

Workshop Agenda

“Educational Workshop for the Autism Research Community: Incorporating Genetic Information into Patient-Centered Outcomes Research”

Location: Westin Crown Center (1 East Pershing Road, Kansas City, MO 64108)

Date: Friday, April 7th 2017

Workshop (1-5PM): Shawnee Mission Conference Room

Reception (5-6PM): Roanoke Conference Room

SUMMARY: Genetic risk factors may explain a degree of variance in patients’ health outcomes. Currently, despite the drive toward precision medicine, genetic susceptibility factors are not widely utilized in health outcomes research. The goal of this educational workshop is to discuss the potential benefits/methods of incorporating genetic information in outcomes research studies. The focus of our discussion will be on autism, to determine the needs, required steps, and challenges for incorporating genetic factors in outcomes research. Because of the existing heterogeneity in autism, such an integrated multidisciplinary approach may be particularly impactful, leading to better sub-typing of patients and the potential to improve outcomes. A number of representatives will share their perspectives on this topic, including leaders from the local autism community, parents, caregivers, and representatives from the autism research community.

This workshop was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award ([EAIN-3885](#)).

Learning objectives:

- (1) Patient-centered outcomes research and how it differs from traditional research (researcher-driven)
- (2) Potential impact of engaging stakeholders throughout the research process
- (3) Autism genetic research, the importance of subject stratification, and potential benefit of incorporating patient perspectives
- (4) Existing autism genetic/phenotypic databases and potential use in evaluating patient outcomes questions

Attendees (~60):

- PCORI EAIN-3885 study team members
- Local autism community representatives (clinicians, caregivers, parent advocates, industry, and community leaders)
- Autism research community representatives (experts in genetics, bioinformatics, and developmental/behavioral sciences)
- Genomic Medicine Conference attendees who are interested on the topic

INTRODUCTION

Zohreh Talebizadeh, PhD	Overall objective of the workshop & PCORI mission/Patient engagement
Yasmeen Long, MA	Video Clip -Welcome message-PCORI program officer
Kieran Pemberton, PhD	Children’s Mercy Research Institute
Kim Smolderen, PhD	Video Clip -PCORI investigator perspective
John Constantino, MD	Video Clip -Welcome message-Autism research community/leadership perspective

PCORI EAIN-3885 MEMBERS’ PERSPECTIVES

Seth Bittker	Parent perspective/community advocate , Autism Research Connections
Mary Anne Hammond	Parent perspective/community advocate , MO Autism Centers
Kiely Law, MD	Parent/clinician perspective & Interactive Autism Network- <i>link to PCORnet</i>
Valerie Hu, PhD	Parent/scientist perspective & subject stratification in autism genetic research
Olivia Veatch, PhD	Genetic/phenotypic repositories (eMERGE, SSC, MSSNG) & applications in research
Jim McClay, MD	PCORI resources/infrastructures (PCORnet) & potential applications for research

RESEARCH COMMUNITY PERSPECTIVES

Clara Lajonchere, PhD	AGRE, Precision Medicine, engaging parents/caregivers in research design
Amy Daniels, PhD	Simons Foundation, SFARI and SPARK initiatives
Amy Brower, PhD	American College of Medical Genetics guidelines & recommendations
David Beversdorf, MD	Brief Introduction-autism research projects at MU
Jacob Michaelson, PhD	Brief Introduction-autism research projects at UIowa

LOCAL COMMUNITY REPRESENTATIVES -*Brief introduction and perspectives*

Keith Gary, PhD	KCALSI-local research assets & Clollaborate2Cure initiative
Tammy Ham	Behavioral Milestones-providing service/therapy/education
Jeff Blackwood, MBA	Pathfinder HI-resources & research opportunities

CONCLUSION

Zohreh Talebizadeh, PhD	Future directions (projected plans & activities for PCORI EAIN-3885)
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Speakers (Name/Affiliation):

- **Zohreh Talebizadeh, PhD**, Children's Mercy, Kansas City, MO
- **Kieran Pemberton, PhD**, Children's Mercy, Kansas City, MO
- **Seth Bittker, BS**, Darien, CT
- **Mary Anne Hammond, BA**, Children's Mercy, Kansas City, MO
- **Kiely Law, MD**, Kennedy Krieger Institute, Baltimore, MD
- **Valerie Hu, PhD**, The George Washington University, Washington, DC
- **Olivia Veatch, PhD**, University of Pennsylvania, Philadelphia, PA
- **Jim McClay, MD**, University of Nebraska Medical Center, Omaha, NE
- **Clara Lajonchere, PhD**, University of California, Los Angeles, CA
- **Amy Daniels, PhD**, Simons Foundation, New York, NY
- **Amy Brower, PhD**, American College of Medical Genetics, Bethesda, MD
- **David Beversdorf, MD**, University of Missouri, Columbia, MO
- **Jacob Michaelson, PhD**, University of Iowa Carver College of Medicine, Iowa City, IA
- **Keith Gary, PhD**, Kansas City Area Life Sciences Institute, Kansas City, MO
- **Tammy Ham**, BioNovus Innovations, Kansas City, MO
- **Jeff Blackwood, MBA**, Pathfinder HI, Kansas City, MO

Speakers-Video Clips (Name/Affiliation):

- **Yasmeen Long, MA** Patient-Centered Outcomes Research Institute (PCORI)
- **Kim Smolderen, PhD** University of Missouri Kansas City, MO
- **John Constantino, MD** Washington University in St. Louis, MO

Invited experts from local/regional areas (Name/Affiliation):

University of Kansas, Lawrence, KS

- **Steven Warren, PhD**
- **Matt Mosconi, PhD**
- **Hossein Saiedian, PhD**

University of Kansas Medical Center, Kansas City, KS

- **Russ Waitman, PhD**
- **Rene Jamison, PhD**
- **Kim Kimminau, PhD**
- **Kathryn Ellerbeck, MD**

Washington University in St. Louis, MO

- **Dustin Baldrige, MD, PhD**
- **Ginger Nicol, MD**

University of Missouri, Columbia, MO

- **Trupti Joshi, Ph.D**
- **Matt Spence**

University of Nebraska Medical Center, Omaha, NE

- **Monirul Islam, MD, PhD**