

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
Children's Hospital Colorado
and University of Colorado Hospital

PEDIATRIC STROKE AWARENESS MONTH



Several members of our staff and stroke team wore purple to support Pediatric Stroke Awareness Month.

Did you know that a stroke can happen at any age? May is Pediatric Stroke Awareness Month and is an opportunity to bring awareness, share knowledge, and support those who have survived stroke. Our HTC treats bleeding disorders but also has a portion of our clinic dedicated to the treatment of pediatric stroke. Our pediatric neurologists work with infants, children, and teens who have had a stroke, and are involved in research to treat and prevent stroke in children. Over the past year our stroke team has grown to include several new staff members including a psychologist, social workers, and additional medical team members. Our stroke team strives to improve the lives of our patients and make a difference in their health.

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. 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.

Our pediatric stroke program works year round to research causes and treatment of stroke in children. Our HTC has a support group that provides help and community to families with a child who has survived stroke. This group meets once a month, but will not be having meetings in June or July. Details about upcoming meetings can be found at our website by going to www.medschool.ucdenver.edu/htc and click on the COMMUNITY tab and finding the Pediatric Stroke Parent Support Group page. You can also follow the support group on Facebook at the page: **Colopedsstroke**.

Pediatric Stroke Awareness



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



Go to facebook.com/ColoradoHTC



Go to twitter.com/HTCColorado



Website: Go to medschool.ucdenver.edu/htc



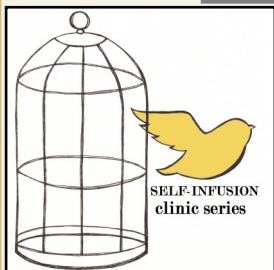
Email: HTC.Newsletter@ucdenver.edu

UPCOMING EVENTS & OPPORTUNITIES



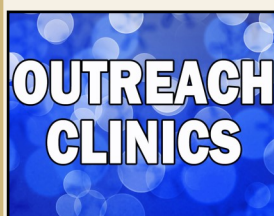
Just a reminder that our clinic, pharmacy, and administrative offices will be closed on Monday, May 27, 2019 in honor of Memorial Day.

Our offices close based on the holiday schedule of the Anschutz Medical Campus. We list the dates closed on our website under the **Contact Us** page at www.medschool.ucdenver.edu/htc. We have after hours contact information listed on our Contact Us page as well, in the event you need to contact our pharmacy or are in need of medical assistance over the holiday.



Our next Self-Infusion Clinic will be held on **Saturday, June 8, 2019** here at our HTC from 9 am to 11 am. At each clinic our nursing staff is on hand to provide support, experience, and guidance as we help patients practice infusing. You can practice with saline or bring your own factor to infuse that day.

While NHF Colorado normally handles registration for this clinic, they are currently undergoing staff changes. For this Self-Infusion clinic, please direct questions and RSVP directly to us at the HTC by email at hemophilia@ucdenver.edu or contact Christine Mashburn at 303-724-0724.



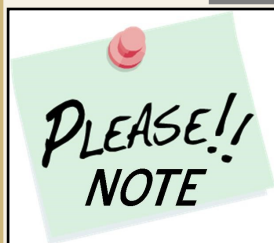
If you do not live in the Denver Metro area, one of our Outreach Clinics might be an easier option for your regular comprehensive care. Our Outreach Clinics offer care and support from our medical, nursing, physical therapy, psychosocial, and research teams. Our experts come to you!

Upcoming Outreach Clinics:

June 25-28, 2019—Billings, Montana

July 31-Aug 2, 2019—Missoula, Montana

See our website for more details at www.medschool.ucdenver.edu/htc and find the Outreach Clinics page under the CLINIC tab.



Our Pediatric Stroke Parent Support Group meetings normally meet the 2nd Tuesdays of the month from 6 pm to 7:30. Please be aware that this group will have a brief summer hiatus and **will not meet in June or July**.

We plan on resuming meetings in August. For details, go to our website at www.medschool.ucdenver.edu/htc and find the Pediatric Stroke Parent Support Group page under the COMMUNITY tab.

RETURN YOUR PACKING SLIPS!

Our Pharmacy is required to have records on file about medications and supplies they send out to our patients. When you receive factor or other items from our HTC Pharmacy, please remember to return the delivery receipt stamped in **red ink**. Instructions are included in the packaging.



These slips must be signed, dated and mailed to us. There is a self-addressed and stamped envelope provided.

Unfortunately, failure to return signed packing slips could result in a delay in receiving your next factor order or possibly being held financially responsible for the order.

Thank you for your help! Returning packing slips is a requirement and we thank you for helping us comply with regulations.

Contact our Pharmacy if you have questions at 303-724-0168 or at hemophilia@ucdenver.edu.

PRESCRIPTION COVERAGE ALERT

Our staff wanted to give our bleeding disorder patients a heads up to be sure to double check your insurance prescription coverage for 2019. If you use Express Scripts as your prescription provider, please note that some significant changes have been made to some of their excluded medications.

If you are currently on Eloctate, Recombinate, Xyntha, or Xyntha Solofuse, you may have issues and need alternative medications. **Please check with your insurance company to find out what is covered and with your doctor at our HTC to make sure you are able to access the right medication for you.**

Changes to coverage of medications often come during a renewal period, and these Express Scripts changes take effect July 1, 2019. Contact your health plan to verify coverage of your prescriptions and if you need help please feel free to contact us to make sure you're covered.

Our Pharmacy and insurance counselor are happy to help confirm any changes. Contact us at 303-724-0724.



Teens Remain Highly Satisfied with Hemophilia Treatment Center Care



Improving the health, safety, and well-being of adolescents is a national priority. Making sure teens who have bleeding disorders are confident and educated to take care of their own medical needs as they mature is a focus in Hemophilia Treatment Centers (HTC)

nationwide. Parents or

guardians are responsible for managing bleeding disorder care for small children including scheduling appointments and infusing factor. But as children with a bleeding disorder grow older, HTCs help teach young adults skills and encourage them to take on these responsibilities.

Are teens satisfied with how their HTC helps prepare them?

Patient Satisfaction Surveys (PSS) of HTCs can help us find out. A national PSS was conducted in 2015 and 2018. PSS data shows us levels of HTC satisfaction and how they change over time. We looked at the survey results from families

with teenagers, as the PSS included two questions specifically asking how well HTCs help teenagers

prepare to care for themselves independently.

“I feel my son is being prepared for his transition to adulthood for his bleeding disorder care.”

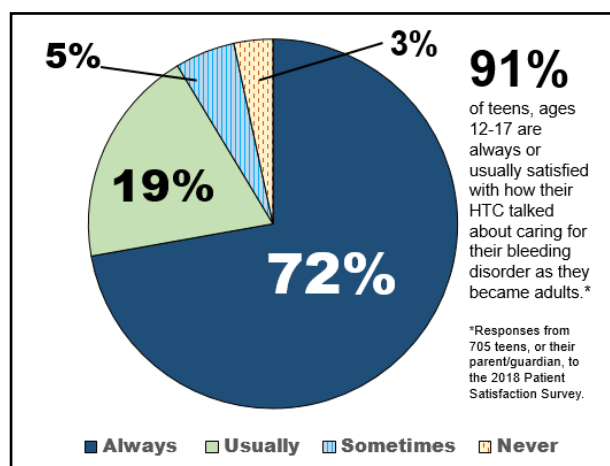
Parent of teen with severe hemophilia from Tennessee

One question asked how satisfied teens were with how their HTC encouraged them to take charge of their own care. The other asked about satisfaction with the way their HTC talked about how to care for their bleeding disorder as they became adults. Over 700 teens age 12-17 (or parents/guardians) from over 130 HTCs across the U.S. answered these ‘teen transition’ questions in 2015 and 2018.

How satisfied are teens with their HTCs?

Results in both surveys were overall positive: over 90% of teens in both years were always or usually satisfied with how HTC providers talked to them about treating their disorder as they became an adult. In both years, 92% of teens reported being always or usually satisfied with how HTC staff encouraged them to manage their own care.

What did we learn? The high levels of “always” and “usually” satisfied teens in both years is evidence that HTCs are consistently doing a very good job helping teens learn to manage their disorder. We also learned that HTCs which only care for people up to age 18 are doing equally well helping teens with transition as those HTCs that care for people of all ages.



Each region, and each center, received their own survey responses, which allows them to see if they improved or not from 2015 to 2018. Reviewing satisfaction over time helps us understand how well HTC efforts are working to prepare teens to manage their bleeding disorders as they become adults.

All HTCs are trying to improve and learn ways to help their teens progress and learn self-care and independence.

Our hope is that with each passing year, more and more teens will always be satisfied with the help their HTCs give, and able to take on the challenge of managing their bleeding disorder as they become adults.

“I have been doing self-care for a while, and I didn’t need a talk once I turned 12.”

Teen with severe hemophilia from Massachusetts

Asking the teens themselves about their experience adds powerful understanding about how HTCs are of value to the bleeding disorders community. You can learn more about the survey results at www.htcsurvey.com.

RECENT HEADLINES

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

Being Fin's mom: Life after your newborn has a stroke

Updated Data for uniQure's Phase 2 Trial for AMT-061, Gene Therapy for Hemophilia B Presented

Signs of Stroke in Babies and Toddlers

Talking About School Shootings

Why We Can't Forget Children During Stroke Awareness Month

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 then find the **RESOURCES** tab, and go to the **NEWSROOM** page. Find other stories at our Facebook page at www.facebook.com/ColoradoHTC/

UPCOMING EVENTS

Mark Your Calendars:

May 27: Clinic, Pharmacy & Admin closed for Memorial Day

June 8: Self-Infusion Clinic at the HTC

June 14-16: RMHBDA Family Camp—Anaconda, MT

June 25-28: Outreach Clinic—Billings, MT

July 4: Clinic, Pharmacy & Admin closed for Independence Day

July 12-13: Leadership Training at Mile High Summer Camp

July 14-19: Mile High Summer Camp

July 31-Aug 2: Outreach Clinic—Missoula, MT

Aug 24: NHF CO Unite for Bleeding Disorders Walk-Denver, CO

Sept 2: Clinic, Pharmacy & Admin closed for Labor Day

Sept 7: RMHBDA Unite for Bleeding Disorders Walk—Billings, MT

Sept 14: RMHBDA United for Bleeding Disorders Walk—Kalispell, MT

See more at our Events Page on our website:

www.medschool.ucdenver.edu/htc find **RESOURCES** tab, go to **EVENTS**

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or toll free at 888-297-0724

Pharmacy Main: 303-724-0168

or toll free at 888-724-7427

Web page:

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

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