



“Wherever your research takes you...**serve the whole family!** Listen to moms! Listen and watch...I have felt so unheard over the years and watched my child flounder because people (therapists) were going by the book and not by the child”.

parent participating in the study

Family Newsletter

Fifth Edition, Jan 2017

Message from the Researchers



It's a Wrap!

Hello families and children who participated in the On Track research study!

First, we send best wishes to you and your family for 2017. **Second**, we thank

you a million times for participating in our study! We could not have done the study without you and we hope the results ultimately will help you and other families. **Finally**, we want to give you an update on study progress.



Over 600 families across the USA and Canada participated in the study and the last assessments were completed in August 2016. Everything we collected during the assessments has been entered into a database and we are now working on the results of the study.

The study had two main aims:

1

Create developmental curves for things we measured (balance, strength, joint range of motion, endurance, participation in leisure and recreation, and in self-care activities). The statistical analysis will link children in different classifications or ability levels.

2

Create percentile graphs from these growth curves to show how children relate to other children with similar abilities and also how an individual child is developing for who they are – not in relation to other children.

The results will help when developing future programs and services that will support children, based on a child's unique features and requirements. Based on a child's progression, the focuses of therapy



intervention for the next period of time could be tailored to best meet the needs of your family and child. We will make the study results available to guide discussions between therapists and families.

Another aim of the study was to examine therapy and other professional services children receive and how those services were related to the progression of development in the areas we measured. Once we have completed the developmental and percentile graphs, we will also work on this study aim.

A final aim of the study involved 83 families from several sites across the USA and was related to extended measures of activity performance of children. We collected actual step counts and movement amounts for children over a week. We will be able to make more general development graphs to further describe levels of participation.

We expect to have all the information analyzed by the end of March 2017 and will be completing reports and papers on the findings throughout the year.

We will share a report on the study findings with families as soon as we can and encourage you to visit the study website for updates.

Visit our website!

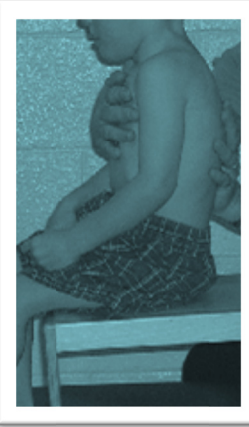
www.canchild.ca/en/research-in-practice/current-studies/on-track

As always, if any of you have specific questions or comments, please feel free to email any of us at any time. Thanks again for your participation!

Featuring Assessments Used in the On Track Study

Spinal Alignment and Range of Motion Measure (SAROMM): The SAROMM is one of the many assessments that were conducted as part of the On Track study.

The SAROMM is an assessment designed for children with cerebral palsy. Scores allow the therapist to document a child's current movement and to monitor for any movement limitations over time. It consists of two sections:



The spinal alignment section documents the spine curve and its flexibility.

The range of motion and muscle extensibility section examines the joint movement and muscle flexibility in a child's arms and legs.

Parent to Parent



Parents Reflect on Research Team

The On Track Study has been fortunate to have seven mothers of children or young adults with CP serve as members of the research team. Many thanks to Lisa Diller, Paula Drew, Nancy Ford, Marquitha Gilbert, Tina Hjørngaard, Kim Rayfield, and Barbara Taylor for their

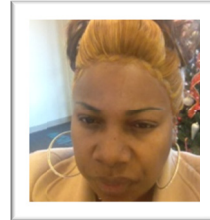
ongoing contributions. We asked them to share some of their thoughts on what it has been like to participate as members of the research team. The following are their reflections on the past three years:



**Barbara
Taylor**

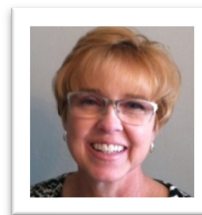
"I would encourage any parent to take part in a research team like the On Track Study. First, you are doing something positive to benefit your child and others; it is a way for you and your child to contribute to advancing medical/ therapeutic knowledge and practice. It's intellectually interesting; I certainly learned a lot about how research is carried out and all the necessary mechanisms for accuracy and accountability. You get to meet other parents, virtually and in person. Most important, by participating in research that serves our children, we (and our kids) are creating the kind of world we want our kids to live in—one in which their abilities and needs are driving the

research questions that get asked. It's empowering: you feel part of a larger whole. This is how progress gets made!"



**Kim
Rayfield**

"I'm glad that I was presented with the opportunity to be part of the research team. It showed me that as a parent I have a lot to offer as well as a voice to speak. It's important for parents to express themselves and share their priorities with professionals and researchers. It was truly a pleasure working with the women of the research team, putting our ideas together for a good cause—children and their parents."



**Paula
Drew**

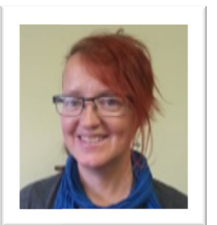
"First, to be asked by Lynn Jeffries was an honor—encouraging me to share my personal insights of being Dillard's Mom—living life with cerebral palsy. I noticed an instant connection with the other amazing moms—sharing information was an extension of a support group as well as a source of valuable ideas and resources. I also experienced immediate acceptance as a valuable member of the entire group, when all involved listened, asked opinions, and considered what we shared collectively. I truly enjoyed the conversations especially when one parent would feed off another or add to the line of a particular subject to only further advance our thought process. The parent column in the Newsletters and the videos

in which we (and our children) shared our messages were awesome! I hope that our participation will improve the lives of other families—especially the precious children and young adults who "master" CP every day. Cerebral palsy brought us together, but the love of our children and the dedication to others made us a team."



**Lisa
Diller**

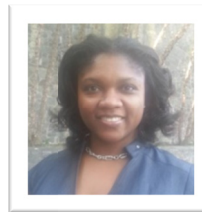
"As a parent, I appreciated having the opportunity to participate in the research process as a collaborator with other parents and the research team. Inclusion of parents in the research design and process facilitates more robust outcome measures and allows parents to have a voice in shaping research that is relevant to their child's disability. Most importantly, I have enjoyed listening and sharing experiences with a supportive, caring group of parents and researchers, thank you."



**tina
hjorngaard**
mother of Mika

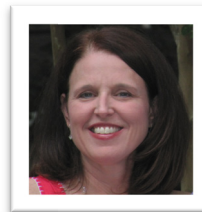
"I am honoured by the experience of participating with a group of researchers and parents of children with cerebral palsy because it is a means by which to include perspectives based on actual 'field practice' with our children. To me, it is where theory and lived knowledge meets practice. I am committed to participation in this research that endeavors to 'give back' to

and benefit knowledge and practice for kids in the future. It is critical to my involvement that parent collaboration embeds language and knowledge of lay people (parents) to inspire directions for new research. Parent collaboration asks questions that academic research does not necessarily inquire. I have learned from and contributed to a dedicated collective of respectful and inclusive minds and hearts as a member of the Parent Research Team."



**Marquitha
Gilbert**

"We always wonder if we are doing enough, or could do more... being a part of this project helped me to see, do and feel that I can impact beyond my usually limited circle of influence. The best Mom-advocate experience, with tangible impact..."



**Nancy
Ford**

"It was an honor and a privilege to participate on the research team with an incredibly passionate group of parents and researchers. The common theme that united all of us together was a desire to improve the lives of children with cerebral palsy and their families. We believe that parents and families working together with a dedicated team of professionals, including doctors and therapists, can greatly improve patient outcomes with collaborative research as

the epicenter. Parents have a unique perspective on the day to day life of a child with CP and can and should play a very important role in research. Plus we had great fun working together virtually as a team!!”

On Track Videos Feature Children and Families

During the past year, the seven parent members of the research team worked closely with Sarah Glenn from ProjectVideo Inc. to produce two short videos:

- ❖ Checking-up and Checking-in: Partnering with Families of Children with Cerebral Palsy
<https://canchild.ca/en/resources/270-checking-up-and-checking-in-partnering-with-families-of-children-with-cerebral-palsy-video>
- ❖ Creating the Future: Engaging Children with Cerebral Palsy in the Circle of Care
<https://canchild.ca/en/resources/271-creating-the-future-engaging-children-with-cerebral-palsy-in-the-circle-of-care-video>

The themes for the videos emerged from the parents’ discussions of what families want to know about the development of their children with cerebral palsy. The entire parent team worked on the script, selected the background music, and provided input in editing the videos. The videos feature Lisa Diller’s, Nancy Ford’s, and Marquitha Gilbert’s children and families.



Lisa Diller, Noelle Ford, and Alexander Diller share their experiences about being featured in the videos:

“The videos provide a glimpse into the everyday lives of families enjoying time together and in the community. Thoughts shared from the children, parents, and siblings helped create the bigger picture of accepting the challenges of cerebral palsy and living a full, active, life. Each of us has unique gifts to share. I hope this video provides insight to families of children with cerebral palsy to recognize the gifts their child brings to their lives and the larger community. Our family is grateful for the opportunity to share a snapshot of our life.”

Lisa Diller

“My experience from participating in the video was great. What I learned from the video was that I am good at describing what people should say about me vs. what people should not say about me. Another thing I learned in the video was how people should look at me vs. how people should not look at me. I would like to say to kids, their parents and families is that I am not a kid in a wheelchair. The world needs to see that I am more than that. Even though I struggle with certain things I can still find a way around them. I am a very independent person. Even though I am a little different from the rest of the world I am a very happy person. Even though I have special needs does not mean that I do not have a purpose in life. I do have a purpose in life. My purpose in life is to serve God.”

Noelle Ford, age 17

"As I look back upon the videos that have been created, I would like to highlight my goals for the videos as well as how it has affected me. First, I would like to show our audience that we are not defined by the boxes we check. This means, that even though we may be differently abled, we are still people, and should not be treated differently than anyone else. In terms of the video process, I enjoyed participating, and loved being able to have a behind-the-scenes look at how a professional video is made. This experience has also helped me in school as we have an opportunity to create an educational video on Passover. Overall, I have fond memories, of this time, and will always remember what I've seen and learned."

Alexander Diller, age 12

Resources: Let's Play

 **outdoorsforall.org**
To enrich quality of life for children and adults with disability through outdoor recreation.

The Outdoors for All Foundation transforms lives through outdoor recreation. Founded in 1979 in the Pacific Northwest, Outdoors for All is a national leader in delivering adaptive and therapeutic recreation for children and adults with disabilities. Each year more than 2,400 individuals exercise their abilities thanks to the training and support of more than 700 volunteers. Outdoors for All enriches the lives of individuals with disabilities and families by helping them get out and enjoy the great outdoors. Programs includes snowboarding, snowshoeing, cross country and downhill skiing, cycling, hiking, yoga, kayaking, day camps, rock-climbing, camping and custom events.



disabledsportsusa.org

Disabled Sports USA's mission is to provide national leadership and opportunities for individuals with disabilities to develop independence, confidence, and fitness through participation in community sports, recreation and educational programs. Every day, working hard to pursue our vision that "every person, regardless of ability, has an equal opportunity to participate in sports and recreation in their community."



rallycapsports.org

Mission: To create positive sports environments fostering social integration, healthy living, and greater self-confidence for children and young adults with special needs.

Contact Us

Coordinator for Canada/USA - CIHR

Barb Galuppi galuppi@mcmaster.ca

Coordinator for USA/Canada - PCORI

Monica Smersh msmersh@uw.edu

Georgia Regional Coordinator

Erin English Wentz

ewentz810@gmail.com

Oklahoma Regional Coordinator

Jennifer Miller/Amanda Porter

jenn_miller@rocketmail.com

Amanda-Porter@ouhsc.edu

Philadelphia Regional Coordinator

Tracy Stoner

tls55@drexel.edu

Seattle-Tacoma Regional Coordinator

Allison Yocum

allison@waypointpediatric.com

Happy New Year!