

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

MARCH IS BLEEDING DISORDERS AWARENESS MONTH

RUN RED

MARCH 1-31, 2021 - ANY PACE, ANY PLACE

The National Hemophilia Foundation has a fun way to get in your steps and raise funds for those with bleeding disorders. Check out their [Run Red program](#) and learn how you can help.

organizations have grown, worked together, and built communities to support those with bleeding disorders in meaningful ways. The National Hemophilia Foundation, the Hemophilia Federation of America, and local bleeding disorder support chapters, HTC's, and family members have all worked to bring awareness to those with hemophilia. As the years have gone by and we've learned more about rare bleeding disorders, support has grown to include those with von Willebrand disease and other

von Wille— *What!?*



1-2% of people live with von Willebrand Disease (vWD) in the U.S.

A person with vWD...

- Affects males and females equally
- Cannot form a platelet plug
- Is *not* contagious
- Has treatment, but no cure

www.hemophiliafed.org 

Look online for resources to share information about bleeding disorders with your friends on social media. Von Willebrand disease is one of the bleeding disorders that many have never heard of, but affects many throughout the US.

rare clotting deficiencies. In 2016 the US Department of Health and Human Services officially broadened this month of awareness to include all with bleeding disorders, not just hemophilia.

We hope you can find ways, for the rest of March and throughout the year, to spread awareness to those in your circles about bleeding disorders. Many opportunities are out there, including sharing on social media, participating in local and national events, and finding ways to provide financial support to organizations that make a difference.

NHF has a [virtual Run Red campaign](#), asking members to get in their running (or walking) steps and raise funds for bleeding disorders. NHF Colorado will be hosting a virtual [State Advocacy Day on April 22nd](#) where participants can meet with Colorado Senator Ginal and Representative Mullica and get to break out to chat in specific districts. You can register now for this opportunity to make a difference by advocating with local leaders at the cohem.org website. There will be training and Q&A sessions, plus those who attend will receive a dinner voucher, so check it out and get involved!

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Did you know that HFA and NHF have graphics and ideas ready to help you share information about bleeding disorders? Check out their resources at hemophiliafed.org and hemophilia.org.

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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.cuanschutz.edu/hemophilia-thrombosis



Email:

HTC.Newsletter@ucdenver.edu

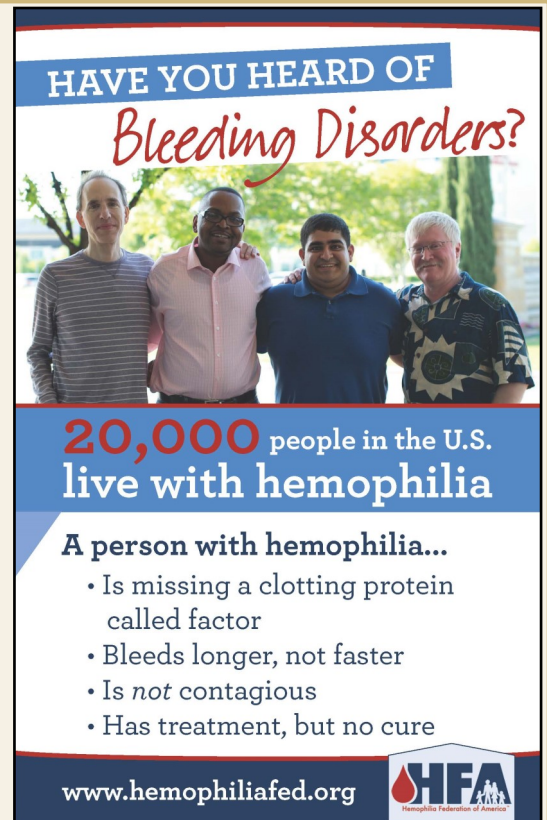
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Last year was a challenge as we all went into lockdown while we normally would be reaching out to advocate for those with bleeding disorders. However, 2020 proved we can still find ways to connect and make a difference.

Local NHF chapters such as [NHF Colorado](#) and the [Rocky Mountain Hemophilia and Bleeding Disorders Association](#) have adjusted and have found unique options to work with local members of the bleeding disorder communities to bring education, community activities, and advocacy opportunities.

We ask that you continue to help us support those with bleeding disorders by staying involved, being creative, and advocating for those who still need support. We thank our local chapters, our local HTC staff, and all the parents, families and friends who consistently go the extra mile to support those with bleeding disorders.

Learn more about how you can get involved with your local chapters at [cohemo.org](#) and [rmhbda.org](#), or national resources such as [hemophilia.org](#) or [hemophiliafed.org](#), follow us at [Facebook](#) or [Twitter](#), or share and subscribe to this newsletter. Working together we can make a difference, bring awareness, and provide support for those with bleeding disorders both locally and around the world.




HAVE YOU HEARD OF
Bleeding Disorders?

20,000 people in the U.S.
live with hemophilia

A person with hemophilia...

- Is missing a clotting protein called factor
- Bleeds longer, not faster
- Is *not* contagious
- Has treatment, but no cure

[www.hemophiliafed.org](#) 

NEW RESEARCH ONGOING AT THE HTC



Dr. Beth Warren displaying the motion tracking technology that will be used to help her study patients and their movements during research funded by a recent award from the NIH.

Did you know that many of our HTC staff don't just work in the clinic to help our patients with their needs, but are also involved in many ongoing and upcoming research projects?

Dr. Beth Warren's research project proposal to determine how movement patterns may contribute to joint and muscle bleeding was recently funded through the National Institute of Health (NIH) K23 mentored research award program. She will be mentored by Dr. Marilyn Manco-Johnson, Co-Director here at our HTC, and Dr. Jim Carollo, the Director of the Children's Hospital Colorado Center for Gait and Movement Analysis. This project will take place over the next five years.

This research will evaluate both children and adults with hemophilia as they perform different movements (e.g. walking, jumping, hopping) over force plates in a room full of cameras, so that many details about movement patterns can be collected. Participants will then use a new smartphone app called the POBOY (Prevention of Bleeding by Optimizing prophYlaxis), developed by our University of Colorado HTC, also under the direction of Dr. Warren, to track bleeding events, hemophilia medications, and physical activities. All of these data will be used to determine if certain movement patterns make patients with hemophilia more likely to have bleeds, so that we can better prevent bleeding.

We are excited to see how this project helps our patients in the future and will share more information as it moves forward.

Congratulations to Dr. Beth Warren for the dedication and planning that was involved to make this research project possible!

PEDIATRIC STROKE RESOURCES AVAILABLE

Pediatric Stroke Parent Support Group

VIRTUAL ZOOM Meeting

Tuesday
April 13, 2021
6:30-7:30 pm

Our [Pediatric Stroke Parent Support Group](#) is now meeting online. We will continue meeting online a while longer to keep everyone safe. We hope you can join us for our next online meeting on **Tuesday, April 13, 2021 from 6:30-7:30 pm.**

This group meeting welcomes everyone in the family to join. Your child does not need to be treated at our center to attend.

To join, please RSVP by contacting us at strokesupport@ucdenver.edu or (303) 724-8520.

Follow us on Facebook for the latest on our meetings at www.facebook.com/Colopedsstroke.

Did you know that our pediatric stroke patients have some wonderful resources available through [Roundup River Ranch](#)? This is an amazing resource that offers a unique support system for kids with specific disorders and diagnoses, including pediatric stroke.

Normally Roundup River Ranch holds in-person camps, but due to COVID-19 restrictions they will have all camp sessions online this year. Camp is free to qualifying individuals ages 7-17, and to their families for

family camp with kids ages 5-17. Learn more about the camps available at RoundupRiverRanch.org or contact their Camper Recruitment Team at 970-524-5713 or CamperRecruiter@RoundupRiverRanch.org.



In addition, Roundup River Ranch also offers a really fun perk called Joy Delivered, where campers receive a fun box with art projects, activities, games, jokes and songs four times a year. Check out this resource at RoundupRiverRanch.org/Joy.



We have fliers about these two wonderful resources [available at our website](#) and you can learn more information by contacting any of our [Psychosocial Team](#)— Dr. Emily Wheat, Bryn Dunham, Whitney Tedeschi or Cindy Nederveld.

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 earlier this month 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.

RECENT HEADLINES

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

BioMarin's Roctavian, Gene Therapy for Hemophilia A, Gets FDA Regenerative Medicine Advanced Therapy Status

Nuwiq Shows a Low Risk of Developing Inhibitors in Hemophilia A Trial

FDA Puts Efanescotocog Alfa on Fast Track Designation to Treat Hemophilia A

Recent Study Shows Hemlibra Can Help Manage Acquired Hemophilia A

Study Shows Esperoct Highly Effective as Prophylaxis Treatment for Hemophilia A

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.

March is Bleeding Disorders Awareness Month

Apr 7: NHF CO Education Series-Spanish Language Program-VIRTUAL

Apr 12: NHF CO-BioMarin Gene Therapy Jeopardy-VIRTUAL

Apr 13: Pediatric Stroke Parent Support Group

Apr 17: World Hemophilia Day

Apr 22: NHF CO State Advocacy Day-VIRTUAL

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

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or toll free at 888-724-7427

Web page:
medschool.cuanschutz.edu/hemophilia-thrombosis

PLEASE
PLACE
STAMP
HERE