



# NEWSLETTER

## CHILD NEUROLOGY SOCIETY 35<sup>th</sup> Annual Meeting Program Preview



### 35th Annual Meeting

October 18-21, 2006

Davis L. Lawrence Convention Center/Westin Convention Center Hotel

Pittsburgh, PA

#### Wednesday, October 18

7:30 AM - 5:30 PM

#### NEUROBIOLOGY OF DISEASE IN CHILDREN SYMPOSIUM

##### Spinal Muscular Atrophy

Supported by grants from the National Institutes of Health (NIH grant 1 R13 NS40925-01), Families of Spinal Muscular Atrophy, the Claire Altman Heine Foundation, Inc., and the Child Neurology Society.

##### CME ACTIVITY

Moderator: Bernard L. Maria, MD, MBA, Jeffrey Edwin Gilliam Chair and Executive Director of the Children's Research Institute, Medical University of South Carolina, Charleston, SC

7:30 AM – 7:45 AM

##### Introduction and Statement of Goals

Bernard L. Maria, MD, MBA

##### CLINICAL NEUROLOGY OF SMA

Moderator: Susan Iannaccone, MD, FAAN  
University of Texas Southwestern Medical Center, Dallas, TX

7:45 AM – 8:15 AM

##### Historical Descriptions of SMA

Victor Dubowitz, MD, PhD, FRCP, DHC  
Hammersmith University London, UK

8:15 AM – 8:45 AM

##### Clinical Classification and Disease Heterogeneity

Barry Russman, MD  
Oregon Health & Science University Portland, OR

8:45 AM – 9:30 AM

##### Modern Diagnosis and Management

Tom Prior, PhD  
Ohio State University Columbus, OH  
AND  
Susan Iannaccone, MD

9:30 AM – 9:50 AM

##### Question and Answer Session

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# CHILD NEUROLOGY SOCIETY

## From the President



Ann Tilton, MD  
CNS President

### Springing Forward to Fall

It is hard to believe, with spring having barely arrived, that preparations are well underway for the annual fall meeting in Pittsburgh scheduled in mid-October. Final ACCME approval of the scientific program, followed by distribution of registration information via regular mail and on-line registration for the meeting will all unfold over the course of the next month. This year's meeting offers an exciting scientific program in what truly is an exciting venue. As everyone who has been to Pittsburgh in recent years knows, it is a remarkably vibrant and inviting "renaissance city," much different than the city you may remember or may only have read about from decades ago. A hearty round of applause goes out to Mary Curry and Roger Larson for the very extensive and largely invisible preparatory work they perform year-round to ensure the success of this and every CNS annual meeting. Mary's comprehensive oversight of the annual meeting goes back to the very first gathering in Ann Arbor in 1972. Roger's work with the scientific program committee and with exhibitors dates back to the Halifax meeting in 1988. With next year's meeting set for Quebec City and the following year scheduled to be held in Santa Clara, they are currently setting their sights on the 2009 meeting, all the while maintaining their focus on the innumerable background details requiring immediate attention to ensure the success of this year's meeting, a meeting first envisioned three or four years ago.

There are, of course, a number of others working hard behind the scenes this year and every year. Foremost among these are the CNS Awards Committee, chaired this year by Philip Pearl, and charged with selecting the Sachs, Hower, and Young Investigator Award recipients, and the Scientific Selection Committee, chaired by Gary Clark. Gary's appointment, like each of his predecessor's, is for two years. The two year rotation of chairs on this committee, bolstered by the extraordinary multi-year commitment and collective wisdom afforded by its 12-14 committee members, strikes a much needed balance of continuity and originality. Gary's two-year appointment gives him the creative license and flexibility to design an educational curriculum on a larger canvas than one year would afford; what can't be scheduled this year in a tight three-day framework can be planned for the following year; breakfast seminars that "show" well this year, based on attendance and survey feedback may "grow" into a full scientific symposium next year; ideas generated by the many Special Interest Group meetings scheduled during the annual meeting may be pitched to the Scientific Program Chair and/or Committee on-site or in correspondence soon after; well-thought out and clearly articulated suggestions entered in the post-meeting on-line survey regarding prospective sessions or speakers may spark a "conversation" that bears fruit, if not the next year, then in subsequent years as Gary passes on to his successors the resources and insights gained from two years on the front line.



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The goal, for Gary and for his committee, is to weave a coherent program choreographing some of the best new work being done on the bench top with the best new practices being developed and offered to our patients in the exam room and at bedside. As any past chair of the committee can attest, this is a truly daunting and draining responsibility, all the more so given the growing diversity of sub-specialty interests within our subspecialty of child neurology. Recognizing this growing diversity of interests and needs, and the limited framework the annual meeting provides to meet them, we are moving toward development of a program committee with a better balance of representation from the full spectrum of "bench top" to private practice neurologists that make up the Society's membership. This, along with the splendid opportunity

afforded attendees to review the 150+ abstracts selected from the roughly 250+ abstracts submitted each year, will ensure the continued vitality of the CNS Annual Meeting.

Quickly, on a separate topic: in my last letter I discussed work done by representatives of the CNS and the CNF to clarify their relationship and move toward bringing the two entities and their separate but complimentary missions closer together. This is an important and attainable goal for the next two years. Under the sage direction of Carl Crosley, a task force meeting in Chicago earlier this month made significant progress toward meeting this goal.

Sincerely,



Ann H. Tilton, MD

## NEW WEB RESOURCE FOR EPILEPSY RESEARCH OPEN FOR BUSINESS

Go to: <http://www.epilepsyresearchresource.org>



American Epilepsy Society **CURE** Epilepsy Foundation **Tuberous Sclerosis Alliance** The Epilepsy Therapy Development Project **FACES** Milken Family Foundation **NINDS** **PACE**

# RESOURCES IN EPILEPSY RESEARCH

HOME ABOUT FUNDING CURRENT RESEARCH

Login

### Resources in Epilepsy Research

This resource was developed by a group of organizations with the common pursuit of finding a cure for epilepsy. A listing of the organizations currently participating in this resource can be found under the "About" tab.

This site is designed to help to match researchers with the proper funding opportunities. This online database is a comprehensive listing of all available funding through these organizations with instructions on how to apply for funding consideration as well as links to more information. To see a listing of funding opportunities, click on the "Funding" tab.

In addition to matching researchers with funding, this site keeps an inventory of all currently-funded research in order to encourage project collaboration and ensure that there is not duplication in research. To see a listing of currently funded research by all the participating organizations, click on the "Current Research" tab.

Many thanks to the participating organizations for keeping their information up-to-date.

# CHILD NEUROLOGY SOCIETY 35th Annual Meeting Program Preview

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## **Wednesday, October 18 continued**

9:50 AM – 10:20 AM

### **Break**

### **MOLECULAR MECHANISMS IN SMA**

Moderator: *Christine J. DiDonato, PhD*  
Northwestern University  
Chicago, IL

10:20 AM – 10:50 AM

### **Molecular Mechanisms in SMA**

*Charlotte Sumner, MD*  
National Institutes of Health  
Bethesda, MD

10:50 AM – 11:20 AM

### **SMN Function in the Cell**

*Stephen Kolb, MD, PhD*  
Hospital of the University of Pennsylvania  
Philadelphia, PA

11:20 AM – 11:50 AM

### **SMN and Neurodevelopment**

*Christine Beattie, PhD*  
Ohio State University  
Columbus, OH

11:50 AM – 12:20 PM

### **Animal Models of SMA**

*Christine J. DiDonato, PhD*

12:20 PM – 12:40 PM

### **Question and Answer Session**

12:40 PM – 2:05 PM

### **Lunch**

### **TRANSLATIONAL RESEARCH**

Moderator: *Kathryn Swoboda, MD*  
University of Utah  
Salt Lake City, UT

2:05 PM – 2:35 PM

### **Search for Active Compounds**

*Christopher E. Henderson, PhD*  
Columbia University  
New York, NY

2:35 PM – 3:05 PM

### **Use of Animal Models in Preclinical Testing**

*Arthur Burghes, PhD*  
Ohio State University  
Columbus, OH

3:05 PM – 3:35 PM

### **Human Trials**

*Kathryn Swoboda, MD*

3:35 PM – 3:55 PM

### **Question and Answer Session**

### **FUTURE DIRECTIONS**

Moderator: *NINDS Program Director, Jill Heemskerk, PhD, Bethesda, MD*

3:55 PM – 4:50 PM

### **Panel Discussion**

*Darryl De Vivo, MD, Columbia University, New York, NY*  
*John T. Kissel, MD, Ohio State University, Columbus, OH*  
*Mary Schroth, MD, University of Wisconsin Hospital, Madison, WI*  
*Sakamuri V. Reddy, PhD, Medical University of South Carolina, Charleston, SC*  
*Douglas Kerr, MD, PhD, The Johns Hopkins Hospital, Baltimore, MD*

4:50 PM – 5:00 PM

### **Closing Comments**

*Bernard L. Maria, MD, MBA*

6:00 – 8:00 PM

### **Opening Reception**

8:00 – 10:00 PM

### **Movement Disorders**

8:00 – 10:00 PM

### **Independently Staged/ Accredited Satellite Symposium**

*Sponsored by UCB Pharma*

**Thursday, October 19**

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7:00 – 8:30 AM

**Breakfast Seminar 1: Drooling***Organizer: Peter Blasco MD, Child Development & Rehabilitation Center, Portland, OR***Breakfast Seminar 2: Epilepsy Case Management***Doug Nordli, MD, Children's Memorial Hospital, Chicago, IL***Breakfast Seminar 3: RVU's and You***Carmela Tardo, MD, Children's Hospital of Louisiana, New Orleans, LA*

9:00 – 12:00 NOON

**Symposium II: Presidential Symposium: Cerebral Palsy***Organizer: Ann Tilton, MD, President, CNS  
Speakers: Leland Albright, MD, University of Pittsburgh, Pittsburgh, PA  
Janice Brunstrom, MD, St. Louis Children's Hospital, St. Louis, MO  
Terrance Edgar, MD, Marshfield Clinic, Marshfield, WI  
Mauricio Delgado, MD, Texas Scottish Rite Hospital, Dallas, TX*

12:00 - 1:30 PM

**Poster Session 1: A, B, C, D**

1:30 – 3:00 PM

**Symposium III: Neonatal Neurology***Organizer: Frances Jensen, MD, Children's Hospital, Boston, MA  
Speakers: Michael Johnston, MD, Kennedy Krieger Institute, Baltimore, MD  
Donna Ferriero, MD, University of California San Francisco, San Francisco, CA  
Frances Jensen, MD,  
Kevin Staley, MD, Denver Children's Hospital, Denver, CO***Symposium IV: Early infantile epileptic encephalopathies — a "Interonopathy?"***Organizer: Edward Novotny, MD, Yale University, New Haven, CT  
Speakers: William Dobyns, MD, PhD, University of Chicago, Chicago, IL  
Harry Chugani, MD, Children's Hospital of Michigan, Detroit, MI  
Gary Mathern, MD, UCLA, Los Angeles, CA  
Jeff Golden, MD, CHOP, Philadelphia, PA*

3:30 – 5:30 PM

**Platform Session 1: Malformation and Tumors of the Developing Nervous System"****Platform Session 2: Epilepsy and Epileptic Syndromes****Moderated Poster Session: Epilepsy***Edward Novotny, MD, Yale University, New Haven, CT*

6:00 – 10:00 PM:

**Independently Staged/  
Accredited Satellite Symposium***Sponsored by Abbott Pharmaceuticals***Friday, October 20**

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7:00 – 8:30 AM

**Breakfast Seminar 4: Neurologic Manifestations of Inborn Errors of Metabolism***Organizer: Amy Goldstein, MD, University of Pittsburgh, Pittsburgh, PA***Breakfast Seminar 5: Feeding Dysfunction***Organizer: Brian Rogers, MD, Oregon Health Sciences University, Portland, OR***Breakfast Seminar 6: Neurology of Famous Musicians: In Words and Music***Organizer: Phillip L. Pearl, M.D., Children's National Medical Center, Washington, DC*

9:00 AM – 10:00 AM

**Phillip R. Dodge Young  
Investigator Award Lecture****Bernard Sachs Lecture**

# CHILD NEUROLOGY SOCIETY 35th Annual Meeting Program Preview

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## **Friday, October 20 continued**

10:00 AM – 12:00 NOON

### **Symposium V: Leukodystrophy**

*Organizer: Adeline Vanderver, MD, Children's National Medical Center, Washington, DC*

*Speakers: Prof. Marjo van der Knaap, Amsterdam, The Netherlands*

*Sakku Bai Naidu, MD, Kennedy Krieger Institute, Baltimore, MD*

*James Garbern, MD, Children's Hospital of Michigan, Detroit, MI*

*Adeline Vanderver, MD*

*Hugo Moser, MD, Kennedy Krieger Institute, Baltimore, MD*

12:00 NOON – 1:30 PM

### **Poster Review: E, F, G, H, I, J**

1:30 – 3:00 PM

### **Symposium VI: Stroke and Epilepsy**

*Organizer: Elaine Wyllie, MD, Cleveland Clinic Foundation, Cleveland, OH*

*Speakers: John Lynch, MD, NIH, Bethesda, MD*

*Neil Freidman, MD, Cleveland Clinic Foundation, Cleveland, OH*

*Jack Pellock, MD, Medical College of Virginia, Richmond, VA*

*Elaine Wyllie, MD*

1:30 – 3:00 PM

### **Symposium VII: Sleep**

*Organizer: Suresh Kotagal, MD, Mayo Clinic, Rochester, MN*

*Speakers: Suresh Kotagal, MD*

*Sanjeev Kothare, MD, St. Christopher's Hospital, Philadelphia, PA*

*David Gozal, MD, PhD, University of Louisville, Louisville, KY*

3:30 – 5:30 PM

### **Platform Session 3: Injury and Repair of Developing Nervous System**

### **Platform Session 4: Neurogenetics and Movement Disorders**

### **Moderated Poster Session: Clinical Dx/Rx**

*Robert S. Rust, MD, University of Virginia, Charlottesville, VA*

6:00 – 10:00 PM

### **Reception & Banquet**

## **Saturday, October 21**

7:00 – 8:30 AM

### **Breakfast Seminar 7:**

#### **Neonatal Brain Monitoring**

*Organizer: Eli Mizrahi, MD, Texas Children's Hospital, Houston, TX*

### **Breakfast Seminar 8: Nursing**

*Ricki Hobdell, PhD, RN, Wayne, PA*

### **Breakfast Seminar 9: Positional Orthostatic Tachycardia Syndrome (POTS)**

*Organizer: Kenneth Mack, MD, Mayo Clinic, Rochester, MN*

9:00 AM – 10:00 AM

### **Hower Award Lecture**

10:00 AM – 12:00 NOON

### **Symposium VIII: Future of Therapy in Child Neurology**

*Organizer: Evan Snyder, Burnham Institute, La Jolla, CA*

*Speakers: Speakers & Talks TBA*

## CHILD NEUROLOGY NURSES

### Association of Child Neurology Nurses (ACNN) News

The Association of Child Neurology Nurses (ACNN) is an international nonprofit organization of nurses caring for children with neurological conditions. Membership is open to all nurses caring for children with neurological conditions. Our members have varied academic backgrounds ranging from associate through doctoral degrees. Currently, we have members from the United States, Canada, the Bahamas, and Iceland. Since the inception of the organization in 1984, by a group of nurses working with child neurologists, ACNN has continued with their goal to provide educational offerings at the time of the Child Neurology Society (CNS) meetings.

The mission of ACNN is to promote the health of infants, children, and adolescents, provide the highest standard of care to those with neurological problems, contribute toward improving quality of life for these families, and provide a forum for the professional growth of the membership. ACNN promotes nursing research, education, and collaboration toward the goal of excellence in clinical practice.

Attendance at the annual ACNN meetings has increased every year from an initial 25 – 30 to the 80 who attended in 2005. This represents seventy three percent (73%)



Photo Credit: Ada Hegion

ACNN Officers (L-R): Janet Brucker, Ricki Hobdell, Cathy Ascher.

of our total membership. Current membership is 110 with a significant percent of members being advanced practice nurses either as Clinical Nurse Specialists or Pediatric Nurse Practitioners.

Plans for the current year include a strengthening of committees. The research committee is beginning to provide information about the research process as well as provide succinct updates of current research on our web site. Secondly, the clinical practice committee is refining and finalizing telephone triage guidelines for presentation to the CNS Practice committee. Finally, regional planning is addressing formation of regional support and conference networks.

#### ACNN Travel Grant

ACNN gratefully acknowledges the Child Neurology Society contribution of Travel Grants for ACNN members. Two Travel Grants (\$500 per grant) are available to current ACNN members. The deadline for application is June 16, 2006. For information please contact ACNN President Ricki Hobdell at (215) 427-5113 (w).