

State of the Science and Treatment Decisions in Cerebral Palsy Workshop 2014

Wednesday November 12, 2014

- 8:00 a.m.** **Welcome and opening remarks**
Walter Koroshetz, MD, Acting Director
National Institute of Neurological Disorders and Stroke,
National Institutes of Health
- 8:15 a.m.** **State of the evidence in Cerebral Palsy**
Iona Novak, Cerebral Palsy Alliance
- 8:45 a.m.** **Current clinical intervention strategies related to age groups of those with Cerebral Palsy: Infants and young children; school age; teens and young adults**
Mauricio Delgado, University of Texas Southwestern Medical Center at Dallas
- 9:15 a.m.** **When does the science suggest that we intervene? Ages and stages of brain and muscle plasticity as they apply to Cerebral Palsy**
Diane Damiano, National Institutes of Health
- 9:45 a.m.** **Addressing evidence for more effective rehabilitation through basic and clinical neuroscience research**
Andrew Gordon, Teachers College, Columbia University
- 10:15 a.m.** **Break**
- 10:30 a.m.** **Panel discussion on family and patient perspectives on treatment options**
Moderator: Codrin Lungu, National Institute of Neurological Disorders and Stroke
Cynthia Frisina, Reaching for the Stars. A Foundation of Hope for Children with Cerebral Palsy
Karen Pape, Medical Advisory Board, Reaching for the Stars. A Foundation of Hope for Children with Cerebral Palsy
Hank Chambers, Rady Children's Hospital, San Diego
Jennifer Lyman, Parent
- 11:30 a.m.** **Outcome assessments in Cerebral Palsy**
Peter Rosenbaum, McMaster University
- 11:50 a.m.** **Innovative assessment technologies**
Terrence Sanger, University of Southern California
- 12:15 p.m.** **Lunch**

Database and Registry Tools: What are their Strengths and Weaknesses?

- 1:00 p.m.** **Patient-oriented research approaches and their utility in rehabilitation**
Sarah Daugherty, Patient Centered Outcomes Research Institute
- 1:30 p.m.** **Electronic medical records and health care databases**
Ejaz Shamim, Mid-Atlantic Permanente Medical Group
- 2:00 p.m.** **CP registries**
Deborah Gaebler, Rehabilitation Institute of Chicago
Marshalyn Yeargin-Allsopp, Centers for Disease Control
Michael Shevell, McGill University Health Centre
- 2:30 p.m.** **Comparative effectiveness research from adult stroke rehab perspective; Comparison of clinical trials vs prospective observational designs**
Susan Horn, International Severity Information Systems, Inc.
- 3:00 p.m.** **Discussion**
Moderator: Deborah Hirtz, National Institute of Neurological Disorders and Stroke
- 3:30 p.m.** **Break**

Status of Current Research

- 3:45 p.m.** **Current CP funding allocations**
Yvonne Wu, University of California at San Francisco
- 4:00 p.m.** **Family perspectives and concerns**
Paul Gross, Hydrocephalus Association
- 4:30 p.m.** **Summary of progress from day 1 – What are the major goals? What issues need to be addressed?**
Jonathan Mink, University of Rochester Medical Center
- 5:00 p.m.** **Adjourn**

Thursday, November 13, 2014

8:30 a.m. Panel Session on stakeholders view of current research funding and perspectives; accomplishments, gaps and goals

Moderator: Ralph Nitkin, Eunice Kennedy Shriver
National Institute of Child Health and Development
Daofen Chen, National Institute of Neurological Disorders
and Stroke
Kelly Dunham, Patient Centered Outcomes Research Institute
Marshalyn Yeargin-Allsopp, Centers for Disease Control
Darcy Fehlings, University of Toronto
Debby Weinberg, The Weinberg Family Cerebral Palsy Center

Possible Approaches and Research Strategies; Next Steps and Future Planning

9:30 a.m. Discussion: What will be the best methodologies and most useful tools to address important questions and provide rational therapies? What are the gaps that first need to be addressed?

Moderator: Diane Damiano, National Institutes of Health
Annette Majnemer, McGill University Health Centre
Codrin Lungu, National Institute of Neurological Disorders
and Stroke
Jonathan Mink, University of Rochester Medical Center
Iona Novak, Cerebral Palsy Alliance
Richard Stevenson, University of Virginia

10:30 a.m. Break

10:45 a.m. Discussion: Logistics of progress: Are there preclinical and/or translational questions that should be addressed first or concurrently? What are the priorities, what is needed to move forward? Who are the responsible partners? What are the immediate, medium and long term goals? Summary of recommended next steps.

Moderators: Deborah Hirtz, Diane Damiano, National Institutes of Health

12:00 p.m. Adjourn