

## Cerebral Palsy Research Network Meeting Minutes

Tuesday, April 26, 2016

via Teleconference

**Attending:** Amy Bailes (Cincinnati), Nancy Clegg (Texas Scottish Rite), Pritha Dalal (UCSD), Paul Gross (CPRN), Ed Hurvitz (UMich), Jacob Kean (Utah), Jeff Leonard (Nationwide), Aga Lewelt (Jacksonville), Dennis Matthews (Colorado Children's), Allison Oki (Utah), Ken Rogers (AI duPont), Debbie Thorpe (Chapel Hill), Yvonne Wu (UCSF)

### Action Items:

**All:** Review SOP outline and send email to Paul if you want to volunteer to work on any of them. Email Paul if you want to help plan the research prioritization application to PCORI.

**Brian:** (continued) Email introduction of Rich Finkel to Paul regarding the SMA research agenda planning process.

**Jacob:** Create a version of the IRB Protocol for informed consent.

**Next Call is Monday, May 9, 2016 at noon ET (WebEx to view Epic forms)**

**415-655-0001 Access code: 193 515 152**

### Agenda/Notes:

**Call Playback:** Playback Number: (605) 562-0029 Access Code: 881-975-274# Reference #20

MP3 Download of the Call:

<http://www.cpresearch.net/wp-content/uploads/2016/04/2016-04-26-CPRN-Investigator-Call.mp3>

#### IRB Protocol

Garey Noritz has received preliminary feedback from an expedited review from the Nationwide IRB. Most issues were simple check box updates but the waiver was challenged and Garey will bolster the argument. Aga asked for a version of the IRB with informed consent for University of Florida Jacksonville.

#### Forms Update

**Epic:** Garey Noritz reported that the non surgical forms were deployed this week at Nationwide and were functioning very well with regard to productivity in clinic. He noted some minor changes that were needed for "Unknown" in some instances and a few form spelling errors. The goal is to link these forms to the Epic Foundation Smart Data Elements that are released in June so that we can have non surgical forms available this summer for all Epic sites. Nancy confirmed that minor testing is happening at Texas Scottish Rite Hospital (TSRH). Surgical forms and PT forms are expected to trail non surgical form release. Exact plan for additional forms release is TBD but TSRH is on track for October.

**CERNER:** No update on Cerner forms at this time.

#### PCORI Resubmission Status

The study team for the PCORI lower limb surgical study is working on a revised LOI for May 4. Based on feedback from PCORI, the new proposed study is limited to spastic diplegics between 2-12 years of age that have been indicated for surgery. They will be analyzed in four groups – SDR, orthopedic surgery, botox and watchful and waiting. The sample size has been reduced from 2500 to 1500. We will be requesting more

detailed information about those four groups from your centers from the past year prior to the site selection and full application. We will share the LOI after submission.

#### PCORI Conference Grant

CPRN is pursuing a conference planning grant from PCORI to assemble the CPRN Investigator team and a set of patient and caregiver stakeholders. We will conduct an educational series of webinars on clinical research, patient centered research, Quality improvement and collaborative networks to build an educated base of patient, caregivers and providers. We will then survey both the providers and the patients/families about top research questions. Then a conference would be organized to prioritize the research areas. This effort will form the basis of the CPRN research and quality improvement agenda. Ed Hurvitz and Aga Lewelt volunteered to help review the application.

#### Standard Operating Procedures (SOPs)

Paul requested volunteers to help with key SOPs such as data access. Aga, Debbie, Ed and Jeff volunteered to help work on data access and authorship SOPs. The executive committee will work on the other SOPs for now. The goal is to form a few working groups that develop a recommended SOP and bring it back to the group in a few months for approval.

#### Patient Powered Registry

The goal of this effort is to capture long term patient reported outcomes (PROs) for people with CP. Initially these PROs will be the GOAL and CP-Child collected as part of the registry directly in the EMR from MyChart or other patient portals. But we also want to be able to collect PROs from people that are not served by CPRN centers. In particular, the adult registry group has defined a set of PROs that they want to collect. We have selected REDCap hosted at the University of Utah for our patient registry platform. This location and selection will afford us the capability of linking the clinical registry with the PRO registry to track patients for the long term.

#### Leadership Changes

The CPRN leadership team agreed that it needed to add PM&R and neurology to the leadership team. Ed Hurvitz has been invited to serve in that capacity for PM&R and has accepted. Ed has been a very supportive participant at every phase of the registry definition and is a welcome addition to the team. A discussion about an appropriate choice for neurology is ongoing.