Cerebral Palsy Research Network Meeting Minutes
Tuesdy, July 5, 2016
via Teleconference

Attending: Anastasia Arynchyna (Alabama), Amy Bailes (Cincinnati), Kristie Bjornson (Seattle), Heather Brien (UTMB), Fay Callejo (Columbia), Pritha Dalal (UCSD), Thuy Dao (Seattle), Kerry Day (UVA), Matt Ferguson (TSRH), Julie De Filippo (Michigan), Paul Gross (CPRN), Michelle Haynes (UVA), Susan Horn (Utah), Ed Hurvitz (Michigan), Michael Kruer (Phoenix), Dennis Matthews (Colorado), Tyra Mattingly (Colorado), Freeman Miller (AI duPont), Thomas Naughton (Phoenix), Garey Noritz (Nationwide), Cindy O'Donnell (AI duPont), Michael Partington (Gillette), Aloysia Schwabe (Texas Childrens), Manish Shah (UT Houston)

Action Items:

Kerry: Provide scope of work (patients to be enrolled, follow-up, etc.) to help with internal processes at sites.

Paul: Schedule a call to review the draft research plan.

Agenda/Notes:

- **Call Playback:** http://www.cpresearch.net/wp-content/uploads/2016/07/20160705-CPRN-Investigators-Call.mp3
- **Playback Number:** (605) 562-0029 **Access Code:** 881-975-274# **Ref** #26

Review of changes to the Research Plan from LOI
The study team discussed and affirmed that prior gait related surgeries would be excluded from the study. While this limits the participants it makes the data cleaner and the results stronger. We have changed inclusion criteria for age to start at three since so few sites do interventions on two year olds. We are adding the capture of baseline and follow-up videos to be used in conjunction with the Edinburgh Gait Scale as a secondary outcome measure. These will be uploaded and evaluated centrally. We have also narrowed the primary outcome measure to the CP CAT. We will still use the GOAL as a secondary outcome measure since it has unique domains that it captures.

Site Enrollment Targets
Paul welcomed the addition of Washington University/St Louis Children's Hospital and UT Health System to the study.

The methodology for selected site targets was based off of the site surveys. We are shooting to enroll 750 surgeries of which 250 would be Selective Dorsal Rhizotomy. We started with an assumption of 70% enrollment of eligible patients due to consent and other challenges. After allocating 70% of the SDRs, we allocated a percentage (up to 70%) of the available orthopedic surgeries to get to roughly half of the enrollment target. The rest of the enrolled patients would come from Botox/Phenol and PT only. All patients would be enrolled sequentially until a planned target for Botox and PT are attained.

Q&A

Susan Horn asked about the importance of capturing adverse events. Amy Bailes and others felt that the capture of adverse events was very important. Examples were given. Paul encouraged Susan to target these questions to a bigger group of PIs given the large number of grant admins on the call.

Ed Hurvitz asked about cost sharing for PI and clinical research assistants (CRA). Kerry explained that institutions would initially carry the burden of patient enrollment after the initial $25,000 payment but just until funds were released by UVA in support of patient enrollment activities.

Kristie Bjornson asked about data collection in non Epic sites. Paul explained that this study was funded to support CRAs to do chart abstraction and the CPRN Registry data collection methods may be applied but were not required for the study.

Amy Bailes requested a scope of work that could be used within in her institution that would describe the protocol broadly, targeted enrollment and commitments of the site. Paul and Kerry agreed to provide one to all sites along with their specific enrollment targets by intervention.