

Hope in Action: An EL-PFDD Meeting on Angelman Syndrome

April 7, 2025 | 10:00 a.m. to 3:00 p.m. ET

Meeting Agenda

10:00-10:05 a.m. Welcome

Tim Franson, MD, Moderator

Principal, Faegre Drinker Consulting

10:05-10:15 a.m. Opening Remarks

Amanda Moore

Chief Executive Officer

Angelman Syndrome Foundation

Ryan Fischer

Chief Operating Officer

Foundation for Angelman Syndrome Therapeutics

10:15-10:25 a.m. Overview of Patient-Focused Drug Development

Michelle Campbell, PhD

Associate Director, Stakeholder Engagement & Clinical Outcomes

Office of Neuroscience

Center for Drug Evaluation and Research

Food and Drug Administration

10:25-10:35 a.m. Overview of Angelman Syndrome Symptoms

Ron Thibert, DO, MSPH

Director, Angelman Syndrome Clinic

Massachusetts General Hospital for Children

10:35-10:45 a.m. Discussion Format Overview and Demographic Polling

Tim Franson, Meeting Moderator

Topic 1: Symptoms of Angelman Syndrome and Impact on Daily Life

10:45-11:10 a.m. Panel Remarks from Caregivers of People with Angelman Syndrome

11:10 am.-12:30 p.m. Polling and Facilitated Discussion

12:30-1:00 p.m. Break

1:00-1:10 p.m. Overview of Angelman Syndrome Treatment Approaches

Elizabeth Berry-Kravis MD, PhD

Director, F.A.S.T. Center for Translational Research

Rush University Medical Center

Topic 2: Views on Current Approaches to Treatment and Future Treatments

1:10-1:35 p.m. Panel Remarks from Caregivers of People with Angelman Syndrome

1:35-2:45 p.m. Polling and Facilitated Discussion

2:45-2:55 p.m. Pre-Meeting Survey Data Presentation

Ryan Fischer

Chief Operating Officer

Foundation for Angelman Syndrome Therapeutics

2:55-3:00 p.m. Closing Remarks

Tim Franson, Moderator