

# The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



University of Colorado  
Anschutz Medical Campus  
Hemophilia and Thrombosis Center

Affiliated with  
Children's Hospital Colorado  
and University of Colorado Hospital



The HTC treats bleeding disorders such as hemophilia and von Willebrand disease, but did you know we also have a portion of our clinic dedicated to the treatment of pediatric stroke? About 90% of all strokes occur in adults over 50. Stroke is very rare for a child. In fact, stroke in children occurs in only 1.2 out of every 100,000 kids. Children's Hospital Colorado sees about 20 new childhood strokes a year.

Stroke in children can happen as early as in the womb and can be caused by a variety of factors, some of which are still not yet discovered. The highest risk of stroke anyone will have in their lifetime is during birth, as babies brains are more susceptible to injury. Perinatal stroke is estimated at 1 in 1600 to 5000 births nationwide. Our stroke clinic specializes in the treatment of children who have experienced stroke and our neurologists, Dr. Jennifer Armstrong-Wells and Dr. Timothy Bernard, have done pioneering research into the treatment and prevention of childhood stroke.

**May is Pediatric Stroke Awareness Month** and throughout the month we at the HTC support efforts to spread the word about the signs and symptoms of stroke in children. The HTC has a Pediatric Stroke Parent Support Group that meets about once a month to provide learning, support, and opportunities to connect with other families facing this rare condition.

Many people recognize the symptoms of stroke in adults but fail to register those similar symptoms when they occur in children. Symptoms are often missed because of the lack of awareness that children can experience stroke. For all ages it is important to remember **F.A.S.T: Face** Drooping, **Arm** Weakness, **Speech** Difficulty, and when these are present it is **Time** to call 911. Prompt diagnosis and treatment of stroke is critical for any age.

In addition to the F.A.S.T symptoms, babies may show early signs of stroke if they experience seizures, repetitive twitching of face, arm or leg, and problems with sleep apnea. Signs of stroke in developing children may also be marked by decreased movement on one side of the body, or showing preference for one hand before the age of one. While the causes of most perinatal and childhood strokes are unknown, risk factors can include congenital heart disease, blood clotting disorders, infections (e.g. meningitis), head trauma, and some genetic diseases and disorders. No previous risk factor is identified in about half of childhood stroke cases.

Our stroke program works year round to research causes and treatment of stroke in children and can always use your help in spreading the word about stroke. Just knowing the signs and symptoms can make the difference in the life of a child. Please support our efforts to spread the word by sharing posts from the HTC website, our HTC social media pages or other pediatric stroke resources, and liking and sharing our new Colorado Pediatric Stroke Facebook page.

[Stroke graphic courtesy American Heart Association & International Alliance for Pediatric Stroke]

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## PEDIATRIC STROKE AWARENESS MONTH

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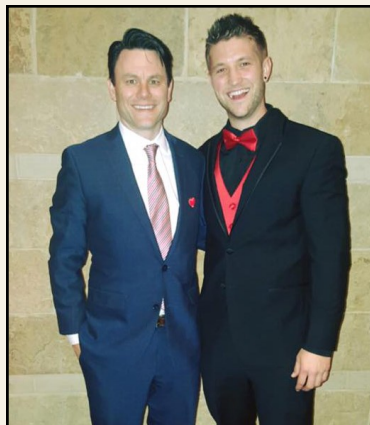


Website: Go to [medschool.ucdenver.edu/htc](https://medschool.ucdenver.edu/htc)



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# HTC PATIENT SPOTLIGHT: BRADEN EVERLY



Dr. Bernard with Braden at the Denver Heart Ball, Feb 2016.

Our HTC doctors often tell us how lucky they are to work with inspiring patients who overcome so much and reach out to help others. Our pediatric stroke patients are no exception.

In February, Braden Everly, one of our stroke patients, was honored at the Denver Heart Ball and shared his story.

Braden grew up in Littleton, Colorado and was 12 years old and attending a birthday party

for a friend when he was hit with symptoms that were frightening and confusing. He suddenly felt like he was walking sideways on the grass, his left side started responding strangely and his speech and understanding began to be unclear.

Braden was having a stroke and neither he nor anyone around him knew what was wrong. Pediatric stroke is very rare, and often doctors are unable to find the cause. Care can be complicated when no one expects a child to experience stroke. In Braden's case, severe dehydration likely contributed to triggering his stroke, and he is a strong advocate of maintaining healthy hydration and bringing awareness to stroke symptoms at any age.

Treated at Littleton Hospital and Children's Hospital Colorado, Braden faced surgeries, physical therapy and, most difficult, a readjustment to the direction of his life. Dr. Timothy Bernard has worked with Braden from the start, and looks to Braden as a major inspiration for creating the programs now available through the University of Colorado and our clinic to treat kids who experience stroke. Braden is grateful for the care "Dr. Timmy" provided and considers him his role model.

***"He [Dr. Tim] gave me hope when I had none. He stayed up late, woke up early and worked without an end in sight for a 12 year old boy that he barely knew. He cared for me like a son and I will be forever grateful."*** Braden Everly

Braden admits that at first, dealing with the consequences of stroke and serious surgery was painful, emotional, and difficult. He gives credit to his parents and family for their support, even though they faced other serious challenges on top of his own diagnosis. One sister was being treated for leukemia and another was scheduled for back surgery

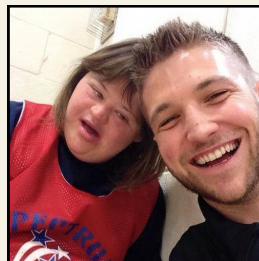


Braden recovering from his stroke.

the same week he had his stroke.

While Braden loved to play football and was very athletic, once he was diagnosed with stroke he needed to reassess how he could involve sports in his life. He couldn't play football, but he jumped at the opportunity to work as an assistant coach for a 3<sup>rd</sup> grade football team. It was just what he needed. Braden was able to focus his emotions and developed his own motto: ***"The only disability in life is a bad attitude."***

Throughout his high school years he worked with the Columbine High School's Challenge Program, helping other students with disabilities. His experience with what it was like to struggle to recover from stroke gave him a deeper insight into what other students were going through.

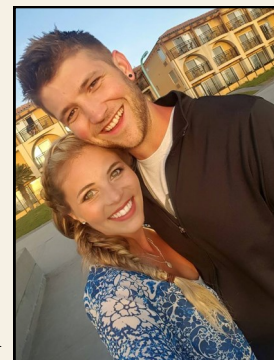


Braden working with special needs friends at Stepping Stone.

***"I had been there. I knew what it was like to not be able to communicate what I was thinking. I knew what it was like to be talked to like a baby when, in my head, I could comprehend everything around me,"*** Braden explained.

He took this understanding and his passion to make a difference and earned a degree in Special Education from the University of Northern Colorado in Greeley.

Braden now works as the Program Director of Stepping Stone Support Center, a pre-vocational program for adults with special needs. He and his girlfriend, Alyssa Dunlap, recently started their own business last fall called Zaqavi Apparel, a clothing line inspired by the capabilities of people with special needs. He hopes their motto "Live Limitless" encourages others to chase their dreams without looking back, stepping outside their comfort zone and into possibility.



Braden and Alyssa started Zaqavi Apparel in 2015.

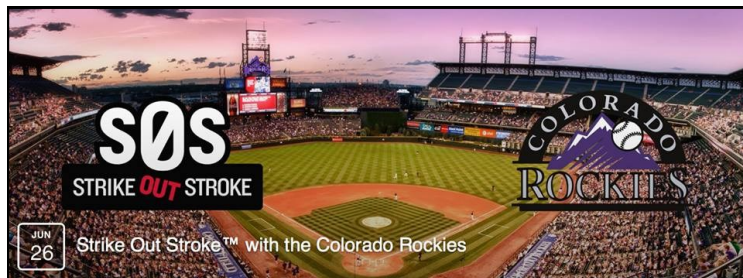
Braden is admired by friends, family, co-workers, and all of our staff who have had the pleasure of meeting him. He and Alyssa are personal trainers, regularly hike with their two pit bulls, and have made fitness and health the keystone of their lives.

You can learn more about Braden's experience in a video provided by the American Heart Association, learn about Stepping Stone Center, and Zaqavi, by visiting our website : [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) click the **RESOURCES** link, then the **NEWSLETTER** link in the dropdown menu. Once there, click the **CURRENT DIGITAL NEWSLETTER & ARCHIVES** and find **May 2016**.

[All photos courtesy: Braden Everly]



## STRIKE OUT STROKE



### MARK YOUR CALENDAR!

Join **STRIKE OUT STROKE™** to teach the warning signs of stroke and to act **F.A.S.T.** by calling 911

**Sunday, June 26th - 2:10 pm**

**Coors Field**

**Colorado Rockies vs Arizona Diamondbacks**

## MILE HIGH SUMMER CAMP

Mile High Summer Camp will be on **July 10-15, 2016** at Rocky Mountain Village at Easter Seals in Empire, Colorado. The Leadership Camp begins two days earlier on July 8th and is for those ages 14-18.

For more information and to find registration forms, please go to **cohemmo.org** and find their camp pages and links to the forms.

All registration fees and forms are due by **June 1, 2016.**  
**NO EXCEPTIONS.**



## STROKE PATIENT RAISES FUNDS FOR RESEARCH



Madison Haines presenting a check and one of her tee shirts to Dr. Armstrong-Wells.

Madison Haines of Benkelman, Nebraska, had a strong and sudden headache but she didn't think too much of it when she went over to her best friend's home last October. It wasn't until she was unable to respond and began to speak in gibberish did anyone suspect something was off.

When Amy Haines saw her daughter, she knew something was terribly wrong. Madison's face was drooping on one side and while she seemed to understand, she struggled to reply. When she did try and speak her words came out garbled. "My head said 'stroke' but my heart said, 'she's only 16,'" said her mother, Amy.

Rushed to the hospital and transferred to Children's Hospital Colorado, doctors confirmed what her mother thought was impossible. Madison was having a stroke. "I didn't know this happened until it happened to us," said Amy.

This month Madison and her family were back in Colorado presenting a check to the University of Colorado Pediatric Stroke Research Center to encourage further research on stroke in children. Their small town and Dundy County Stratton High School joined together to rally around Madison to raise funds for her and pediatric stroke research. The local FBLA and FCCLA chapters in her high school worked with local businesses to provide sponsors to create purple tee shirts and sold them to raise the money and awareness that stroke can indeed happen in kids just like Madison.

Madison's recovery is going very well and while she still struggles with speech, which is the area where the stroke occurred in her brain, most people might not even notice. She is working with speech therapy and has some obstacles to overcome, but hard work has enabled her to do better in school than before her stroke. She and her best friend are even planning on a trip this summer to Australia where they both will compete in a golf competition. We at the HTC would like to thank Madison and her very supportive community in Nebraska for their efforts to help bring awareness and make possible additional research into pediatric stroke.

### School and Community Raise Pediatric Stroke Awareness



The local paper covered Madison's story and the fundraising efforts at her school.

## RECENT HEADLINES

These are a few of the headlines that we've recently featured on our home page.

We maintain a Newsroom page at our website with a list of the news we feel may be of interest to our patients and families. To see more head to: [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) then find the **RESOURCES** tab, and go to the **NEWSROOM** page.

**US Health Officials Brace for Battle with Zika**

**CSL Behring's Idelvion Receives Marketing Exclusivity from FDA**

**Biogen Announces Intent to Spin off its Hemophilia Business**

**Woman Fights for Females Living with Bleeding Disorders**

**US Dept. of Health and Human Services Supports Study of Zika Virus Blood Screening Test**

## UPCOMING EVENTS

**May 22:** NHF CO Education Dinner for Spanish Speakers

**May 24:** Pediatric Stroke Parent Support Group at BIAC

**May 27-29:** NHF CO Family Camp-Allenspark, CO

**May 30:** Clinic and Admin closed for Memorial Day

**June 4:** Denver Heart & Stroke Walk

**June 6-8:** Outreach Clinic-Billings, MT

**June 26:** Strike Out Stroke with the Colorado Rockies at Coors Field

**July 4:** Clinic and Admin closed for Independence Day

**Jul 8-10:** Mile High Camp Leadership Pre-Retreat-Rocky Mountain Village

**Jul 10-15:** Mile High Summer Camp-Rocky Mountain Village

**July 21-23:** NHF Annual Meeting-Orlando, FL

**July 24-28:** WFH World Congress- Orlando, FL

**July 29-31:** RMHBDA Family Camp-Rollins, MT

**Aug 1-2:** Outreach Clinic-Missoula, MT

See more at our Events Page on our website: [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) find **RESOURCES** tab, go to **EVENTS**

### Hemophilia & Thrombosis Center

13199 E. Montview Blvd., Suite 100  
Aurora, CO 80045

Clinic Main: 303-724-0724

or toll free at 888-297-0724

Pharmacy Main: 303-724-0168

or toll free at 888-724-7427

Web page:

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