

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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Hemophilia and Thrombosis Center
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MAY IS PEDIATRIC STROKE AWARENESS MONTH

Did you know that the month of May is Pediatric Stroke Awareness Month? A stroke is much more common among adults, but it can happen to anyone at any age. Teenagers, kids, infants and even babies in the womb can have a stroke. One of the top ten causes of death in children is stroke, so it's important to learn about the symptoms and what to do if you recognize the signs of stroke.

A pediatric stroke means that it is a stroke that is happening to anyone who is not yet an adult. And adult strokes often manifest with different or much more noticeable symptoms than those in children or in babies. Sometimes pediatric stroke can be caused by conditions out of anyone's control, such as a heart problem, sickle cell disease, or a serious infection like meningitis or encephalitis. Other times, stroke may be due to an injury, dehydration, metabolic disorders, or blood clotting problems. Genetic conditions or birth defects are other reasons for a stroke in children but sometimes there is no cause found.

F.A.S.T. is how we come together to end stroke®
Learn the stroke warning signs

F.A.S.T.

Face Drooping	Arm Weakness	Speech Difficulty	Time to Call 911
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Symptoms of a stroke for children can be similar to those in adults, especially in teens and older kids. Everyone should know these symptoms because it's important to get care right away if someone is experiencing a stroke. One way to remember these symptoms is to think of the word **F.A.S.T.** Does their **Face** droop on one side? Is one **Arm** weaker than the other, or are they unable to raise them evenly? Is their **Speech** slurred, garbled, or do they have difficulty speaking? If someone of any age shows these symptoms, even if they go away, it is **Time** to call 9-1-1 immediately.

Graphic: American Stroke Association at stroke.org

Stroke is an emergency no matter their age and needs immediate attention.

In younger children, some of the symptoms in adults may be evident, but in the case of babies it is harder to tell. Newborns may have seizures, be extremely sleepy, or have twitching of the face, leg or arm. Older babies can have symptoms that include a tendency to only use one side of their body, severe vomiting, sudden difficulty walking, or loss of balance.

Children and teens may have a sudden severe headache, often with vomiting and sleepiness. They are more likely to have typical stroke symptoms like numbness on one side, sudden confusion, difficulty speaking or understanding others as well as difficulty walking, being dizzy, loss of balance, and new onset of seizures. If you see any symptoms that look like a stroke, it may be one.

A child experiencing a stroke needs immediate medical attention, just like an adult would. While it is still rare for a child to experience a stroke, it is critical to get the care they need if they do show symptoms. Many smaller hospitals can assess the symptoms and do some initial tests, but they may send the child to a higher level hospital for emergency care. Many of our pediatric stroke patients were first

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Meet Connor Moyer, Stroke Survivor. See our Patient Spotlight on page 2. Photo: Sarah Urbanek

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Find us on Facebook, Twitter, and our website for frequent updates on news and events.



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PATIENT SPOTLIGHT: CONNOR MOYER, STROKE SURVIVOR



Connor has more recovery but is doing remarkably well. His family, including his mom pictured here, spent many hours providing support and prayers for his recovery. Photo: Sarah Urbanek

In September of 2023, 14-year-old Connor Moyer of Cheyenne, Wyoming was enjoying camping at a lake with his aunts, uncles, and cousins when he experienced a stroke. He was lucky to be with family members who realized something was

wrong while they were on the lake. One of his aunts, a nurse, recognized his symptoms and began to care for him as they rushed him to shore. They called 9-1-1 and he was flown from Glendo, Wyoming to Loveland, Colorado. There they performed a CT scan and realized they needed to send him down to Children's Hospital Colorado for the specialized care they could provide.

After just a few days in the hospital, Connor was sent back home on blood thinners, but only two weeks later Connor experienced two more strokes while studying in the library at school. He was rushed to the local hospital and again life-flighted to Children's Hospital Colorado where he was admitted into the Pediatric Intensive Care Unit. He stayed there for three weeks and continued to have strokes while doctors tried to figure out why. He had

to lay flat on his back with no movement, even to sit up and eat or drink, to try and mitigate the possibility of having more strokes. This left him stiff and sore and caused muscles to weaken.



Connor being treated for his strokes at Children's Hospital Colorado. Photo: Sarah Urbanek

Connor then experienced two larger strokes while in the hospital. He couldn't wake up for several days, and when

he did, he struggled to communicate. His condition was very concerning, and doctors were searching to find out what was causing his arteries to constrict so severely that strokes were happening repeatedly. Connor ended up having an angiogram, which caused painful internal bleeding in his thigh. He also had a brain biopsy and had to deal with swelling, pain, and some hemorrhaging on his brain. Doctors believe his initial stroke was caused by a possible tear to his carotid artery.

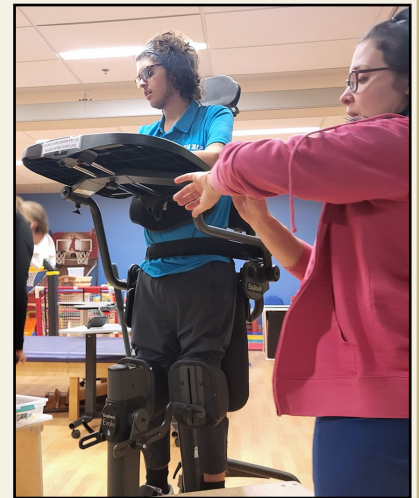
Some of the larger strokes he experienced left him unable to use his left side, and he had to spend five weeks on the rehab floor to regain the ability to sit up, crawl, stand and walk again. The strokes affected his personality, his vision, and his ability to process the world around him.

Like many stroke survivors, Connor faces mental and physical fatigue when working to overcome the problems a stroke can bring. Before his strokes, he was taking mostly honors and AP courses, but he missed a lot of school, and the mental fatigue has made learning difficult. It was challenging to get back to school and get caught up while also going to physical therapy, occupational therapy, speech therapy, and counseling to help him in his recovery.

Before his strokes, Connor was learning to play hockey and had just joined a local team. He has had to work very hard to gain enough strength to go ice skating again, though he's not sure he'll be playing hockey anytime soon. Connor has gone from a very serious condition, where the damage looked very bad and his prospects seemed bleak, to moving very

steadfastly and determinedly toward a near full recovery. He still does physical therapy once a week and recently has been able to jog and run. He has also worked hard to gain enough strength to be able to do archery, another of his hobbies. He loves to watch hockey, especially his favorite team, the Toronto Maple Leafs. He also enjoys theater, film, and binge-watching shows like "Supernatural" and "The Walking Dead."

Connor credits the love and support from his family and friends, as well as his faith and the prayers of people all over the country for helping him along the path to recovery. He shared that he always had his family



Connor putting in the hard work to recover from his strokes with the team at Children's Hospital Colorado. Photo: Sarah Urbanek

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[Continued from page 2] by his side during the two months in the hospital, with his siblings, nana, mom, stepdad, dad and stepmom all coming regularly to be with him.

His family would plan picnics for him to go outside of the hospital and get to be with siblings, aunt, uncles, cousins, and friends. His older brother flew home from college to be with him, and Connor shared how grateful he was for all the support he received, and especially how everyone treated him like he was normal. He shared, **“My entire family spent time learning what my diagnosis meant, and how to help me the most. They are all there to support me, always.”**

Connor not only has a strong support system and a positive attitude, but he also has a great sense of humor. Much of his recovery included family joking with one another or teasing him a little to lighten the mood. He has developed a love for telling jokes and making people laugh. He shared that the strokes affected his emotions, making it hard at first to express his feelings correctly. However, now he feels mostly happy and loves joking and smiling. While Connor has made and met many goals in the past eight months of recovery, including PT, OT, and speech targets, he also is a teenager that would love to not have some goals for a little bit!

Recently, Connor attended the Pediatric Stroke Education Seminar held at our HTC in April. He was one of the

panelists sharing their experiences with pediatric stroke, and is a great example of how hard work, good medicine, lots of prayer, and family support can lead to a strong recovery. Connor and his family expressed gratitude for the stroke team, Dr. Bernard, and the residents, fellows, and attending physicians who did so much to help him recover. Connor’s case was unique, and his family credits Dr. Bernard for spending a lot of time patiently explaining what was happening and why his case was so challenging.

Our HTC stroke team and all those who worked with Connor are so happy he is on his way to recovery and grateful to have been able to work with him and his family.

We wish Connor the best in his future and know he will be able to make a big impact in whatever he does!



Connor worked with physical therapists and occupational therapists to recover from his strokes. Photo: Sara Urbanek

DROPS OF LOVE PROGRAM



We have a new program at our HTC called “Drops of Love” to celebrate our staff.

If anyone at our center went above and beyond when you visited, we would love to hear about it!

Just scan the QR code and let us know!

TAKE THE SURVEY!

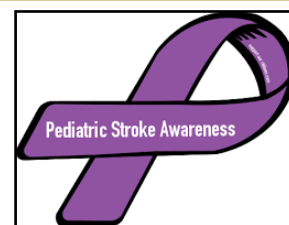
Our HTC is participating in the Fourth National HTC Patient Satisfaction Survey. If you or someone you care for had contact with our HTC in 2023, we want to hear from you! Use the QR code or go to htcsurvey.com to take it today! The survey will be closing soon! Let us know how we’re doing!!



[Continued from page 1] seen in a local community with medical professionals who recognized and began treating their stroke before sending them to Children’s Hospital Colorado, which houses neurologists and specialists along with the critical tools to treat stroke in children.

Our HTC has included a Pediatric Stroke program since 2006 and hosts a [Pediatric Stroke Parent Support Group](#), which meets regularly to provide connection and support as they share the challenges of managing the care of their child. You can learn more about pediatric strokes, some of the causes, and how they are treated at our [website](#), and at Children’s Hospital Colorado’s [website](#).

You can also follow us on [Facebook](#) to find out more about the support group and activities that we have throughout the year. If you have questions about pediatric stroke or are seeking treatment for a child who has survived a stroke, please contact us at our HTC at 303-724-0724.



RECENT HEADLINES

These are a few of the headlines that we've recently featured on our Newsroom page or on Social Media:

New Study Shows Long Term Benefits of Gene Therapy for Severe Hemophilia A

FDA Approves New Hemophilia B Gene Therapy Product BEQVEZ

New Long-Term Data Shows Emicizumab Safe, Effective in Hemophilia A Patients

Study Shows Wristband Tracking Activity Improves Quality of Life in Severe Hemophilia Patients

FDA Approves IXINITY for Use in Children 12 and Under with Hemophilia B

We maintain a newsroom page at our website with a list of news articles that may be of interest to our patients and families. Go to medschool.cuanschutz.edu/hemophilia-thrombosis/resources/newsroom to read more. We also share news on our [Facebook](#) and [Twitter](#) accounts.

Sign up to get this newsletter delivered directly to your email box each month! Just go to eepurl.com/bnszoz or scan the QR code and fill out the form!



QR Code to Subscribe!

UPCOMING EVENTS

Mark Your Calendars:

Please note. These dates may be tentative and subject to change. Please check appropriate websites for confirmation of events.

May 27: HTC Clinic, Pharmacy, and Admin offices closed for Memorial Day

June 8-9: NBDF Colorado Family Camp—Allenspark, Colorado

June 16: Father's Day

June 19: Juneteenth

June 22: Families on the River with Backpacks + Bleeders

July 4: HTC Clinic, Pharmacy and Admin offices closed for Independence Day

July 12-14: Teen Leadership Weekend

July 14-18: Mile High Summer Camp

See more at our Events Page on our website:
medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar

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