

Cerebral Palsy Research Network Meeting Minutes

Monday, February 6, 2017

via Teleconference

Attending: Kristie Bjornson (Seattle), Nancy Clegg (TSRH), Paul Gross (CPRN), Ed Hurvitz (Michigan), Jacob Kean (Utah), Jeffrey Leonard (Nationwide), Dennis Matthews (Colorado), Tyra Mattingly (Colorado), Garey Noritz (Nationwide), Jerry Oakes (Alabama), Ken Rogers (Al duPont), Brandon Roque (Alabama), Debbie Thorpe (UNC)

Action Items:

All:

Dennis: Check on status of Epic form / SDE comparison with Colorado's existing usage.

Paul: Send mail to Jerry Oakes, Rob Bollo and Jeff Leonard to clarify neurosurgery element issue raised as a result of the Epic form creation.

Remember to include SOP for PIs that transfer to other institutions.

Next Call is Monday, March 6, 2017 at Noon 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 #48

MP3 Download of the Call:

<http://www.cpresearch.net/wp-content/uploads/2017/02/20170206-CPRN-Investigators-Mtg.mp3>

Registry Status

Epic Forms – Garey Noritz reported feedback on the new Epic forms tied to the Epic SDEs that have been rolled out in Nationwide's clinic since Tuesday, January 31. Clinicians reported that the forms worked well though initially appeared somewhat overwhelming until it became clear that not all fields were required. The biggest change is the additional birth history information. Garey intends to review the forms for how elements are pulled into the note and to confirm spelling and grammar before making them available to the other sites. Children's of Colorado should finalize their review of their local SDEs to the new forms to be ready to receive the new forms from Nationwide.

IRB Challenges – Paul reviewed challenges that have occurred in our reliance IRB and Utah IRB efforts. New direction from NIH on reliance IRB requirements and a Trial Innovation Center grant to University of Utah have temporarily slowed down the approval of our IRB protocol requests. Two sites, Seattle and Texas Scottish Rite, are in the queue at Nationwide for their reliance IRB approval and two sites, Alabama and Primary, are awaiting REDCap IRB approvals at the University of Utah. Jacob summarized that organizational changes have been the source of delay but there is an open dialogue and a strong sentiment of support from the Utah IRB both as a future reliance IRB and for the Community registry. We hope to get through these delays soon.

Research CP Webinar Series and Workshop – Paul reviewed the details of decisions that have been made since the last meeting. Due to budget, space and optimal size for meeting dynamics, we have decided to restrict the size of the meeting to only 35 participants of which 20 will be from the community and 15 will be clinicians and therapists. While we had originally hoped this meeting could include all CPRN investigators, but the first round PCORI feedback made us pursue a more open track. The webinar series, survey and meeting will be open to the public from a virtual perspective, but the face to face meeting will be limited. If you are very interested in participating, we will need you to participate in all the webinars. We do plan to ask professionals to give examples of their commitment to research and participation in CPRN will be valued highly in the application process.

We have begun promoting Research CP to the community and expect AACPDM to be promoting it to the membership. We provided materials for email and social media last week and hope you can find a channel to distribute to your clinic population so we much reach a diverse group of people from the community.

Expansion of CPRN – As we are approaching the one-year mark since sites were invited to join the founding institutions, the leadership team discussed the expansion of CPRN to other sites. The leadership team's view was generally that we should be inclusive of new sites that demonstrate commitment but wanted the input of the investigator team. The leadership team reviewed the exemplary commitment as demonstrated by Michael Kruer and Phoenix Childrens – they have engaged their extended team, had their IT implement forms in Allscripts, and have requested CPRN's approval to submit an IRB protocol for the registry. Everyone agreed the decision that Phoenix Children's should be invited to the network. But investigators expressed the sentiment that we should not add more sites until we are farther along unless they demonstrate significant commitment. Garey mentioned that we should have an SOP for investigators that move to a new site. Paul has written this SOP as it is a well worn path for HCRN.