Cerebral Palsy Research Network Meeting Minutes
Monday, August 29, 2016
via Teleconference

Attending: Amy Bailes (Cincinnati), Kristie Bjornson (Seattle), Nancy Clegg (TSRH), Marcia Greenberg (UCLA), Paul Gross (CPRN), Susan Horn (Utah), Jacob Kean (Utah), Jeff Leonard (Nationwide), Christopher Lunsford (UVA), Garey Noritz (Nationwide), Ken Rogers (AI duPont), Brandon Roque (Alabama)

Action Items:

All: Please let Paul know if you are interested in being part of the pediatric Patient Reported Outcomes study group.
Please let Amy Bailes (amy.bailes@cchmc.org) if you are interested in joining the QI study group.

Paul: Update the meeting invites to be for the first Monday and third Tuesday of each month.

Agenda/Notes:

- ◦ **Call Playback:** http://www.cpresearch.net/wp-content/uploads/2016/08/20160829-CPRN-Investigators-Call.mp3

- ◦ **Playback Number:** (605) 562-0029 **Access Code:** 881-975-274# **Ref** #31

Patient Powered Registry
Paul described that the initial vision of CPRN included the marriage of a patient reported outcomes (PRO) registry with the clinical registry. In some cases, PROs will be collected as part of clinical practice. But for many in the community not seen at a CPRN center, or for centers that do not have an onsite PRO collection capability, the CPRN PRO Registry will be a key solution. We have selected REDCap for this patient registry which will be hosted at the University of Utah. We are building a portal called MyCerebralPalsy.org which will provide community access to the CPRN PRO Registry. Mary Gannotti, and Debbie Thorpe are leading the adult study effort which will launch the first PRO surveys. They are working with the adult Community Advisory Committee (CAC) that we formed to get feedback on research priorities and their initial survey questions. We plan to expand the CAC imminently with pediatric focused parents and teen patients. **We are interested to know who would like to join Jacob Kean, Unni Narayanan and Paul in planning the surveys beyond CP-CAT, GOAL and CP-Child for the pediatric focus of the CPRN PRO registry.**

Quality Improvement
Amy Bailes is going to lead an effort to establish our QI processes. She is joined by Garey Noritz, Mary Gannotti, Rob Bollo and Paul Gross. Amy has the benefit of working around the folks that have significant expertise in building and running QI networks. We are going to start meet monthly (or so) to discuss QI processes and metrics for CPRN. **Please let Amy know if you would like to join our effort.**

CPRN Registry Forms

Epic has now completed and released the CPRN CDM in its Foundation system through a series of system updates. Garey Noritz and Jim Menke at Nationwide Children's Hospital (NCH) have reviewed the non-surgical elements and have found a number of misinterpretations and omissions. We have started a dialogue with Epic about getting those SDEs corrected. A complete comparison of the Epic SDEs to the CPRN CDM is being completed at the University of Utah this week. We plan to implement the complete set of non-surgical forms as implemented at NCH with these Epic SDEs (working around known issues) and release these forms to other sites initially. Jeff Leonard of NCH has volunteered to test the neurosurgery forms so we plan to implement those immediately following the non-surgical forms. Lawson Copley of Texas Scottish Rite Hospital has shared the neurosurgery form screen shots with Jim to simplify the implementation. Marcia noted that the SCALE implementation still needs to be updated to the current CDM. This is among the list of discrepancies found in the Epic SDEs.

Paul engaged a 1st medical student at Harvard who is an ex-Google employee to work with Ben Shore at Boston Children's Hospital on the Cerner forms implementation. They have had two meetings and Gavin, the med student, is shadowing Ben during his clinic to better understand the workflow.

AACPDM Side Meeting
We are having a side meeting at AACPDM on Friday, September 23 from 12:30 to 1:30 pm. The purpose is to meet face to face and discuss network progress, challenges and future plans. Room TBD.

Meeting Schedule
Our established meeting schedule is the first Monday of the month at noon ET and the third Tuesday of the month at 2 pm ET. Since many months have passed, the weeks have shifted so September meetings need to be reset to maintain this schedule. Paul will update the meeting schedule.

CPRN Leadership meetings happen Wednesday at 5 pm ET as needed.