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 and Prevention  
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