

**Muscular Dystrophy Coordinating Committee
Natcher Conference Center Room D
Bethesda, Maryland
March 17, 2015**

Agenda

- 8:30 am **Welcome and Introductions**
 Alan Guttmacher, MDCC Chair
 Eunice Kennedy Shriver National Institute of Child Health and Human
 Development (NICHD), National Institutes of Health (NIH)
- 8:45 am **Conflict of Interest Statement, General Info**
 Glen Nuckolls, MDCC Executive Secretary
 National Institute of Neurological Disorders and Stroke (NINDS), NIH
- Reports from Federal Agencies**
- The National Institutes of Health**
- 8:50 am National Institute of Neurological Disorders and Stroke
 Walter Koroshetz, Acting Director, NINDS
- 9:10 am National Heart, Lung and Blood Institute/Parent Project Muscular
 Dystrophy (NHLBI/PPMD) Workshop on Dystrophic Cardiomyopathy
 Jon Kaltman, Program Director, NHLBI
- 9:25 am Newborn Screening
 Tiina Urv, Program Director, NICHD
- Department of Defense**
- 9:40 am The Duchenne Muscular Dystrophy Research Program, Congressionally
 Directed Medical Research Programs
 Marielena McGuire, Program Manager, CDMRP
- Food and Drug Administration**
- 10:00 am Office of New Drugs, Center for Drug Evaluation and Research
 Devanand Jillapalli, Medical Officer
- Social Security Administration**
- 10:10 am Office of Disability Policy
 Melissa Spencer, Acting Deputy Associate Commissioner
- 10:30 am **Break**
- Health Resources and Services Admin (HRSA)**
- 10:45 am Maternal and Child Health Bureau, Division of Services for Children with
 Special Health Needs
 Joan Scott, Chief, Genetic Services Branch

11:05 am **Department of Education**
Office of Special Education and Rehabilitative Services
Sue Swenson, Acting Assistant Secretary

Discussion of the Draft 2015 Action Plan for the Muscular Dystrophies

11:25 am Introduction to the Draft Action Plan
Glen Nuckolls

MDCC Member Comments on the Draft Action Plan

11:40 pm Brian Denger, Parent Project Muscular Dystrophy

11:50 am Valerie Cwik, Muscular Dystrophy Association

12:00 pm **Working Lunch**

12:30 pm *Daniel Perez, FSH Society

12:40 pm Peter Wald, MDCC member

12:50 pm *Anne Rutkowski, CureCMD

1:00 pm Julie Bolen, CDC

Public Comments on the Draft Action Plan

1:10 pm *Sharon Hesterlee, Myotonic Dystrophy Foundation

1:20 pm Summary of responses from Request for Information
Tom Cheever, NINDS

1:35 pm **Open Discussion of the Draft Action Plan**
Alan E. Guttmacher, Chair

2:15 pm **Break**

Implementation of Care Guidelines

2:30 pm MDA Clinic Program
Valerie Cwik, MDA

2:50 pm Progress on Care Guidelines for Muscular Dystrophies
Natalie Street, CDC

3:10 pm Care Guidelines for CMD
*Anne Rutkowski, CureCMD

3:30 pm PPMD Clinic Certification Program
Kathi Kinnett, PPMD

3:50 pm Open discussion of Care Guidelines and Implementation
 Alan E. Guttmacher, Chair

4:20 pm **Public Comment Period**

4:50 pm **Closing Remarks**
 Alan E. Guttmacher, Chair

5:00 pm **Meeting Adjourned**

*Indicates presenters that will participate via phone/internet.