

## **Cerebral Palsy Research Network Meeting Minutes**

Monday, May 1, 2017

via Teleconference

**Attending:** Rob Akin (AI duPont), Anastasia Arynchyna (Alabama), Kristie Bjornson (Seattle), Alesia Blanchard (Colorado), Marcia Greenberg (UCLA), Paul Gross (CPRN), Susan Horn (Utah), Ed Hurvitz (Michigan), Jacob Kean (Utah), Michael Kruer (Phoenix), Christopher Lunsford (UVA), Tyra Mattingly (Colorado), Bethany Norton (Phoenix), Ken Rogers (AI duPont), Brandon Roque (Alabama),

### **Action Items:**

**All:** [Watch video recording of this webinar](#) so that you can decide whether to opt-in to Michael Kruer's proposed collaboration. Paul will follow-up with specific request. Presentation begins about 15 minutes into the recording.

**Next Call is Tuesday, May 16, 2017 at 2pm ET**

**Dial-in: (515) 739-1030 Access Code: 881-975-274#**

### **Agenda/Notes:**

**Call Playback:** Playback Number: (515) 739-1039 Access Code: 881-975-274# Reference #59  
or [Play webinar](#)

### **Meeting Notes**

**PCORI follow-up** – The study executive team prepped for and conducted our follow-up Q&A with the PCORI staff. We focused most of our discussion on their willingness to support an observational design for this funding mechanism. The net of the discussion was that while they do support this in a few studies, their review process is biased toward an RCT for their Large Pragmatic Trials RFA. They reiterated that they did not believe we made a strong enough case for why an RCT would not be appropriate. And further emphasized that our observational design did not convince them that we could control for confounders. We argued these points sufficiently on the call but they did think that a resubmission with stronger emphasis on these two key issues would be sufficient to achieve a fundable score.

We plan to approach NIH with this design given their recognition of its need in their strategic plan and past indication that they would be interested. We also plan to consider dividing the study into smaller questions and cohorts that could target PCORI funding mechanisms that do fund observational designs.

### **Registry Update**

Epic forms progress is ongoing. Paul has created a distribution list of internal Epic analysts at sites. Please encourage your Epic analysts to share their progress and issues on that distribution list.

### **Governance**

Paul has completed a first draft of CPRN standard operating procedures with the help of several people. He will be putting this out to the Executive Committee for review and then sharing it with the Investigator committee. A key portion of that is how CPRN will consider new research proposals. Today we will test a variant of that SOP by hearing a proposal from Michael Kruer, M.D. at Phoenix Children's Hospital.

### **Research Proposal**

Michael Kruer gave an overview of his planned R01 study of the genetic causes of cerebral palsy and proposed that CPRN collaborate by identifying patients with cryptogenic causes of CP and connecting them to Michael's lab for consent and screening. Numerous PIs expressed support for the concept and did not feel that identifying patients with unknown causes of CP would be difficult nor would the regulatory issues around introducing them to Dr. Kruer. Paul and Michael will follow-up with mechanisms of support for this study.