

# The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

May 2023  
Volume 13, Issue 5



Hemophilia and Thrombosis Center  
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with  
Children's Hospital Colorado

## MAY IS PEDIATRIC STROKE AWARENESS MONTH

Did you know that stroke can happen at any age? Infants, teens, kids, adults, even babies in the womb can have a stroke. The month of May is Pediatric Stroke Awareness Month, a great opportunity to let people know that stroke can happen to anyone, including kids.

Treating pediatric stroke requires a qualified and experienced team that understands the complex nature of stroke in kids, as well as the challenging psychosocial needs of our patients and families. Our [Pediatric Stroke Program](#) at the HTC utilizes the expertise and strengths of the University of Colorado Hemophilia and Thrombosis Center and resources from Children's Hospital Colorado. These resources make it possible for children to benefit from comprehensive, multidisciplinary services specific to their needs. Our team has over 15 years of experience treating children with stroke.

A cornerstone of our program includes the ability to address neurological, neurosurgical, hematological, neuropsychological, and rehabilitation needs in one place. Beyond the medical needs, we also have a strong and experienced team who can assist with challenging emotions surrounding having a stroke, difficulties with returning to school, and addressing the financial burdens associated with having a child with a complex medical condition. We also participate in every major stroke study in the United States, as well as contribute to the International Pediatric Stroke Study. Our access to the latest research trials and studies allows us to provide our patients with the most up-to-date care possible.

Our team treats all types of strokes and hosts a [Pediatric Stroke Parent Support Group](#) that meets regularly to help parents connect who have children in similar circumstances. These meetings are open to all families of children who have survived a stroke, regardless of whether they are treated at our clinic. You can find more information about this group at our website.

Surprisingly, pediatric stroke is in the top ten causes of death in children, so it is important to know the signs of stroke. Adult stroke symptoms are summarized by remembering: **F.A.S.T.** Does their **F**ace droop on one side? Is one **A**rm weaker than the other or are they unable to raise them up evenly? Is **S**peech slurred or garbled? These symptoms indicate an emergency, and it is **T**ime to call 9-1-1 and get help for a stroke.

Getting treatment right away is critical, no matter what age, so the sooner a patient is treated, the better the outcomes can be. But what do you look for in a child or a baby? Children and teens show many of the same symptoms as adults, but younger kids have less noticeable symptoms. Do you know what to look for?

Learn the stroke warning signs

# F.A.S.T.

Face Drooping	Arm Weakness	Speech Difficulty	Time to Call 911
---------------	--------------	-------------------	------------------

Graphic: American Stroke Association— more details at [stroke.org](http://stroke.org).



Meet Izaiah Ornelas, stroke survivor! Izaiah was just 12 when he had a stroke at school. Photo: Cristi Ornelas.

### INSIDE THIS ISSUE

- May is Pediatric Stroke Awareness Month
- Spotlight: Izaiah Ornelas—Stroke Survivor
- Mile High Summer Camp
- Event Calendar
- News & More

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



Go to [facebook.com/ColoradoHTC](https://facebook.com/ColoradoHTC)



Go to [twitter.com/HTCColorado](https://twitter.com/HTCColorado)



Website: Go to

[medschool.cuanschutz.edu/hemophilia-thrombosis](https://medschool.cuanschutz.edu/hemophilia-thrombosis)



Email:

[HTC.Newsletter@ucdenver.edu](mailto:HTC.Newsletter@ucdenver.edu)

[Continued on page 3]

# SPOTLIGHT: IZAIAH ORNELAS—STROKE SURVIVOR

When most of us think about a stroke, we think it is something that happens to older people. While it is true that most strokes occur over the age of 65, people can have a stroke at any age. Izaiah Ornelas was just 12 years old, participating in his middle school gym class in October of 2021 when he started having a really bad headache. He had sharp pain in his head, his eye started twitching, and he felt dizzy. He asked his PE teacher if he could sit down. As soon as he did, he collapsed.



Izaiah Ornelas in recovery at Children's Hospital Colorado. Photo: Cristi Ornelas.

Thankfully, his teacher reacted right away, noticed some symptoms of stroke, and immediately called an ambulance that took him to the ER. Izaiah lives in Trinidad, Colorado, a small town just north of the Colorado-New Mexico border. The ambulance arrived in just minutes to take him to the local hospital. There they immediately performed an MRI and knew they were dealing with a stroke. He was quickly airlifted to Children's Hospital Colorado in Aurora.

The stroke team at Children's Hospital Colorado got to work right away, working to help him recover from the problems related to his stroke. Izaiah experienced fairly severe paralysis on his left side and spent three months at Children's Hospital, first in the ICU, then progressing to recovery. He had to re-learn how to eat, walk, speak, and deal with memory issues. Once he was on the rehab side of things, Izaiah was a motivated and diligent patient, working with physical therapy and doing his exercises faithfully. In fact, the hospital staff often asked Izaiah to help the younger kids with their exercises because he was such an engaging and friendly young man. He enjoyed working with the kids there and having the chance to help others while he was recovering.

Izaiah still has very little mobility in his left hand but has made huge progress. He went from a wheelchair, to walking with a cane, and now he can walk well. He still has physical therapy, occupational therapy, and speech therapy to help him as he continues to improve. Izaiah is

dedicated to his therapy and is a powerful example to all around him of making the effort to overcome a challenge.

When Izaiah was released from the hospital and able to go home, the tight-knit community in Trinidad welcomed him home with a parade. His family, friends, his school, and the community around him are a big part of effective recovery, helping him with accommodations and providing the support he needs to get back to his life.

The school was able to make an Individualized Education Program (IEP) which is a specialized plan based on Izaiah's specific needs. This includes support for his speech to text technology and allowing him to have a little extra time to get to and from classes.



The city of Trinidad, Colorado welcomed Izaiah home with a parade, including the fire department and ambulance team who joined to celebrate his recovery. Photo: Cristi Ornelas.

Izaiah has a love for the outdoors, enjoys going magnet fishing, and has mastered playing video games with just one hand and his chin! He has two supportive siblings and a wonderful extended family, making it a little easier to manage all the things he has had to face in the past few years. He is interested in engineering and astronomy and is looking forward to high school next fall. He wants to go to the Colorado School of Mines and is excited to work toward that goal. In the meantime, he has become a strong advocate for others who have survived a stroke and is not shy to tell his story and help others.

We are thrilled to have been able to work with Izaiah through our Pediatric Stroke Program and look forward to seeing what amazing things he can accomplish in years to come.

[Continued from page 1]

Symptoms in newborns or young children can include seizures, such as twitching of the face, leg, or arm. Babies who have experienced a stroke often show a marked decrease in movement in one side of the body as they learn to reach, crawl and walk. They can also show a strong preference for one hand before the age of one. Older kids may have other warning signs, such as a sudden, severe headache, especially with vomiting and sleepiness. They can have weakness or numbness on one side, sudden confusion with difficulty speaking, understanding, or walking, and loss of balance or coordination. If a child exhibits any of these symptoms, you should call 9-1-1- right away.

You can learn more about pediatric stroke, what causes them, and how we can help at our [website](#). You can also follow us on [Facebook](#) to find out more about our support group and activities we host. 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.

## NHF COLORADO UPCOMING EVENTS

**June 24, 2023:** Backpacks + Bleeders: Whitewater Rafting the Cache la Poudre

[Sign up today](#) to join Backpacks + Bleeders as they take a half-day whitewater rafting trip down the Lower Poudre near Fort Collins, CO.



**Aug 26, 2023:** [NHF Colorado Unite for Bleeding Disorders Walk](#)—Sloan's Lake, CO.

Mark your calendars now to join us in raising awareness and funds for NHF Colorado and their programs at the annual Unite Walk!

For more information on NHF Events, go to [cohemo.org](http://cohemo.org) or contact Hanna Beary at [hbeary@hemophilia.org](mailto:hbeary@hemophilia.org).

## MILE HIGH SUMMER CAMP 2023—SIGN UP NOW!



Mile High Summer Camp is right around the corner and it's time to sign up! [Registration is open](#) and NHF Colorado is excited to have our campers back to learn, grow, and have a ton of fun! Camp is a powerful opportunity for kids with bleeding disorders to connect with others in the community in a fun, safe environment. **The last date to apply will be June 15, 2023, no exceptions.**

Our HTC staff attends camp and is involved in teaching and supporting patients as they learn to self-infuse, learn about their disorder, and discover ways to manage their own care.

Registration gives priority to participants with bleeding disorders. As capacity allows, siblings/relatives will be admitted to camp. Families will be notified by July 1 if siblings/relatives are admitted to camp.

This year camp has a few changes, so be sure to check the [NHF Colorado website](#) for full details.

**Campers Ages 7-13:** The main Mile High Summer Camp will be at Rocky Mountain Village from **July 23-27, 2023.**

**Campers Ages 14-15:** Teen Leadership Campers will be able to enjoy a fun adventure at the Teen Leadership Weekend, **July 21-23**, and then join the main Mile High Summer Camp **July 23-27!**

**Campers ages 16-17:** Bleedership in Training (or BITs). These campers will attend the Teen Leadership Weekend, **July 21-23**, and then join the main Mile High Summer Camp, **July 23-27** as assistant leaders at camp. They will be paired with cabin counselors and Bleedership counselors to help with daily activities at camp.



NHF is also recruiting young adults ages 18 and up who are willing to guide our younger campers and gain leadership skills as one of our **Bleedership Counselors**. These young adults will provide support for campers in all activities and **must be available July 21-27, 2023**. Applications for this program are open now! Apply today!

For more information and details about camp, please see the camp pages at [cohemo.org](http://cohemo.org), or contact our camp director Hanna Beary at [hbeary@hemophilia.org](mailto:hbeary@hemophilia.org) or 646-499-0684.

## RECENT HEADLINES

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

**Study Shows Female Hemophilia A Patients & Carriers Undertreated**

**AstraZeneca, Sernova Join Forces on Cell Therapy Research**

**FDA Asks for More Information on Concizumab from Novo Nordisk**

**Survey of HTC Clinicians Shows Changes in Treatment Trends over 22 Years**

**Sanofi Announces Results from Two Phase 3 Trials of Fitusiran**

**Dr. Beth Warren Discusses Differences in Factor and Non-Factor Prophylaxis in ASH Publication**

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](https://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](http://eepurl.com/bnszoz) and fill out the form!

## 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 29:** Clinic, Pharmacy, and Admin offices closed for Memorial Day

**June 10-11:** NHF Colorado Family Camp—Highlands Presbyterian Camp, Allenspark, CO

**June 24:** NHF Colorado Backpacks + Bleeders Rafting Event

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

**July 21-23:** Teen Leadership Weekend

**July 23-27:** Mile High Summer Camp

**Aug 10-11:** RMHBDA Teen Retreat—Rollins, MT

**Aug 11-13:** RMHBDA Big Sky Family Camp—Rollins, MT

**See more at our Events Page on our website:**  
[medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar](https://medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar)

**ME-WE-HTC** We create hope.

### 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:

[medschool.cuanschutz.edu/hemophilia-thrombosis](https://medschool.cuanschutz.edu/hemophilia-thrombosis)

PLEASE  
PLACE  
STAMP  
HERE