



TASKFORCE ON CHILDHOOD MOTOR DISORDERS

Hyperkinetic Symptoms in Childhood

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June 7-9, 2008

Neuroscience Center, Conference Room C & D

Sponsored by:

**The National Institutes of Health
National Institute of Neurological Disorders and Stroke
Office of Rare Diseases
The Don and Linda Carter Foundation**

Workshop Schedule

Saturday, 6/7/08

6:00-9:00 pm: Welcome Reception (Bethesda North Marriott)

- Light buffet and refreshments

Sunday, 6/8/08

8:15 am: Walk from hotel to Neuroscience Center (NSC)

- Shuttle bus available at Marriott

8:30-9:00 am: Continental Breakfast at NSC

9:00-10:15 am: Introduction

- Purpose and history of the taskforce
- Agenda and format of this meeting
- NIH involvement in hyperkinetic disorders research: Daofen Chen
- Example videos of hyperkinetic disorders in children, with discussion

Moderator: Terry Sanger

Panel: Daofen Chen, Jon Mink, Mark Hallett

10:30-12:00 noon: Current terminology and definitions

- Current definitions:
 - dystonia, chorea, athetosis, choreoathetosis, myoclonus, tremor, tics, stereotypies
 - electrophysiological diagnosis of hyperkinetic disorders (Mark Hallett)
- Problems with current definitions
- Which words will we define?

Moderator: Jon Mink

Panel: Diane Damiano, Ronit Mesterman, Katherine Alter, Francisco Valero-Cuevas, Erin Butler

12:00-1:00 pm: *Lunch at NSC*

1:00-2:30 pm: Hyperkinetic elements of dystonia

- Current definitions
- Brief review of quantitative measurements
- Video presentation and discussion of defining elements
- Preliminary definition

Moderator: Mark Hallett

Panel: Kathy Swoboda, Alec Hoon, Sharon Gorman, Hans Forssberg, Colum MacKinnon, Sudarshan Dayanidhi

2:45-4:15 pm: Chorea

- Current definitions
- Brief review of quantitative measurements
- Video presentation and discussion of defining elements
- Preliminary definition

Moderator: Tony Lang

Panel: Ed Dabrowski, Barbara Kornblau, Eileen Fowler, Dagmar Sternad, Hyder Jinnah, Abbie Collins

4:30-6:00 pm: Athetosis and choreoathetosis

- Current definitions
- Brief review of quantitative measurements
- Video presentation and discussion of defining elements
- Preliminary definition

Moderator: Darcy Fehlings

Panel: Barry Russman, Mark Gormley, Jessica Rose, Kristen Krosschell, Donald Gilbert, Rebecca Lehman

6:00 pm: *Walk back from NSC to Marriott (shuttle available)*

6:30-7:00 pm: *Reception (location TBA)*

7:00-9:00 pm: *Dinner (location TBA)*

Monday, 6/9/08

8:15 am: *Walk from hotel to Neuroscience Center (NSC)*

- Shuttle bus available at Marriott

8:30-9:00 am: *Continental Breakfast at NSC*

9:00-10:30 am: Definitions and distinction of other disorders:

Myoclonus, Tremor, Tics, Stereotypies

- Current definitions and possible need for child-specific definitions
- Brief review of quantitative measurements
- Distinction from dystonia, chorea, and athetosis
- Preliminary definitions and discussion of possible overlap of definitions

Moderator: Harvey Singer

Panel: Robert Chen, Hilla Ben-Pazi, CJ Malanga, Margaret Barry, Toni Pearson

10:45-12:30 pm: Final definitions and next steps

- Final consensus definitions
- Need for further information and research, measurement tools, outcome studies
- Next steps for the taskforce

Moderator: Terry Sanger

Panel: Daofen Chen, Mark Hallett, Jon Mink

12:30-1:30 pm: *Box Lunch and departure*

We gratefully acknowledge support for the reception, dinner, and food service during the meeting from Allergan Inc., The Stanford University department of Neurology and Neurological Sciences, The Don and Linda Carter Foundation, and The Crowley-Carter Foundation.

Note: Luggage can be stored at the NSC for those participants leaving after the last session on Monday. Taxis will be available to take participants to the hotel or airport after the meeting.

Resources

Hotel:

Bethesda North Marriott Hotel and Conference Center
5701 Marinelli Road
North Bethesda, MD 20852
Direct: 301 822 9272 (please make your own reservation)
Fax: 301 822 9203

Meeting Room:

NIH Neuroscience Center (NSC; Note: this is NOT on the main NIH campus).
Conference Rooms C, D, & E
6001 Executive Blvd.
NSC Conference Center Ph: (301) 435-1478
(may be used as an emergency number during the meeting)

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