

Cerebral Palsy Research Network Meeting Minutes

Tuesday, August 22, 2017

via Teleconference

Attending: Anastasia Arynchyna (Alabama), Kristie Bjornson (Seattle), Alesia Blanchard (Colorado), Nancy Clegg (TSRH), Pritha Dalal (UCSD), Marcia Greenberg (UCLA), Paul Gross (Utah), Jacob Kean (Utah), Allison Oki (Primary), Neil Panlasigui (Seattle), Ken Rogers (AI duPont)

Action Items:

Next Meeting is Wednesday, September 13, 2017 at 5:30 pm ET in Montreal

All: Please volunteer for one of our two subcommittees [here](#).
Please read and circulate the [PERF grant opportunity](#) with your colleagues.

Alesia: Find out how many records/patients have been entered into the CPRN forms.

Ken: Schedule a call with Paul to discuss the bones module in Epic.

Agenda/Notes:

Call Playback: Playback Number: (641) 552-9478 Access Code: 430970# Reference #19
or [Play the recording online](#)

Meeting Notes

Registry Status – WE are still finalizing first transfer from Nationwide Children’s Hospital (NCH). There is a very active dialogue between the DCC and NCH about the spec, memory issues, and security. As of this call, NCH has been able to export the data set thereby overcoming memory issues. We need to finalize the transfer and the load into the registry on the Utah side.

Other Epic sites are making progress. Nancy Clegg reported that while Texas Scottish Rite thought they were complete, there was pushback from clinicians about the number of forms to be opened so they are re-organizing the workflow. Alesia Blanchard at Children’s of Colorado reported that they are deployed and collecting data but waiting for NCH to complete their transfer process to work on transfer of Colorado’s data. She did note that they extended their clinic appointments from 30 minutes to 45 minutes to accommodate the change in workflow. Ken Rogers said that AI duPont has requested the “bones” module from Epic. Paul asked to have a follow-up call to understand the ramifications.

REDCap Registry is moving along with more than 245 records predominantly from Seattle Children’s Hospital but Gillette and Primary have entered some patients. Anastasia from Children’s of Alabama reported that she has a backlog of patients to enter but needed to consult with additional providers before being ready.

Other Network News – Dr. Jerry Oakes who was on the founding CPRN team and lead the neurosurgery task force to define the registry data elements for Selective Dorsal Rhizotomy and Intrathecal Baclofen Pumps is retiring from neurosurgical practice. He continues to have a senior leadership role at

Children's of Alabama but asked to be relieved of his CPRN duties concomitant with his retirement from neurosurgery. Paul expressed deep gratitude for the time and effort that Dr. Oakes spent helping launch CPRN.

The CPRN Executive Committee (EC) has invited Dr. Jeff Leonard, Chief of Pediatric Neurosurgery at Nationwide Children's Hospital, to represent neurosurgery on the CPRN EC. Jeff has been very involved in getting surgical forms built in Epic at NCH and led the effort to define the manuscript standard operating procedure for CPRN. Jeff has accepted and joined the EC! Please welcome Jeff.

UT Health – Houston and Dr. Manish Shah have joined CPRN. Dr. Shah is a pediatric neurosurgeon who trained with TS Park in Washington University in St. Louis and does research in neuroimaging in cerebral palsy. UT Health has an IRB approval for the registry and will be using REDCap to capture data initially.

Texas Children's Hospital and Dr. Aloysia Schwabe have also received approval for the CPRN Registry and have been invited to join the network. Dr. Schwabe is a PM&R doctor who leads the CP efforts at TCH.

NIH Meeting – Paul has organized a meeting of multiple NIH Directors and leaders from NINDS and NICHD (and potentially others) to discuss funding opportunities for CPRN focused research. Susan Horn and Diane Damiano will be participating in the meeting and others may be asked to join us on October 5 in Bethesda. The objective of the meeting is to educate NIH on how CPRN has fulfilled numerous aspects of the NIH CP Strategic Plan and to determine how to best approach multi-institute funding opportunities given the heterogeneity and longitudinal requirements for studying the condition.

AACPDM Meetings – There will be a CPRN investigator meeting at AACPDPM on Wednesday, September 13 at 5:30 pm (location TBD). There will also be an informational session for site candidates on Friday at 12:30 pm. CPRN is giving two presentations during the meeting – a QI breakfast seminar covering CPRN QI strategy and the ITB pump protocol as well as a free paper session on initial findings from the registry. Both presentations are on Friday morning.

CPRN Subcommittees – Paul reviewed the purpose of the survey to request volunteers for two CPRN subcommittees – Scientific Review and Manuscript Review. The Scientific Review Subcommittee (SRS) is an internal NIH-like study section for CPRN studies. Experience reviewing and applying for grants is invaluable for this committee. Manuscript Review Subcommittee (MaRS) is an internal editorial board to improve manuscript acceptance and assure CPRN quality. Experience being a primary manuscript writer or being a journal editor is ideal. We are looking for representation from all disciplines on these committees.

CPRN Internal RFA – We have been encouraged to apply for an infrastructure grant from the Pediatric Epilepsy Research Foundation (PERF). Deborah Hirtz, who is a pediatric neurologist, a former NINDS program officer in the Division of Clinical Research and an advisor to CPRN, sits on the board of this organization. She believes that we would be well positioned for a grant but we need a neurodevelopmental pediatrician or a pediatric neurologist to partner with to apply for this grant. The grant application does not need to be epilepsy focused but could enhance our data collection for epilepsy. If you have a qualifying physician in your CP practice that would be willing to partner with DCC to write this grant, please have them contact Paul. We will partner with the clinician who is best suited to pursue this grant opportunity that will be \$50,000-\$100,000 per year for two years.