



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

January 29, 2025 | 10:00 a.m. to 3:00 p.m. ET

### Meeting Agenda

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| <b>10:00-10:05 a.m.</b>  | <b>Welcome</b><br><i>Tim Franson, MD, Moderator</i><br><i>Principal, Faegre Drinker Consulting</i>  |
| <b>10:05-10:15 a.m.</b>  | <b>Opening Remarks</b><br><i>Amanda Moore</i><br><i>Chief Executive Officer</i><br><i>Angelman Syndrome Foundation</i><br><br><i>Ryan Fischer</i><br><i>Chief Operating Officer</i><br><i>Foundation for Angelman Syndrome Therapeutics</i>   |
| <b>10:15-10:25 a.m.</b>  | <b>Overview of Patient-Focused Drug Development</b><br><i>Michelle Campbell, PhD</i><br><i>Associate Director, Stakeholder Engagement &amp; Clinical Outcomes</i><br><i>Office of Neuroscience</i><br><i>Center for Drug Evaluation and Research</i><br><i>Food and Drug Administration</i> |
| <b>10:25-10:35 a.m.</b>  | <b>Overview of Angelman Syndrome Symptoms</b><br><i>Ron Thibert, DO, MSPH</i><br><i>Director, Angelman Syndrome Clinic</i><br><i>Massachusetts General Hospital for Children</i>  |
| <b>10:35-10:45 a.m.</b>  | <b>Discussion Format Overview and Demographic Polling</b><br><i>Tim Franson, Meeting Moderator</i>  |
| <b>Topic 1: Symptoms of Angelman Syndrome and Impact on Daily Life</b> |   |
| <b>10:45-11:10 a.m.</b>  | <b>Panel Remarks from Caregivers of People with Angelman Syndrome</b>   |
| <b>11:10 am.-12:30 p.m.</b>  | <b>Polling and Facilitated Discussion</b>   |
| <b>12:30-1:00 p.m.</b>   | <b>Break</b>  |

**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*