

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with
Children's Hospital Colorado

PEDIATRIC STROKE AWARENESS MONTH

May is Pediatric Stroke Awareness Month! We realize that 2020 and much of 2021 has been different than normal, but many things continue regardless of a pandemic. One is that children can still experience a stroke. Though our clinic has gone through closures, limited hours, restrictions, and shifting many visits to tele-health since last year, our stroke team is still working with patients in every way we can.

Stroke and blood clots have been in the news a lot lately, but our team at the HTC know a lot about these life changing events and how they can impact the life of a patient. Our Pediatric Stroke team treats all children who have survived stroke. They can be babies, toddlers, school kids, teenagers, even infants who had a stroke before they were born. Though pediatric stroke is not common, the consequences can be as significant as a stroke in an adult. Pediatric strokes are in the top ten causes of death in children, so it is important to know the signs of stroke, in both children and adults.

Getting treatment right away is as important for kids as it is for adults, as the sooner a patient is treated, the better the outcome may be. Signs of stroke in adults can be more recognizable than in children, but as kids grow, many of the same symptoms appear. Younger children have less noticeable symptoms, so it is important to know what you are seeing.

SPOT A STROKE

F.A.S.T.

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

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

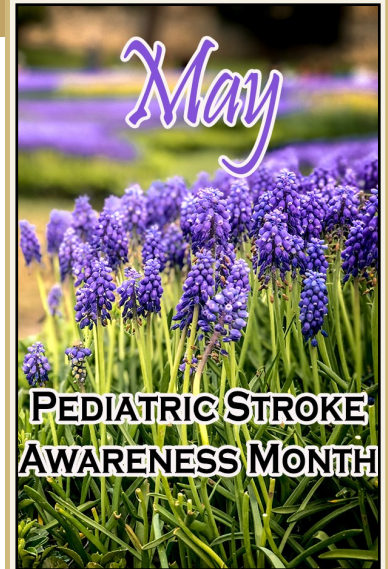
Do you know the symptoms of stroke? For adults, the easy way to remember them is to think of the word **FAST**. Does the person's **Face** droop to one side? Is one **Arm**

weaker than the other or are they unable to raise both arms up evenly? Is their **Speech** slurred or garbled and confused? These symptoms indicate an emergency, and it is **Time** to call 9-1-1- to get help for a stroke.

While strokes are far more common in older people, when teens and kids experience stroke, they can also show these symptoms. In addition, children will also exhibit symptoms such as seizures, twitching of the face, leg or arm, and problems with sleep apnea. Babies can show a marked decrease in movement on one side of the body. If a baby shows a strong preference for using one hand over another before the age of one, this could be a sign of stroke. Other warning signs in children can be severe headache, especially with vomiting and sleepiness, numbness on one side of the body, sudden confusion, difficulty speaking, walking or understanding, loss of balance or coordination. All these symptoms warrant immediate calls to 9-1-1 or a medical doctor for advice and support.

[Continued on page 2]

May 2021
Volume 11, Issue 5



INSIDE THIS ISSUE

- Pediatric Stroke Awareness Month
- Sarah Weiss, Pediatric Stroke Patient, Wins Award
- Take the Patient Satisfaction Survey
- 2021 Mile High Summer Camp Info
- Register Now for Empact Parenting
- Upcoming Events
- News

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



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



Go to twitter.com/HTCColorado



Website: Go to

medschool.cuanschutz.edu/hemophilia-thrombosis



Email:

HTC.Newsletter@ucdenver.edu

[Continued from page 1] A child who survives a stroke needs specialized care and treatment. Our Pediatric Stroke program began in 2006 and we work closely with Children's Hospital to provide the best resources for patients and families in both therapies and follow-up care. Our HTC hosts a Pediatric Stroke Parent Support Group that allows families to meet and support one another through the unique and challenging experience of a child surviving a stroke. You can learn more about pediatric strokes, what causes them, how they are treated and how we can help at our website here: <https://medschool.cuanschutz.edu/hemophilia-thrombosis/resources/pediatric-stroke>.

You can also follow us on [Facebook](#) to find out more about our support group and activities 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 the HTC at 303-724-0724.

SARAH WEISS PEDIATRIC HERO AWARD WINNER



We would like to congratulate one of our pediatric stroke patients, Sarah Weiss, for winning the Stroke Hero Award in the 2021 Pediatric Hero Awards from the American Stroke Association. Sarah is from Nebraska and has worked with our stroke program for several years. She is an active fifteen-year-old who survived her stroke at age eleven.

Sarah has worked hard to recover her physical abilities after losing the use of her right hand and arm. She's regained her speech and most of her mobility and has worked to share awareness of pediatric stroke to those around her. She created cards and bookmarks with the F.A.S.T signs of stroke and participates in awareness programs through the [American Heart Association](#) and [Go Red For Women](#) events.

She's been a delight for us to work with and we congratulate Sarah on her accomplishments and making a huge difference with her advocacy and example. You can watch a video congratulating Sarah for her award at the [American Stroke Association website](#).

SUMMER CAMP 2021 INFO



So, what is up with camp this year? That is something NHF Colorado has been working hard to figure out! With so many changes, adjustments, and a desire to meet the needs of all campers, it's been challenging, but plans are coming together.

2021 will have a hybrid of in-person and virtual events for both Family Camp and Mile High Summer Camp. Plans are still being set, but include Mile High Summer camp consisting of a 3 day virtual camp, along with a day -program experience in July, and possibly an overnight experience in August. Dates are not quite firm, but will be announced by the end of May.



Family Camp will include a series of activities with many opportunities. There will be a virtual campfire and games and an in-person gathering in July, and a possible overnight event in August.

Please stay tuned, and check in regularly with NHF Colorado through their website cohemo.org and by subscribing to their email list — scroll down to the bottom of the page to sign up.

NHF Colorado [has a survey about how you feel about in person events here](#) to help them plan.

In addition, they also need camp counselors this year. You can [learn more about this opportunity at their website](#).

NEW APP TO TRACK YOUR BLEEDING DISORDER

How to get started...

1. Download the app from the Apple store:



2. Let a member of our team know you are interested and we will send you an email with further information.

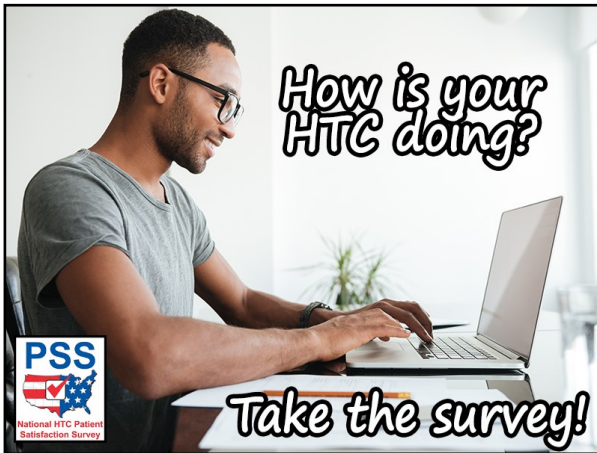
For more info contact:

Hana Durkee
Email: hana.durkee@cuanschutz.edu
Phone: 303-724-0422

Track bleed-
ing events,
medications,
& activities
that may have
contributed to
bleeding.

Currently
available on
iPhone or
iPad.
[Android development
is in process!]

THIRD NATIONAL PATIENT SATISFACTION SURVEY NOW OPEN!



How satisfied are you with your HTC services? HTC bleeding disorder patients and caregivers throughout the US are invited to tell us by taking the Third National Patient Satisfaction Surveys (PSS). The survey is now open and available to all who were treated by an HTC during 2020 to let us know how your care was.

Our HTC sent out paper copies of this survey in March to all our bleeding disorder patients. We encourage our bleeding disorder patients to take this survey online as it is easier for processing, however we included a survey and a self-addressed, stamped envelope if sending by mail is easier for you. If you did not receive a paper copy, please just go to the website to fill out a survey at htcsurvey.com.

This survey is anonymous but both the paper survey and the online version allows a patient to identify the center at which they received care. This helps our center by allowing us to get honest feedback from

patients about their care in the past year. Nearly all HTCs had to make major adjustments in 2020 due to the COVID-19 pandemic. In response, questions have been added to this survey asking patients for feedback on tele-health as well as in-person care. You can respond to this survey whether or not you were seen in person, via tele-health, or sought support over the phone, as long as you were receiving care during 2020.

The survey is brief and is available in both English and Spanish. We ask that parents of young children fill out one survey per child, and any patients who are 18 and up fill out their own survey. For questions, or to learn more about the earlier surveys, please go to htcsurvey.com.

REGISTER NOW FOR 2021 EMPACT PARENTING PROGRAM



Do you have a teen with special needs or a medical condition? Are you looking for tools on how to be a better parent? You may be interested in a special parenting program that is uniquely designed to help parents of teens and young adults with serious medical conditions or special needs.

This Empact Parenting Program will be hosted by the Hemophilia and Thrombosis Center and is specifically targeted to parents with teens and young adults with bleeding disorders. It will be co-facilitated by Dr. Emily Wheat, PhD, who is our psychologist at the HTC and head of our Psychosocial Team. She will be joined by [Danna Merritt](#), author of the program, [Ruben Aguirre](#), a parent of a child

with hemophilia, and [Ben Marth](#), a parent of a child with autism.

The Empact Parenting program is designed to help parents understand the teen brain and mindset through puberty, and how this will impact their decisions. Parents will learn about parenting attitudes, and discussions will cover topics like sex, tattoos, alcohol, bullying and career planning. This robust program encourages parental personal awareness, improves family health, viability, engagement, and interaction. It also connects parents with others going through the same thing, helping parents not feel so alone during this time of life with their teens.

This is a 12-week program that will be held on Tuesday evenings from 7-8 pm MT and held weekly on zoom. This program will begin August 10, 2021 and run through October 26, 2021. Parents will receive access to online educational videos and content, and hard copies of the parent handbook and materials. Normally a \$399 value, this program is **free** through Bayer Pharmaceuticals by using the QR code. To participate you must be a parent of a teen or young adult (ages 12 and older) and must have access to the internet and a computer or tablet with a camera. If you have questions or want more information about this program, [we have more details on our website here](#), or contact Dr. Emily Wheat at 303-724-7900 or at Emily.Wheat@cuanschutz.edu.



This program is free by using this QR code to register. Contact us if you have questions about signing up.

EMPACT

RECENT HEADLINES

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

Roctavian, Gene Therapy for Hemophilia A, Shows Potential from Early Data

First Patient Dosed in Marzeptacog Alfa (MarzAA) Phase 1/2 Study

Jivi May Prevent Bleeds in Minor Surgery for Hemophilia A Patients

Dosing Begins for Efanesoctocog Alfa Trial for Boys with Hemophilia A

Graphic Novel Shares Life with Hemophilia, Dungeons and Dragons

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. Go to medschool.cuanschutz.edu/hemophilia-thrombosis/resources/newsroom to read more. We also share news on our [Facebook](#) and [Twitter](#) accounts.

UPCOMING EVENTS

Mark Your Calendars:

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

May 31: Clinic, Pharmacy, and Admin Offices Closed for Memorial Day

June 18-20: RMHBD A Education Weekend and Annual Meeting, Fairmount, MT

July 5: Clinic, Pharmacy, and Admin Offices Closed in honor of Independence Day

Mile High Summer Camp TBA (Virtual and Day-Camp Dates Coming Soon)

NHF CO Family Camp Tentative Dates Aug 27-28

Pediatric Stroke Support Group on hiatus until September

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

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

PLEASE
PLACE
STAMP
HERE