



We really appreciate and thank you from the bottom of our hearts for giving your time to participate in the **On Track Study!**

## Family Newsletter First Edition, March 2014

Greetings families! The On Track research team is excited to share news about how the study is going. We hope you find this first newsletter interesting and useful. We plan to keep in touch with you with more newsletters like this one.

### How is the study funded?

The study was first funded by the Canadian Institutes of Health Research (CIHR). In 2013 the project received added funding from the US Patient-Centered Outcomes Research Institute (PCORI). The extra funds will enhance parts of the study and will let us add more study visits.

### Who is participating?

So far over 250 Families and Children with CP, under the age of 11 years

More than 70 Therapist assessors, across 35 North American cities

Visit <http://bit.ly/1k8uJ7Z> to see a map of all the study sites across Canada & the US



### What will the study tell us?

The study will help us:

- See the “big picture” when it comes to treatment options and family engagement and how it all fits together
- Develop future programs and services that will support children, based on a child’s unique features and requirements
- Create percentile graphs to show how children relate to other children with similar abilities
- Create developmental curves using a statistical analysis that will link children in different classifications or ability levels



All the moving and bending kids do for us, the measurements and the questions we ask: these will help us put the pieces of the puzzle together! We are asking everyone to do all the same things at each visit so we can look at patterns and get an idea of how things change or stay the same over time.



Once all the visits for this study are completed in 2016, we will have a chance to look at the 'big picture' and see how everything fits together. This will help develop **future programs** and services that support children based on their unique features.

### **The CIHR funding gives us 2 visits—the First and the 12-Month Visit**

This information will be used to create **percentile graphs** which will:

- ✦ Show how children change in physical development and participation in daily life and how that relates to other children with similar abilities
- ✦ Help parents and therapists monitor if a child is developing as expected
- ✦ Make it easier for therapists and families to work together to provide services that are most beneficial and meaningful for each child and their family



### **The PCORI funding adds a 6-Month, 18-Month and 24-Month Visit to the mix**

This means that many families in the study will have a total of 5 visits. The extra visits will be used to carry out a 'join the dots' statistical analysis to create **developmental curves** which will:

- ✦ Link together the information about each child, and then link the different children in each classification or ability level
- ✦ Allow us to begin to make a prediction about the pattern of development of children in the same classification level
- ✦ Help us to give families and health care professionals a pretty good idea about what to expect

If your family is participating in the 2-visit study, and you would like more information about the 5-visit study, please talk to your On Track assessor or the study coordinator in your area. Contact information is listed on the last page of the newsletter.

You can read more about the study at [http://www.canchild.ca/en/ourresearch/on\\_track\\_study.asp](http://www.canchild.ca/en/ourresearch/on_track_study.asp)

### **Parent Investigators**

We are so thrilled to be working alongside an amazing group of seven parents who are part of our research team. The parent team brings a valuable point of view to our regular study meetings. They are spread across the map and they all have 'lived' the experience of having a child with CP. They bring a rich and grounding value to our study.

The parent members are helping us polish off our Family Feedback form, a form that will give you information about the results of your child's assessment. Stay tuned, we appreciate your patience while we finalize the layout and do some testing to make sure it is working correctly. Parents are also creating a final "exit" questionnaire which will give

you the chance to tell us in your words what you think is most important about your child and his or her progress while in the study. Also, please remember that you are always encouraged to add comments to the study booklets. Feel free to use the opposite blank page or the page at the end of the booklet to include any additional information you would like us to know about your child. If filling out the questionnaires online, feel free to use the "comments" section. Our parent team also plays a big role in putting together newsletters like this one, finding resources, and passing on helpful tips.

**HELLO!**

My name is

Mom

Feel free to contact the parent team if you have ideas to share! Their contact information is listed on the study website.

## Parent Investigator Profiles

In each newsletter we will feature two of the parents. In this issue, we would like to introduce you to: Kimberly Rayfield and Barbara Sieck Taylor.



**Kimberly Rayfield** is a single mother of three children in Philadelphia, Pennsylvania. Over the years Kim has been tested with many obstacles but she seems to overcome them with flying colors. In

2001, her youngest son Jymere (age 14) was struck by a vehicle at age two. From that very moment her life changed dramatically. Not only did she become the voice for Jymere, but she became an advocate for people with disabilities of all ages. Kim is also a cancer survivor.

What gives her strength? Kim's inner strength comes from her son Jymere. His smile and strive for life runs her motivation. She has made it her goal in life to make sure

that Jymere gets to enjoy life as much as any other child his age. He gets to play in the park and play baseball (catcher or pitcher). He is involved in the local community center where he plays "hide & seek," board games, and does arts and crafts with the other children.



### **Barbara Sieck Taylor**

lives with her husband Mark and her son William, 22, in Pittsburgh, Pennsylvania. She has over 30 years of experience in the nonprofit sector, working as a

professional actress, a nonprofit administrator, a program officer for two foundations, a fund development officer, and most recently as executive director of a professional association for philanthropies. For six years, she served on the board of directors of the ARC of Greater Pittsburgh, including one year as its chair. For two years, she directed ACHIEVA's Disability Health Policy Forum, an advocacy project focused on oral health care for people with disabilities in Pennsylvania.

As a parent volunteer, for eight years she was the co-director of Conductive Education of Pittsburgh (now Steps to Independence); creation of this program brought a special education system designed specifically for children with CP, and widely used in the U.K. and Europe, to the Pittsburgh region for the first time.

Barbara was a parent consultant to the Move & Play study (2006-2009). She co-authored a commentary published in 2010 in *Physical & Occupational Therapy in Pediatrics* titled [Parent Perspectives: The Family-Therapist Relationship](#).

Her most meaningful accomplishment is that William, who has cerebral palsy and intellectual disabilities, is healthy, happy and enjoys loving support from his family and friends.

## Parent to Parent: Therapy in Natural Environments

My name is Kimberly Rayfield and my son's name is Jymere. As a parent of a child with a disability, I know it's hard trying to get everything done in your day—no matter how hard we try we can't always do it. In trying to balance the needs of all of my children, I learned to incorporate new ideas about therapy. In Pennsylvania, early intervention services are provided in natural environments. Natural environments include not just the home but also places in the community that are part of family routines and where young children learn and play.

As a young child, Jymere's early intervention services were often provided in the community:

- ✦ Sometimes the physical therapist and I would take Jymere to the park while my older son, Darryl, practiced basketball
- ✦ When Darryl's games conflicted with Jymere's PT, we took the physical therapist with us to the gym, where we worked on positioning on the bleacher so that Jymere could watch the game and I could learn how to position Jymere
- ✦ The physical therapist also went with us to the supermarket to work on positioning in the cart while I shopped
- ✦ We scheduled therapy sessions at a local recreation center, where Jymere learned to ride his bike, play ball, and play with other children on the floor mats
- ✦ Jymere, his speech therapist, and I would also go to the library for the "reading for tots" program
- ✦ The three of us even went to McDonalds for lunch to work on Jymere's swallowing
- ✦ I used my membership at the *Please Touch Museum* to bring the occupational therapist and work on Jymere's sensory motor skills and stretching.

I encourage parents to utilize the resources that are in their community (natural environments) and incorporate them in their therapy sessions, which sometimes involves the whole family. When discussing options with your child's therapists speak from your heart on what you want your child to try to do or be able to do!



## Resources **CanChild** Centre for Childhood Disability Research

- ✦ *CanChild* Centre for Childhood Disability Research 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.
- ✦ Founded in 1989, *CanChild* is a world leader in the field of childhood disability. *CanChild's* cutting-edge research and strategies for making findings available to a wide range of audiences make *CanChild* the top source for childhood disability information.
- ✦ The public, web-based resources on the *CanChild* website are accessed by over 3000 people per month from over 100 countries. The website provides electronic access to *CanChild* documents including past and current research, articles, Keeping Currents, measures, and links to interesting websites
- ✦ The website gives a customized experience for parents, service providers, and researchers

- CanChild's* multi-disciplinary team includes researchers from pediatrics, rehabilitation medicine (physiatry), occupational therapy, physiotherapy, speech and language pathology, kinesiology, social psychology, epidemiology and biostatistics.
- The Director of *CanChild*, Jan Willem Gorter, MD, PhD, FRCP(C), is also a member of the On Track research team. Dr. Gorter has training in rehabilitation medicine with a special clinical and research interest in transition services for youth with developmental disabilities. He is a key member of the On Track leadership team and plays an important role in raising awareness of the exciting work we are doing with this study.

### How can you access the On Track Study website hosted by *CanChild*?

Go to:  
[http://www.canchild.ca/en/ourresearch/on\\_track\\_study.asp](http://www.canchild.ca/en/ourresearch/on_track_study.asp)

## Contacts

### Coordinator for Canada/USA - CIHR

Barb Galuppi

[galuppi@mcmaster.ca](mailto:galuppi@mcmaster.ca)

### Coordinator for USA/Canada - PCORI

Monica Smersh [msmersh@uw.edu](mailto:msmersh@uw.edu)

### Georgia Regional Coordinator

Erin English Wentz

[ewentz810@gmail.com](mailto:ewentz810@gmail.com)

### Oklahoma Regional Coordinator

Jennifer Miller/Amanda Porter

[jenn\\_miller@rocketmail.com](mailto:jenn_miller@rocketmail.com)

[Amanda-Porter@ouhsc.edu](mailto:Amanda-Porter@ouhsc.edu)

### Philadelphia Regional Coordinator

Tracy Stoner

[tls55@drexel.edu](mailto:tls55@drexel.edu)

### Seattle-Tacoma Regional Coordinator

Allison Yocum

[allison@waypointpediatric.com](mailto:allison@waypointpediatric.com)

