The Duchenne Community & Federal Research Agencies:
Yesterday, Today, & Tomorrow
The Dupont Circle Hotel
March 9, 2020 8:45am – 12:00pm

In 2000, upon PPMD’s request, the National Institutes of Health (NIH) held the first-ever federal workshop on Duchenne muscular dystrophy. Since that time, Duchenne care, research, and therapy development has made major progress impacting the lives of all those living with Duchenne and Becker. To mark twenty years since that initial gathering, PPMD has invited leaders from the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Department of Defense (DOD) to present to a PPMD breakfast forum with Duchenne and Becker families.

The meeting will cover the investment to date from three key federal agencies, the progress from Duchenne and Becker programs, and include a cross-stakeholder discussion about where we go from here to accelerate progress in confronting Duchenne and Becker muscular dystrophy.

8:00am  Registration opens

8:45 - 9:00  Welcome and Overview
Pat Furlong, President and CEO, PPMD

Rememberance of Dr. Stephen I. Katz, former Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

9:00 - 9:20  Reflections on the first Workshop in 2000
Steven Groft, Ph.D., Office of Rare Diseases Research, National Center for Advancing Translational Sciencesm (NCATS), NIH

9:20 - 9:45  Overview of NIH, National Institute of Neurological Disorders and Stroke (NINDS), and the Muscular Dystrophy Coordinating Committee (MDCC)
Glen Nuckols, Ph.D., Program Director, NINDS

9:45 - 10:00  Report from NIAMS and the Wellstone Centers Program
Thomas Cheever, Ph.D., Program Director, NIAMS

10:00 - 10:10  Q&A from audience

10:10 - 10:25  Report from National Heart, Lung, and Blood Institute (NHLBI)
James Kiley, Ph.D., Director, Division of Lung Diseases, NHLBI

10:25 - 10:40  Report from Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)
Melissa Parisi, M.D., Ph.D., Chief, Intellectual and Developmental Disabilities Branch, NICHD

10:40 - 10:55  Panel Discussion and Q&A with all NIH speakers
Moderators: Annie Kennedy and Ryan Fischer
10:55 - 11:10  **Report from the CDC, National Center on Birth Defects and Developmental Disabilities (NCBDDD)**  
Natalie J. Street, M.S., C.G.C., Health Scientist, Rare Disorders and Health Outcomes Team

11:10 - 11:25  **Report from Congressionally Directed Medical Research Programs (CDMRP)**  
Marielena McGuire, Ph.D., Program Manager, Congressionally Directed Medical Research Programs

11:25 - 11:40  **Moderated Q&A**  
*Moderators: Pat Furlong and Ryan Fischer*

11:40  12:00  **Closing Remarks**  
*Pat Furlong*