



“...we are happy to participate in this study in hopes that my child's experience and challenges - and the results of your findings - will indeed **help someone else** with unique challenges and abilities...”

parent participating in the study

Family Newsletter

Fourth Edition, May 2016

Study Update

WOW! We have completed about 80% of the study visits with over 700 children and families across Canada and the U.S. The last visits will be completed by August of this year. Our study team has a strong focus on getting information out to all interested parties as soon as we possibly can, in ways that are most meaningful and helpful. We always welcome new ideas - please feel free to contact us to share your thoughts.



Visit our website!

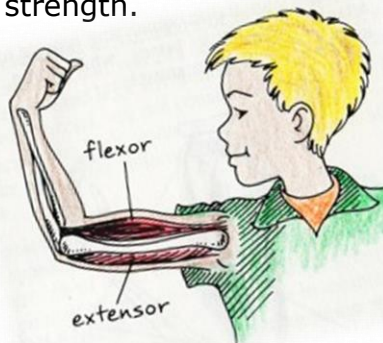
www.canchild.ca/en/research-in-practice/current-studies/on-track

It's brimming with all sorts of information for therapists and families! It's your 'go-to' place to find materials like the feedback forms, family newsletters, and parent-to-parent articles written by the parent researchers on our team. As we move into the next phase of

the study, we will be adding more and more products and results, including an exciting new video production that the parent researchers are putting together now. The family feedback forms we are sending out after the visits are meant to give you some immediate, brief feedback about the visits. Know that much more detailed results will be available at the end of the study once we have completed all the visits over time for the large group of children in the study.

Featuring Another Assessment Used in the On Track Study

Functional Strength Assessment (FSA): Muscle strength is important for movement; however, measuring muscle strength in young children with CP can be challenging. The FSA allows a therapist to estimate muscle strength in major muscle groups by having the child complete and potentially resist movement at specific joints. The therapist assigns a score which allows the therapist to document and track the child's functional strength.



From An Assessor's Point of View

"In the ever-changing world of healthcare, I believe information from studies like the On Track Study is critical. As we know, children with cerebral palsy and other movement disorders are not all the same; they have very diverse and individual needs, and these needs can change rapidly as children grow and develop. I believe the information we are gathering in this study will help us and the families we serve to make informed decisions about service delivery and resource management.

In the families I have seen throughout this study, some of the children have periods of great change during the 6 months between visits, and I see an opportunity to take advantage of these times with an increase in appropriate services. Inversely, some children have plateaus or significant medical issues that may warrant a decrease in services. I think this research will help insurance companies to understand (and hopefully, cover) the diverse and changing needs of children in these situations. I expect it will also support therapists in making clinical decisions concerning service delivery and frequency of services.

This information will be extremely useful in educating families about expectations, goal setting, and resource allocation. Sometimes, money going toward frequent therapy sessions may be better spent on equipment, home modifications, or respite to help the family health as a whole. I believe we can provide this information to families making these difficult decisions and lessen their stress. At the same time, it then becomes possible for therapists to manage the needs of their community and spend their time as wisely as possible. Now, instead of making service decisions based on first come, or practice habits, or schedule availability, these decisions can be guided by a child's unique needs and research."

Carrie Ferguson
Study Assessor, Oklahoma

Parents told us-

"...we were able to continue OT/PT with the rehab centre for children. Unfortunately, school age kids get taken over by the school division therapists. We had much better service and help from the rehab centre for children."

"...there were one central electronic medical records that my son's doctors / specialists / therapists viewed...A computerized records system which facilitates in the coordination of care. What we have now is acceptable but has room for improvement...the state's early intervention services opened the door for so many opportunities."

Parent Investigators

Our Parent Researchers are busy, busy, busy as ever. They are currently involved with filming two videos for the study to share their families' perspectives on living well with CP and the importance of participating in research. In each newsletter we are featuring one or two of the parents. In this issue, we would like to introduce you to Lisa Diller.



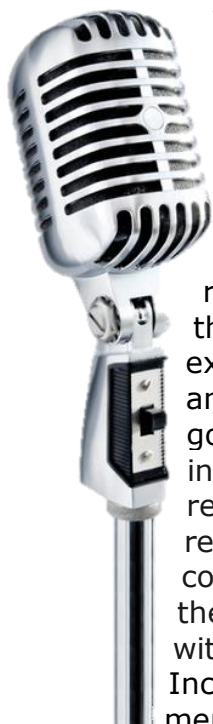
Lisa Diller lives with her husband, son 12 and daughter 11 in Seattle, Washington. She enjoys supporting her children's many activities and volunteering at their school and church. Her

12-year-old son has diplegic cerebral palsy and is active in community, school, and church activities, and continues to receive intermittent physical therapy services. Lisa is a physical therapist and divides her work schedule between an outpatient clinic, private home health neuro practice, and as teaching associate in the school of physical therapy at the University of Washington.

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 hjernegaard, 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.

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

tina hjorngaard

"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.

Would you like to be part of a research team?

- ❖ Ask your child's service providers about opportunities in your community.
- ❖ Consider PCORI's Ambassador Program: www.pcori.org/get-involved/become-pcori-ambassador



Travel Tips From Our Parent Researchers

- ✎ Be super-conservative in scheduling vacations.
- ✎ Schedule down time for your child when you arrive.
- ✎ Take a nap or rest time every day—a little preventive rest makes a lot of difference in an over-stimulating time.
- ✎ Visit with others who have been to a vacation spot before you start the trek; of course, check websites for valuable info.
- ✎ If have an only child, bring a friend, relative, or companion for them.

- ✎ Travel as a group, for example: students in the same class might vacation on a cruise with their parents, teachers, aides.
- ✎ Have back-up plan for inclement weather &/or delays.
- ✎ When traveling by air: Allow more than an hour for connections in an airport. Wear comfortable, easy on/off clothing & shoes. Tag luggage, walker, wheelchair etc. with name, address, phone number, & mark with a colorful ribbon/ unique tag so it's easy to spot.
- ✎ Arrive early and take advantage of pre-boarding.
- ✎ When possible, keep walker, crutches on the plane unless it's necessary to load under the plane just before entering.
- ✎ If not in a hurry, allow others to deplane before you, allowing ground crew time to bring equipment to you.
- ✎ Remember to bring your handicap parking placard.

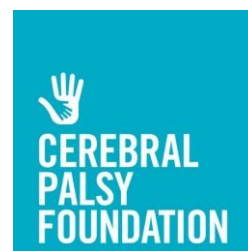
Featured Resources: Research



CanChild Centre for Childhood Disability Research (canchild.ca)

is a research and educational centre

located at McMaster University in Hamilton, Ontario, Canada. CanChild's research is focused on improving the lives of children and youth with disabilities and their families.



Cerebral Palsy Foundation (yourcpf.org)

is dedicated to funding research and educational activities directly relevant to discovering the cause, cure and evidence based

care for those with cerebral palsy and related developmental disabilities.



**CDC
Cerebral Palsy
Research**

(www.cdc.gov/ncbddd/cp/research.html)

CDC has been studying CP since the early 1980s. This information can help look for causes and risk factors of cerebral palsy, evaluate the effectiveness of prevention efforts, raise awareness of the signs and symptoms, and help families and communities plan for services.



**Cerebral Palsy
Research Registry
(CPRR)** (cpregistry.org)

is a multi-institutional collaborative effort whose

primary mission is to improve our understanding of cerebral palsy. Representatives from Northwestern University Department of Physical Therapy and Human Movement Sciences, the Rehabilitation Institute of Chicago, and the University of Chicago have developed and continually improve the CPRR to promote research and new discovery in the field of cerebral palsy.

Here's how to **CONTACT US!**

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thank you!