

Cerebral Palsy Research Network Meeting Minutes

Tuesday, June 21, 2016

via Teleconference

Attending: Amy Bailes (Cincinnati), Nancy Clegg (Texas Scottish Rite), Pritha Dalal (UCSD Paul Gross (CPRN), Susan Horn (Utah), Ed Hurvitz (UMich), Jacob Kean (Utah), Jeff Leonard (Nationwide), Aga Lewelt (Jacksonville), Tyra Mattingly (Colorado Children's), Jerry Oakes (Alabama), Allison Oki (Utah), Michael Partington (Gillette), Ken Rogers (Al duPont), Debbie Thorpe (Chapel Hill), Yvonne Wu (UCSF)

Action Items:

Amy,

Bill/Marcia,

Debbie,

Dennis/Tyra,

Pritha: Ask your CMIO when your institution plans to upgrade to Epic 2015.

Christopher: Ask your CMIO when they will take the next Epic System Update.

Paul: Resolve remaining site questions for PCORI study (clinical outcome measure of gait).

Next Call is Tuesday, July 5, 2016 at 2 pm ET

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

Agenda/Notes:

Call Playback: Playback Number: (605) 562-0029 Access Code: 881-975-274# Reference #25

MP3 Download of the Call:

<http://www.cpresearch.net/wp-content/uploads/2016/06/20160621-CPRN-Investigator-Call.mp3>

IRB Protocol

Jacob Kean reviewed status and plan to maximize sample: best case waiver of consent, fall back to opt-out consent which retains 90-95% of sample, worst case is informed consent. Paul took a poll of callers status. Most sites are in various stages of writing protocol or discussing details with members of IRB to anticipate any issues.

Epic Forms Update

Epic is releasing the CPRN data model in its next system update (SU). This SU is only available to sites on Epic 2015. Many of you are on Epic 2014. If I haven't done so already (with you copied), please reach out to your CMIO to determine when your organization will upgrade to 2015. The non-surgical forms should be ready for usage toward the end of summer so any Epic 2015 sites will be able to use them just by taking the SU. If you are a 2015 site, please ask when you will take the next SU.

BAAs

BAAs have gone out to everyone except Alabama, UCSD, Sickkids. These should be going out shortly. BAAs might need to trail IRB protocol approvals for reference in some institutions.

PCORI Application

Interactions should be targeted to both the PI and the Grant admin. Open Q&A. **How do we estimate budgets?** \$25K in the first year and your estimate of your ability to enroll based on the site survey. We will provide more guidelines shortly. Travel for 1-3 people once per year. \$800-\$1000 for travel, lodging and meals. **When will site selection be complete?** We have said one week from tomorrow but we will try to have information EOD Monday, June 27th. It will be most challenging for “small” sites (approximately 25 eligible per year). Powering SDR is the biggest variable.