



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 Research 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.

We would like to acknowledge the generous support of the Staubitz Charitable Trust, Art & Linda Staubitz, and several donations made in memorial of Art Staubitz.

Registry Funding



Cerebral Palsy Research Registry

Newsletter

2011 Volume 3, Spring/Summer Issue 1
 NU IRB #STU00021726
 Newsletter Editor: Isabel Aguilar
 maria-aguilar@northwestern.edu 312.503.1820
 Registry Coordinator: Donna Hurley
 d-hurley@northwestern.edu 312.503.3342

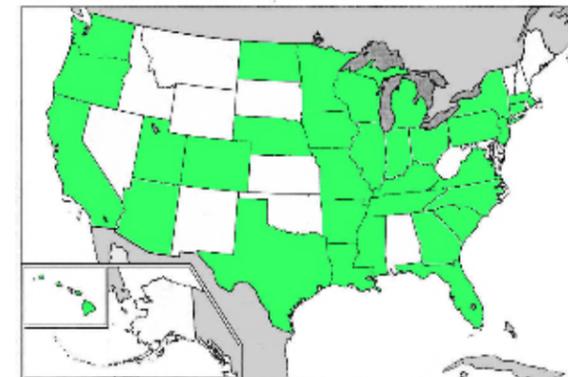
Greetings from the Cerebral Palsy Research Registry!

We hope that this newsletter finds you and your families well. The CPRR team has been working diligently to promote and expand the registry and it appears that our efforts have been successful.

Over the past six months,

The CPRR has been represented at the following scientific conferences:

- American Physical Therapy Association
- Illinois Early Intervention Symposium
- Naperville, IL School District 203 Continuing Education program
- The CPRR has **grown** from 360 participants to 528 participants!
- The CPRR team's manuscript titled "The Cerebral Palsy Research Registry: Development and Progress Toward National Collaboration in the United States" has been accepted for publication in the **Journal of Child Neurology**
- The CPRR is in communication with two new institutions and one professional organization that want to join the registry as **Participating Institutions**
- The CPRR database is being reformatted by Northwestern University's Bioinformatics Department



The CPRR has assisted three new research studies with recruitment

- Dance for motor learning in children with cerebral palsy
- Impact of social factors on medical, communicative and behavioral co-morbidities among children in the CPRR
- Medical home in children with cerebral palsy

The CPRR now has participants from 32 different states!

Thank you to all the participants and families who have joined the CPRR and those who have shared their stories of success, challenges and hope. Please continue to email or call with your ideas, thoughts and concerns.

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

Cerebral Palsy Research Registry
 c/o Northwestern University
 Physical Therapy and Human Movement Sciences
 645 North Michigan Avenue Suite 1100
 Chicago, IL 60611



**ASK THE EXPERT...Kristine Cichowski,
Director of The Life Center
at the Rehabilitation Center of Chicago**

What is the Life Center?

The Life Center stands as the largest depository of resources specific to people with disabilities. Think of the Life Center as a cozy bookstore where all resources are related to persons with disabilities and their families. Visitors are encouraged to browse through a comprehensive collection of resources that include magazines, books, videos, music, art, poetry and connecting with other visitors. All Life Center resources are organized according to 8 topic areas:

- Medical Information & Care
- Caregiving & Equipment
- Housing & Transportation
- Education & Employment
- Support & Wellness
- Recreation & Leisure
- Finance & Law
- Inspiration & Hope

Information about support groups, classes, government programs, vendors of disability oriented products/services, and disability-specific organizations, are also included in our collection to connect you with resources that span key topics of life. Knowledgeable staff members are available to help visitors and professionals find resource information, as well as help them use the Center's computers to find additional information on our web site.

What are some of the aims and goals of the Life Center?

The word LIFE is an acronym for:

- L earning
- I nnovation
- F amily
- E mpowerment

Anyone touched or living with a disability understands the enormous amount of day-to-day learning and the ongoing requirement to be very innovated in finding the best solution for each person. The goal of the Life Center is to create a place where those with disabilities, their families, teachers, coaches and the community can access information and resources to help enable inclusion in play and within the community. We also understand the vital importance of family and friends in developing a sense of empowerment. Becoming empowered is facilitated through greater knowledge of resources and connecting with people who understand and can help. It is our hope that access to information and resources will assist persons with disabilities and their families in developing a sense of confidence and motivation to pursue their dreams.

Who would benefit from resources and programs offered at the Life Center?

The Life Center was designed for those with a disability however anyone that would like to learn more about a disability is welcome. The more people we can reach to shed myths and fears that surrounds disabilities the greater the opportunity for inclusion for those with a disability.

Where can I find more information about your programs?

For more information on the Life Center go to <http://www.lifecenter.ric.org>



NATIONAL NEWS

We are very pleased to announce that **March 25th** has officially been designated "**National Cerebral Palsy Awareness Day**" by the U.S. Senate. **Senator Johnny Isakson sponsored the effort, along with Senator Robert Casey**

National Cerebral Palsy Awareness Day has now been put on the National Health Observance Calendar permanently and we are thrilled to see so many organizations and groups around the country marking the day in a variety of ways that draw much needed attention to Cerebral Palsy. The establishment of National Cerebral Palsy Awareness Day helps shine an important light on CP and those persons and families impacted by it.



WANTED

The CPRR would like to have photos of a variety of Registry participants with or without their families to be used to promote the CPRR. Types of advertisement would include the website header, brochures, scientific posters, etc. No names are included in these advertisements, a consent form needs to be signed prior to use and you will be notified if your photo is to be used.

REWARD

Email photos to d-hurley@northwestern.edu or mail photos to Donna Hurley, PT, DPT, 645 N. Michigan Ave, Suite 1100, Chicago, IL 60611

Family Focus: Meet 3 wonderful moms who are making a difference!

Patricia Herbst, Executive Director, Center for Independence Through Conductive Education

What is Conductive Education and how does it work?

Conductive Education is an integrated program of developmental learning which focuses on the whole person: physical, academic, social, emotional and language. Conductive Education also focuses on functional skills that lead to independence: dressing, feeding, walking, and sitting. One of the primary elements of Conductive Education is the group setting. Group education motivates the child to complete tasks, encourages accomplishments, and supports confidence and effort. Conductive Education's strength is that it teaches control of movement and capitalizes on the child's ability to learn through language and repetition.

Who would benefit from the Center of Independence through Conductive Education?

Conductive Education is one option for children with cerebral palsy, but it may not be appropriate for all. For Conductive Education to be successful, the child must have good visual and auditory skills, he/she must be able to benefit from a group setting, tolerate the intensity of the program, and the child's level of cognition must be at a point where the child is able to interact with others and follow verbal directions.

Do you have any advice for parents of children with Cerebral Palsy?

Have really high expectations for your child! All children with cerebral palsy can learn and it is very easy to be pessimistic early on when the child has complex problems that not only include a motor disorder, but also communication, learning and social disabilities. I wish I could go back and tell myself as a young mother that my child was going to be okay and not to place too much credence on standardized tests or his slow progress in motor skills! I also believe that children with cerebral palsy and their families have way too much on their plate and it's stressful and difficult to manage it all. My best advice is come up with a plan that focuses on the whole child: core academics/education, life-skills, functional independence and friendships. Recognize that you cannot possibly do it all, but also recognize that focusing on education without significant time devoted to daily life skills results in a child unable to live independently.

Where can I find more information?

<http://www.center-for-independence.org>

Annie Marie Splitstone-Reaching for the Stars, Chicago Chapter

What is Reaching for the Stars?

Reaching For The Stars (RFTS) is the only parent-led, national non-profit education and research foundation for pediatric cerebral palsy in the US. RFTS membership includes 10,000+ parents and caregivers of children with cerebral palsy (CP) across the country.

What is the national letter writing campaign ?

A common thread among RFTS members is a concern that little progress has been made towards treatment or a cure. The key to making progress is to increase the investment in research and a key step is gaining dedicated federal funding to conduct nationwide research and surveillance for CP. With a dedicated commitment we believe we can make strides towards finding a cure and the best treatment for CP by understanding risk factors, the cause, which treatments are most effective and why there are different clusters of prevalence and types of CP in different parts of the country. We know dedicated parents and caregivers of children with CP are best suited to share their personal reasons why this research is so critical and why the time to act is now. Hence the impetus to start a new national letter writing campaign to support other efforts of RFTS to gain federal funding.

Where can I find more information?

<http://www.reachingforthestars.org>

Meade Whitaker, Connecting Families on facebook

What made you want to start Cerebral Palsy facebook page?

I wanted to create a site where parents of children diagnosed with cerebral palsy could ask questions and receive advice from other parents that are in a similar situation. After creating my own facebook page, I discovered an already established page "Chicago CP Family Connection" and have decided to utilize this page instead of having a competing one.

What challenges and obstacles have you faced as a mother with a child diagnosed with Cerebral Palsy?

Finding and learning about state programs, becoming familiar with special needs terms, and connecting with other families to share ideas and solutions has been difficult. Learning how to interpret subtle behaviors as well as having the confidence to make your own interpretations has been very challenging.

What advice would you give to parents who have a child newly diagnosed with Cerebral Palsy?

You have to be the messenger of services, always making sure that everyone knows what is new with your child. As a mother you are the connection between your child and all of his caregivers. Take every opportunity to meet other families affected by cerebral palsy. Do not be shy when it comes to telling your story you never know what advice you might receive. Most importantly, continue to have high expectations despite setbacks and frustrations.

Where can I find more information?

For more information search for us on facebook: Chicago CP Family Connection.



