

# 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

## BACK TO SCHOOL IN 2022



Summer is nearly over and soon many children, teenagers, and young adults will be heading to school. Whether it's starting elementary or moving into college, families of children with bleeding disorders often have additional items on their to-do list to prepare for the new school year.

The beginning of the school year is a great time to set clear guidelines and address problems that could arise, even if your school is already aware of your child's bleeding disorder. A child may or may not want to share his or her bleeding disorder or may be uncomfortable trying to explain it to their peers, but schools and teachers should be informed so they can provide appropriate care and accommodations.

Most schools have medical forms to fill out, and often have special protocols when it comes to helping the school understand and meet the medical needs of a child with unique health issues. These forms often need signatures from nurses and input from medical providers. Our nursing staff is ready to help families prepare these forms for your school. Your medical team at the HTC is experienced with helping families provide the needed information to schools and giving practical advice on handling any problems that arise.



It is best to reach out to the school at the start of the school year and ask to talk to or meet with teachers, nurses or administrators who may be involved in any medical care. Nearly all children with hemophilia and other bleeding disorders qualify for Section 504 of the Americans with Disabilities Act that prohibits discrimination and provides regulations requiring accommodations. Many children may need an Individualized Educational Program (IEP) through their school to get the accommodations they need. Our HTC provides Individualized Health Plans (IHP) for families outlining what the school may need to know to treat your child in the event of an injury. Reach out to our nursing staff if you need support in getting forms completed, need [Continued on page 2]

August 2022  
Volume 12, Issue 8



Chill Factor Team Captain Kim Hurdstrom with her daughter at the Unite for Bleeding Disorders Walk . Photo: Merilee Ashton

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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](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)

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an IHP, or just need help with navigating how to best inform your child's school on their needs. Our **nursing line is 303-724-0364**.

Most of the time schools will work with you and have a plan in place for your child, but sometimes schools

need more information to fully understand a bleeding disorder or other medical condition. If you need to set up a meeting with your child's teachers, our HTC staff has resources to help. The NHF and the HFA both have some powerful resources online to help share information with schools about your child's needs. Take some time to check out their resources at [stepsforliving.hemophilia.org](https://stepsforliving.hemophilia.org) or [hemophiliafed.org/home/for-patient-families/resources/toolkits](https://hemophiliafed.org/home/for-patient-families/resources/toolkits).

It's not just kids in K-12 that need help; college bound students should know that there are resources available to them as well. Most colleges have a disability resource officer or office on campus that provide accommodations. A huge college campus can be a problem for those on crutches or experiencing a bleed. Most colleges provide quicker ways

across campus or have other helps for those with medical needs. Reach out to discover what resources are available and how your college student can access them.

In addition, college kids who infuse will also need to have a safe way to store factor medication and supplies, as well as knowing where to go for additional supplies and medication. Students should also be aware of which HTC is closest to them or who to call if they have a problem. Our nurses and pharmacy staff are prepared to answer questions about these issues as well.

The best way to touch base with our nursing staff is to call our **nursing line at 303-724-0364**, and for any questions on how best to manage your pharmacy needs, contact our **pharmacy directly at 303-724-0168**.

Start the school year right by knowing your rights, how to advocate for your child's needs, and learning about resources for proper medical care at school.

Get ahead of the game and prepare now to make this a great school year for everyone!



**Pediatric Stroke Parent Support Group**  
 Temporarily On Hold

Our [Pediatric Stroke Parent Support Group](#) is on hold temporarily as we make some adjustments within our center. We hope to soon provide this service in a way that will best fit the needs of our families.

Please check our website and Facebook page for more information and details on upcoming meetings.

If you have any questions, feel free to contact us at [strokesupport@ucdenver.edu](mailto:strokesupport@ucdenver.edu) or (303) 724-8520. Follow us on Facebook for the latest at [www.facebook.com/Colopedsstroke](https://www.facebook.com/Colopedsstroke).

## OUTREACH CLINICS CONTINUE

Our HTC has held two Outreach Clinics this year and have two more scheduled for our patients who live farther away from our center in Colorado.

Patients who live in these areas should be contacted by our HTC, however if you live closer to Billings or Missoula, Montana and would like to meet with us there, please feel free to reach out to our schedulers at 303-724-0724.

Our upcoming clinics will be:

**Missoula, MT — September 28-30, 2022**  
**Billings, MT — October 26-27, 2022**

Please see our Outreach Clinic page on our website at: [medschool.cuanschutz.edu/hemophilia-thrombosis/clinic/clinics/bleeding-disorders/outreach](https://medschool.cuanschutz.edu/hemophilia-thrombosis/clinic/clinics/bleeding-disorders/outreach) for details and directions to these locations. If you have questions about attending one of our Outreach Clinics, please contact your medical team or our schedulers at 303-724-0724 for more information.

# COLORADO UNITE WALK A SUNNY SUCCESS



HTC staff members Marni Mazzarello, Kate Hoeft, Nancy Spomer, and Jenn Brown at the walk. Photo: Merilee Ashton

Earlier this month many of our HTC staff joined with patients, friends, and families to support NHF Colorado at the annual Unite for Bleeding Disorders Walk. The walk was held on August 13, 2022 at Sloan's Lake Park and provided a great opportunity to connect and have fun while raising funds and awareness for those with bleeding disorders.

The Unite for Bleeding Disorders Walk is one of the only fundraisers for NHF Colorado and provides support for the many educational and community events and resources for patients with bleeding disorders in the Rocky Mountain region. This includes Education Days, Backpacks + Bleeders, local community events, and Mile High Summer Camp. The funds make it possible for kids with bleeding disorders to experience camping, hiking, skiing, rock climbing and more, all in a safe way with medical staff on hand. Camp and many of these activities would be financially out of reach for many in the

bleeding disorder community without the generous support of donors.

Our HTC team, Chill Factor, was thrilled to meet and exceed our goal this year with over \$5,000 raised. Turnout this year was wonderful and our staff members were excited to walk along our patients and their families around beautiful Sloan's Lake. The day was sunny, and the fun was plentiful, including a chicken dance, awards for top donors, and many booths from local and national sponsors. There were even doughnuts and breakfast burritos for participants to enjoy before and after the walk.

Thank you to all who were able to contribute or participate in the walk. NHF Colorado still needs some help to reach their goal and be able to provide their incredible programs to families. If you would like to donate to NHF Colorado, go to: [uniteforbleedingdisorders.org](https://uniteforbleedingdisorders.org) and click on "Find a Walk" to search for the Denver event.

If you are in Montana or Wyoming, you still have the chance to contribute to your local bleeding disorders community through the Rocky Mountain Hemophilia and Bleeding Disorders Association and join their walk in Billings, MT on September 10, 2022 at Zoo Montana. Find their walk page at: [uniteforbleedingdisorders.org](https://uniteforbleedingdisorders.org) and click on "Find a Walk" and scroll to find the Montana and Wyoming walk page.



Right: Walkers starting around the lake; Below: Most of our Chill Factor team before the race; Below right: Laura Singer-Fox and her kids pass the finish line. All photos: Merilee Ashton



## RECENT HEADLINES

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

**Hemlibra Improves Joint Health in Younger Hemophilia A Patients in Trial**

**Recombinant von Willebrand Factor Prophylaxis May Reduce ABR for VWD Patients**

**FDA Approves Rebinyn for Routine Prophylaxis in Patients with Hemophilia B**

**Freeline Shares Positive Data from Gene Therapy Trial**

**Sanofi Shares Data from Two Phase 3 Studies**

**NHF Requests Risk Evaluation & Mitigation Study for Pending Gene Therapies**

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](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.**

**Aug 25-27:** NHF Bleeding Disorders Conference, Houston, TX

**Aug 27:** NHF CO Lakeside Breakfast and Goat Yoga

**Sept 5:** Clinic, Pharmacy & Admin offices closed for Labor Day

**Sept 10:** RMHBDA Unite for Bleeding Disorders Walk — Billings, MT

**Sept 18:** Backpacks + Bleeders: Boulder Canyon with Front Range Climbing Company

**Sept 24:** NHF CO Women's Wellness Retreat — Glenwood Hot Springs, CO

**Sept 28-30:** HTC Outreach Clinic — Missoula, 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)

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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:

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

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