

Agenda
Muscular Dystrophy Coordinating Committee Meeting
April 27, 2016
Neuroscience Center, Conference Room C/D
6001 Executive Blvd., Bethesda, Maryland 20892

8:30 Welcome and introductions

Stephen I. Katz, MDCC Chair

8:45 Conflict of interest policies and general meeting information

Glen Nuckolls, MDCC Executive Secretary

8:55 New member presentation

Plavi Mittal, Jain Foundation

9:15 Meeting reports

Pulmonary Outcome Measures for Duchenne

Abby Bronson, Parent Project Muscular Dystrophy

2016 MDA Clinical Conference

Valerie Cwik, Muscular Dystrophy Association

9:45 Topic I: Sharing of clinical trial data through public/private partnerships

Using ClinicalTrials.gov and Other Sources of Information about Clinical Trials

Deborah Zarin, Lister Hill National Center for Biomedical Communications, National Library of Medicine

10:20 Break

10:30 The Duchenne Regulatory Science Consortium – A public-private partnership to facilitate sharing of clinical data for the development of regulatory tools to accelerate drug development.

Jane Larkindale, Duchenne Regulatory Sciences Consortium, Critical Path Institute

11:00 Discussion of data sharing

11:30 Topic II: Patient access to care, services and medical equipment

Facilitating Mobility and Workforce Integration

Annie Kennedy, Parent Project Muscular Dystrophy

12:00 Lunch

12:45 Access to Genetic Testing and Interdisciplinary Care

Kristin Stephenson, Muscular Dystrophy Association

Applying for Disability Benefits: The SSA Perspective

Michael Goldstein and Alayna Ness, Office of Disability Policy, SSA

CMS Resources and Services

Terri Postma, Centers for Medicare & Medicaid Services

2:15 Discussion of possible activities through MDCC to address access issues

3:00 Break

3:15 Topic III: Data on the NIH supported muscular dystrophy research workforce

Glen Nuckolls, NINDS

3:35 Discussion of workforce analysis and other data mining

4:10 OnPAR: A Public/Private Partnership for Supporting Research

Tom Cheever, NIAMS

4:15 Closing remarks

Stephen I. Katz