealous or competitive. His scientific and medical publications, both original peer-reviewed articles and invited reviews and textbook chapters, number more than 200, but perhaps he is best known for his classical textbook, *Child Neurology*, the first edition published in 1974. The 8th edition, still in preparation at the time of his death, will be published posthumously.

He participated in many international and national professional meetings throughout the world and was well known and venerated in Canada and throughout Latin America, Europe and Australia.

Apart from his medical and scientific contributions, John Menkes was a published playwright. His novels and plays include titles, "The Angry Puppet Syndrome" (a story about adverse effects of a medication and how they affect people's lives), "After the Tempest" (a play about opposing sentiments amongst Jews in Vienna just after the War) and "Views of Fuji" (a love story about a man who developed cancer). He owned a house in Wales, where he used to isolate himself 3-4 months annually to do his creative non-medical writing. He was a voracious reader and a master chess player as well. He loved wildlife and was especially fascinated by whales. John's favourite philanthropic organizations were Medecins sans Frontiers (Doctors without Borders),

World Wildlife Federation and CalArts, a college for art students. He was devoted to his loving wife Myrna and she remained equally devoted to him.

One of the highlights of my own life is to have known this gentle, patient, authentic, sincere and brilliant man and to have been inspired by his life and work. The World, our discipline of paediatric neurology and I personally miss him greatly and remember him fondly.

*Contributed by  
Harvey B. Sarnat M.S., M.D., F.R.C.P.C.  
Calgary, Alberta, CANADA  
6 December 2008  
An unabridged version of this tribute will  
appear in the Journal of Child Neurology.*

## CHILD NEUROLOGY SOCIETY In Memoriam



1924 – 2008

### WILLIAM DEMYER, MD

I have the sad task of relating Bill DeMyer's passing on September 1, 2008 at the age of 84. Dr. DeMyer passed away six months after falling ill with colon cancer. From the time of diagnosis until his death, he came to work, saw patients, completed and edited his new book on history taking, and taught his final two-month-long, five-day-per-week resident neuroanatomy course. He completed the course on Sept 1st.

That Dr. DeMyer would accomplish so much at the end surprised no one who knew or worked with him. Dr. Mark Dyken fondly relates the story of Bill as a neurology resident being the preeminent neuroanatomy expert at Indiana University. His first publication, 55 years ago as a resident, dispelled the notion that procainamide altered the course of Huntington disease. He was Indiana University's first tenure-track neurologist. His subsequent research resulted in four major contributions. First, his neuroanatomic studies using silver stains and other methods defined the details of the medullary pyramids and larger corticospinal tracts. His subsequent work with Wolfgang Zeman provided us with the modern nosology of Pelizaeus-Merzbacher disease, and with Ed Hodes he provided the clinical framework that allowed Ed's lab to isolate the first *PLP1* genes mutation in humans. While doing this, he worked with his wife, Marian DeMyer. Marian, who is Professor Emeritus of Child Psychiatry at Indiana University, and Bill published together on childhood autism, and helped dispel the myth of the refrigerator mother in this disorder.

Finally, Dr. DeMyer's landmark early clinicoanatomic research on holoprosencephalies and median cleft face syndrome (DeMyer sequence), and subsequent expansion of that research,

provided us the framework on which our clinical and molecular understanding of these disorders now hangs. His pithy summation, that "the face predicts the brain" both affirms and belies the elegance of his work.

Always the teacher, he expanded his teaching far beyond local students and residents. Through his timeless programmed text *Techniques of the Neurologic Examination*, first published in 1969 and now in its fifth edition, he taught the neurologic examination to a large proportion of the members of the CNS. His aforementioned new text, and a chapter in Dr. Maria's *Current Management in Child Neurology* are being published posthumously.

For those of us who feel that this seems all very one dimensional, Bill also had some time on his hands away from IU. Taking up tennis at age 27, he was nationally ranked as an amateur player, and played until 2007. Besides raising a family, he and Marian also started ballroom dancing... at age 50. They participated in various national championships over the years and and built – then ran – a dance a dance ballroom until 2006.

I'd like to close where I started. Dr. DeMyer was voted the outstanding teaching professor at IUSM multiple times in his 50 year career. I consider him my friend, as much as one can befriend one whom one holds in awe. He taught me, and many in the CNS, how to be a neurologist, and those of us who knew him carry with us his example of living, working, and practicing with a grace to which most only can aspire. He was a good man, and we miss him.

by Laurence E. Walsh, MD

## UPDATE:

# The Claire Chee Award for Excellence in Child Neurology Nursing



The Claire Chee Award for Excellence in Child Neurology Nursing was established by the Association of Child Neurology Nurses in the year 2000. This award, given annually, recognizes and honors the nurse who, *as a member of the ACNN*, has rendered distinguished service within the profession of child neurology nursing.

The recipient is one who demonstrates, through strength of character and competence, a commitment to the care of children and their families with neurological disorders. She/he is acknowledged by her/his peers as one who renders qualities of compassion, resourcefulness, leadership, knowledge, communication, and inspiration.

Candidates for the Award for Excellence may be submitted by any member of the Association of Child Neurology Nurses or the Child Neurology Society to the Award Committee. The Award Committee will evaluate the nominations and determine the most deserving candidate for the year. The Award will be presented at the Annual Meeting of the Association of Child Neurology Nurses.

Please submit nominations by April 30, 2009 using the ACNN nomination form posted on the CNS website Annual Meeting page; you may also request a copy directly from Tamara H. Langhoff, RN, MS, CPNP (tlanghoff@mcw.edu).

## Practice Committee

PLEASE BE AWARE OF THE FOLLOWING SYNDROME:

### Brown-Vialetto-Van Laere Syndrome (BVVL)

A progressive neurodegenerative motor neuron disorder, BVVL specifically includes palsies of the cranial nerves. Onset of symptoms varies from infancy to the third decade. Typically, the first recognizable symptoms can include a variety of the following:

- vocal cord paralysis
- ptosis, facial weakness
- slurred speech
- dysphagia
- visual difficulty secondary to optic atrophy
- neck and shoulder weakness
- limb weakness
- autonomic dysfunction
- respiratory compromise.

However, sensorineural hearing loss is a primary component of the syndrome, and it may not be discovered until late in children due to the mildness of the hearing loss or the

more obvious symptoms that manifest first. If the other palsies have manifested without hearing loss, then the syndrome is referred to as Fazio-Londe syndrome.

BVVL shares similar characteristics that are also found in ALS, SMA, Madras motor neuron disease (MMND), Athabaskan syndrome and Moebius syndrome, among others. Sometimes a more general descriptive term such as "bulbar palsy" is used without regard to etiology. Currently a worldwide identification and sample collection is underway, and more patients are needed to participate in the research to isolate the gene for BVVL.

If you are interested in having a patient participate in the collection, please email [info@bvvlinternational.org](mailto:info@bvvlinternational.org) or view a more comprehensive review of the syndrome at [www.bvvlinternational.org](http://www.bvvlinternational.org).

## FOCUS ON RARE SYNDROMES

Beginning with this issue we will regularly feature a capsule summary of a rare and unusual syndrome child neurologists should be aware of in their practice.

Submissions from CNS members, as well as from affiliated interest groups or non-profit parent/patient support and research groups are welcome.

Send to:  
[nationaloffice@childneurology.society.org](mailto:nationaloffice@childneurology.society.org)



## UPDATE:

# The Child Neurology Telephone Encounter Guides: An ACNN and CNS Collaborative Project

BY JULIE M. SPRAGUE-MCRAE MS, RN, PNP-BC

Imagine for a moment, a perfect child neurology world. All of the fellowships are filled to capacity. There is same day access for urgent and two week access for non-urgent appointments. There are a bountiful number of pediatric registered nurses, clinical nurse specialists, nurse practitioners and physician assistants with child neurology specialty training and extensive experience. Well... it is not a perfect world for child neurology.....

Child neurology is an impacted pediatric specialty. The national shortage of child neurologists presents a challenge for timely access to child neurology services. The Child Neurology Workforce Study (Polsky & Weiner, 2003; Polsky et al., 2005) found that new patients wait an average of 49-53 days for an initial consultation appointment. Compounding the access issue is the geographical distribution of child neurologists in the United States. For example, in the northeast, there is a higher percentage of child neurologists (1.4-1.6 per 100,000 children) than in the West (.71- 0.8 per 100,000 children).

With the rising cost of health care and the need to thoughtfully utilize resources, innovative, multidisciplinary and collaborative efforts can be part of the solution to providing adequate access to child neurology services. In an impacted practice, innovative practice models can improve earlier and timelier access to child neurology care.

Telephone management is one strategy for providing care to children with complex chronic illness (Letourneau et al., 2003). This management however, must be done by skilled professionals with specialized child neurology training. Since many pediatric clinicians are generalists, initial training usually occurs in an apprenticeship format. A collection of specialized child neurology

educational reference content is needed for new or less experienced registered nurses and advanced practice clinicians (PNP, CNS or PA), medical students and rotating house staff.

At the Child Neurology Society's request, the Association of Child Neurology Nurses has developed a collection of Child Neurology Telephone Encounter Guides. The project was initiated in 2005 and during the 2007 meeting in Quebec, a prototype for Epilepsy was presented to the Child Neurology Society's Executive Board. The guide was well received and the Association of Child Neurology Nurses Clinical Practice Committee was encouraged to move forward. During 2008, in collaboration with our Child Neurology Society liaison, Dr. Leslie Morrison, we expanded the project's scope, developing 11 Child Neurology Telephone Encounter Guides. Content was extensively reviewed by clinicians throughout the United States and Canada. Nursing practice was peer reviewed by ACNN registered nurses, pediatric nurse practitioners and clinical nurse specialists and medical content was reviewed by CNS affiliated child neurologists. Participating nursing clinicians and physicians have been recognized within each Telephone Encounter Guide.

The Child Neurology Telephone Encounter Guides are designed with an emphasis on process oriented rather than acute triage and a focus on nursing case and care management. This design takes into consideration the differences in practice site culture, resources and provider and nursing preference. They are presented as a three part collection with an educational topic overview, a quick reference pocket guide and a data tool. The educational topic overview is a great resource for new, less experienced or rotating staff (cross-covering

float nurses, medical students or house staff). The pocket guide is a quick reference resource for those previously familiar with the educational topic overview. The data tool is offered as a worksheet to guide the telephone encounter or it can be adapted for electronic charting, protocol development, quality management and staff educational training.

The Child Neurology Telephone Encounter Guides can be used in a private, managed care or tertiary level child neurology practice. They also operate on a number of levels depending upon the focus of the call, issues that arise, the clinician's scope of practice and child neurology provider, nursing and practice site preference.

They can be used on a primary level for basic data collection or in an impacted practice, on a secondary level for a detailed assessment to determine acuity and priority for evaluation or follow-up. If a practice chooses, they can operate on a tertiary level for an interval history or pre-evaluation history. This is the most innovative application, improving access to real-time health care interventions, maximizing the child neurology provider's time, enhancing patient evaluation and management efficiency and expanding office patient care time. Since the Child Neurology Telephone Encounter Guides complement the office visit, they share a similar structural design.

The Child Neurology Telephone Encounter Guides focus on assessment, not diagnosis and the interventions are based upon the clinician's scope of practice. Acuity decisions are deferred to an individual practice as well as preferences for level of use and other procedures such as standing orders and pre-evaluation criteria. They are also designed for "licensed" personnel and the action plans require consultation with a child

neurology provider based upon outlined criteria. If however, the clinician handling the call is an advanced practice clinician (NP or PA), the interventions are more independent, but in alignment with scope of practice and state licensing regulations. Ultimately however, the clinician handling the telephone encounter judges how much or how little of the Telephone Encounter Guide to utilize and what to defer to an office visit. This is determined by the purpose of the call, identified concerns and again, the clinician's scope of practice.

In the fall, we showcased the Child Neurology Telephone Encounter Guide project during the 2008 CNS meeting in Santa Clara. The project generated a great deal of enthusiasm among physicians and nurses as there is currently no consolidated child neurology educational content designed for registered nurses or advanced practice clinicians (NPs, CNS, or PAs). Several academic affiliated physicians identified an urgent need for this content within their own child neurology programs recognizing the benefit for not only nursing staff, but for medical students and residents.

We met with the Executive Boards of the Child Neurology Society, Child Neurology Foundation and Child Neurology Nurses Association to further explore options for dissemination. At the end of the week, nurse practitioners Ruth Rosenblum and Maria Chico along with Dr. Leslie Morrison and I presented "Responding to Phone Calls: Telephone Triage and the Telephone Appointment Visit" at one of the CNS sponsored Breakfast Seminars.

Plans to publish the Child Neurology Telephone Encounter Guides are underway and they should be available for purchase by early summer. We will offer two books. The comprehensive edition of the Child

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TELEPHONE ENCOUNTER GUIDELINES, continued from page fifteen

Neurology Telephone Encounter Guides will include 11 educational topic overviews, data collection tools and quick reference guides. This will be available in soft cover and eBook. The quick reference edition, the Child Neurology Telephone Pocket Guides will cover 11 topics and be available in a pocket sized soft cover.

On one last note, we want to recognize the incredible team of registered nurses, advanced practice nursing clinicians (clinical nurse specialists and nurse practitioners), nursing students and child neurologists that participated as content authors, contributors, reviewers and editors. Thank you for your input as we created this educational collection to help care for child neurology patients and their families.

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