

# The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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University of Colorado  
Anschutz Medical Campus  
Hemophilia and Thrombosis Center

Affiliated with  
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and University of Colorado Hospital

## MAY IS PEDIATRIC STROKE MONTH



Did you know that a stroke can happen at any age? Even before babies are born they can experience stroke. May is Pediatric Stroke Awareness Month and is an opportunity to bring awareness, share knowledge, and support those who have experienced stroke. Our HTC treats

bleeding disorders but also has a portion of our clinic dedicated to the treatment of pediatric stroke. Our two neurologists, Dr. Armstrong and Dr. Bernard, work with infants, children, and teens who have had a stroke, and are involved in research to treat and prevent stroke in children.

While 90% of all strokes occur in adults over 50, strokes still happen to children, including babies in the womb. It is still rare for a child to experience a stroke—about two to three children in every 100,000—but it is important to bring awareness that it does occur. There are a variety of factors that cause pediatric stroke, some that are yet unknown, but our clinic and support group help families and patients with recovery. The symptoms of a stroke in adults are better known than those of a stroke in a child. Some symptoms of pediatric stroke may be missed because many people are unaware that a child can even have a stroke.

For all ages it is important to remember F.A.S.T (Face drooping, Arm weakness, Speech difficulty, and when those are present, Time to call 9-1-1). A prompt diagnosis and treatment of stroke, no matter what the age, is critical to all who experience stroke. Children may exhibit these symptoms but it may be hard to notice them in a baby.

Additional symptoms of pediatric stroke in infants are seizures, repetitive twitching of the face, leg, or arm, and problems with sleep apnea. Babies who show marked decreased movement on one side of the body or show a preference for one hand before the age of one may also be exhibiting signs of stroke. Most children will not favor one hand or the other until after they become a year old.

While causes of most pediatric strokes are unknown, risk factors may include congenital heart disease, blood clotting disorders, infections such as meningitis, head trauma, and some genetic disorders. In about half of childhood stroke cases there is no previous risk factor identified.

Our pediatric stroke program works year round to research causes and treatment of stroke in children. We encourage all to share the signs of stroke and spread the word that it can happen to anyone, regardless of age. Simply having the knowledge of the symptoms can make a huge difference in the health and recovery of a child who is experiencing a stroke. Our HTC has a monthly support group, the Pediatric Stroke Parent Support Group, that provides help and community to families with a child who has experienced stroke. Learn more at our website here: [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) and click on the COMMUNITY tab.



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

**TOP 10**

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



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# UPCOMING EVENTS & OPPORTUNITIES

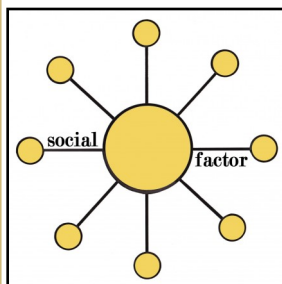


Our offices, pharmacy, and clinic will closed on Monday, **May 28, 2018** in honor of Memorial Day. Please make plans accordingly if you need medication or medical attention. If you need assistance over the long holiday weekend, please see

our after-hours contact information at our website: [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) & click CONTACT US.

The Bleeding Disorder Parent Support Group will meet on **May 29, 2018** at our HTC in the administrative side of our clinic from 6 pm to 7:30 pm. This group is open to parents of children with bleeding disorders; both childcare and dinner are provided. We will meet once a month on the last Tuesday of every month. The agenda is up to parents and it is an opportunity for people to come together to share knowledge, experiences, frustrations, and triumphs in a safe environment. Please RSVP to Angela Blue at [angela.blue@ucdenver.edu](mailto:angela.blue@ucdenver.edu) or 303-724-0167.

**Bleeding Disorder Parent Support Group**



NHF Colorado's Social Factor is hosting a gathering of those in the bleeding disorder community in the Southern Colorado area in Colorado Springs on **June 23, 2018** at the Sonterra Grill: 28B S Tejon St., Colorado Springs, CO. For details, and to RSVP to this event please go to: [cohemo.org](http://cohemo.org).



Mark your calendar for the annual NHF Unite for Bleeding Disorders Walk. The Denver Metro walk will be on Saturday, **August 25, 2018** at Sloan's Lake Park in Denver starting at 9 am (check in at 8 am).

The RMHBDA also will hold walks in Montana. The first will be in Billings, MT on **September 8, 2018** at Zoo Montana. The second will be on **September 15, 2018** in Kalispell, MT at Lawrence Park. Both will begin at 10 am with a 9 am check in.

For any of these or other walks to support bleeding disorders throughout the country, please go to: [uniteforbleedingdisorders.org](http://uniteforbleedingdisorders.org).



## Let Your Voice Be Heard! Take the National HTC Patient Satisfaction Survey Today!

Our HTC is participating in the National HTC Patient Satisfaction Survey! If you, or someone you care for, had contact with us in 2017, we need to hear from you! You can take the survey online at [www.htcsurvey.com](http://www.htcsurvey.com), or fill out the paper survey you should have received from us in the mail. **All surveys must be completed by June 30, 2018.**

This survey is a follow up to the survey done in 2015. The input from our patients helped our center identify areas of strength and where we need to improve. Your voice now can help our HTC know how we are doing.

Please go to [www.htcsurvey.com](http://www.htcsurvey.com) to take the survey or to find out more information. The survey only takes a few minutes of your time! Thank you for your valuable input!

## Genetic Counseling With Telemedicine

Our HTC has a high number of people who participated in the **My Life, Our Future** (MLOF) program, and we wanted to make our female participants aware of this opportunity. If you are a female with a family history of hemophilia A or B, and you participated in the MLOF genotyping initiative, you may be eligible to enroll in a NHF sponsored Telegenetic Counseling Study.

The goal of this study is to measure the value of genetic counseling while providing genetic results to participants. All participants would receive genetic counseling using telemedicine, a secure video chat between the participant and a genetic counselor. All information produced by the session would remain confidential.

To see if you are eligible, to sign up, or to contact those leading this study for questions, please go to the NHF study page by going to [hemophilia.org](http://hemophilia.org), click on the **RESEARCHERS & HEALTHCARE PROVIDERS** tab, and find an article about this trial under the **RESEARCH** section (located on the right hand side). You can also access this through our online newsletter at [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) and click on the RESOURCES and then NEWSLETTER tabs.

## HTC SPOTLIGHT: ANGELA BLUE



If you were able to attend some of our recent events, you may have met our new Program Director, Angela Blue. Angie joined us six months ago and has become a vital part of our HTC staff. She comes to us from the Children's Hospital of Minnesota's Hemophilia Center where she worked as their Program Manager for nine years. Before that she worked for six years at the University of Minnesota's Center for

Bleeding and Clotting Disorders as their Hemophilia Pharmacy Coordinator. Her experience is a huge asset for our HTC and her wonderful personality brings calm energy to our staff.

She shared her thoughts with us on what brought her to working with the bleeding disorders community. "When I was young, one of my favorite teachers had a son my age who had hemophilia. Sadly, this boy passed away when we were 11 years old from HIV which he contracted through contaminated factor products. I remember feeling so shocked and scared when that happened. Ten years later I was working as a pharmacy technician at the University of Minnesota and I had the opportunity to work with the hemophilia pharmacy program. I was interested because I knew someone who had suffered the worst fate and was hoping I could do something to help these patients and families.

After I started working at the HTC at the University of Minnesota I realized what a special area of medicine this is because the whole team was so involved and would pour their hearts into the care they were giving. Even more so - the patients and families that I met and got to

know were the most resilient and incredible people I had ever met. It is the same here at the HTC in Colorado as I believe it is across the entire country. The staff at HTCs are (in my opinion) the best of the best in the medical field and the patients are the most brave and resilient group of people I could ever imagine. I've seen kids and teens (and adults) overcome their biggest fears time and time again, it never ceases to amaze and inspire me."

As the Program Director, Angie works with various HTC staff and organizations, coordinating with research, quality improvement, and supporting the community events, such as those led by NHF Colorado or the Rocky Mountain Hemophilia and Bleeding Disorders Association. She is involved in the planning and support of our outreach clinics, special training programs at the HTC, and works to compile data and reports for HTC grants and research projects. She is paying particular attention to expanding our outreach efforts, and is working with the regional HTCs to help find ways to continually improve the quality of care for patients in our area.

Angie is a creative person who loves music, playing piano, singing, and attending concerts. She loves Broadway musicals and even got to go see Hamilton when it was in Denver earlier this year! She loves outdoor concerts and is looking forward to experiencing the fun venues we have in town. She likes to bike, ski, run and rollerblade. She's even done rollerblading marathons! She likes that she's closer to skiing now, but also enjoys travel.

We at the HTC are thrilled to welcome Angie to our HTC and are so happy she's working with us! You can meet Angie at our Bleeding Disorder Parent Support Group, at upcoming NHF events, or other HTC sponsored activities.

## OUTREACH CLINICS 2018

Every year our HTC schedules Outreach Clinics designed to allow patients to schedule their annual comprehensive visits at a location closer to their home. The clinics in Montana and Grand Junction are usually a few days once a year, while our Colorado Springs clinic is held quarterly.

Our staff does reach out to schedule local patients, but if these clinics are more convenient to your location and you would like to know more, please contact Pat Casias at 303-724-1325 or speak with our front desk schedulers at 888-297-0724 or 303-724-0724.

Details, forms and maps to these locations are available on our website at: [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) Click on the CLINIC tab and find the OUTREACH CLINICS page.

### Confirmed Clinics for 2018:

**June 19-21, 2018: Billings, MT**

**Sept 26-28, 2018: Grand Junction, CO**

**August 13-14, 2018: Missoula, MT**

**Colorado Springs, Date TBD**

## RECENT HEADLINES

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

**BioMarin Announces First Patient Dosed in Gene Therapy Study for Hemophilia A Patients with AAV5 Antibodies**

**Takeda Secures Takeover of Shire in \$62B Deal**

**Study Suggests Prophylaxis Could Reduce Hospitalizations for VWD Patients**

**Sharon Funk Discusses Physical Therapy and Bleeding Disorders on Ask the Expert Podcast**

**NHF Encourages Patients to Participate in the Second National HTC Patient Satisfaction Survey**

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:

**May 28:** HTC Clinic, Pharmacy & Admin closed for Memorial Day

**May 29:** Bleeding Disorder Parent Support Group

**June 3:** NHF Colorado Programa de Español: Greeley

**June 8-10:** NHF CO Family Camp

**June 16-21:** Camp for Kids with Neurologic Disorders at Roundup River Ranch

**June 19-21:** Outreach Clinic-Billings, MT

**June 23:** NHF CO Social Factor: Colorado Springs

**July 13-15:** Mile High Summer Camp-Leadership Retreat

**July 15-20:** Mile High Summer Camp

**Aug 8-12:** RMHBDA Family Camp-Rollins, MT

**Aug 13-14:** 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

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Pharmacy Main: 303-724-0168  
or toll free at 888-724-7427

Web page:  
<http://medschool.ucdenver.edu/htc>

PLEASE  
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STAMP  
HERE