

Cerebral Palsy Research Network Meeting Minutes

Tuesday, January 17, 2017

via Teleconference

Attending: Anastasia Archnya (Alabama), Amy Bailes (Cincinnati), Kristie Bjornson (Seattle), Nancy Clegg (TSRH), Pritha Dalal (UCSD), Marsha Greenberg (UCLA), Paul Gross (CPRN), Susan Horn (Utah), Diana Hernandez (Utah), Ed Hurvitz (Michigan), Jacob Kean (Utah), Aga Lewelt (Jacksonville), Tyra Mattingly (Colorado), Jerry Oakes (Alabama), Allison Oki (Utah), Ken Rogers (Al duPont), Brandon Roque (Alabama), Christine Thorogood (Jacksonville),

Action Items:

All: Determine which media you can distribute information about the Research CP workshop including email, snail mail, Facebook, website, clinic or support group handout.

Paul: Get Epic forms to Ed Hurvitz in support of IRB. (done)
Develop materials to support promotion of Research CP workshop and webinar series.
Explore child care costs and options for supporting.

Next Call is Monday, February 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 #45
MP3 Download of the Call:

<http://www.cpresearch.net/wp-content/uploads/2017/01/20170117-cprn-investigator-mtg.mp3>

Status Updates

PCORI CER Application – Per the email from Dr. Rich Stevenson (UVA), PCORI moved their date of notification to late March. Paul reviewed all PCORI Board of Governors' meetings and found no reference to this date change nor any discussion of it being related to the potential repeal of the ACA. None of the financial discussions indicate that they plan to alter their funding amounts or timeline as their funding is secure through 2019.

Epic Forms – while things slowed over the holidays, Epic forms have been deployed (update: will be imminently deployed) for Nationwide's non-surgical clinic visits. After a brief usage and iteration, these forms will be made available to sites that are ready. Al duPont, Children's of Colorado and UVA are queued up to take the non-surgical forms when they become available. Neurosurgery forms have been reviewed with Dr. Jeffrey Leonard, chief of pediatric neurosurgery at Nationwide, and some changes in the forms' representation of data elements are being made. Nationwide will pilot these after the alterations are made.

IRBs and BAAs -- UVA received IRB approval for the registry bringing us to six IRB approvals for the registry! Several additional Business Associate's Agreements (BAAs) have been completed. In a discussion with Texas Scottish Rite Hospital, their legal counsel noted that Nationwide's IRB approval letter specifically references a Data Use Agreement (DUA). Some sites are requiring a DUA as a result of this. We are asking Dr. Garey Noritz and Nationwide to amend their IRB to reference a DUA or a BAA. Many sites have been satisfied with a BAA in support of the registry.

Standard Operating Procedures (SOPs) – Jeff Leonard has been leading a subcommittee on authorship and publication SOPs. The group has developed a draft SOP that is being reviewed and revised by the subcommittee and will soon be shared with the investigator committee for feedback. Susan Horn from the Utah DCC is working on the initial draft of the data access SOPs. Given how central the role of data access is to the vision of CPRN, the executive committee will provide the first round of edits and feedback before distributing that SOP. The key issue for data access is how do we maximize the impact of the data that we are collecting but maintain the quality of analysis that will be critical to building the brand for CPRN for high quality, high impact research. The direction is to make sure that biostatistical resources from the DCC will be assigned and involved in any data analysis to assure quality of interpretation of the data.

Pediatric PRO Registry – This registry is now called the CPRN Community Registry. The pediatric PRO study group is doing a comparison of the PEDI-CAT and CP PRO domains. Once this analysis is complete, we will engage our new pediatric community advisory committee to provide input in to which domains are most important so we can choose which tool is most appropriate for our annual baseline measure.

QI Study Group – The QI study group met and decided to initially pursue a QI protocol for Baclofen pumps that was developed by Dr. Rob Bollo, CPRN investigator and neurosurgeon at Primary Childrens. Rob is doing some initial data analysis on their data from a pilot of the protocol with three sites. He will present the data to the CPRN investigator committee at a future call. Sites that would participate in this QI protocol would need to collect baseline infection data but the protocol compliance data fields are already incorporated into the REDCap and Epic forms (and hence our choice for our first foray into QI). Amy Bailes, QI study group leader, recommended that we use the research agenda workshop to set priorities for implementation of the AACPDM care pathways like hip surveillance for our future QI work.

Research CP Webinar Series and Workshop – Per prior emails, CPRN and CP NOW (Michele Shusterman's nonprofit) received a conference grant from PCORI for \$50,000. The goal of the supported workshop is to set a patient-centered research agenda for CP. The workshop is targeted for June 2017 for up to 50 people split roughly evenly between community members and clinician researchers. To be invited to the workshop, attendees will need to apply and participate in five one-hour webinars to provide a baseline of terminology and knowledge before arriving at the workshop. The webinars will cover the following topics:

- An overview of the Research CP effort and collaborative research networks
- Clinical research methods
- Quality improvement methods
- Patient-centered research and patient-reported outcomes
- Clinical and patient-powered registries

Webinars will have pre and post surveys to reinforce learning objectives and track engagement and completion of webinars. Following the webinar series, there will be a survey to both the provider community and the CP community on most important research questions and outcomes to improve.

The results of this survey will then be synthesized during a 1.5-day workshop in Chicago in mid-June. Community participants will be compensated for their time in the webinars and workshop as well travel reimbursement. Providers will be reimbursed for travel on an as needed basis.

Discussion: Given that we will require a diverse set of community participants that are very engaged, we want to reach out to each of your local communities through flyers, email, snail or presentation at support group meetings. How could we best support you in doing this? Key suggestions included:

- User friendly language about the time commitment, compensation and goals to be shared:
 - o As a Facebook post (Cincinnati, Michigan)
 - o An email blast to past clinic visitors (Seattle)
 - o A paper mailing to past clinic visitors (Utah, maybe Cincinnati)
 - o Information for a clinic website
- Any provision for child care?