



**Registry Funding**  
 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.  
 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.

# Cerebral Palsy Research Registry Newsletter

2010 Volume 1, Issue 2

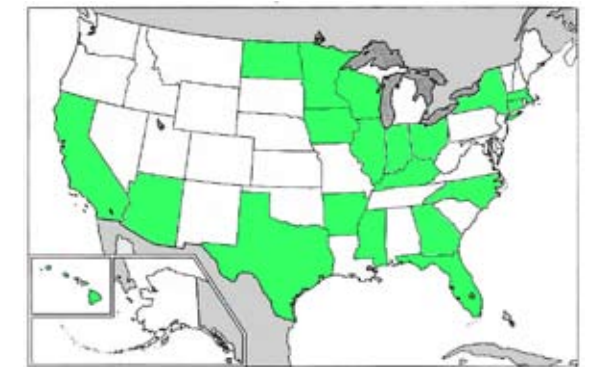
## Greetings from the Cerebral Palsy Research Registry!

As we eagerly await the transformation that Spring and Summer bring to our outdoor lives; longer daylight hours, new flowers blooming, wildlife returning, the CPRR also has anticipated a new transformation. We now have a new logo and within a few months, will have a website re-design: same address, [www.cpregistry.org](http://www.cpregistry.org), new look.

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Another transformation is the development of an adult intake questionnaire. Adults with cerebral palsy have different needs and information that is important to include in the CPRR. Adults are defined as persons 18 years-old or older, those who can legally sign a consent form as well as those who require a guardian to sign for them. Adult questionnaires can be requested by contacting Donna Hurley, PT, DPT at (312)-503-3342 or [d-hurley@northwestern.edu](mailto:d-hurley@northwestern.edu).



## We're Expanding...

The CPRR is excited to announce that currently there are 315 participants from 20 different US states enrolled in the registry! Our website has been instrumental with this effort. The green states on the map represent CPRR participant locations.


## Spreading the Word...



Donna Hurley with the CPRR table at the CP Inspires! Expo

The CPRR has been spreading the word of its mission and benefits to a wide variety of interesting people. We have had display tables at: CP Inspires! Expo, LaRabida Children's Hospital Cerebral Palsy Symposium, SPEED Early Learning Center Family Night, and the Chicago Chapter of Reaching for the Stars Cerebral Palsy Awareness Day.

Upcoming events include participating at: United Cerebral Palsy annual conference, the Northern Illinois School PT-OT Conference, Cerebral Palsy Research Conference sponsored by the University of Michigan, and the American Association of Cerebral Palsy and Developmental Medicine conference.

  
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## Ask the Physical Therapist

Theresa Clancy, PT has been a pediatric physical therapist for 20 years. Theresa currently works at the Rehabilitation Institute of Chicago in the outpatient department and specialty clinics, participates in research and speaks at continuing education programs.

The CPRR asked Theresa what advice she gives to persons with cerebral palsy and/or their parents regarding physical therapy.

**Parent/Caregiver Advice:** Enjoy your child/young adult. Don't get

caught up regretting things of the past and worrying about the future so that you are missing the present. Family outings are equally important, if not more so, than physical therapy sessions. Children with cerebral palsy can spend many hours with adults (therapists, teachers, physicians, orthotists) and need to spend time with children their own age.

**Persons with Cerebral Palsy Advice:** Don't let your physical limitations prevent you from trying new activities or pursuing what you think you'll enjoy. There are many resources today, including your physical therapist and/or rehab team that can assist with adapting, modifying and/or creating tools and equipment so that you can meet your goals.

**Therapy Sessions:** Therapy sessions are important for many reasons, but it is not the end-all and be-all. Sessions should teach the child and caregiver strategies so that they can continue to work toward their goals while at home. Physical activity is essential in everyone's life: the person with cerebral palsy, the caregiver, the other family members. The key is to find a physical activity the child enjoys and continue with it as they grow. Some activities children enjoy include swimming, horseback riding, dance, karate, animal care, soccer, sailing, bowling, yoga. Children need to learn how to move the best they are able to, enjoy moving, and continue to move as they grow into adults.

## Family Focus Meet Kiel Moses

My name is Kiel Moses and I am a thirty-two year old man who is originally from Evanston Illinois. I was born with visual, physical, and learning disabilities. These disabilities have acted as valuable life lessons for me as I have grown up. From a very early age I had to, with the help of my parents, learn to advocate for my needs in school. I was originally placed in remedial classes for kids who were not viewed as smart. I had to fight to get in to classes that were more appropriate for me and my ability level. These early educational experiences set a tone for me to understand that I was going to have to advocate for my own best interests instead of waiting for others to do it for me. I was always a part of the process in my educational experience whether it was accompanying my parents at my Individual Educational Plan (IEP) meetings or getting outside support for myself through the school system, I was from the beginning a part of my own scholastic adventure. This early personal involvement helped me understand that it was my own responsibility to help me get the best possible educational experience. As a result, I was able to advance scholastically out of the remedial classes where I was originally placed and find classes that better fit my needs and ability level.

More recently, I have gotten involved with connecting narrative to various creative modalities to tell personal stories of people with disabilities. I have used theater, creative writing, and dance to help create personal narratives of people with disabilities. These creative experiences have been extremely powerful and helpful in me cultivating my own personal voice by helping others to create their personal works of creativity. These experiences have helped me find a way out of the stereotypes that many able bodied people have toward people with disabilities. I have found that these creative narratives can help change the understanding of what it is like to be disabled. Through theater, dance, and writing people with disabilities can find a way to express their personal stories that can break through the common stereotypes and misconceptions that all people with disabilities are weak, feeble-minded, and/or otherwise incompetent. After discovering how creative modalities could positively impact people with disabilities, I found an educational program that would allow



Now is the time to explore summer options for your child. Programs can be found at your local park district or special recreation, library, community college (grade school students), children's therapeutic out-patient clinics and/or hospitals.

Below are a few Chicago area resources for summer camps (listed alphabetically):

### Camp Schwab: Children with Adaptive Mobility Play

Camper must be able to follow directions, be continent of bowel and bladder, walk or self-propel wheelchair, not run off from the group.

August 2nd-August 6th

Lisa Thornton, MD

773-522-5857

### Caring for Kids

Summer sports camps (baseball, tennis, golf, kayaking, and more) as well as Teen programs

710 N. Lake Shore Drive, 3rd floor

Jenny DiLaura

312-238-5010

www.ricsports.org

### Chicago Park District

Special Recreation – Adaptive sports

Daniel Tun

312-742-4913

daniel.tun@chicagoparkdistrict.com

www.chicagoparkdistrict.com

me to study this more closely. I ended up earning a master's degree from DePaul University in 2009. My degree was in interdisciplinary studies with a focus in Disability Studies. This scholastic achievement was helpful in my growth, understanding, and awareness of how people with disabilities can use the creative arts in their lives to tell their stories to others around them.

Currently, I have been accepted into a doctoral program at Syracuse University in New York where I will be studying disability studies with an emphasis in education. This scholastic experience will allow me to further explore the rich power that creative modalities can have on the lives of people with disabilities. I believe that this experience will help me to further explore how people with disabilities can be powerful change agents in their own lives and the communities where they live. I hope to eventually teach and continue to use these

### City Kids, Inc

Preschool and various specialty camps

5669 N. Northwest Highway, Chicago

Kacy Hertz

773-467-5669

www.citykidsinc.com

### Judd Goldman Sailing

Adapting Sailing in Chicago

NE Corner of Burnham Harbor

312-747-7684

www.juddgoldmansailing.org

### Summer Conductive Education Camp for Children with Cerebral Palsy

The Center for Independence through Conductive Education

June 21st–July 16th, July 20th–August 13th

Countryside, Chicago and Lake Zurich locations

708-588-0833

www.Center-for-Independence.org

### Summer Outreach Therapy Programs

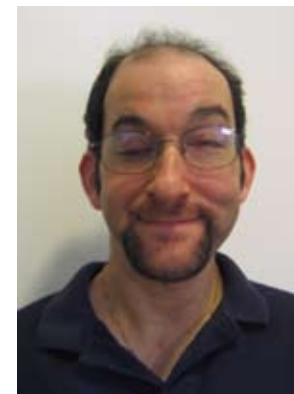
Aquatic Therapy, Fitness Fanatics, Picture Communication Pals, Chatter Books Club, Lose the Training Wheels, Crafty Kids and more.

Easter Seals of DuPage and Fox Valley Region

630-620-4433

www.dfvr.easterseals.com

creative modalities to help people with disabilities find creative outlets to tell their personal stories.



Kiel Moses

## Research Update...

All research studies that the CPRR has assisted with recruiting for are listed on our website, www.cpregrity.org. Two studies that were added since the last newsletter:

- “Video Game Based Rehabilitation with Cerebral Palsy”, Dr. Mark Shapiro, the Rehabilitation Institute of Chicago
- “Quantification of Quality of Life and Levels of Participation in Children with Mild to Moderate Cerebral Palsy”, Dr. Michael Msall, the University of Chicago

Future studies we hope to secure funding for include “Physical and Social Changes in Persons with Cerebral Palsy Across the Lifespan” and “Supports and Barriers Contributing to Volunteer Participation in Research Studies”.

## The Cutting Edge: Stem Cell Technology

*Disclosure: The CPRR neither supports nor recommends any of the services and/or institutions mentioned in this article.*

The topic of stem cell research as a therapeutic intervention for children with cerebral palsy often comes up in conversation when enrolling participants into the CPRR. There have been several articles and testimonials written in newspapers, magazines and seen on television stating that a transfusion of stem cells has wonderful, if not miraculous, benefits for children with cerebral palsy.

Unfortunately, many of those claims have been inflated and sometimes untrue.

Because cerebral palsy is such a heterogenous diagnosis, meaning that the cause of injury, timing of injury and resulting motor, sensory and neurological involvement is so varied, researchers are trying to ascertain the when, who and how stem cell therapy can benefit children with cerebral palsy.

Scientists who perform this research continue to perfect results in animal studies so that they can transfer that knowledge to clinical trials in humans. Many institutions, Duke University, University of Arizona, Medical College of Georgia, University of Texas-Houston, are at the beginning stages of investigating cord-blood transplants for children with cerebral palsy.

Some families go out of the country to obtain stem cell infusion treatments. These procedures do not follow the United States' Federal Drug Administration's recommendations and should be viewed as extremely experimental.

Research in the area of stem cell transplantation will continue and hopefully will provide us with specific procedural interventions that result in positive outcomes. When will we know these necessary answers? Five years? Ten years? Twenty years? No one can predict that, but until there is peer-reviewed, scientific evidence to support this intervention, it is best to be cautious and ask probing questions of the researchers.

### References:

Patoine, Brenda, Annals of Neurology, October 2009

Bartley J, Carroll J, Expert Opin, Biol.Ther. (2003)2(4):541-549

## Teaching Opportunities



The Department of Physical Therapy and Human Movement Sciences, located in downtown Chicago, IL is looking for children and adults with cerebral palsy, as well as their families, to assist teaching physical therapy students about this condition. Lab sessions are generally two hours with compensation of free valet parking and a small stipend. May/June 2010 and Fall dates are available. If you are interested, please contact Kristin Krosschell, PT, MS, PCS at 312-908-6790 or k-krosschell@northwestern.edu.