

Cerebral Palsy Research Network Meeting Minutes

Tuesday, July 18, 2017

via Teleconference

Attending: Anastasia Arynchyna (Alabama), Kristie Bjornson (Seattle), Nancy Clegg (TSRH), Pritha Dalal (UCSD), Mary Gannotti (Hartford), Paul Gross (Utah), Jacob Kean (Utah), Jeff Leonard (Nationwide), Neil Panlasigui (Seattle), Ken Rogers (Al duPont), Brandon Roque (Alabama)

Action Items:

Next Call is Tuesday, August 22, 2017 at 2pm ET

Dial-in: (641) 552-9473 Access Code: 430970#

Agenda/Notes:

Call Playback: Playback Number: (641) 552-9478 Access Code: 430970# Reference #7
or [Play the recording online](#)

Meeting Notes

Registry Status - The REDCap Registry has 140 records (and growing) from three sites. Two sites are adding just neurosurgical cases and one is adding patients from all disciplines. The first extract from Epic from Nationwide to Utah is imminent and should have approximately 600 records. These will be merged into the registry with an extract of the REDCap records in coming weeks. The hope is to support a high-level analysis for the AACPDMD presentation on the registry in September.

Registry Forms – Reminder that the Epic forms are available by making a request of your Epic TS to Nationwide (pchounet@epic.com who is their Epic TS). The forms available now are the non-surgical forms. Neurosurgical forms are in test at NCH and Paul owes NCH/Jeff Leonard a comparison of the current test forms with the Common Data Model (REDCap). Orthopedic surgery and PT/OT forms have been developed and are in review at NCH. Dr. Jim Menke, who developed the Epic forms at Nationwide, has retired and a new team is in place to move that work forward. (Thank you Dr. Menke for all your hard work!) The orthopedic surgery and neurosurgery forms will not include note generation during the test phase to make sure that the data entry requirements are minimal before generating appropriate notes.

Gillette is still offering to do Cerner forms but has been under resourced for this task while supporting their initial rollout of Cerner that started in February. Paul is also pursuing alternatives at Seattle Children's.

Community Registry – The Utah IRB provided some initial feedback on the protocol and Jacob Kean is iterating on those requests. Many items were about additional training required for Utah staff members working on the community registry and should be completed shortly. The Utah IRB confirmed that the review is an expedited review. We have also received substantial feedback from a survey methodologist at University of Utah. We will be responding to these items in parallel with the IRB requests. We are considering adding a subset of the clinical registry forms that are deemed to be comprehensible to and

reliable from community members if the language is made more lay friendly. We have also received a license agreement from Boston University for CP PRO which will enable us to move forward with incorporating that measure into the community registry.

Adding sites – Numerous candidate sites have been following our work and are in various stages of submitting the registry IRB protocol and/or implementing the Epic forms. UT Health Houston has submitted the IRB protocol and is the next site to be added (Dr. Manish Shah). Texas Children’s Hospital has requested Epic forms but has not submitted the IRB protocol yet. Wade Shrader at Mississippi Children’s has also taken steps to get his site on board.

AACPDM dialogue – Investigators may have noticed a reference to CPRN from the Research Committee of AACPD. CPRN is in a dialogue with AACPD leadership and the Research Committee about sustaining support for our network operations. Discussions will continue through the AACPD meeting and may take the shape of financial support for the registry or meetings.

Research CP – The Research CP planning team (Paul Gross, Michele Shusterman, Amy Bailes, Susan Horn, Ed Hurvitz and Jacob Kean) have completed an initial draft of the manuscript for Research CP. We hope to complete it in August for submission to Developmental Medicine and Child Neurology.

Study Groups – In addition to the two PRO study groups (adult and peds), an ITB Pump QI group led by Rob Bollo and Amy Bailes is kicking off next month to advance our first QI protocol. In addition, a revision of the PCORI study concept is being considered that narrows the CER to SDR v. serial Botox.