

Cerebral Palsy Research Network Meeting Minutes

Monday, November 7, 2016

via Teleconference

Attending: Anastasia Arynchyna, Amy Bailes (Cincinnati), Kristie Bjornson (Seattle), Alesia Blanchard (Colorado), Rob Bollo (Utah), Nancy Clegg (TSRH), Marcia Greenberg (UCLA), Paul Gross (CPRN), Jacob Kean (Utah), Garey Noritz (Nationwide), Jerry Oakes (Alabama), Bill Oppenheim (UCLA), Ken Rogers (Al duPont), Brandon Roque (Alabama), Debbie Thorpe (Chapel Hill)

Action Items:

All: Do you have a developmental pediatrician that wants to participate in our PRO study group?

Jacob: Write up talking points for Site PIs to discuss PRO registry with IRB liaisons.
Explore whether University of Utah would be willing to leverage its reliance capability.

Paul: Reach out to Dr. Paul Lipkin at Kennedy Krieger re: Interactive Autism Network IRB and patient recruitment at Autism Treatment Network sites.

Next Call is Monday, December 5, 2016 at 12 pm ET

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

Agenda/Notes:

Call Playback: Playback Number: (605) 562-0029 Access Code: 881-975-274# Reference #34

MP3 Download of the Call:

<http://www.cpresearch.net/wp-content/uploads/2016/11/2016-11-07-CPRN-Investigators-Mtg.mp3>

Grants Update

CPRN has submitted six grant applications to date (2X on the PCORI CER grant, 2X on the PCORI conference grant, one Pedal with Pete for the Patient Reported Outcomes registry submitted last week and one to APTA). Amy Bailes, Ph.D. from Cincinnati Children's just received notice that her application for a study entitled "Toward a practice based evidence model for studying physical therapy dose in cerebral palsy" was funded by the APTA. The study will validate the usage of an EMR form to capture the details of a PT session. If this study is successful, we will work to add these fields and form to the registry and our EMR support. Amy collaborated with Mary Gannotti and Susan Horn from CPRN and others to plan this study and write the grant.

Paul encouraged others to consider grant ideas before we are able to formally plan our research agenda. We are tentatively planning our CPRN research planning meeting for early June 2017.

Patient Reported Outcomes (PRO) Registry

Paul revisited the issue of whether sites would need to submit site specific IRBs to promote the patient reported outcomes (PRO) registry to clinic patients even if they were not directly participating in the research. Jacob Kean, who is writing the IRB protocol for the PRO registry, described the PRO registry as more of an external community effort than a CPRN clinic research effort. He will write up talking points

for site PIs to discuss with their IRB liaisons. Jacob will also explore if the Utah reliance IRB capability could be leveraged for sites that will be required to submit an IRB (e.g., for sites that are participating in the research like UNC Chapel Hill.) Paul will reach out to the PI of the Interactive Autism Network that has a similar capability to see how patients were recruited from the Autism Treatment Network.

The adult study group, led by Mary Gannotti and Debbie Thorpe, has developed two surveys that will be ready to test with their adult community panel in December for launch in Q1.

The pediatric PRO study panel (Jilda Vargus Adams, Mary Gannotti, Paul Gross, Susan Horn, Jacob Kean, Aga Lewelt, Unni Narayanan, Brandon Roque, Ben Shore, Michele Shusterman) will begin monthly meetings shortly. Paul is seeking a developmental pediatrician or pediatric neurologist from a CPRN site that would consider joining the group.

Quality Improvement Plans

Paul reviewed the vision of CPRN's intertwining of clinical research and QI from his experience with Hydrocephalus Clinical Research Network (HCRN). Paul and Amy Bailes recently went to a QI learning conference put on by Cincinnati Children's Hospital that runs five existing QI networks (including Improve Care Now) and five emerging networks (include Cystic Fibrosis and Autism). Cincinnati has a different vision for QI implementation than what has been done in HCRN. CPRN is considering a blending of the two paradigms. Preliminary QI plans for CPRN include an HCRN-like protocol to reduce ITB pump infections that Rob Bollo (Primary/Utah) has been developing with three centers. We are also considering a hip surveillance QI effort. The QI team will meet to develop our plans and bring them back to the group.