



World Cerebral Palsy Awareness Day
September 4, 2012

Cerebral Palsy Research Registry
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Cerebral Palsy Research Registry Newsletter

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Greetings from the Cerebral Palsy Research Registry!

Welcome to the Spring-Summer issue of the CPRR newsletter. The CPRR's focus for this past six-months has been on local recruitment, a de-identified research study and communication with national and international institutions and professional associations regarding Cerebral Palsy Registries. With so many family and social commitments on your schedule this time of year, we hope that you can carve out some time to not only read this issue of the Cerebral Palsy Research Registry newsletter, but visit our website at www.cpregistry.org as well.

Below are some CPRR highlights from the past six months:

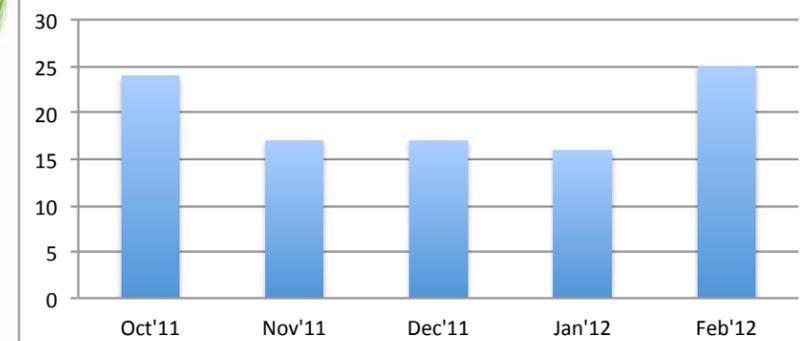
- Enrollment has increased from 698 to 804
- The CPRR has participants from 34 different states. We're looking for participants from: NV, ID, MT, WY, SD, NM, KS, AL, AK, WV, MD, DE, RI, NH, VT, ME, and MS
- Assisted with recruitment for five new research studies
- Completed a research study titled "Impact of Social Status in Medical and Developmental Outcomes Among School-aged Children with Cerebral Palsy" by Drs. Hurley, Msall, and Bauer using de-identified information from the first 500 school-aged children in the CPRR. Statistical analysis is being conducted and results will be published in the fall newsletter.



Look At Us Grow!
For more information about the
CPRR visit online at:
cpregistry.org



**Participant Recruitment
Total in the CPRR: 804!**





March 25, 2012
National Cerebral Palsy Awareness Day

March 25th is National Cerebral Palsy Awareness Day. The establishment of National Cerebral Palsy Awareness Day helps shine an important light on cerebral palsy and those persons and families impacted by it. 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. This year CPRR participant families have raised awareness by hosting speakers at their local school, showcasing wheelchair basketball, and featuring a disability awareness “Did you know?” into morning announcements. The CPRR assisted with an editorial in a local Chicago newspaper to raise awareness in the community. Below are some fun and entertaining ideas on hosting or organizing an event for next year:

- Host a community picnic with local support groups.
- Create fundraisers to support your local Cerebral Palsy organization such as walks/runs or bake sales.
- Invite a speaker to talk with children about disabilities at your local school district. Speakers may include a teenager or adult with a disability; a person who works with people with disabilities, such as an interpreter; or the parent of a child with a disability.
- Create a bulletin board at your local library or public school for Cerebral Palsy Awareness Day.
- Provide a storytime, snack or craft session with school children to discuss Cerebral Palsy.
- Partner with local schools, places of worship or Boys and Girls Clubs to arrange an inclusive community sporting event. Children with disabilities can participate, with few or no adaptations, in almost any sport.
- Write articles or Letters to the Editor to your community newspaper.
- Arrange a disability awareness community fair at a school or other central location that offers activities for children. Prepare booths and displays that help people without disabilities to better understand the needs of people with disabilities.



Kayla Conway’s Mission To Find Research

My name is Kayla Conway, and I am a nineteen year old freshman at San Jose State University, in San Jose CA, and I have left-sided hemiplegic Cerebral Palsy. I had a very hard time accepting my disability growing up because of all the torment and teasing. Eventually I learned that this disability was not something to hate, but something that I should embrace.

One day I was feeling a bit down, preparing for surgery in the coming months when I thought to myself, “Why am I having so many health issues? I wonder if there are any research studies documenting health problems that people with Cerebral Palsy will most likely face one day.” I searched the Internet. I contacted 23 different Cerebral Palsy alliances, registries, doctors, and specialists. A few organizations replied, but only confirmed that there is not enough research done on adults with Cerebral Palsy and the possible ailments that may accompany the disability in our

later years. For me, those later years have already begun. We, (the Cerebral Palsy community), have the right to know what to expect. We deserve an understanding of what we can change today to prevent these ailments and ultimately ensure a stronger, healthier way of life.

As I went on this “mission” to find research, one woman answered my email and gave me hope. Donna Hurley works for the CPRR, and she not only reaffirmed that there needed to be more research done but that there actually was an upcoming study that will be happening on adults with Cerebral Palsy and the health issues they may face in the coming years. Here I am today, just nineteen years old, but I have had seven surgeries, arthritis, scoliosis, mechanical lower back pain syndrome, and chronic pain. For me, research is not something I hope to happen, it’s something I need to happen. I want to change the world someday. I want to be a part of every research study possible and hopefully one day become an advocate for people with Cerebral Palsy.

Many say that research isn’t done because there’s not enough demand for it, but there are many people out there that don’t have a voice and are unable to express their fears. I’m here writing this because I want to give people of all ages with CP a voice. They get their chance to say, “I’m scared of my future health and I deserve to know what I may be facing later.” With research we can work on the prevention of these ailments starting at a young age. We can bring attention to the importance of physical therapy and we can give a better life over all, not only to this generation but to all generations to come.

Written by Kayla Conway



Meet
“Handicap This”

Mike Berkson and Tim Wambach met in the summer of 2001. Tim was hired to help Mike, a 12 year old with cerebral palsy, as his aide in elementary school. Tim quickly discovered that Mike was different than most kids his age. It wasn’t because of his wheelchair or cerebral palsy. Mike possessed a razor-sharp quick-witted sense of humor beyond his years. It bonded the two unlikely friends immediately.

Working together Mike & Tim created the Keep On Keeping On Foundation. Its early mission was to raise awareness about severe physical handicaps and have fundraisers to support individuals who were living with them. Mike and Tim decided they wanted to take their educational speeches and turn them into a theatrical show. In January of 2010, Handicap This! rolled onto the stage and made its debut. Their message is not only about cerebral palsy but also about encouraging others to overcome obstacles. Their message affects all audience members, receiving standing ovations 15 out of 16 shows! They’ve had public performances, recently rolling onto the stage at North Shore Center for the Performing Arts in Skokie, Illinois for three performances. They’ve also performed for middle school, high school, and college audiences. They are working to find a sponsor for a national college tour.

Handicap This! continues to work in partnership with the Keep On Keeping On Foundation. Wambach has also written a short book chronicling their experiences, *How We Roll*, with all sales going directly to the foundation. <http://www.keeponkeepingon.org/howweroll.html>



For more information about Mike, Tim, Handicap This! or the Keep On



Great Reads for Parents and Children



1. Chicken Soup for the Soul: Children with Special Needs: Stories of Love and Understanding for Those Who Care for Children with Disabilities By Jack Canfield, Mark Victor Hansen, Heather McNamara and Karen Simmons

-A collection of stories from the sublime to the heartwarming by those who have been touched by a child with special needs

2. Someone Like Me By John W. Quinn

-An inspirational autobiography about John Quinn. John speaks of his childhood as one of eight, his teen years on the wrestling team and his determination to join the Navy. John eventually retires as Senior Chief in the Navy but only after struggling to hide his diagnosis of cerebral palsy and his battle with alcoholism.

3. Exordinary People With Disabilities By Deborah Kent and Kathryn Quinlan

-Nearly 50 people with disabilities are profiled in this collection including: Thomas Edison, Beethoven, Harriet Tubman, and Tom Cruise

4. I’m Like You, You’re Like Me: A Child’s Book about Understanding and Celebrating Each Other By Cindy Gainer

-Children interact with people who are different from themselves. Together they discover their similarities and differences

5. My Holly By Julie Leavitt Wolfe

-A story about a young brother’s understanding and acceptance of a sister with Cerebral Palsy

6. Don’t Stop The Music By Robert Perske

-Follow a teen hero and heroine who have cerebral palsy through thrills, romance, and adventure all rolled into this “who-done-it”

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 advertisements 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.

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



