

# StrokeNotes

Ranked No. 1 in more specialties than any other pediatric hospital in the nation in U.S. News & World Report's 2012-13 survey of Best Children's Hospitals.



The Children's Hospital of Philadelphia Pediatric Stroke Program

Fall 2012 • Volume 2 • Issue 2

## My Fund- and Awareness-Raiser

By Renee, 13



My name is Renee. I created a fundraiser for the CHOP Pediatric Stroke Program. I ordered purple bracelets that say, "Pediatric Stroke Awareness" and "Kids Have Strokes Too!" on the outside and "Perseverance" on the inside, as a little internal message.

My school allowed me to sell them during a free period,

so every day I set up a table with posters and the bracelets and sold them to fellow classmates and teachers. I also sold them to friends on my ski team and at the country club I belong to. My parents sold some to their friends, too.

While I was raising money for the Stroke Program, I was raising awareness about kids having strokes, too. I had a stroke when I was 9 from an AVM (arteriovenous malformation) in my brain. Thanks to Dr. Jay Storm, a neurosurgeon at CHOP, and all of the staff in the CHOP Stroke Program and Children's Seashore House, I have very few lasting effects from my stroke.

I ended the fundraiser at my school on May 1, but I didn't stop there! I'm still selling the bracelets! So far I have raised over \$700. The bracelets are \$3 to \$5 each, depending on what people wish to donate. If you wish to purchase one for yourself, feel free to contact my mom at [gracebutler@verizon.net](mailto:gracebutler@verizon.net). **SN**



## A Smoother Cruise to the Beach

Beachwheels (or Surf Chairs<sup>®</sup>) are wheelchairs equipped with special wheels that roll over soft sand and other

challenging terrain. Started in 1992, the Long Beach Township Beach Patrol Beachwheels Program in New Jersey is one of the largest programs of its kind in the country. The program is funded by donations from Long Beach Island businesses and service organizations and by contributions from individual residents of Long Beach Township and Long Beach Island, N.J.

The Beachwheels Program currently has seven chairs for children and 39 chairs for adults, with one chair specifically designed for fishing. The chairs are equipped with retractable or removable footrests, armrests, and umbrellas, safety restraints and antiroll handles.

Beachwheel chairs are available for free on a weekly basis (Saturday to Saturday) to anyone staying at a Township of Long Beach address. Because there is a limited number of chairs, reservations must be made in advance (it is recommended to reserve a chair as early as January).

To learn more about the program or make a reservation, visit [www.lbtbp.com/beachwheels](http://www.lbtbp.com/beachwheels) or call 609-361-1200. Special thanks to our patient Lauren and her mother, Marianne, for letting us know about this wonderful resource. **SN**





# My Story

By Alex, 15

In the fall of 2007, I was 11 years old and going into sixth grade when I had the most traumatic experience of my entire life.

When I woke up that morning, how was I supposed to know that this day would not be like any other? It started off like any normal day, the same school routine that I had been following for the past seven years: get up, get dressed and eat breakfast, brush teeth, and then pack up to leave for school.

That year, I had been selected to be one of only two sixth-graders on the varsity soccer team at the Montgomery School. On this particular day, we were getting out early from school to travel from Montgomery to the Shipley School in Bryn Mawr to play a soccer game. Within the first few minutes of the game, I started to feel very light-headed and dizzy and couldn't walk straight. I told my coach that I didn't feel right and she took me out of the game. They laid me down on the sideline and tried to give me liquids, but when my dad got there, he knew something wasn't right. He carried me to the car and drove me to Bryn Mawr Hospital, where soon after, I passed out in the waiting room. I was transferred in an ambulance to The Children's Hospital of Philadelphia (CHOP), where I was diagnosed with a ruptured aneurysm.

The next day was a full day of procedures, including an operation to "clip" the aneurysm. I do not remember much from the first few days after my operation. My parents later told me that when I first woke up I had a breathing tube and couldn't talk, so I used a little white board to write down the various questions I had. They also told me that while my ruptured aneurysm was being repaired, I had experienced a stroke. Because of the stroke, I developed left-side paralysis. So, following a

month in the CHOP Pediatric Intensive Care Unit (PICU), I spent a month in the CHOP rehab hospital (the Seashore House) for inpatient therapy. After the time in the Seashore House, I developed hydrocephalus and had another operation to implant a shunt in my brain to help drain the excess fluid.

Many different experiences and the wonderful people at CHOP helped me stay entertained and have a good time while I was recuperating. Not only were the staff, nurses and doctors so nice and helpful, they were always willing to do whatever they could to help me fully recover. Some of the great experiences that helped me recover and pass the time included swimming in the pool for physical therapy, playing bingo, winning prizes on my TV, meeting a few famous sports players, playing Dance Dance Revolution in physical therapy, baking brownies



Alex, pictured here with Lois Robbins, M.S.W., of the Pediatric Stroke Program, came to CHOP with her mom and her mom's co-workers at Vanguard to tour the Hospital, learn about pediatric stroke and deliver more than 100 blankets Vanguard staff made for the children at CHOP.

Many different experiences and the wonderful people at CHOP helped me stay entertained and have a good time while I was recuperating.

in occupational therapy, and much more. The great staff at CHOP played a major role in helping me return to a regular life. (That and getting a brand-new puppy when I was finally discharged!)

Over the past few years I have pretty much gotten back into my regular routine, even though I have had to make a few changes. Although I have had to return to CHOP to have my shunt replaced six times, luckily, I have not had to have it replaced for two years.

Currently, I am a junior and an honors student at Villa Maria Academy High School. I have played on the tennis team since my freshman year and I played varsity starting in my sophomore year. I am also on the yearbook committee, working on the academics section. I love to "extreme coupon" and use the savings to purchase items for a local food bank. I never let my injury slow me down. For instance, I love to do exciting things like ride roller coasters, and this year I zip-lined in California with my dad! Recently, I took a trip to CHOP with my mom's work colleagues to deliver blankets for the children in the Hospital.

Overall, I believe that this experience has influenced my life in a positive way and has helped me understand just how lucky I am so that I can try to help other children who are less fortunate than me. **SN**

# Fall Fitness & Fun

By Heather Atkinson, P.T., D.P.T., N.C.S.  
Physical Therapist



As the long, lazy days of summer fade away and the hustle and bustle of a new school year begins, it is often hard to find time for exercise. This year, get the whole family involved in some fun activities that promote fitness and family bonding at the same time! Here are some ideas to get you started:

1. Since it is often said that children grow faster than the blink of an eye, now is a good time to ask your school or outpatient therapist if your child needs any new equipment, braces or splints. Often bones grow faster than muscles, which can cause the muscles to feel tight. Your therapist can evaluate this and recommend stretches to help. For children who have increased tone in certain body parts, growth can also sometimes cause muscles to feel stiff. Your physician or therapist can tell you if a consultation with Physical Medicine and Rehabilitation is recommended.
2. Breathe in the brisk autumn air with a hike through a local park. Walk along a path for endurance or over uneven terrain to challenge balance. Notice birds migrating south or squirrels collecting nuts. Collect fall leaves of different colors and paste them into an art project, creating your own special masterpiece. Find inspiration at <http://bit.ly/NdzLRz> or <http://bit.ly/czHT1F>.
3. Enjoy one of the many family festivals at the Camden Children's Garden. Upcoming highlights include "Faeries and Wizards Festival" (Sept. 22–23), "Mum Madness and Pumpkin Parade" (Oct. 13–14), and "Goblins in the Garden" (Oct. 27–28). Check out [www.camdenchildrensgarden.org](http://www.camdenchildrensgarden.org) for details!
4. When was the last time you went to the zoo? Kids can practice lots of walking (sometimes in costume!) and may even be able to see hippos gobble pumpkins for lunch. Visit [www.philadelphiazoo.org](http://www.philadelphiazoo.org) or [www.capemaycountyzoos.org](http://www.capemaycountyzoos.org) for more information.



5. Fall events abound at our local children's museums. At the Garden State Discovery Museum, you can help make apple cider, be amazed by a butterfly release or participate in the annual Pumpkin Palooza ([www.discoverymuseum.com](http://www.discoverymuseum.com)).

However you decide to enjoy the fall, remember that any activity can be adapted into something fun and therapeutic. Whether it is raking and jumping into leaves, carrying a pumpkin with two hands, stuffing straw into a scarecrow, or flapping both arms like a butterfly getting ready to migrate to Mexico, children of all abilities can discover the many wonders autumn has to offer.

Have a safe and happy fall! **SN**



The Children's Hospital of Philadelphia  
Pediatric Stroke Program  
Cordially Invites You and Your Family to Join Us for Our  
**Picnic and Activities Day**  
Saturday, September 22, 2012 • Noon to 4 p.m.  
Greater Plymouth Community Center Park  
2915 Walton Road  
Plymouth Meeting, PA 19462  
Please R.S.V.P. by Thursday,  
Sept. 20, 2012 to Lois Robbins  
at [robbinsl@email.chop.edu](mailto:robbinsl@email.chop.edu)  
or call 267-426-0218.

The Children's Hospital of Philadelphia  
PEDIATRIC STROKE PROGRAM

## Research Spotlight

By Lauren Beslow, M.D.

I have recently begun a research project using an optical imaging machine to evaluate blood flow and brain oxygen content. This machine uses light and is noninvasive; in other words, it does not hurt the patient at all!

For this study, I am recruiting children ages 2 to 19 with arterial ischemic stroke during acute hospitalization. As a patient's head of bed position is changed from flat to elevated to about 30 degrees, I will measure blood flow and will then compare the blood flow in the half of the brain with stroke to the half without stroke.

I will use this same noninvasive optical imaging machine to examine the blood flow of healthy children ages 2 to 19 without stroke and compare both sets of results. My goal is to better understand how blood flow in a child's brain is changed after a stroke in the hopes of improving care for our young hospitalized patients.

If you have a child who has not had a stroke who is interested in coming to The Children's Hospital of Philadelphia for a single visit for this study, please contact our Stroke Research Coordinator, Rachel Bastian, at 267-426-7332. Parking at The Children's Hospital of Philadelphia will be covered by the study and subjects will receive a gift card for their participation. **SN**

## I Wonder *By Elise, 16*

I wonder sometimes if people can really understand me, or I wonder if I keep myself locked up with no way to open up to me. I wonder sometimes if I'm ever gonna be like I used to be: wild, athletic, pretty and free. I wonder if anyone can even see my scars and my pain that came, came to be a part of me. I wonder if that's all they can see, my scars, not me, beneath them. Sometimes I wonder, when oh when did I come to be not like them.

## PACT to the Rescue

Stroke patient Bryant recently needed surgery, which meant his mother needed to spend some time living at CHOP to be near him. But there was no one to take care of Bryant's beloved dog Baby Powder while they were away.

Our social worker intern, Alexandra Blinder, put out the call to all the social workers in the Hospital, asking if anyone knew a person or an organization that would be able to help out. That's when we were connected to an organization called People/Animals = Companions Together (PACT) and its founder and president Melvin (Buzz) Miller.

One of the goals of PACT is to provide foster care for the pets of military personnel who are deployed. They also educate children about companion animals and assist in finding foster and permanent homes for animals.

Buzz was able to use the same procedure for finding foster homes for the animals of military personnel to help Bryant and Baby Powder. Bonnie, one of PACT's foster family members, was matched with Baby Powder. She was able to pick the dog up from the SPCA and bring her to the foster home. Bonnie sent Bryant and his family daily emails about Baby Powder, as well as pictures. It made being in the Hospital a little less stressful knowing that their dog was receiving care in a loving and nurturing home.

When Bryant was discharged from CHOP, Bonnie brought Baby Powder back home to be reunited with Bryant and his mother. Both families have enjoyed getting to know each other, and if Bryant needs to come back to CHOP, he knows that Baby Powder will have a great foster family to stay with during his hospitalization.



Buzz, foster parent Bonnie, Baby Powder and Bryant and his mother were the first in what we hope will be many successful pet foster matches.

In fact, this first match has started a new relationship between PACT and CHOP. Buzz and his team have met with the social workers and agreed to consider fostering other animals for families in a similar situation. For more information about PACT, call 610-581-4141, email [info@pactforanimals.org](mailto:info@pactforanimals.org) or visit [www.pactforanimals.org](http://www.pactforanimals.org). **SN**

## Presentation of a Scholarship to Derek Marshall at Graduation in June 2012 *By Arthur Handel, teacher, Winslow High School*

When this night is over, I'm sure that everyone in the audience will agree that our school has many remarkable students and teachers. There is another wonderful teacher here, and his name is Derek Marshall. You're probably wondering why Derek isn't sitting here with my colleagues. The reason is that Derek is actually a student. In his unique way, he has taught all of us at Winslow High School what is really important in life. From him we have learned to always respect others. We have learned how very precious life is and about not taking things for granted.

When you feel that life is not treating you right, learn from Derek Marshall. His gift is to make us aware of our great fortune, our healthy back and legs. Sometimes

people appear not to notice him, but he always notices them. When you envy someone, learn from Derek Marshall. He feels not so much envy as desire; the desire to continue putting one foot in front of the other, to be independent. When you complain that your life is so terribly complicated, learn from Derek Marshall. He knows that there is infinite joy in the simple things such as getting out of bed in the morning and confidently meeting all the challenges that each new day brings.

Derek may not give us the gift of witty conversation or cute jokes to be laughed over and repeated. What he gives us is so much more. Like every great teacher, he gives us opportunities to discover the richness of our

character, our abilities, our patience; the opportunity to fully discover our spirit more profoundly than we have ever imagined. By following Derek's example, we want to strive harder, seeking answers to life's many questions, and never becoming frustrated with questions that have no answers. How can any of us dare hang our heads when we see Derek every day, holding his head high?

To ensure that this determined young man continues his education, the Derek Marshall Scholarship Fund has been established. For the next several years, local business owners will be contributing to an account at the Fulton Bank. Maybe one day Derek will teach the world to forget its own needs and desires and focus on doing the right thing. He's already taught all of us here hope and faith. **SN**

## Wes' Courageous Journey Continues



Wes (circled) recently co-piloted a helicopter on a trip to Hawaii thanks to Dream Come True.

Wes came to CHOP in February 2010, at age 17, after a hard blow to the head during a hockey game caused him to suffer a stroke. He spent 55 days at CHOP struggling for his life and survived. But the stroke caused him to lose many fine motor skills, and he was discharged in a gurney. He never thought he'd walk again.

But with up to five hours of therapy a day (including physical, occupational, speech, respiratory, recreational and neuropsychological therapy), and a mix of weight training and swimming, he has moved from gurney to wheelchair to walker to cane and can now walk without braces. The 6-foot-5-inch 19-year-old recently walked

with classmates from the Hill School in Pottstown to receive his high school diploma. During the graduation ceremony he received a Special Headmaster's Prize for Personal Courage.

Thanks to hippotherapy and a leg rehabilitation device by Bioness Inc., Wes is now learning to walk with even greater speed, stability and confidence. The Bioness L300 is worn in two parts: as a small transmitter in the shoe and a device strapped below the knee. When Wes walks with the device on, the L300 sends electronic signals to stimulate the peroneal nerve which, in turn, signals underactive muscles to help him lift his foot off the ground.

In addition, thanks to a hand rehabilitation device, Wes is now working to regain use of his right hand. The Bioness H200 device straps to his forearm and extends to his hand and sends electrical stimulation into his arm to help his hand move. He wears it for at least 90 minutes a day to increase range of motion, re-educate muscles and increase blood circulation, and it's working. He is now able to tie his shoes, send text messages, fasten buttons and write with his right hand.

He recently co-piloted a helicopter on a trip to Hawaii thanks to Dream Come True, a Lehigh Valley-based organization that enriches the lives of children who are chronically or terminally ill. He plans to attend Penn State–Lehigh Valley part-time in the fall and hopes to one day get back on the ice.

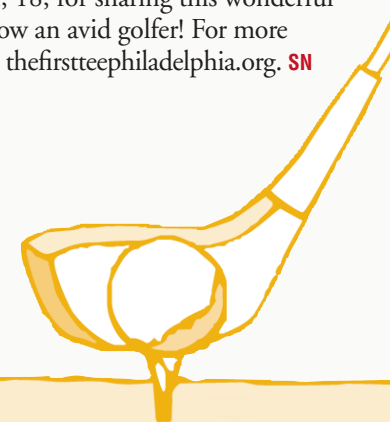
Wes' courageous story is making headlines. The Breinigsville, Pa., resident was recently featured in an article by Tim Darragh of the local newspaper *The Morning Call* and in a video on the paper's website. To read the story about Wes, visit <http://bit.ly/N9DyhW>. To view the video, visit <http://bit.ly/MPxQjr>. **SN**

## Growth Through Golf

The First Tee of Greater Philadelphia is a local organization that strives to impact the lives of young people through golf. The organization offers golf classes for children ages 6–18 in the spring and fall after school and on Saturdays, and Monday through Saturday during the summer. Home school classes are also offered throughout the year. Classes are held at FDR Golf Club at 20th Street and Pattison Avenue in South Philadelphia and the Walnut Lane Golf Club at 800 Walnut Lane in Roxborough.

The goal of the classes is not only to improve a child's golf game, but also to aid in character development by reinforcing the values inherent in the game of golf. The organization offers a safe and friendly environment, an opportunity to build friendships, professional golf instruction, leadership and character building, fun games and activities, participation in local and national events, and professional career skills training.

Thanks to Zakki, 18, for sharing this wonderful resource. He is now an avid golfer! For more information, visit [thefirstteephiladelphia.org](http://thefirstteephiladelphia.org). **SN**



## Never Say Never

On August 18, 2005, Connor's football team was in the middle of practice when he felt a sharp pain in his head, the onslaught of a headache unlike anything he had ever felt.

"I couldn't hear what the coach was saying," he recalls. "I couldn't concentrate."

He blacked out and woke up feeling numb. He was taken to a local hospital and then transferred to CHOP. When Connor arrived at CHOP he wasn't able to swallow. He didn't eat for four days. His right side was paralyzed. Beyond his own immediate health, Connor didn't want to be a burden to anyone else. He wanted to be independent and live his life as any other boy his age.

"I didn't want to hold people back," he says. "I didn't want them to have to take care of me."

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While the stroke may have sidelined him, Connor never lost hope. Football kept him motivated, and his family and friends kept his spirits up.

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This desire to remain independent fueled Connor. He began to do all the exercises he was shown to strengthen his body. He also had a date in his mind. The football squad was going to have their team photo in a few days and Connor wanted to be a part of it. He was entering his eighth day at CHOP, and he needed to pass a few tests before he could be released. He walked as instructed, but the doctors were still wary. They wanted to take every precaution before discharging him.

Fortunately, Connor was discharged in time for the team photo. He was greeted with hugs and showered with questions. When it was time for the picture, Connor was in familiar territory, huddled around his teammates.

"I was as happy as can be," he recalls. He stayed close to the team all season, cheering them on and helping out as

the water boy. Staying connected added some normalcy in his life.

When it was time for middle school to start, Connor wanted to get out on the field with the rest of his buddies, but had to watch as they were issued jerseys. It was hard for him, but he still wanted to be involved with the team. He approached his coach and asked if he could be the team manager. His coach agreed and Connor was thrilled to once again be around the sport he loved.

"It was nice," says Connor. "I was back within the game. I was happy again."

Connor managed the team for the next few years. While his health was improving, he still had to make an annual pilgrimage to CHOP. Each time he was examined, Connor would ask if he could play football. And each inquiry was met with a resounding, "No." It became a standard routine. Connor's doctors were astonished at his progress. He seemed to defy the odds and they were amazed at how well he recovered. But football is a vigorous contact sport that can have physical repercussions.

In the fall of his junior year, Connor's visit to CHOP fell on Columbus Day. During the routine examination he reflexively asked if he could play football. The answer that followed astonished him. His doctors said, "Yes, you can play." Connor was thrilled.

"I looked at my mom and said, 'I'm going to play,'" he recalls.

As Connor was preparing for his senior year he realized he was way behind his teammates in strength and conditioning. Feelings of uncertainty began to creep into his head. He wasn't sure if he could compete. It had been six years since he played football, and he knew it was an uphill climb. Yet, it was the game he loved, and suddenly it was within his grasp.

"I decided to go out for the team," says Connor. "I said to my friends, 'Let's do this.'"

Connor hit the weight room, barely weighing 95 pounds. He began to lift with a fierce desire and increased his bench press by 100 pounds by the end of the spring practice. He went off to minicamp to train and made the team as linebacker. His dream was realized.

"It was great to have him out there," says his head coach. "To see him out there and playing was inspirational to our kids. We were very excited to see him play."

Connor plans to attend Penn State next fall and remains determined. While the stroke may have sidelined him, he never lost hope. Football kept him motivated, and his family and friends kept his spirits up.

"All the thanks to my family and coaches and teammates, they all played an important part," he says. "They supported me throughout this." **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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 The Children's Hospital of Philadelphia®

Hope lives here.

Founded in 1855, The Children's Hospital of Philadelphia is the birthplace of pediatric medicine in America. Throughout its history, a passionate spirit of innovation has driven this renowned institution to pursue scientific discovery, establish the highest standards of patient care, train future leaders in pediatrics, and advocate for children's health. A haven of hope for children and families worldwide, CHOP is a nonprofit charitable organization that relies on the generous support of its donors to continue to set the global standard for pediatric care.

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