

# SSADH EL-PFDD MEETING AGENDA

## 7:00 – 7:50 REGISTRATION / CONTINENTAL BREAKFAST

### 7:50 – 8:40 WELCOME & OPENING REMARKS

7:50 – 7:55 Welcome by Carolyn Hoffman

7:55 – 8:10 History of SSADHD by Dr. Michael Gibson

8:10 – 8:25 Role of FDA by Dr. Michelle Campbell

8:25 – 8:40 Goal of the Meeting & Polling Test by Dr. Mousumi Bose

### 8:40 – 12:50 MORNING SESSION

8:40 – 9:05 Phenotype & Current Treatments by Dr. Philip Pearl

9:05 – 9:45 Seizure Panel Discussion & Audience Polling

Presentations by 2 Affected Individuals and Caregivers (10 minutes)

Audience Polling & Moderated Discussion

9:45 – 10:25 Intellectual Disability Panel Discussion & Audience Polling

Presentations by 2 Affected Individuals and Caregivers (10 minutes)

Audience Polling & Moderated Discussion

### 10:25 – 10:40 MORNING BREAK

# SSADH EL-PFDD MEETING AGENDA

- 10:40 – 11:20 Behavior Panel Discussion & Audience Polling  
Presentations by 2 Affected Individuals and Caregivers (10 minutes)  
Audience Polling & Moderated Discussion
- 11:20 -12:00 Sleep Discussion & Audience Polling  
Presentations by 2 Affected Individuals and Caregivers (10 minutes)  
Audience Polling & Moderated Discussion
- 12:00 – 12:05 Morning Session Closing Remarks by Dr. J-B Roulett

## **12:05 – 1:05 LUNCH BREAK**

### **1:05 – 5:20 AFTERNOON SESSION**

- 1:05 – 1:15 Afternoon Opening Remarks by Dr. Philip Pearl
- 1:15 – 1:55 Speech Panel Discussion & Audience Polling  
Presentations by 2 Affected Individuals and Caregivers (10 minutes)  
Audience Polling & Moderated Discussion
- 1:55 -2:00 Physical Limitations Panel Discussion & Audience Polling  
Presentations by 2 Affected Individuals and Caregivers (10 minutes)  
Audience Polling & Moderated Discussion

### **2:35 -2:50 AFTERNOON BREAK**

# SSADH EL-PFDD MEETING AGENDA

- 2:50 – 3:05 Prevalence, Current Diagnosis Methods, Future Diagnosis Methods by Dr. Sarah Elsea
- 3:05 - 3:45 Diagnostic Odyssey Panel Discussion & Audience Polling  
Presentations by 2 Affected Individuals and Caregivers (10 minutes)  
Audience Polling & Moderated Discussion
- 3:45 – 4:00 Participating in Clinical Trial by Dr. Melissa DiBacco
- 4:00 – 4:40 Clinical Trial Panel Discussion & Audience Polling  
Presentations by 2 Affected Individuals and Caregivers (10 minutes)  
Audience Polling & Moderated Discussion

**4:40 – 5:20** **AFTERNOON SESSION: CLOSING REMARKS**  
**NEXT STEPS**  
**THANK YOU**