



Cerebral Palsy Research Registry Newsletter

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Greetings from the Cerebral Palsy Research Registry!

Hello and thank you for your continued interest in the CPRR.

The CPRR is supported by three institutions: Northwestern University, Department of Physical Therapy & Human Movement Sciences, The Rehabilitation Institute of Chicago and the University of Chicago, Department of Developmental & Behavioral Pediatrics. Working together as a team, the physicians and researchers strive to keep the CPRR up and running so that more research in the area of cerebral palsy can be achieved.

Below are some examples of cerebral palsy research these institutions are currently involved in.



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



**NORTHWESTERN
UNIVERSITY**

Researchers and PhD students in the **Northwestern University Physical Therapy and Human Movement Sciences** department are engaged in several research studies aimed at understanding the mechanisms underlying movement impairment found in the arms of children with hemiplegic cerebral palsy. Using haptic robots and electromyogram (EMG) to measure the strength of isolated arm and hand muscles, researchers compare the results with the child's brain mapping (through Diffusion Tensor Imaging MRI) to obtain a comprehensive picture of why isolated joint movement is difficult in some children with cerebral palsy. Other researchers are developing an assessment of selective motor control of upper extremity movements in children with cerebral palsy.

CPRR has
reached 895
participants
from 38
states!



The Rehabilitation Institute of Chicago is capitalizing on their engineering and robotics expertise to create innovative rehabilitation technology. Looking at task specific training to improve walking and increase joint range of motion of the ankle and wrist, robotic devices have been developed with proven results! Using video gaming to engage children while using these devices has been well received by the participants. Other biofeedback training includes an elliptical bicycle for older children and body supported treadmill training for children young and old. Additionally, a variety of studies for adults with cerebral palsy have been performed in the areas of bladder control and muscle spasticity.



**THE UNIVERSITY OF
CHICAGO**

The University of Chicago, Departments of Neonatology and Developmental & Behavioral Pediatrics is collaborating with researchers in Norway in a study investigating early prediction of cerebral palsy in the young infant.

High-risk, very low birth weight, premature infants admitted to the Neonatal Intensive Care Unit at the University of Chicago will receive three neurodevelopmental assessments, (two therapist administered and one computer generated) at 12 weeks post term age. Results from these three tests will be compared with neurodevelopmental outcome at 2 years post-term age. A larger study is looking at these same infants is being performed simultaneously by the department of Neonatology. Findings from these studies may aide in providing resources and support to the families and children who need them most.

To learn more about these and other open research studies, go to <https://www.cpreistry.org/current-studies.php>.

Best wishes for a safe and restful summer.

Donna S. Hurley, PT, DPT

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



Participating in Research by Sandra Hinckley



Sandra is a CPRR participant who lives in western United States. She is a busy woman- wife, mother to a beautiful 3-year-old daughter and full-time student, getting her Bachelor's degree in Accounting. She was excited to be able to participate in a balance research experience and hopes to be able to complete more studies in the future.

In January 2013, I had the opportunity to travel to Temple University in Philadelphia to participate in a cerebral palsy research study. In addition to my travel and hotel expenses, I was paid a small stipend to participate in this one-day study.

I had joined the Cerebral Palsy Registry in early 2012 after finding the organization online and was excited to be picked for a study so quickly! When I first enrolled in the CPRR, I thought most of the studies would be focused around stem cell research, but I was surprised by the diversity of the studies being conducted.

The study that I participated in was focused on balance. The purpose of this study was to understand how persons with cerebral palsy use their vision to help with balance and to prevent falling. A virtual reality set-up was used to assess balance. There was also a short paper survey, and they used a Wii balance board to test my balancing skills as well. Not only did it help their study, but it gave me current information on my condition to know how to further improve myself.

It was nice to work with people who were familiar with cerebral palsy, and they were always willing to aid me as needed. I enjoyed getting the chance to travel, seeing the campus, and meeting new people. I am honored to have been a part of something that is beneficial for the whole CP community. I am grateful to Temple University and to the physical therapists for their dedication to improving the quality of life for those with cerebral palsy and other disabilities.

World Cerebral Palsy Day, October 2, 2013

World Cerebral Palsy Day is an innovative way for 17 million people with CP to tell the world what they need to make their lives better and it's a way to turn some of those ideas into reality.

The 2012 World Cerebral Palsy Day was a world first! Three *ideas* from the 472 posted were shortlisted, and now have the chance to be turned into *reality*.

- Fold up motorized wheelchair
- Documentary: Cerebral Palsy in the 21st Century
- The wheelchair with solar power

The major winner of the 2012 campaign went to a talented team from the University of Virginia (USA), which developed a solar powered wheelchair with retractable panels. View a video of their entry on the World CP Day YouTube Channel at <http://www.youtube.com/WorldCPDay>.

World CP Day 2013

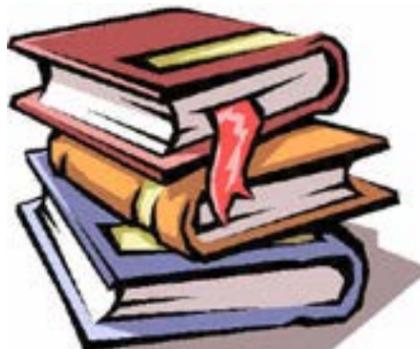
From July 14th to October 31st 2013, you will have the opportunity to tell the world what your idea is. Go to the World CP Day website <http://www.worldcpday.org>, click on the 'Post an Idea' button and send a 1 minute video telling how you want to change the world. Feeling camera shy? You can simply submit your idea in writing!

The most popular ideas will be presented to designers, innovators, engineers and investors keen on turning your dreams into reality.



Like many families and organizations, the CPRR has been affected by the economy. Our initial seed grant has expired and unfortunately this forced us to eliminate the CPRR recruiter position, affecting direct recruitment, correspondence and database/website management. Two grants for funding were submitted but were not accepted. This appears to be a similar trend for CP Registries around the world. The next step for the CPRR will be to go to industry for support. If you know of a corporation that would like to contribute to funding part or all of the CPRR please contact

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312-503-3342.*



CPRR Research Symposium

In the 2012 Fall-Winter newsletter, a questionnaire was sent out to survey CPRR participants their interest in a cerebral palsy research symposium. Unfortunately, only 7 participants replied, therefore, at this time there are no plans to conduct such a symposium.

Here are some organizations and websites that may be of interest to members interested in aging with CP, connecting parents/kids and advocating for either you or your child. More community resources are listed on the CPRR website.

- Reaching for the Stars
<http://reachingforthestars.org>
- CP Alliance
<https://www.cerebralpalsy.org.au>
- United Cerebral Palsy
<http://www.ucp.org>

Meet Sled Hockey Player Brad Pawelkiewicz

How long have you been playing sled hockey?

I have been playing sled hockey for 10 years with the Chicago Hornets.

How does sled hockey differ from regular hockey?

Sled hockey and regular hockey are not so different in terms of rules and penalties. Really sled hockey has two sticks with picks at the end of them to propel yourself and skate with the puck and the nets are a little bit shorter than in regular hockey. There is still checking in sled hockey and there are still fights in the adult leagues. As in regular hockey you use your legs to skate and move with the puck with just one stick.

Who is your favorite NHL team and why?

My favorite NHL team is the Chicago Blackhawks because I live close to Chicago and I have been a Hawks fan all my life.

What kind of equipment and uniforms do you wear?

We wear almost all the same equipment as regular hockey players such as: elbow pads, shin guards, shoulder pads, helmet, and gloves the only thing that could be different is we have to wear neck protectors and have two half sticks instead of one.

What is your favorite part about playing sled hockey?

My favorite part about sled hockey is the fact that I get to enjoy a great game and travel around the country, for little to no cost because all of our equipment is from donations when we play abled bodied kids.

What is your least favorite part?

My least favorite part about sled hockey is the fact that there are not more sled hockey teams that are closer to play to make it more competitive.

What would you say to someone who might be interested in joining your team?

If you like to play hockey and play a team sport with other disabled kids who enjoy the same things as you sled hockey and the Chicago Hornets might be right up your ally.

What are some of the benefits you've experienced training and playing this sport?

Some of the benefits of playing sled hockey are that I get to play a great game with a great group of people while having fun and staying physically fit.



Cerebral Palsy and Asthma

Respiratory issues, especially asthma, affect many people with cerebral palsy. Preterm infants have a high risk for asthma because their lungs have not fully developed prior to birth. Babies born full-term who have early viral respiratory infection are also at risk. This is why RSV prevention and influenza immunizations are important. Data from the CPRR shows that 1 in 9 participants require medications for asthma.

What is asthma? Asthma is a chronic (long-term) lung disease that inflames and narrows the airways. Asthma causes recurring periods of wheezing (a whistling sound when you breathe), chest tightness, shortness of breath, and coughing. The coughing often occurs at night or early in the morning.

What are asthma "triggers"? An asthma trigger is a thing, activity or condition that makes asthma worse. When you come in contact with a trigger it can cause a sudden worsening of symptoms that is often called an asthma attack, episode or flare-up. Common asthma triggers include smoke, respiratory infections, allergens (animals, mold, pollen), irritants (cleaning products), exercise, and emotions (laughing or crying, stress). Knowing what causes your asthma symptoms is an important step to controlling your asthma.

Why do I have to take medicine for my asthma?

By taking the right medicine at the right time, you can:

- Breathe better
- Do more of the things you want to do
- Have fewer asthma symptoms

Some asthma medicines relax your airways and help you breathe easier, while other treatments reduce the swelling and inflammation in your airways. It's important to follow your healthcare provider's advice about your treatment. *You need to take these medicines all the time, even when you feel well.*

Where can I get more information on asthma? Your physician, pharmacist, and the American Lung Association are great sources of information on asthma: <http://www.lung.org>

-Information from the American Lung Association and the CPRR team.