

## Cerebral Palsy Research Network Meeting Minutes

Monday, August 1, 2016

via Teleconference

**Attending:** Anastasia Arynchyna (Alabama), Amy Bailes (Cincinnati), Fay Callejo (Columbia), Nancy Clegg (TSRH), Marcia Greenberg (UCLA), Paul Gross (CPRN), Susan Horn (Utah), Ed Hurvitz (Michigan), Jacob Kean (Utah), Jeff Leonard (Nationwide), Christopher Lunsford (UVA), Tyra Mattingly (Colorado), Freeman Miller (Al duPont), Jerry Oakes (Alabama), Aloysia Schwabe (Texas Childrens), Manish Shah (UT Houston), Christine Thorogood (Jacksonville)

### Action Items:

**All:** Please update Paul and Jacob with the status of your IRB submission if you have not done so.

**Paul:** Schedule a call with Rich Stevenson to discuss the research plan.

### Agenda/Notes:

- **Call Playback:** <http://www.cpresearch.net/wp-content/uploads/2016/08/20160801-CPRN-Investigators-Call.mp3>
- **Playback Number:** (605) 562-0029 **Access Code:** 881-975-274# **Ref #27**

### CPRN Registry Forms

The Epic Smart Data Elements for CPRN are being released in stages. Only a subset made the targeted June release date. Nationwide Children's Hospital has implemented the non-surgical forms using this subset of elements which would enable us to share these initial forms with other Epic 2015 sites with minimal effort. Garey Noritz is conducting a review of the Epic SDEs that are available to determine if it represents a minimum viable set. When the more complete set of SDEs and Texas Scottish Rite forms become available in Epic, we would then expand the data collection.

### CPRN IRBs

Primary Children's Hospital and Colorado Children's Hospital have submitted the CPRN Registry protocol to their IRBs. Al duPont is leveraging the PEDSnet reliance agreement and is in process. EMR Form based data collection can begin prior to the IRB because it is part of usual care. IRB approval will be necessary to set the date for which data collected by EMR form can be used for the registry. A question was asked about how quality assurance would happen. Susan Horn described the method for checking data quality and completeness and that most QA would be done electronically. Site visits would not likely be necessary for the registry.

### Business Associate Agreements

BAAs are coming in slowly. From a timing perspective, they trail the IRB approval because the BAA is only required at the point that we want to transfer EMR data to the Data Coordinating Center in Utah.

### PCORI Application

The PCORI application, which is over 700 pages, is in review at UVA. Rich Stevenson could not make the call so a follow-up Q&A session will be scheduled.