

Muscular Dystrophy Coordinating Committee
Bethesda, Maryland
April 7, 2014
Agenda

- 8:30-8:50 am **Welcome, Introductions, and Conflict of Interest Statement**
Alan Guttmacher, MDCC Chair, NICHD/NIH
John Porter, MDCC Executive Secretary, NINDS/NIH
- 8:50-9:20 am **Scientific Update on Congenital Muscular Dystrophy**
Carsten Bonnemann, NINDS/NIH
- 9:20-9:40 am **Congenital Muscular Dystrophy Report**
Anne Rutkowski, Cure CMD
- 9:40-10:00 am **Wellstone Centers Report**
Glen Nuckolls, NIAMS/NIH
- 10:00-10:20 am **Department of Defense Duchenne Muscular Dystrophy Program Report**
Marielena McGuire, DMDRP
- 10:20-10:40 am **Break**
- 10:40-11:00 **Muscular Dystrophy Association Report**
Valerie Cwik, MDA
- 11:00-11:20 am **Facioscapulohumeral Muscular Dystrophy Report**
June Kinoshita, FSH Society
- 11:20-11:50 am **Development and Use of Patient-Reported Outcome Measures in Myotonic Dystrophy and Facioscapulohumeral Muscular Dystrophy**
Chad Heatwole, University of Rochester
- 11:50-12:50 pm **Working Lunch/Open Discussion**
- 12:50-1:20 pm **NIH Report**
John Porter, NINDS/NIH
- 1:20-1:40 pm **Centers for Disease Control and Prevention Report**
Julie Bolen, CDC
- 1:40-2:10 pm **Development of FDA Guidance for Regulating Duchenne Muscular Dystrophy Products**
Pat Furlong, Parent Project Muscular Dystrophy
- 2:10-2:30 pm **Duchenne Muscular Dystrophy Report**
Brian Denger, Parent Project Muscular Dystrophy

2:30-2:50 pm	Break
2:50-3:20 pm	A Model of Effective Coordination of Expertise and Resources in Therapy Development Justin Fallon, Brown University
3:20-4:00 pm	Improving Coordination through the MDCC All
4:00-4:30 pm	Public Comment Period
4:30 pm	Close