

StrokeNotes

The Children's Hospital of Philadelphia Pediatric Stroke Program

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A Year to Remember



By Quinn, 16

On March 22, 2011, during my freshman year in high school, I went to rugby practice, just like most days in the springtime. During a drill, I tackled my best friend. When he went down, he tried to catch himself and his elbow went right into the back of my head. I am big, but he is even bigger. All of his weight plus momentum went right into the back of my head.

The next part is foggy for me because I was struggling to stay conscious. I tried to get up, but fell. I spoke with a mumble. Then I started to vomit. I just wanted to lay down and fall asleep. My coach called my mom, and she rushed to the field. My teammates helped put me in her

car but I kept on vomiting and felt pretty bad so my mother drove me to a local hospital.

The doctors evaluated me and determined I had a bad concussion. However, during the CT scan they found a mass in my upper left side cerebral cortex. They told us it was probably a tumor or an infection. At that moment, I was truly scared for the first time in my life.

I was taken by ambulance to CHOP's ED. The ED doctors checked me out and I was admitted. Sometime the next day I was taken to have an MRI, which confirmed that I had suffered a stroke. We couldn't believe it. We didn't know kids had strokes.

We were told that it had happened about three days before my concussion. If I had not been hit in the head at rugby practice, the stroke would have probably gone unknown for a long time. I would have just had mysterious headaches and not known why. The concussion occurring helped us find out I had a stroke.

I will always have a little bit of scar tissue in my head and I have headaches, but I am feeling better every week. I miss my sports, but the extra time allows me to do what I really love, which is music, and focus on my

schoolwork and try new things. I recently joined the robotics club. After high school I want to study engineering.

This past summer I went to Camp Cranium, a camp for children with brain injuries. The experience really opened my eyes. I realized how much I love to help people. Also, that I have it pretty good. My situation could have been worse, and I got off pretty easy. The kids at Camp Cranium are the toughest kids I have ever known. Camp Cranium was one of the best experiences of my life. When I'm older I would love to volunteer there.

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In some ways I am a totally different person than I was before my stroke. I wouldn't choose to have a stroke or a concussion, but I am stronger for my experiences.

If you have a similar experience and are scared, worried or overwhelmed, when all seems lost just remember to believe in yourself and believe in your doctors. **SN**



Camp Cranium

By Elise, 15

Camp Cranium is a nonprofit camp for kids with brain injuries ages 6–18 that was founded in 2008. A five-day sleepaway camp that takes place at Camp Victory in Millville, Pa., Camp Cranium is a place where these unique children can experience the freedom and fun of just being kids. It is supported by medical staff from The Children’s Hospital of Philadelphia as well as one-to-one counselors.

There are plenty of fun activities at Camp Cranium, including arts and crafts, music, fishing, paddle boating, swimming in the pool or lake, a talent show, a dance, a concert, movie night, and a campfire for making s’mores. It is probably one of the only camps where kids in wheelchairs can fly down a zip line or climb all the way to the top of a rock-climbing wall. Volunteers and kids alike make brand-new friends and relationships, and children have the opportunity to develop self-confidence and meet other kids just like them.

Camp Cranium is my favorite camp that I’ve ever been to. There are people from The Children’s Hospital of Philadelphia there, so I feel very comfortable. It’s as if I am being left at a family member’s house for a week. Every year I meet new kids there who are just like me. I know that I will never get bored of anything at Camp Cranium because there are always new, exciting and special things to do each year. When I go home I’m happy to see my family, but sad to leave all of my old friends and the new friends I make each year. Sometimes when I get home from camp I find being home can be really boring compared to being at Camp Cranium. But I always keep in touch with my friends and counselors that I’ve met there, and sometimes we get together or share pictures. What keeps me coming back every year is not only the new and familiar faces but the zip line, which is my favorite ropes course we do at camp. I also look forward to the unique arts and crafts they have each year. My older brother has come with me and been a counselor for all three years that I’ve gone to Camp Cranium. He loves it just as much as I do and is always excited every year when camp rolls around because he also becomes friends with a lot of the campers and the counselors. **SN**

Fundraiser for Summer Fun

I had a dine-and-donate fundraiser for Camp Cranium at PJ Whelihan’s pub in Maple Shade, N.J. this past summer. Ten percent of the profits went to Camp Cranium. I told my friends and family and made up posters with my mom that we hung up around PJ’s. We also made the flyers for the fundraiser and gave them to teachers at school. Overall we raised around \$700. We got \$500 from PJ Whelihan’s and another \$200 from other donations. Camp Cranium costs about \$200 for each camper. If you don’t have the money there is something called ‘camperships’ where the camp or a parent whose child is going will pay the money. With the money we made from the fundraiser, three campers will be able to go to Camp Cranium. — Elise

Everything’s Okay

By Alesia Shute

On Nov. 6, 2011, I had the opportunity to speak at the Stroke Support Group Conference. Being a cancer survivor since age 7 and a longtime “resident” of CHOP as a child, I was honored to return as a guest of a group affiliated with the Hospital.

I spent a large portion of my childhood fighting cancer at CHOP. All my life I always felt that I had a story to tell, and after a lot of thought and tireless hours trying to get my words on paper, I finally wrote a book about my journey and decided to share it with the world. It is called *Everything’s Okay* because despite all I have been through and all that my family has been through, I have learned from my life and grown in ways I never imagined, and everything really is okay!

I donate 100 percent of my book profits to the Hospital. My mission is very clear: to help others who are facing situations similar to mine, guiding them through my words and encouraging them to share their stories. I try to help families understand that others have been in their shoes before and are here to listen and help them feel that “everything’s okay,” or is going to be okay, no matter where their journey might take them.

The true purpose of my story is to offer hope and inspiration to families in need. In September, I released a new comic book version of *Everything’s Okay*. In this version, you can not only read but also see what I have been through, and you can experience it all in less than an hour.

I am excited to have had the opportunity to share my story and meet you all and learn about the many ways we are connected. To those of you I met, I was truly touched as I listened to your stories.

To learn more about my book visit my website www.everythingsokaybook.com or email me for more information at alesia@everythingsookaybook.com. I look forward to our paths crossing again and continuing this journey together. **SN**

Occupational Therapy: One-handed Devices and Techniques

By Todd Levy, Senior Occupational Therapist

Occupational therapy helps children who have experienced stroke develop and improve skills needed for everyday independence. Below are some tips to help you make the most of your child's occupational therapy:

- Be involved. Caregivers are the key to success in any school or medical-based OT program.
- Participate in therapy sessions.
- Play an active role in writing realistic and achievable goals.
- Openly discuss your feelings and thoughts about your child's therapy.
- Work on OT recommendations with your child at home.
- Document your struggles and your child's struggles with daily activities throughout the week, and share these with your therapist.
- Be open to one-handed techniques. Independence is very important to quality of life.

Children generally find their own ways of doing things, which is great. But there are also some great one-handed devices and one-handed techniques out there to help your child dress, groom, play sports and games, type, and even drive.

Here are some ideas you might find helpful:

- Personal care: Ponytail device, scrub brush, tube squeezers, soap pumps, nail care
- Dressing: One-handed shoelace tying, elastic laces, button hooks, elastic waistbands, snaps

- Driving: Driving evaluations at facilities in the area
- Electronics: Smartphones, word processors, mini laptops, small keyboards, one-handed keyboards
- Eating: Velcro lunch bags, lunch boxes with latches, suction cup bowls, plate guards
- Activities/Sports: Turning pages of a book, squeezing squishy balls, pouring a drink, finger painting, catching balls, opening packages, stringing beads, swinging, playing a tambourine. For more ideas, visit Children's Hemiplegia and Stroke Association (www.chasa.org/hand.htm)
- Exercise: Wrist/ankle/hand weights, yoga mat, dumbbells

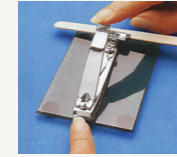
Where to buy:

- AbleData.com • Amazon.com • Target (target.com) • Xtenex (<http://xtenex.com>)
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Ponytail device



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Tube squeezer



“Fitting IN”

By Wes, 18

Fitting in is something that I've been trying to do since a young age. But something happened to me when I was 16 years old that changed my perspective. Ever since that brisk second day of February in 2010, there would be no more fitting in; just purely standing out.

That's the day I suffered a stroke. I haven't fit in since, so I do not even bother trying to be one of the “cool kids,” doing the next cool thing, wearing cool clothes, or trying to always hang out with the cool kids. I don't want to swim downstream with all the other fish. I want to swim upstream.

I'm not like everyone else. Some may say that I walk a little slow, have some different mannerisms or talk a little different than everybody else. But all that doesn't mean that I'm not just as smart, if not smarter. I don't have an afternoon sport; I may be the only one without one. I may be the only one who is allowed to wear sneakers, even though I wish I could wear boat shoes like I used to. But I'm a human being, too, just trying to eke by. You know,

make it through the next day, just like everybody else. The only difference is that some people look at the next day as just that: the next day. But I look at the next day as the first day of the rest of my life.

We get out of life what we put into it. Why not let it be filled with hopes, dreams and hard work? With individualism you can stand out in life, be successful — e.g., cure diseases, end world hunger, suffering or child labor, or become the next President of the United States — and, if you are lucky, you just might change the world for the better.

Stop worrying about what you do not have, and start worrying about what you do have. Stop worrying about having the next “cool thing” and trying to fit in. Instead, be concerned about what you are doing, not what other people are doing or what they think of you.

Everyone has the choice to fit in or be different. Making the choice to fit in may be simple, but everybody who chooses to stand out will be a better person, and maybe you will make the world a better place to live in. Wouldn't that be nice! **SN**

Please feel free to contact the Pediatric Stroke Program to suggest upcoming story topics and activities. Contact Lois Robbins at **267-426-0218** or robbinsl@email.chop.edu.




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