

# The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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Hemophilia and Thrombosis Center  
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with  
Children's Hospital Colorado

## MAY IS PEDIATRIC STROKE AWARENESS MONTH

Our HTC Clinic has been working under strict and limited conditions since mid-March. With state, local, and campus restrictions slowly shifting, our clinic too is slowly moving toward a schedule that includes more in-person visits. Please watch our website and social media accounts for more information as we carefully move to more clinical care with protocols in place to keep everyone safe.

With the changes and restrictions that have faced all of us over the past several months, it may be easy to forget there are many facing physical challenges that have nothing to do with COVID-19. At our HTC we treat patients with bleeding disorders, but we also have a staff fully dedicated to treating pediatric stroke patients. May is Pediatric Stroke Awareness Month and we always strive to bring awareness that strokes can happen at any age.

Babies can have strokes before they are born; infants, toddlers, school kids, and teenagers can all have strokes. Pediatric strokes can affect children in different ways and are caused by a variety of factors. Though pediatric stroke is not common, the consequences can be as significant as a stroke in an adult. Pediatric strokes are among the top ten causes of death in children so it is important to know and share the signs of stroke so that anyone can recognize the symptoms. Getting treatment right away is important regardless of age as the sooner treatment is made available the better the outcome for the patient.



The signs of stroke can be more obvious and recognizable in adults than in children. However, as kids grow they can exhibit the same symptoms as adults as well as other less noticeable symptoms. Do you know the signs of stroke and what to look for in children?

For adults, we often stress recognizing some major signs. Does their **Face** droop on one side? Is one **Arm** weaker or are they unable to raise them up

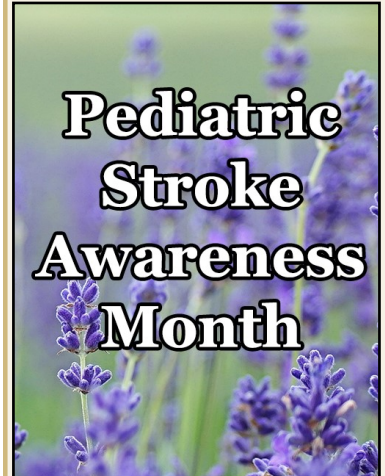
evenly? Is their **Speech** slurred or garbled? These symptoms indicate an emergency and it is **Time** to call 9-1-1 and get help for a stroke.

Older children can still have these symptoms and may also have additional things to watch for. But how do you notice signs of stroke in a baby?

Babies and younger children often exhibit symptoms such as seizures, twitching of the face, leg or arm, and problems with sleep apnea. Babies who show a marked decrease in movement on one side of the body, or show a strong preference for one hand before the age of one, may be exhibiting signs of stroke.

Older kids may have other warning signs, such as sudden severe headache, especially with vomiting and sleepiness, numbness on one side of the body, sudden confusion, difficulty speaking or understanding, and difficulty walking, loss of balance or coordination. If a baby or child exhibits any of these symptoms, it is an emergency and you should call 9-1-1 right away.

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



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# SPOTLIGHT: AMANDA PALYO—STROKE SURVIVOR

By Kim Richfield



Amanda Palyo and her dad at her high school graduation from Rock Canyon High School. Photo: Kristin Palyo

When most people think about a stroke survivor, a child or teenager is not what comes to mind. Although strokes in this population are rare, they can occur at any age. Amanda Palyo knows this all too well - she survived multiple strokes when she was just 12 years old. Although Amanda is currently thriving as a freshman at CSU, her journey was not easy.

In 2013, Amanda and her family went on a trip to NYC. While she was there, she started feeling dizzy and nauseous. At first, she thought it was just the flu, but after being rushed to the hospital, Amanda and her family learned she had a stroke. This quickly led to many medical interventions, including multiple neurosurgeries. About a week after her first stroke, she had a second one.

Amanda was eventually airlifted to Children's Hospital of Colorado (CHCO). Between her time in NYC and CHCO, Amanda was hospitalized for about eight weeks. At first, she could not walk or talk, and she had to learn to do these things all over again. When she was finally discharged, she returned to school and continued her rehabilitation through occupational therapy, physical therapy, and speech therapy. This was not an easy process - the right side of Amanda's body was weak and would shake. She would become frustrated. Despite this, Amanda stuck with it and saw a lot of progress.

Throughout recovery, Amanda yearned to go swimming, an activity she had been doing competitively since she was 5 years old. After months of therapy, she finally got back in the water. This was the first time since having her strokes that Amanda felt normal. She did not worry about the right side of her body being weaker or getting fatigued easily.

A year later, Amanda entered her first meet since getting back into competitive swimming. She caught the eye of an official who thought she should try Paralympic swimming. Initially, Amanda did not feel ready to compete at such a high level, but eventually she decided to go for it.

Amanda's first Paralympic competition took place in Indianapolis in June 2017. She came in 3rd place in the 100 Backstroke event and set a new personal record. In fact, Amanda's time in this event was even faster than

she swam it before her strokes! This earned her a spot on the Team US Emerging Team. Then, in 2019, Amanda received a bronze medal in this same event swimming for Team USA at the Parapan Am Games in Peru.



Amanda Palyo (right) with her Bronze Medal at the Parapan Am Games in Peru in 2019. Photo: Mark Reis.

Swimming in the Paralympics invigorates Amanda and gives her goals to strive for. She has met new friends who inspire her, and she travels around the US and the world to compete. Most importantly, it helped her accept what happened to her and realize how much she is capable of.

These days, Amanda is still swimming and training for the next Paralympic competition in Tokyo (which was planned for 2020 but has now been postponed until 2021). She will be a college sophomore this fall and is studying psychology. Amanda recognizes that she received a lot of support while recovering from her strokes and wants to give back in some way by helping others. Although Amanda's strokes caused her to have issues with her attention span, she has managed to balance her studies, work, swim practice and social life.

Of course, Amanda has had her ups and downs. A neurosurgeon who treated her in NYC told her that her recovery would be like a marathon. She has found this to be true and acknowledges that getting to where she is today has taken a lot of energy and a long time. Amanda continues to have weakness on her right side. Some days are challenging physically, others emotionally. From time to time she gets down on herself for not being at 100%. Still, Amanda believes it was worth all the hard work and focuses on her goals and her future. She credits her family with being there for her throughout her journey.

*May has been designated as **Pediatric Stroke Awareness Month** in order to recognize that this serious medical condition can affect individuals of all ages.*

*HTC would like to thank Amanda Palyo for sharing her inspiring story!*

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When a child survives a stroke, they will need specific and specialized care. Our Pediatric Stroke Program at the HTC began in 2006, utilizing strengths from the University of Colorado Hemophilia and Thrombosis Center (HTC) and Children’s Hospital Colorado. Patients receive care at the HTC clinic on Anschutz Medical Campus and have powerful resources available through this unique union. The program provides comprehensive, multidisciplinary services for pediatric patients and their families who are diagnosed with stroke and stroke-related diagnoses.

The goal of our Pediatric Stroke program is to provide the best possible care for our patients from stroke onset through long-term follow up. Our team is committed to providing state-of-the-art care to children with stroke

through innovative research, as well as participation in international pediatric stroke research trials.

The Pediatric Stroke Program treats all types of strokes in children and provides access to many resources to help children recover. In addition, our program has a Pediatric Stroke Parent Support Group that meets monthly to provide support for families going through recovery with their children. With the pandemic situation, these meetings have been on hold, but they will resume once it is safe to do so. You can follow our support group at our Facebook page at [www.facebook.com/Colopedstroke](http://www.facebook.com/Colopedstroke), or see our group webpage at [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) and look under the COMMUNITY tab. If you have questions about pediatric stroke or are seeking treatment for a child who has survived a stroke, please contact us at the HTC at 303-724-0724.



# DO YOU KNOW?

Strokes occur in toddlers, children and teens.  
**Stroke is an emergency at any age.**



## SPOT A STROKE

# F.A.S.T.

Face Drooping	Arm Weakness	Speech Difficulty	Time to Call 911
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If your child has one or more of these signs, don't delay — call 911 or the emergency system.

If it looks or feels like a stroke, it may be one.

### Additional Warning Signs in Children:

- Sudden severe headache, especially with vomiting and sleepiness
- Sudden numbness or weakness on one side of the body (face, arm and/or leg)
- Sudden confusion, difficulty speaking or understanding others
- Sudden trouble seeing in one or both eyes
- Sudden difficulty walking, dizziness, loss of balance or coordination
- New onset of seizures, usually on one side of the body

## FACTS TO KNOW



Signs of stroke are often missed in children and teens because of **LACK OF AWARENESS.**



About half of children who had a stroke had a **PREVIOUSLY IDENTIFIED RISK FACTOR.**



Stroke is one of the **TOP 10 CAUSES OF DEATH** in children in the U.S.



The clot-busting drug tPA and clot retrieval devices **AREN'T FDA APPROVED FOR USE IN CHILDREN.**

**Medical conditions associated with stroke include:** Sickle Cell Disease, Moyamoya Disease, Arterial Dissection, Autoimmune Disorders, Congenital Heart Diseases and Blood Clotting Disorders.

Learn more at [stroke.org](http://stroke.org).

International Alliance  
for Pediatric Stroke  
[iapediatricstroke.org](http://iapediatricstroke.org)

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The American Stroke Association and the International Alliance for Pediatric Stroke — collaborating to treat and beat stroke in infants and children.

With the constantly changing situation this year due to the COVID-19 pandemic, NHF Colorado has made some substantial adjustments to keep our campers safe.

Family Camp, which was scheduled for June, has now been changed to a Virtual Family Campfire on June 5th. You can register for this fun evening by going to [cohemio.org](http://cohemio.org).

In addition, NHF Colorado had to make significant changes to Mile High Summer Camp this year. NHF Colorado will have weekly online activities during the month of July for our campers, but it will not take place in person. More details will be coming on the virtual fun NHF Colorado is planning. Please see their website for more information at [cohemio.org](http://cohemio.org).

## RECENT HEADLINES

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

### **NHF Switches Annual Conference to Online Virtual Resource**

### **BioMarin's Gene Therapy for Hemophilia A Remains on Track for US Approval**

### **Study Finds Prophylaxis is Better than On-Demand Treatment for Adults with Hemophilia A**

### **NHF Colorado will Host Family Campfire in Virtual Online Activity**

### **New Bloodstream Media Podcast Tackles Pain**

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 go to: [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) then find the **RESOURCES** tab, and go to the **NEWSROOM** page. Find other stories at our Facebook page at [www.facebook.com/ColoradoHTC/](http://www.facebook.com/ColoradoHTC/)

## UPCOMING EVENTS

### **Mark Your Calendars:**

**Please note. These dates may be tentative and subject to change due to the outbreak of COVID-19. Please check appropriate websites for confirmation of events.**

**Jun 5:** NHF CO VIRTUAL Family Campfire

**June 15-19:** Billings, MT Outreach Clinic—Tele-health

**Jul 3:** Clinic, Pharmacy, and Admin closed for Independence Day

**July:** VIRTUAL Mile High Summer Camp Activities each Wednesday from 9 am-11:30 am (must register online)

**July 27-31:** Missoula, MT Outreach Clinic—Tele-health

**Aug 1-8:** NHF Annual Conference—A fully VIRTUAL Conference

**Aug 22:** NHF CO Unite for Bleeding Disorders Walk

**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**

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