KANSAS CITY AREA LIFE SCIENCES INSTITUTE, INC.

Regional Strategic Assessment Neuroscience Working Group
Neurodevelopment Subcommittee Meeting Agenda

Date and Time: Wednesday, June 8, 2016 from 1:00 – 3:00 pm
Location: Children's Mercy Genome Center
2420 Pershing Road

Attendees:

David Beversdorf, MD
University of Missouri
John Colombo, PhD,
University of Kansas
Keith A. Gary, PhD
Kansas City Area Life Sciences Institute
Matthew W. Mosconi, PhD (Chair)
University of Kansas
Sarah Soden, MD
Children's Mercy
Steven Shapiro, MD, MSHA
Children's Mercy
Zohreh Talebizadah, PhD
Children's Mercy
Steven F. Warren, PhD
University of Kansas

Welcome and Introductions

Matt Mosconi opened the meeting by welcoming the group and turned the floor over to Keith Gary for an update on the May 20 KCALSI Path to 2025 Steering Committee Meeting. Dr. Gary shared that the Steering Committee was tasked with overseeing the entire strategic assessment process and the meeting was convened to update the group on progress made by the various working groups and task forces.

Dr. Gary shared that the Neurodevelopment group's progress was positioned in the middle of other teams, with some groups having identified specific strategies/projects while one group has not yet launched (Messaging and Marketing). He also noted that the Steering Committee, while pleased with progress to date, encouraged team leaders to maintain momentum and identify specific project metrics and outcomes.

Dr. Mosconi reviewed the agenda for the meeting, noting it was his hope that discussions would lead to some specific strategies for which specific milestones and metrics could be addressed. Zoreh Talebizadeh requested the opportunity to share an update for her current PCORI-funded project.

Dr. Talebizadeh received a PCORI award focused on community engagement around the topic of incorporating genetic data to improve patient outcomes. She has established a community advisory board (33 members) comprised of PCORI-funded researchers, patients/caregivers, physicians/healthcare providers, industry, health IT, and community leaders. She has developed a website to facilitate communications, education, and meetings/webinars. In addition to the website, the project will develop a position paper on the topic as a deliverable. Her planned next step is to use the platform for increased emphasis on autism spectrum disorders research. She wanted to be sure the subcommittee was aware of this ongoing PCORI engagement project and its developed website. Several questions were directed to how the platform would support potential projects.

Dr. Mosconi mentioned that two specific items were distributed to inform discussion of potential project areas: 1) a concept paper developed by John Colombo describing a translation corridor for neurodevelopmental disorders, and 2) a position paper shared by Dr. Beversdorf describing strategies for stratifying ASD patients for the purpose of moving toward precision medicine. A general discussion of these papers ensued.

Dr. Gary found it difficult to discern from the Beversdorf paper where exactly regional strengths matched up with the variety of topic areas (genetic studies, biomarkers, outcomes, etc) discussed. In the area of genetics for example, many other parts of the country have greater expertise and a longer history of research. Others generally agreed that this would not be a good area for project development.

Dr. Mosconi felt that generating a database of ASD phenotypes might be an area of potential regional opportunity. Such a database does not exist and would be valuable to area ASD researchers. Others were concerned with the degree of variability in assessing phenotypes which could undermine the integrity of the data.

Discussion centered on several aspects delineated in the Beversdorf position paper. There was recognition of rich and plentiful clinical samples available in the region. There was a discussion in the paper regarding induced pluripotent stem cells (iPSCs) in support of biomarker development. It was noted that there is limited work in this area within the region (K-State and KUMC have some assets) and a stigma regarding any stem cell research remains in Missouri. Some recent work exploring the serotonin transporter gene as a robust heritable biomarker was discussed.

Steve Warren was skeptical that establishing new databases or registries would serve as a differentiating capability for the region. He pointed out that experts in the ASD field are well known and investigators interested in particular components of that research gravitate to those investigators regardless of where they are located.

Sarah Soden shared that CMH was involved in a CDC-funded SEED grant with University of Missouri and Washington University. The Study to Explore Early Development (SEED) is one of the largest studies in the United States to help identify factors that may put children at risk for autism spectrum disorder (ASD) and other neurodevelopmental disabilities. The study will also support improved physical, developmental and behavioral characterization of children with developmental disabilities, including health conditions and outcomes. John Constantino at Washington University in St. Louis is the lead PI for the Missouri cooperative, which also includes the Thompson Center (Steve Kanne) and Children's Mercy (Cy Nadler). Official notice of the award would come 7/1/16. (NOTE: grant was awarded)

There was significant time spent discussing Pathfinder Health Innovations (PHI), a start-up company that provides back end office support for autism clinics. They currently serve 250+ clients across the US and have expressed an interest in developing strategies for collecting data specifically for research. There was discussion regarding potential projects PHI could support and questions regarding potential hurdles of accessing the clinical data. Jeff Blackwood, PHI's President and CEO, serves on Dr. Talebizadeh's PCORI Community Committee and KCALSI has solid connections with PKI. The group agreed to attempt setting a meeting with Blackwood at the PHI offices to discuss their company capabilities and potential collaborations.

Steven Shapiro noted, that with the exception of the PHI discussion, much of the conversation was not focused on developing new, novel, projects. He felt that with Cerner and Google gigabit

capabilities in Kansas City, projects that include their participation would likely be transformative for the region.

Next Steps

- *KCALSI will contact Jeff Blackwood at Pathfinder Health Innovations to arrange a meeting with the Neurodevelopment subcommittee.*