

Parent to Parent



Bringing the Family's Voice to Research

The Canadian Institutes of Health Research (CIHR) and the Patient-Centered Outcomes Research Institute (PCORI), our study funding agencies, are supporting research that is responsive to the preferences, values, and experiences of patients, families, and caregivers. To achieve this goal, healthcare consumers are included in each step of the research process: identifying the research questions, planning and conducting the study, analyzing the data, and sharing the results with interested parties.

Including parents as research team members ensures that:

- ❖ research questions address priorities and concerns of families and their children
- ❖ study procedures are acceptable and feasible
- ❖ findings are shared in ways that are useful to families and children and inform decision making

Seven mothers of children/young adults with cerebral palsy *bring the family's voice to research* for On Track:

Lisa Diller, Seattle, Washington
Paula Drew, Edmond, Oklahoma
Nancy Ford, Atlanta, Georgia
Marquitha Gilbert, Philadelphia, Pennsylvania
tina hjorngaard, Toronto, Ontario
Kim Rayfield, Philadelphia, Pennsylvania
Barbara Taylor, Pittsburgh, Pennsylvania

Our Parent Researchers meet monthly with study investigators by phone. They have:

- ❖ responded to questions from therapist assessors, advised on ways to share assessment information with families
- ❖ developed an end of study survey for families to tell us in their own words what is important to them when discussing information with therapists about their children.
- ❖ shared their thoughts about what families want to know about the development of their children with CP.

Parent to Parent



Currently the Parent Researchers are involved in producing two short videos.

- ❖ One is about families and healthcare professionals “checking in” to address a family’s questions and priorities, and sharing assessments and results in different ways—customized to help make decisions about rehabilitation services and community programs.
- ❖ One will feature three children with CP and their families, showing the children engaged in various activities and talking about living with CP; demonstrating that children with CP are curious, knowledgeable advocates of their own lives— when connected with the right supports, their ideas can help reimagine possibilities.

We asked our Parent Researches to reflect on their involvement in the “On Track” Study and the inclusion of families as members of the research team:

“One of the most impactful things I can do as a parent of a Differently Able child, is to influence the issues and support we did or did not get to support development of my child. Being a part of this research program allowed me share both my positive and my challenging experiences to benefit families both here and abroad. I can think of few things more fulfilling in this role of ‘Momie’!

The only way to advance science is to be a part of the research and the solution. As a Parent Researcher, I feel as though the challenges and lessons I have experienced due to having a child with CP and other issues can become stepping stones for other families to navigate through a difficult situation. I am honored to have been chosen and to share my knowledge to benefit the greater good.” **Marquitha Gilbert**

“My becoming a participant in research has helped me feel like our whole family, and especially my son, can make a contribution to a body of knowledge that helps other families. We feel really good about sharing what our son has taught us.”

Barbara Taylor

“Participating in research is a means by which to include perspectives based on actual ‘field practice’ with our children; where theory meets practice. I am committed to participation that ‘gives back’ to and benefits knowledge and practice for kids in the future.

Parent collaboration embeds the language and knowledge of lay people (parents) to inspire directions for new research, asks questions that academic research does

Parent to Parent



not necessarily inquire, and diversifies and deepens the meaning and application of research." **tina hjernegaard**

"I feel that information is key; if what I can share is of benefit to families and researchers then use me up!" **Kim Rayfield**

"Giving our child/ teen/ young adult a "voice" by their/our input in lay person's language. Sharing in a manner of acceptance. Listening to one another with attention to details. As thoughtful group, inspire one another working for a better present & future by nudging memories of past experiences that illustrate a point/ position to aid parents, children, caregivers, research team, etc.

Keeping HOPE in the forefront of our team so it might resonate with others:

HOPE: H *healthy aspirations of*

O *optimistic desires to*

P *pursue possibilities while*

E *encouraging with enthusiasm!"*

Paula Drew



What are your thoughts about bringing the family's voice to research?

Do you know of parents or individuals with CP who have been on a research team?

Is this something you might consider?

Please email Bob Palisano rjp33@drexel.edu with your thoughts and/or questions.