



Our efforts are child and family driven and rely on support from the community. If you would like to make a donation to the Cerebral Palsy Registry, or if you have information on grants or other fundraising ideas, please contact Donna Hurley at d-hurley@northwestern.edu or 312.503.3342.

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Cerebral Palsy Research Registry Newsletter

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Greetings from the Cerebral Palsy Research Registry!

As the days become shorter and the nights a bit cooler, we look forward to the fall and all that it has in store for us. School is back in session, after school activities replace afternoons at the pool and we begin to gear up for the onslaught of festive holidays.

Before the chaotic scheduling takes over your life, please find some time to not only read this issue of the **Registry News** but also to explore our revised website, <https://www.cpregistry.org>. If you know of anyone who is interested in joining the Cerebral Palsy Research Registry, online registration, both in English and Spanish, is available. Previous newsletters, research studies and a new link for community resources are posted on the homepage.

The Cerebral Palsy Research Registry team is committed to promoting cerebral palsy research by connecting persons with cerebral palsy and their families with researchers. Your ideas and suggestions on how to make this work are always welcome.

Future issues of the **Registry News** will be emailed to families for whom we have an email address. This will cut down on the cost of postage. If you prefer to receive your newsletter via postal mail, no worries! Just call or email the Registry coordinator, Donna Hurley, at 312-503-3342 / d-hurley@northwestern.edu.

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Research Update

Seven researchers have contacted the Cerebral Palsy Research Registry to assist with grant proposals, recruitment efforts or requesting information on a partnership with their institution. For the research studies actively recruiting, letters were mailed out to families in the registry that fit the researchers inclusion criteria. When researchers are beginning a study, they need to obtain grant funding and approval from the ethics committee of their institution; the Registry supports these ideas by agreeing to assist with recruitment once they are funded and approved. Finally, other universities and hospitals around the country are starting to notice us, and wanting to get involved. We are currently working on formalized arrangements to make this possible, but it would mean access to research opportunities nation-wide as more institutions come on board. Individual studies vary with regards to paying travel expenses, but more institutions means more choices for you. This is exciting news for the Registry and all of its participants! The following is a summary of those studies.

Recruitment letters were sent out for:

- “Loss of Independent Joint Control of the Upper Limb in Spastic Hemiparetic Cerebral Palsy”
- “Comparison of Anticipatory Postural Adjustments in Children with Cerebral Palsy and Their Non-disabled Peers”
- “Evaluation of postural control and motor coordination during reaching in individuals with cerebral palsy: a pilot study”
- “Barriers & Supports to Sports & Recreation in Youth with Disabilities: a pilot study”

Intent to participate in recruitment for grant proposals were sent out for:

- “Coordination of whole body movements in children with CP”

Institutions interested in learning more about the Cerebral Palsy Research Registry:

- Children’s Hospital of Pittsburgh, PA
- Gillette Children’s Hospital, Minneapolis, MN

visit us online at <https://www.cpregistry.org>



Ask the Doctors

Dr. Deborah Gaebler-Spira, MD Director of the Cerebral Palsy Program at the Rehabilitation Institute of Chicago.

“My physical therapist thinks that Botox might help my daughter walk better. How would this help?”

Botulinum toxins, commonly referred to as Botox A, have been safely utilized in children over the last 17 years, The safety profile has been good in the published studies with safe dosages. This drug is not FDA approved for children but has been approved in many other countries.

Sitting, diaper/clothing changes and walking can be improved with the use of toxins if there is limited or focal muscle tone that interferes with alignment of the leg, range of motion of the limbs and sitting and standing balance.

The age of the child, severity and type of the muscle tone and functional ability are all taken into consideration when deciding when and where to make an injection. All these factors also make a difference in potential outcome.

It is best if the physical or occupational therapist and the physician talk to discuss the goals of the neurotoxin injection, how it will benefit your child and how the therapist can enhance the effects of botulinum toxins. This treatment is a great example of using a team approach for optimal outcome.

Family Focus Meet Larke Johnson

Larke Johnson is an exuberant 5 ½ year-old girl who has a zest for living. This feisty little girl has never let her diagnosis of spastic diplegia define who she is or what she can do.

With the support of her mother, Christie and her beloved grandmother, BeBe, Larke has been exposed to a variety of activities and outings that most adults haven't. After talking with, or should I say, after listening to Larke tell me about all of her adventures, her love for life shines through her smiling eyes and broad smile.

Here's what I've learned about Larke.

Larke enjoys going to school and is attending a new school for kindergarten this year. She is going to wear a uniform of white and blue and has new school supplies but still needs to buy a book bag. At school she likes to play with her friends, play in the kitchen, ride the bike and go down the slide by herself. Larke can't wait to tell her teacher how “bees work”.

Larke has therapy in school as well as outside of school at Hope Hospital. Her occupational therapist, Paige, helps her hold a pencil better, her speech therapist, Debbie, helps her speech by saying one word at a time when she talks, and her physical therapist, Maggie, has her walk and walk and walk.

On Sundays, Larke goes to church and attends Sunday school. After church, she eats then goes to yoga and karate. Larke is getting her white belt and loves to show off her kicks, punches and cries.

Extracurricular activities in the past have included music lessons (recorder and piano), swimming lessons and speaking engagements for special education courses at local universities. Larke wants to take ballet lessons and voice lessons in the future.

Larke's favorite places to eat are McDonald's and Oberweis Ice Cream and she and her family drove to Miami, FL for vacation. Larke and her two cousins have a business to earn spending money-they collect aluminum cans for recycling. The entrepreneurs have also raised money for cerebral palsy via a lemonade stand.

Thanks for sharing your story with us, Larke. You are an inspiration for people of all ages.



BeBe, Larke, and Christie Johnson

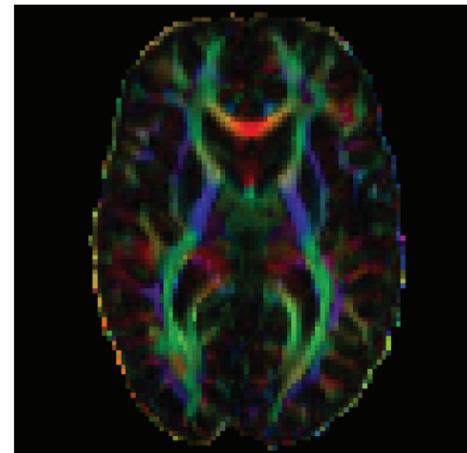
The Cutting Edge: Diffusion Tensor Imaging

Diffusion Tensor Imaging (DTI) is an exciting new use of Magnetic Resonance Imaging (MRI) for brain imaging. While conventional MRIs show the anatomy of the brain, the DTI-MRI shows connecting fibers called the cortical-spinal pathways of the brain. These pathways connect the brain (cortical) with the spinal cord (spinal) and control the movements of the body.

DTI-MRI uses a specific sequence of magnetic pulses to track how water moves in the brain and brainstem. Connecting fibers in the brain are very organized, and if they are intact, water cannot pass through the fibers but instead travels alongside the fiber. When the fibers are damaged, water will go through them. The movement of water affects the MRI signal. This information is entered into a complex computer analysis, and a picture of the cortico-spinal pathways is produced as well as information about its size and integrity.

The DTI-MRI analysis gives researchers a more in-depth picture of brain injury, structure, an overall impression of how intact the pathways are. This could also potentially show change with treatment interventions. The DTI-MRI is currently used primarily for research purposes, but we'll likely see it more in clinical practice in the future because of the information it provides. Researchers at Northwestern School of Physical Therapy and Human Movement Sciences are using the DTI-MRI to understand how motor pathways have been affected by hemiparetic cerebral palsy and are then comparing this information to the child's movement abilities.

In next issue's Cutting Edge... stem cell research.



An example of a DTI image. the colors represent directions of the brain fibers.

We are constantly asked to make transitions in our lives. Some transitions are small: moving dinner from 5:00 to 6:00 or changing shampoo brands. Other transitions are big: a new baby in the house, starting school, changing schools, going to college.

We asked experts at local schools for their input on how to make transitions in the school setting easier for children and parents. The resounding message to parents is COMMUNICATION. Communication between parents, children, teachers, therapists, social workers, school counselors, aides and other significant people involved in a student's life.

Many thanks to the following people for their advice (indicated by their initials in corresponding sections): Karen Bryar, Principal at Blair School, Chicago IL; Shawn Fornek, Principal at the Developmental Learning Program (DLP), Midlothian IL; Hui-Ling Hite, Manager, Office of Services for Students with Disabilities, South Suburban College

Early Childhood... KB

Transitioning from early intervention into a school setting can be very intimidating to parents. It is a huge step for parents to entrust their child to school personnel. Many of the children came into the world fighting for their lives. Their parents have been very involved with all of the care and intervention since birth. Now they have to entrust their child to a group of strangers. I would be very reluctant to do this if I was in their shoes.

One of the best pieces of advice is for parents to meet with the teachers and therapist that will be working with their child. At Blair School, we have an intake meeting. The parents, teachers and therapists talk about the child to ensure everything is in place before the child begins school. It is a way to build trust between the family and school.

Other advice includes being involved in your child's education, establishing good communication with the teachers and therapists, (a communication book is great) and attending parent meetings. Blair School has parent meetings that are based on the parents needs. It is also a good way to meet other parent who are experiencing similar challenges.

Trust takes time to establish. It is always harder for the parent to send their 3-year-old to school than it is on the child!

Grade School... KB



You are comfortable with the school your child attends and now it is time to transition to another school. To help make this process easier for the families, Blair School has developed

transition meetings. Representatives from the new school are invited to come to Blair School and meet the parents. The parents are very happy to have many of their questions answered. These meetings appear to reduce the stress of transitioning from one school to another.

The most important idea stressed to the parents is for them to share informa-

tion about their child with the new school's teachers and therapists. Let the new school's staff know about any equipment that your child has or has on order, his/her communication needs and other concerns that you feel are important for them to know about. At the conclusion of the meeting, the parents are given an information packet with important questions to ask and school contact phone numbers.

The process of building trust begins again with the new school personnel.

High School... SF

Transitioning into high school is a monumental step for our students. To make this transition easier on the students and parents, we have done a wide variety of strategies based upon the specific needs of the individual student.

The teachers from the high school come to our classes in the early spring prior to graduation to meet the students on their home school turf. The administration and staff at the DLP feel that it is a nice way to introduce the new teachers and keep our students in a setting that is comfortable for them. The student can tell the new teacher what his/her interests are, show a sample of his/her current work, and take the new teacher on a tour of the school.

Also during this time of year, the teachers at the DLP will take students to the new school that they will be attending in the fall. This allows staff to assist with transition throughout the remainder of the current school year. Many times the new school visit is combined with a special outing to a restaurant so that the student feels exceptionally special and excited about attending a different school.

With several students, the DLP staff made photo books that incorporate the change so that parents can work during the summer months towards an easy transition in the fall. Pictures include the student's old school and friends, and have an emphasis on the new school, their new teacher and therapists and well as photos of the student in the new school setting when possible.

An introduction to the new school and

BACK TO SCHOOL



staff is beneficial in alleviating the fear of the unknown.

College... HLH

Junior and Senior year in high school is the time to start thinking of transitioning into college. Communication with the high school counselor, viewing college and university websites and visiting the institutions will make this transition easier. Some colleges, like Moraine Valley Community College, offer recruitment and transition services to potential in-district high school students with disabilities.

Post-secondary students with disabilities are guaranteed access to college programs and services by the following federal laws: the Americans with Disabilities Act and Section 504 of the Rehabilitation Act of 1973. To find out what types of services the institution offers, go on the Department of Student Services section on the institution's website. There should be a link for students with disabilities. On this site will be the names of the department's director and staff you can contact with individual questions.

School counselors, both in high school and college, can assist in making college an attainable goal with a smooth transition. Review school websites, visit colleges or universities that you are interested in and make appointments to speak with counselors in the Department of Student Services at those institutions. As the student transitions into higher education, more initiative on the student's part and less dependence on the school administration is expected and encouraged.

