



Cerebral Palsy Research Registry

Newsletter

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Greetings from the Cerebral Palsy Research Registry!

The CPRR 2013 year ends with three major administration changes.

1. The CPRR coordinator position has been reduced to part-time due to funding issues. This change will affect direct recruitment efforts and will cause delays in email and phone correspondences. But all is not lost! The CPRR team is continually searching for grant funding to support the CPRR and remains committed to its participants and the promotion of cerebral palsy research.

2. The CPRR newsletter will now be printed and sent out yearly instead of bi-yearly.

3. A new consent has been approved by our Institutional Review Board (IRB), allowing the CPRR coordinator to provide a participant's name, address, phone number, and/or email address to IRB/CPRR approved researchers. **This is standard procedure for research registries.**

When the CPRR first started, the governing team did not write their consent to allow this exchange of information. Over the past five years, it has become apparent that this change needed to be made in order to promote increased participation in cerebral palsy research studies.



HOW DOES THIS AFFECT YOU?

- ❄️ Your original consent form that was signed when you enrolled will continue to be valid.
- ❄️ When you perform your yearly update online, the **new consent** will be on the CPRR website.
- ❄️ A new consent form will be mailed to all CPRR participants who have a current postal address on file. The CPRR team requests that you **read and sign the new consent** and return it to the CPRR coordinator. Signing the new consent will allow you to get in-depth information regarding research studies you might qualify for.

The CPRR team is cognizant and respectful of privacy issues. Only researchers from established organizations with IRB approval for their studies will be given contact information. If you have questions about these changes, please email me at d-hurley@northwestern.edu or call 312-503-3342.

Best wishes for a safe and healthy 2014!

Donna S. Hurley, PT, DPT

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Don't Forget!

National Cerebral Palsy Awareness Day is March 25, 2014.

World Cerebral Palsy Day is October 1, 2014.

Visit www.worldcpday.org for more information.

Courageous Lauren Walier

Fifteen-year-old Lauren Walier is an advocate for CP awareness and research. She is an ambassador for Reaching for the Stars: A Foundation of Hope for Children with Cerebral Palsy and was an invited speaker at the American Academy of Cerebral Palsy and Developmental Medicine 2013 Conference's Family Forum.

Lauren has raised over \$7000 through fund raisers and lemonade stands. Visit Lauren's Facebook page: Make Lemon Aide for Cerebral Palsy.

Below is an abbreviated version of Lauren's speech, "Be Courageous."

What would you do if YOU KNEW you could not fail? This simple question may help inspire us to try to accomplish our goals! Visualize this... You walk into a crowded room and no one is staring at you from head to toe with curiosity in their eyes. You walk into a grocery store and the cashier says "Would you like to donate a dollar for CP research?" Two words- Be Courageous. Two simple words. Two words that have inspired me. Two words that I hope will inspire you. Two words that I hope will inspire a movement.

My name is Lauren Walier. I have cerebral palsy and this is my story.

From the time I was a baby weighing 14oz. to the millions of falls, bumps, bruises and constant bloody knees, 3 surgeries, Botox injections, hours of weekly therapy sessions, bracing and casts on both feet and legs at the same time to riding a 17- hand thoroughbred horse confidently or a fast go-cart better than any boy in my neighborhood to relearning how to walk 6 different times to spending hours and hours of learning how to read, I have had to be courageous.

When I was in 6th grade, I attended my first Awareness Meeting sponsored by Reaching for the Stars, a Foundation of Hope for Children with Cerebral Palsy (RFTS), called "Successful Adults with CP". This was the worst and best day of my life!

We arrived just in time to hear John Quinn speak. He inspired me because of his successful career and he never once let CP get in the way. We also heard Michael Kutcher speak and talk about his son and that really hit home with me. I always worried about whether my future children will mind if their mother was different. I learned that evening that there was NO federal funding set aside for CP research, no successful treatments and of course, no CURE. I was devastated! That night I knew this was my path! I was on fire inside and ready to make a difference for the 17 million people in the world with CP. I wanted to be the VOICE

for those who do not have their own! I did this by becoming an ambassador for RFTS.

My 1st fund raiser as an ambassador for RFTS validated that this was my calling. My family and I approached a local businessman who ran outdoor concerts in my neighborhood. He agreed to donate 10% of the night's proceeds to RFTS. When we arrived I walked around to all the guests spreading awareness. I ended up meeting 4 families in the audience that have children with CP.

Then I had an opportunity to share my message with the audience. My message was one of hope, awareness and how I wanted to be the Voice for those with CP who do not have their own. Everyone gave me a standing ovation. People had tears in their eyes. It was a very emotional and raw moment.

A week later I received a thank you card in the mail from a woman who attended the concert thanking me and telling me I was making a difference with everything I was doing. She shared that her 19-year-old son, Jake, had CP and was non-verbal. She was grateful I was speaking out on Jake's behalf. Wow! That night I raised \$400 but more importantly it touched my heart and it made me want to fight harder! Let's just say if life gave me lemons, I made lemon Aide that night! Now some of you might think, "Wow, \$400 is a lot of money, but what can that do in the grand scheme of things?"

That's like "stirring an ocean with a teaspoon".

But imagine this. There are 800,000 people with this disability in this country. If every person raised \$400, which is absolutely doable, we will have raised, as a group, over \$320,000,000- (THREE HUNDRED AND TWENTY MILLION DOLLARS), A third of a billion dollars!!! That's a much larger teaspoon!! Think of what we could achieve with all this funding!

As an Ambassador for RFTS, my family and I have come up with a fund raising campaign called "Make Lemon Aide for CP". I invite you to join me to make a difference too! Be Courageous! There are lots of things you can do! Have a lemonade stand in your neighborhood, at your favorite restaurant, (which is what I did and raised \$1,000 at my first one), school or church- anyplace there are people. Make up a donation jar, take it to your favorite ice cream shop and ask if they'll help! Apply to become an ambassador for RFTS! The ideas are endless! It doesn't matter what you do, but it is up to US to get the funding and awareness to beat this thing. My dreams are to one day appear on the Ellen Show, go on Dancing with the Stars, go shoe shopping with my best friend when I graduate from my new therapy program and most importantly, to create a movement so vast and contagious that everyone wants to be a part of it, just like what Susan B. Komen's sister did for breast cancer!

I leave you with two last words! BE COURAGEOUS! Thank you!



The CPRR: Assisting with Research

The CPRR was asked to assist 6 research studies for subject recruitment this past year. Approximately 900 CPRR participants were contacted. The studies were as follows:

- ❄️ Krosschell (Northwestern University--Physical Therapy and Human Movement Sciences), "Test of Arm Selective Control"
- ❄️ Perrault (Rehabilitation Institute of Chicago), "The Stretch Reflex Response in Various Joints"
- ❄️ Zhang (Rehabilitation Institute of Chicago), "Developing a Pivoting-Sliding Elliptical System to Improve Off-Axis Neuromuscular Control of the Lower Limb"
- ❄️ Feldman (Stanford University), "Therapeutic Potential of Myofascial Structural Integration in Children with CP"
- ❄️ Dewald (Northwestern University--Physical Therapy and Human Movement Sciences), "Loss of Independent Joint Control of the Upper Limb in Spastic Hemiparetic CP"
- ❄️ Lee (Shriners' Children's Hospital of Philadelphia), "Functional Electrical Stimulation Assisted Cycling to Improve Fitness and Strength in Children with Cerebral Palsy"
- ❄️ Kruer (Sanford Children's Health Research Center) "Gene Discovery in Inherited Neurological Diseases"

REMEMBER to look at the CPRR website for research study descriptions!



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



Meet Victoria Badillo

Victoria and her father recently participated in a research study for children with cerebral palsy. The study site was in downtown Chicago, IL at Northwestern University, Department of Physical Therapy & Human Movement Sciences. Victoria's original session was scheduled on the same day as one of her volleyball games. She was torn between what to do! Her volleyball team needed her, but she also wanted to do the research study. In the end, she was able to do both. Her presence on the volleyball court helped her team win three games and she re-scheduled her appointment with the research team so that she could squeeze the research study into her busy schedule. Her determination to help others was inspiring and we wanted to know more about this quiet but goal-minded girl. You'll be interested in hearing what she has to say.

How old are you and what grade are you in? I am 10-years-old and in 5th grade.

Who do you live with? I live with my parents, 2 brothers Chris and Eric, 2 sisters Valerie and Vanessa, and my cat Pepper.

What are your hobbies/interests? I like to read all kinds of books. The last book I read was "Ramona the Pest" by Beverly Cleary. I play volleyball and it is my only sport right now. I did play softball, but it got too hard.

How did you hear about participating in a cerebral palsy (CP) research study? My dad got an email from the Cerebral Palsy Research Registry.

Why did you want to participate? I wanted to participate because I thought that it might help me and I thought it would help other people. I also was happy that I would be getting paid to do the study! It wasn't a hard study to do.

How was your experience? Did you travel far? My experience was good and no, I didn't travel far because I live in the suburbs.

Do you think other kids with CP would enjoy participating in research studies? Yes, because they would have fun.

What types of future research studies should be created? I think a foot game should be studied because I think it will make the studies interesting for other kids and it will benefit me so I won't have to have surgery.

Anything more you'd like to say? I would like to do more studies in the future.

