

CPRN Investigators Meeting

AACPDM Annual Meeting
Friday, September 23, 2016



Agenda

- Introductions
- Founding Impetus and Team
- Accomplishments
- Plans for the next nine months
- Future plans (H22017 and onward)
- Sustainability
- Discussion
- SWAG



Founding Team Deep in Research, QI and Registries – Most Met At NIH Meeting 2014

- **Amy Bailes, Ph.D.:** clinical epidemiology
- **Mary Gannotti, Ph.D.:** large data sets and ethnographic research
- **Paul Gross:** 3rd clinical research network and registry
- **Susan Horn, Ph.D.:** pioneer in practice-based evidence
- **Unni Narayanan, M.D., M.Sc.:** PI on large clinical study, outcome measures
- **Garey Noritz, M.D.:** Learn from Every Patient registry and QI
- **Jerry Oakes, M.D.:** HCRN founding member, former Editor-in-Chief, Journal of Neurosurgery: Pediatrics

Registry Accomplishments

- Registry Definition
- Data Center Team and Infrastructure
 - REDCap CPRN Registry Forms
 - Clinical Registry Database
 - Staffing (Project Leadership, Biostatistics, Database Development)
- Epic Progress / challenges
 - Data collection live at Nationwide Children's Hospital
- Cerner "progress" and Allscripts potential
- Patient Powered Registry (PROs)



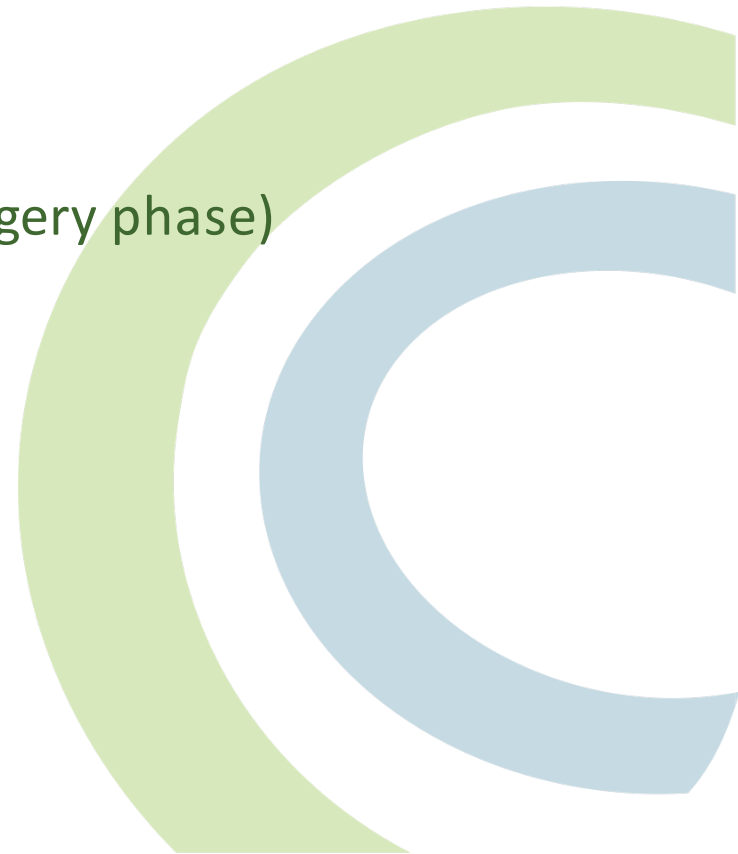
Agreements and Approvals

- IRB Protocol, Submissions, Approvals, Waivers
- BAA approvals (necessary to transfer data to DCC)
- PCORI application agreements with UVA



Active Working Groups within CPRN

- Executive Committee/Leadership Team
- Adult Study Group
- Investigator Committee (currently in the drudgery phase)
- PCORI Study Executive Committee
- Community Advisory Committee (Adults)
- PT study group
- QI study group
- Pediatric PRO Registry group



Five Grant Applications to date

- PCORI
 - Large Scale Pragmatic Trial (2X)
 - Conference Workshop (2X)
- Physical Therapy Session form (APTA)

Considering Pedal for Pete for PRO Registry



Plans for the next six months

- Pilot registry at more Epic sites
 - Expand registry collection to surgical forms
 - Sync with NINDS CDEs
- Launch patient reported outcomes (PRO) registry
 - Adults targeted for year end
 - Peds/Caregivers in Q1
- Advancing QI initiative
- PCORI planning
- Move Cerner development along at Boston Childrens



Plans for H22017 and beyond

- PCORI grant implementation
- Research Prioritization Conference
- Registry expansion

