

Cerebral Palsy Research Network Meeting Minutes

Tuesday, May 24, 2016

via Teleconference

Attending: Amy Bailes (Cincinnati), Rob Bollo (Utah), Nancy Clegg (Texas Scottish Rite), Pritha Dalal (UCSD), Diane Damiano (NIH), Mary Gannotti (Hartford), Paul Gross (CPRN), Susan Horn (Utah), Ed Hurvitz (UMich), Jacob Kean (Utah), Jeff Leonard (Nationwide), Aga Lewelt (Jacksonville), Christopher Lunsford (UVA), Tyra Mattingly (Colorado Children's), Unni Narayanan (SickKids), Tom Novacheck (Gillette), Allison Oki (Utah), Ken Rogers (Al duPont), Brandon Roque (Alabama), Debbie Thorpe (Chapel Hill), Yvonne Wu (UCSF)

Action Items:

All: Fill out site survey by June 22 and return to paul@cpresearch.net.

Jacob: (continued) Create a version of the IRB Protocol for informed consent.

Next Call is Monday, June 6, 2016 at noon ET

(605) 562-0020 pin: 881-975-274#

Agenda/Notes:

Call Playback: Playback Number: (605) 562-0029 Access Code: 881-975-274# Reference #21

MP3 Download of the Call:

<http://www.cpresearch.net/wp-content/uploads/2016/05/20160524-CPRN-Investigators.mp3>

IRB Protocol

Garey Noritz resubmitted the IRB and expects it to be reviewed on June 3. Aga reiterated the need for a version of the IRB with informed consent for University of Florida Jacksonville.

Forms Update

Epic: The plan of record is to adapt the Nationwide non surgical forms (everything but PROs and surgical elements) to the corresponding Epic released SDEs when they come out in June. This process shouldn't take long. Nationwide will retest with the new SDE and then the form will be made available through Epic User Web. The target for this is August 2016. This will give all Epic sites an opportunity to roll out the CPRN Registry in increments. The surgical forms will be released some time after Texas Scottish Rite's Epic rollout in October 2016 – exact plans TBD.

CERNER: No update on Cerner forms at this time.

PCORI Conference Grant

CPRN is submitting a conference planning grant from PCORI on June 1 to assemble the CPRN Investigator team and a set of patient and caregiver stakeholders. We will be informed of a decision by mid July.

PCORI CER Study

The key milestones in completing this grant are June 10th to be invited to full application, July 14th to have site budgets complete and July 25th to have the research plan and application complete at UVA for an August 9th submission to PCORI.

The group reviewed proposal for a site survey to collect information about annual procedures that meet the inclusion criteria for the proposed lower extremity study. Feedback was provided about what would be feasible. Paul will revise the survey and send it out as an Excel spreadsheet. Responses are due June 22 to support site selection and support realistic accrual numbers for the study application. It was recommended that the REDCap form for orthopedic interventions be used for reference lower extremity surgeries.