

## Presentations: Suggested Outline

### **Seth Bittker (Parent perspective/community advocate) Autism Research Connections**

- Portrait of your family (health conditions and alternative treatments)
- Genetic testing/Direct to Consumer (DTC) data and what you learned
- Why are you interested to contribute to the EAIN-3885 project?
- Autism Research Connections and summary of the interviews you conducted
  - What type of genetic research studies could benefit your son (e.g., studying potential role of nutritional/supplemental factors)
- How receptive do you think patient/parents/caregivers might be toward initiatives such as the EAIN-3885 project?
- Your perspectives about the current status of autism genetics field and future directions (e.g., clinical heterogeneity/environmental factors/gene environment interactions/etc.)
- Your perspectives on involving parents/caregivers in genetic research projects (how to engage them, how to incorporate their concerns)
- The potential impact of new initiatives such as Precision Medicine on improving patient health outcomes and/or the direction of genetic research studies
- Ongoing autism initiatives (that you are aware of) and If/How our PCORI project could utilize these resources and serve as a complementary effort
- Your perspectives on the potential impact of the initiatives, such as the EAIN-3885 project, on changing the existing culture in the autism research community
- Your suggestions for future dissemination of findings from the EAIN-3885 project (e.g., reaching out to certain communities/consortiums/etc.)

### **Mary Anne Hammond (Parent perspective/community advocate)**

#### **MO Autism Centers-parent educator**

- Your daughter's story
  - Complex health condition
  - Medication side-effects
  - What type of genetic research studies could benefit your daughter (e.g., studying drug side effects in kids with severe autism e.g., nonverbal)
- Your role as a CMH education coordinator for Autism
  - Your experiences as a parent advocate for Autism
  - Considering your professional role, what you have heard from other parents/caregivers concerns/needs/preferences
- Describing the MO Autism Centers
  - History (how many centers, how many years, etc.)
  - Impact on improving patient care/services & expanding educational activities
  - Potential resource for gathering needs/preferences from local autism community for research (e.g., sending out surveys to local parents to get their feedback on EAIN3885)

### **Kiely Law, MD (Parent/clinician perspective) Interactive Autism Network (IAN) & PCORnet**

- Your son's story
  - What type of genetic research studies could benefit your son
- Considering your professional role, what kind of research questions you think may be of interest to parents of kids with autism (e.g., interest level on finding genetic causes, finding better treatment options, reducing drug side effects/etc.)
- Introducing IAN
  - History (Why it has been developed? objectives/future directions)
  - The role of IAN on moving autism research field forward (e.g., briefly summarizing few papers published based on IAN data)
  - Potential resource for gathering needs/preferences from local autism community for research (e.g., sending out surveys to local parents to get their feedback on EAIN-3885)
  - PCORnet project and IAN (study goals/expected outcomes)
- How receptive do you think patient/parents/caregivers might be toward initiatives such as the EAIN-3885 project?
- Your perspectives about the current status of autism genetics field and future directions (e.g., clinical heterogeneity/environmental factors/gene environment interactions/etc.)
- Your perspectives on involving parents/caregivers in genetic research projects (how to engage them, how to incorporate their concerns)
- The potential impact of new initiatives such as Precision Medicine on improving patient health outcomes and/or the direction of genetic research studies
- Ongoing autism initiatives (e.g., IAN, AGRE, SSC, MSSNG) and If/How our PCORI project could utilize these resources and serve as a complementary effort
- Your perspectives on the potential impact of the initiatives, such as the EAIN-3885 project, on changing the existing culture in the autism research community
- Your suggestions for future dissemination of findings from the EAIN-3885 project (e.g., reaching out to certain communities/consortiums/etc.)

### **Valerie Hu, PhD (Parent/scientist perspective) Subject stratification in autism genetic research**

- Your exposure to ASD and your son's diagnosis
- Brief/lay language summary (schematic presentations/simple figures are preferred) of your ongoing research projects, covering the following topics (if applicable):
  - Objective
  - Hypothesis
  - Utilizing existing autism resources-phenotypic/genotypic data
  - Results
  - Future direction & potential impact(s) on improving patient health/treatment options/ASD subtyping
- Your perspectives about the current status of autism genetics field and future directions (e.g., clinical heterogeneity/environmental factors/gene environment interactions/etc.)
- Your perspectives on involving parents/caregivers in genetic research projects (how to engage them, how to incorporate their concerns)
- The potential impact of new initiatives such as Precision Medicine on improving patient health outcomes and/or the direction of genetic research studies
- Ongoing autism initiatives (e.g., AGRE, SSC, MSSNG) and If/How our PCORI project could utilize these resources and serve as a complementary effort

- Your perspectives on the potential impact of the initiatives, such as the EAIN-3885 project, on changing the existing culture in the autism research community
- Your suggestions for future dissemination of findings from the EAIN-3885 project (e.g., reaching out to certain communities/consortiums/etc.)

### **Olivia Veatch, PhD (Scientist perspective)**

#### **Genetic/phenotypic repositories & their applications in research**

- Brief/lay language summary (schematic presentations/simple figures are preferred) of your ongoing research projects, covering the following topics (if applicable):
  - Objective
  - Hypothesis
  - Utilizing existing autism resources-phenotypic/genotypic data
  - Results
  - Future direction & potential impact(s) on improving patient health/treatment options/ASD subtyping
- Your perspectives about the current status of autism genetics field and future directions (e.g., clinical heterogeneity/environmental factors/gene environment interactions/etc.)
- Your perspectives on involving parents/caregivers in genetic research projects (how to engage them, how to incorporate their concerns)
- The potential impact of new initiatives such as Precision Medicine on improving patient health outcomes and/or the direction of genetic research studies
- Ongoing autism initiatives (e.g., AGRE, SSC, MSSNG, eMERGE) and If/How our PCORI project could utilize these resources and serve as a complementary effort
- Your perspectives on the potential impact of the initiatives, such as the EAIN-3885 project, on changing the existing culture in the autism research community
- Your suggestions for future dissemination of findings from the EAIN-3885 project (e.g., reaching out to certain communities/consortiums/etc.)

### **Amy Brower, PhD (Policy maker & parent perspective) American College of Medical Genetics**

- Your exposure to ASD and your son's diagnosis
- Why are you interested to contribute to the EAIN-3885 project?
- Your perspectives on involving parents/caregivers in genetic research projects (how to engage them, how to incorporate their concerns)
- The potential impact of new initiatives such as Precision Medicine on improving patient health outcomes and/or the direction of genetic research studies
- Ongoing genetic initiatives (that you are involved or aware of) and If/How our PCORI project could utilize these resources and serve as a complementary effort
- Your perspectives on the potential impact of the initiatives, such as the EAIN-3885 project, on changing the existing culture in the autism research community
- Your suggestions for future dissemination of findings from the EAIN-3885 project (e.g., reaching out to certain communities/consortiums/etc.)
- Your perspective on the importance of such engagement/educational projects
- ACMG recommendation and If/How the EAIN-3885 project may be in line with certain guidelines/recommendations

**Jim McClay, MD (PCORI investigator)****PCORI resources (PCORnet) & potential applications in research**

- Introducing PCORnet
  - History (why it has been developed? objectives/future directions)
  - The expected impact of PCORnet on moving research field forward (e.g., briefly summarizing research work done based on PCORnet data/infrastructure)
  - Biorepository core/linking EHR to genetic data (status/future directions)
- The potential impact of new initiatives such as Precision Medicine on improving patient health outcomes and/or the direction of genetic research studies
- Ongoing initiatives (e.g., PCORnet/other EHR infrastructures) and If/How our PCORI project could utilize these resources and serve as a complementary effort
- Your perspectives on the potential impact of the initiatives, such as the EAIN-3885 project, on changing the existing culture in the research community
- Your suggestions for future dissemination of findings from the EAIN-3885 project (e.g., reaching out to certain communities/consortiums/etc.)