

## Cerebral Palsy Research Network Meeting Minutes

Monday, June 6, 2016

via Teleconference

**Attending:** Amy Bailes (Cincinnati), Kristie Bjornson (Seattle), Nancy Clegg (TSRH), Paul Gross (CPRN), Susan Horn (Utah), Jacob Kean (Utah), Christopher Lunsford (UVA), Tyra Mattingly (Colorado), Garey Noritz (Nationwide), Ken Rogers (Al duPont), Brandon Roque (Alabama)

### Action Items:

**All:** Review grants administrator information in the spreadsheet. Update will be requested shortly.  
Determine if you or your alternate PI will be the site PI for the PCORI CER study.  
Review Patient Advisory Committee characteristics below and send recommendations.

**Paul:** Write a paragraph for characteristics of a good Patient Advisory Committee member and duties.  
(see notes below).

**Next Call:** June 21, 2016 at 2 pm EDT.

### Agenda/Notes:

**Call Playback:** Unfortunately, this call was not recorded

#### IRB Protocol Status

IRB Protocol was reviewed at Nationwide on Friday, June 3. A response is being prepared by the IRB chair. Garey will share the results as soon as we are informed. We have not prepared an “informed consent” version of the protocol yet. We are waiting to determine if other modifications are required.

#### PCORI CER application

Paul distributed a list of grants administrators from the last effort on this grant. Not all CPRN sites were participants last year but all sites are welcome this year. Please give some consideration as to whether you want to be the site PI for the application or your alternate CPRN PI. Paul will send a survey to gather grants administration and site PI data immediately following LOI notification.

Amy Bailes clarified that the site survey need not be Jan-Dec but instead any recent contiguous 12-month period.

#### PCORI Conference Application

Paul briefly reviewed the purpose of the application detailing with a planned CPRN investigator meeting that also would provide funding for patient engagement. Following the blueprint for patient-centered research, Paul and Michele are building a Patient Advisory Committee (PAC) that will be populated by adults with CP and caregivers as well as a pediatric set of caregivers. The adult PAC has already been recruited. Paul requested suggestions for the pediatric PAC especially people of color and ethnic diversity. PAC members will be asked to participate in monthly CPRN update calls and self select to participate in specific studies from the design through the dissemination of results. Here is a brief description of time requirements:

#### Patient Advisory Committee Duties and Time Commitment

- One hour a month for engaging in the work plan of CPRN with periodic emails/documents to read.

- Participation in CPRN research priority setting meeting (five hours of prep plus three days including travel) in the next six to nine months. Time and travel will be compensated if PCORI grant awarded otherwise only travel will be reimbursed.
- Optional participation in study panels, e.g., registry, CER study, future yet to be proposed studies. These will require closer to four hours per month throughout the study duration. Compensation will be study dependent.

Ideal PAC invitees would be very engaged in understanding clinical research, treatment options and outcomes. We have an adult panel so we are looking for parents of children 2-21. It would be great to have a teen or two. If you think you have a candidate, please email [paul@cpresearch.net](mailto:paul@cpresearch.net) and [Michele@cpnowfoundation.org](mailto:Michele@cpnowfoundation.org) with your suggested recommendations. We are looking for people across the age, GMFCS and involvement spectrum.