

Cerebral Palsy Research Network Meeting Minutes

Monday, October 3, 2016

via Teleconference

Attending: Paul Gross (CPRN), Susan Horn (Utah), Jacob Kean (Utah), Michael Partington (Gillette), Ken Rogers (Al duPont), Brandon Roque (Alabama), Debbie Thorpe (Chapel Hill)

Action Items:

Paul/Jacob: Create IRB protocol for PRO Registry.

Next Call is Tuesday, October 18, 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 #33

MP3 Download of the Call:

<http://www.cpresearch.net/wp-content/uploads/2016/10/cprn-investigators-call-20161003.mp3>

BAA Windfall

Paul Gross reported that both Nationwide Children's Hospital and the University of Utah agreed to accept the existing BAA that has been executed between the organizations for another research network with data housed at the University of Utah. This acceptance means that many institutions participating in the PECARN, CPCCRN, or HCRN networks already have BAAs in place that might be sufficient. The decision lies with the site transferring the data. Sites that should see if the existing agreements include: Alabama, Boston, Cincinnati, Michigan, Primary, SickKids, Seattle, UCSF/Benioff.

Patient Reported Outcomes (PRO) Registry

Paul asked if sites would require an IRB approval to promote a CPRN PRO registry that is hosted at the University of Utah. Everyone was unanimous that it would be required but that it would also be easy. Jacob will develop and submit the IRB Protocol for the PRO Registry at the University of Utah and share the file protocol with other sites.