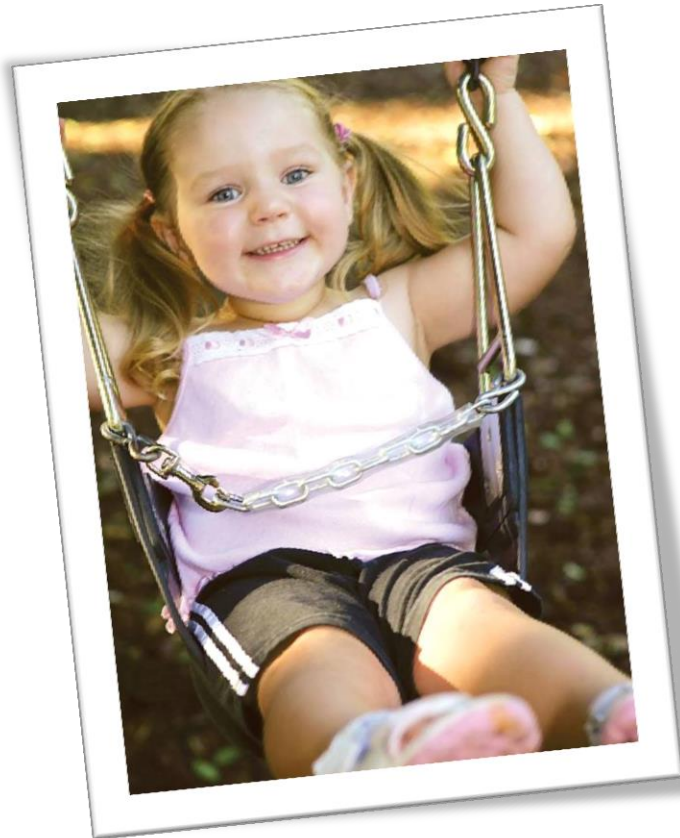




“I find it beneficial to my son and myself to be a part of the **On Track Study**. I have learned a lot about my son by completing the booklet.” *parent participating in the study*

## Family Newsletter

Second Edition, September 2014



Our research team has been busy sharing news about our study. We do this through these newsletters, by sending “E-Blasts” to interested parent and professional groups, by posting our study information and educational material for therapists and families on the CanChild website, and by

presenting at professional meetings. Let us know if you have ideas about other ways or other organizations to include in our “E-Blasts”.

You can send your ideas to Monica Smersh [msmersh@uw.edu](mailto:msmersh@uw.edu)

### Here’s a bit of history about the research that has led us here...

In the earlier study of preschool children called Move & PLAY (2006–2009), we wanted to see what child, family, and service delivery factors helped with movement development and participation in self-care, recreation, and play.



Making sure that a child can participate in all aspects of life is an important goal of rehabilitation. Young children spend most of their time in play. We know that being able to participate from a young age helps children learn new things and lays a good foundation for participation in education, social life, and employment later on.



Rehabilitation therapists and families of children with CP want to find the best interventions. This can be challenging because there are so many factors in how a child develops.

That's where the Move & PLAY study comes in! The results can help us start to answer these questions using research evidence.

Check out our research summaries as they become available on the CanChild website: <http://canchild.ca/en/ourresearch/moveplay.asp>

Under **Measures and Summaries for Practitioners and Families** you will find summaries that were created by parents and therapists, for parents and therapists. Some example topics are:

- Health Conditions
- Recreation and Rehabilitation Services
- Family Life
- Motor and Self-Care Abilities



The **On Track Study** follows in the footsteps of Move & PLAY as we continue learning about the development of children with cerebral palsy or gross motor delay up to adolescence.

## What results can we expect when the On Track Study is finished?

- Developmental curves using statistical analysis to link children in different classifications or ability levels. These will give an overall understanding of functioning of children in different groups.
- Percentile graphs to show how children relate to other children with similar abilities. These will help to interpret how individual children change over time.
- The study will help us see the "big picture" when it comes to service options and family engagement and how it all fits together.
- Results will pave the way for developing future programs and services that will support children, based on a child's unique features and needs.

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)



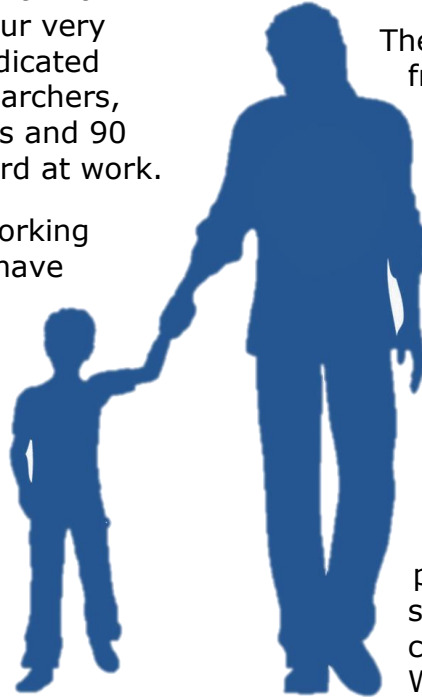
Did you know that we have families participating from 38 locations across North America? You'll find the map on our website. We are always posting new information there so check back often. Please tell us if you

have ideas about other information we could share on our website. You can send your ideas to Barb Galuppi [galuppi@mcmaster.ca](mailto:galuppi@mcmaster.ca)

### How is the On Track study going?

The study team is really pleased with how well things are going! Thanks to our very experienced, enthusiastic, and dedicated team of investigators, parent researchers, clinical site coordinators, recruiters and 90 therapist assessors for all their hard at work.

Parents and children have been working hard too! More than 600 families have agreed to participate so far. Our goal is to get 800 families started with a first study visit by the end of this year.



## Parent Researchers

Our parent researchers are bringing a wealth of life experiences to enhance the quality and content of the study. Their valuable insights and first-hand knowledge of raising children with CP have had a tremendously positive impact.

The investigators continue to learn from the parents and strive to include their suggestions and experiences in ways that are meaningful to the families who are participating in the study. Thanks to the parent researchers we are adding a short, optional survey at the end of the study that will give you a chance to tell us in your own words what you are most interested in learning about your child's development, and how you prefer to receive information. The parent researchers have also started working on some ideas to create video resources for parents. We will be posting the videos on the CanChild website later on.

### Welcome new sites!

In Canada, we have recently trained new therapist assessors to see families in the Simcoe-York region of Ontario and a large rural area in Prince Albert, Saskatchewan.

In the US, we have recently expanded our regions to see families through the Easter Seals Capper Foundation in Topeka, Kansas. We have also trained new therapist assessors to see families at Kennedy Krieger Institute in Baltimore, Maryland and at Good Shepherd Pediatrics in the Lehigh County, Pennsylvania region.





The parent researchers have provided valuable input to the creation of our Family Feedback Forms. These summaries will be sent to families after each study visit. They give a brief report of the measurements done at the visit. After rigorous testing, we are now ready to start sending Feedback Forms. The summaries for all past visits will be sent out soon. Going forward, we will be sending out these forms soon after the visit. We hope families will find these resources useful and we encourage you to discuss the information with your child’s therapist.

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

In each newsletter we are featuring two of the parents. In this issue, we would like to introduce you to Tina Hjorngaard and Marquitha Gilbert.

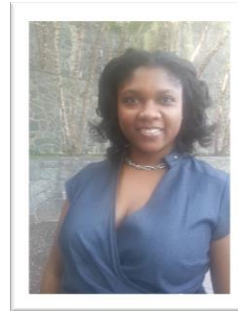
**Tina Hjorngaard’s** contributions to the team are shaped by multiple perspectives as a parent of a 15-year-old girl with cerebral palsy, as a social worker, as a critical disability advocate, and as an accidental activist. She struggles with, and, at times, is conflicted by



living, working, and parenting in a society that holds “pathologizing” views of disability. This is particularly a concern when looking at how and where children with disabilities fit into our Social Tapestry. Tina was a parent consultant to the Move & PLAY Study (2006-2009). She has authored two commentaries published in the professional journal *Physical & Occupational Therapy in Pediatrics* (Parent Perspectives: The Family-Therapist Relationship and Saying Goodbye, 2010; and Family Centered Care: A Critical Perspective, 2011).

**Marquitha Gilbert** lives in the Philadelphia suburbs with her husband Derrick and two young children. She is a college-educated pharmaceutical professional who loves to sing and read and reach out to others to help others through challenges that she has experienced. Her daughter Mari is a surviving

twin, born at 23 weeks gestation, weighing 19 ounces, and barely big enough to fit the clothes of an 11-inch baby doll. Mari is legally blind, has cerebral palsy, epilepsy, hydrocephalus, speech delays, developmental challenges, and some sensory issues. Despite it all, she is happy, engaging, determined, intelligent (albeit delayed), walking semi-independently, and a joy. Mari is now eight years-old, a studious second grader, and a protective big sister of a four-year-old brother who both teaches her and learns from her. The family thanks God for the Blessing of Mari and her continued improvement and inspiration. As her mother, Marquitha is Mari’s “publicist” with various organizations (March of Dimes, Pennsylvania Training and Technical Assistance Network, Merck Allies for Disabilities); advocate with physicians, therapists, teachers, insurance companies; and friend - to play, read, learn, and explore. Marquitha works with various organizations as a parent liaison to ensure insight into care of a child like Mari and a parent like herself.



## Parent to Parent



### **Parent to Parent: Learning to Transition.** By Marquitha Gilbert

Since the birth of my twins, at 23 weeks gestation, I have had to learn to transition... transition into parenthood, transition into losing a child, transition to caring for a child with special needs...and it keeps going. Transitioning means: leaving what you have come to know as your "norm" and going to a place that is unfamiliar, different, sometimes exciting but most often scary. I accepted that each transition has had a lesson that made moving through the transition just a bit more manageable.

**Transitioning from hospital to home:** Few people like being in the hospital. For a fragile child, however, the hospital had a level of security. People and machines that were ensuring appropriate care. As we left, there was fear of losing the extra eyes that watched my child and assured me all was okay; it was leaving the machines that showed me hourly that my child was breathing and functioning appropriately; it was being a parent - in our case, for the first time - with machines and tubes we now took home and had to monitor ourselves. It was scary. *Lesson:* Ask a lot of questions, be comfortable in what you know and don't be ashamed to ask about what you do not understand.

**Transitioning into in-home nursing care:** My home went from being a sanctuary to having many "strangers" - i.e., nurses for day or night shift with different nurses on different days, therapists for all aspects of care - in and out on a regular basis. Things were no longer in their place, things were

missing or broken, and there was no longer peace. I set schedules, parameters and still I felt invaded, yet grateful, since the presence of people abated some of the fear developed from leaving the hospital. *Lesson:* Set ground rules, establish clear expectations on both sides, and make sure that you address any issue early to avoid letting it fester.

**Transitioning into early intervention:** Now, added to the nurses were therapists. Their goal was to teach us ways to integrate little things into our daily routine that would encourage development. *Lesson:* Make sure the therapists understand your family life. Be comfortable saying what is realistic with your routine and that you understand the purpose and intent of the activity.

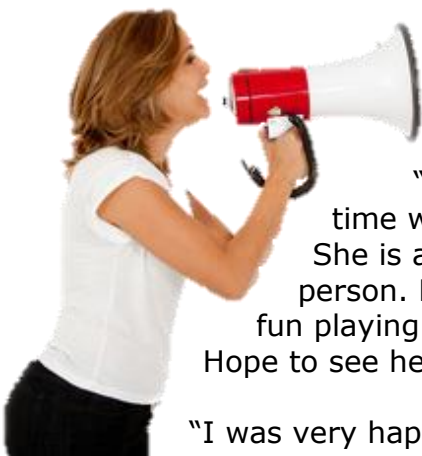
**Transitioning from early intervention into preschool:** The comfort I had with knowing my child was home was now shattered with a new routine based in a school setting. The separation was both normal and terrifying. I now had to learn a new "system" in the school and learn how to let go of what I had just learned how to manage. Therapies were now done in school and were no longer integrated into the family routine. I was less involved in many ways and was feeling left out. *Lesson:* Use the team meetings with the teachers and therapists to fully understand their goals and be sure to share what you see and do at home, ask for ways to duplicate what they do to help observe the development, and be able to share your perspective on improvements or lack of. Keep communication open!

**Transitioning from preschool to elementary school:** When my child attended preschool, the teachers and therapists regularly shared a great deal of information on how she was doing. The preschool staff seemed to have an implicit

understanding that parents are worried, protective, and need some coddling or support through letting go and letting the child grow up. When Mari transitioned to elementary school the philosophy changed. Kids are growing up and need to develop independence - and so do the parents. Regular communication continued, but not the minute-by-minute schedule of what was done, just an overview. *Lesson:* Be sure the Individual Education Plan (IEP) goals align with your developmental expectations for your child. In some areas, you may consider other sources of therapy outside of school, which may still be covered by health insurance, at clinics or by pediatric therapists in your community. School-based therapies often focus on development necessary for doing school work and interacting in school. We added supplemental therapies to focus on general development, such as dressing, walking independently, etc.

No matter what the transition, the challenge, the accomplishment, there is always a lesson. Figuring out what that lesson is and using it to make the next transition more manageable is the biggest lesson of all.

### Things we are hearing from parent participants in the study



"Thank you for inviting us to participate in this study."

"It was a fantastic time with the assessor. She is a wonderful person. My child had total fun playing games with her. Hope to see her again soon."

"I was very happy to answer these questions and I am very

happy to be participating in this research study, thanks so much for the opportunity"



### Featured Resources



- ▶ *CanChild* Centre for Childhood Disability Research is a research and educational centre located at McMaster University in Hamilton, Ontario, Canada. *CanChild* is celebrating its 25th anniversary this year.
- ▶ You are invited to participate in *CanChild's* Family Engagement Day on November 22, 2014. Parents have the option to participate in person OR via live streaming on the web as well via Facebook and Twitter (*CanChild\_ca*). The outline of the Family Engagement Day program is posted on the website and registration is open. See <http://canchild.ca/en/canchild-what-we-can-do.asp>
- ▶ *CanChild's* research is focused on improving the lives of children and youth with disabilities and their families.
- ▶ 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.



- United Cerebral Palsy ([www.ucp.org](http://www.ucp.org)) educates, advocates and provides support services to ensure a life without limits for people with a spectrum of disabilities.
- UCP works to advance the independence, productivity and full citizenship of people with disabilities through an affiliate network that has helped millions.



- Family Voices ([www.familyvoices.org](http://www.familyvoices.org)) is a national, nonprofit, family-led organization promoting quality health care for all children and youth, particularly those with special health care needs.
- Working with family leaders and professional partners at the local, state, regional, and national levels since 1992, Family Voices has brought a respected family perspective to improving health care programs and policies to ensure that health care systems include, listen to, and honor the voices of families.

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