Research CP Overview
Webinar #1
Setting a Patient-Centered Research Agenda for Cerebral Palsy
A Eugene Washington PCORI funded workshop
Paul Gross, Founder and Chairman, CPRN
Ed Hurvitz, MD, Professor and Chair, Physical Medicine and Rehabilitation
University of Michigan Medical Center
Agenda

• Who are we and why are we here?
• What are we trying to accomplish?
• How does Research CP achieve these goals?
• What is a collaborative research network?
• What and how is research funded?
Who are we and why are we here?

• Who:
  • CP clinicians – doctors and therapists that treat people with CP;
  • Community members – people with CP and caregivers to people with CP;
  • Patient advocates – organizations advocating for people with CP;
  • Leaders in advancing research for cerebral palsy.

• Why:
  • To establish a list of priorities for research and improvement that are focused on improving the lives of people with CP.
  • To build relationships among people from the broader CP community committed to advancing CP research.
What are we trying to accomplish?

• Determine most pressing problems and questions to be answered
• Engage the CP community at the outset of the process
• Involve the most committed clinical researchers
• Establish long-term relationships and collaborations to advance CP care
• Broadly communicate our findings to the CP community
• Focus high-quality research on these outcomes/questions

Improve outcomes for people with CP
How does Research CP advance these goals?

• Engages a representative group of CP community stakeholders
• Brings together committed stakeholders in the treatment of CP
• Establishes mutual understanding through our webinar series:
  • Clinical research and comparative effectiveness methodologies (March 15)
  • Quality improvement methodologies (March 22)
  • Patient-centered research and patient-centered outcomes (March 29)
  • Patient registries (April 4)
• Engagement requires watching the webinar and taking a short survey
How does Research CP advance these goals?

- Garners important questions & outcomes from the whole community via a collaborative survey platform
- Engage by adding questions, editing questions or just voting
How does Research CP advance these goals?

• Organizes a workshop to synthesize community input
  • Facilitated meeting to be held in Chicago, June 16-17
  • Meeting will include 20 community representatives and 15 clinicians
  • Participants will be selected by a brief application due by March 31
    • Key criterion will be engagement in Research CP webinars and community survey
    • Applicants will be notified by April 10
    • Community invitees will be reimbursed for hotel and travel and given a stipend of $600
    • Clinician/therapist participants will be reimbursed for travel if required
  • Meeting will result in a prioritized patient-centered research agenda
How does Research CP advance these goals?

• Disseminates the resulting patient-centered research agenda
  • In partnership with the AACPDM
  • Through publication
  • With social media through the Research CP partners and participants

And through the Cerebral Palsy Research Network (CPRN)

• Uses the agenda to plan studies for a collaborative research network
• Forms cross-discipline research teams including the community
• Measures improvements in outcome over time
What is a collaborative research network?

• Clinicians and institutions that agree to work together on a condition
• Operating guidelines to prioritize and pursue research questions
  • Patient-centered research involves the community in:
    • Which questions and outcomes are most important?
    • Designing and executing studies
    • Sharing (disseminating) the results
• Rigorous collection of patient, intervention and outcome data over time
• Data collection at each site centralized in a registry or database
• Improve outcomes via clinical research and/or quality improvement
What is CPRN?

It is:

• A *collaborative research network* to improve outcomes for CP
  • Including 18 centers and multiple disciplines across the US and Canada
  • 25 clinical investigators who have been collaborating since 2015
  • A data coordinating center to manage data for *research and quality*

• A *registry* including clinical data and patient reported outcomes

• Patient-centered from its founding and inclusive of the community
What CP research has been funded?

Ed Hurvitz, MD
Professor and Chair, Physical Medicine and Rehabilitation
University of Michigan Medical Center
NIH funding for Cerebral Palsy

- CP research Funding from 2001-2013 (Wu, Mehravari, Numis, Gross)
  - 392 million dollars, 455 grants
  - Clinical
    - 19% for interventions
    - 9% for clinical trials
  - Basic Science
    - Cellular structure, Brain biology, muscle structure
- Consistent increase in basic and clinical research
- Still relatively small numbers for the prevalence of CP
National Institute for Disability, Independent Living, and Rehabilitation Research (NIDILRR/HHS)

• Emphasis on clinical translation (rather than mechanism, comparative effectiveness or prevention)

• Five current grants that relate to CP

• Areas of emphasis
  • Technology
  • Aging with cerebral palsy
  • Mobility and mobility aids
  • Health, wellness, exercise

• Other Federal: Center for Disease Control (CDC), Agency for Healthcare Research and Quality (AHRQ)
Patient Centered Outcomes Research Institute (PCORI)

• Funding this workshop
• Interest in Comparative effectiveness research
• Funding areas related to CP
  • Pain in CP
  • Health care of women with disabilities
  • Developmental trajectory of motor skills
  • Therapy intensity, comparative effectiveness
• Non Governmental Org—tied to ACA revenues
Foundations

• CP NOW
• Cerebral Palsy Foundation
• Cure CP—Stem cell research
• Cerebral Palsy Alliance Research Foundation
  • Based in Australia
  • 179 projects, 19 million dollars
  • Covers the range from prevention to treatment to quality of life
• Pedal with Pete
  • Yearly $25,000 grant
  • Both collaborate with CP academy
Building Capacity for Research Funding

• Train the next generation of investigators to ask great questions and write excellent proposals
• Advocacy, especially by families and individuals with cerebral palsy
• Create the infrastructure for multicenter studies
  • Preliminary Data is critical!
Summary

• Research CP is a community effort to prioritize research questions
• It includes:
  • a webinar series,
  • a collaborative survey,
  • a workshop, and
  • a whitepaper
• The results of the whitepaper will be used to direct future research
• The Cerebral Palsy Research Network will pursue the top priorities
• The CP community will work with researchers to make it happen
Next Steps

• You will receive three important links in email
  • Post webinar survey (very brief)
  • Application to Research CP workshop (5-10 minutes)
  • An invitation to the Codigital survey collaboration platform
• If you want to apply for the workshop, take the post webinar survey
• Submit your application by March 31st
• Engage in the Codigital collaborative survey for at least 5 minutes per week!
  • Express your ideas, vote on others’ ideas, suggest edits to language