

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

February 2023
Volume 13, Issue 2



Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with
Children's Hospital Colorado

PLAN AHEAD FOR ADVOCACY

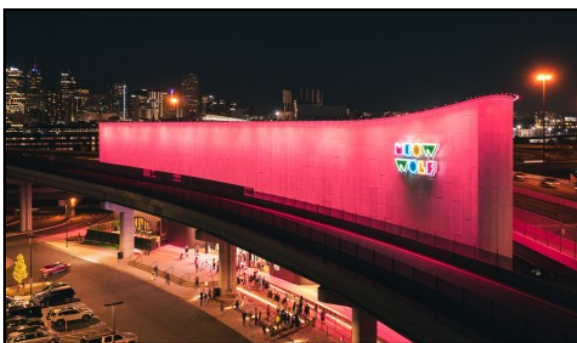
We are excited that next month is Bleeding Disorders Awareness Month! Historically March has been designated as Hemophilia Awareness Month, but several years ago the name changed to include more bleeding disorders. And this year, with things opening up a little more, we hope that 2023 will be a great year for advocacy in the bleeding disorder community.

Bleeding Disorders are rare, and treatment can be expensive. More importantly, bleeds can be painful and the emotional impact of dealing with a chronic condition can be taxing. Bringing awareness to these disorders not only helps those who have them feel supported, but it is an opportunity to make policy makers aware of the impact legislation can have, for both good and bad. When bleeding disorders are overlooked, the consequences can be very challenging, including difficulty getting access to medications and the proper care. When bleeding disorders are included, the health of many can be vastly improved.

Many of our patients and their families advocate to our local, state, and national leaders for support. We have several events coming up in the next couple of months that are easy ways for you to get involved.



Visit the CU Anschutz Medical Campus April 14-19, 2023 at night to see the Fitzsimons Building lit red to honor those with bleeding disorders.



Look for Meow Wolf Denver, at I-25 and Colfax, to turn red for bleeding disorders between March 13-16, 2023!

NHF Colorado is hosting their [Colorado State Advocacy Day](#) on **March 16, 2023** at the Colorado State Capitol. NHF Colorado will be in partnership with [Chronic Care Collaborative](#) as patients and families have the chance to meet with local legislators. This is an opportunity to share stories, concerns, and educate them about bleeding disorders. Even if you aren't sure what you can do or say to help, attending can put a face and name to the people who are most impacted by changes in legislation.

Registration includes a training program before you meet with your local leaders. Register and learn more at cohemo.org.

[NHF Washington Days](#) is a national level advocacy program where people affected by bleeding disorders can meet with legislators in Washington DC to discuss federal level funding of bleeding disorder programs. NHF Washington Days will be held **March 8-10, 2023**, and is planned to be an in-person experience. Registration is required to attend but there is no cost to attend other than travel expenses. If you miss the opportunity this year and want to attend in the future, contact your local NHF Chapter about how you can get involved.

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Make plans to join NHF Colorado for the Colorado State Advocacy Day on March 16, 2023 at the State Capitol. Find out more details on how you can get involved at cohemo.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

CHANGES COMING SOON TO MEDICAID COVERAGE

The Federal Government has indicated that the pandemic emergency is ending as of May 11, 2023. This doesn't mean that COVID-19 is gone, but it does mean that many temporary federally funded initiatives will change or be discontinued.

This will include the way that Medicaid and CHIP/Child Health Plan + will be covered. Because of this, anyone who is on Medicaid or the CHIP/Child Health Plan + will need to re-enroll before May 11, 2023 or they will lose their coverage.

It is critical that if you or your child are on these federally funded plans that you verify your current phone, email, and mailing address with them. If you have moved since March of 2020, you will need to update your information. These programs will send you re-enrollment or coverage change details to your current contact information on file. To update your information, please use one of the following methods:

For Colorado residents:

- Visit [Colorado.gov/PEAK](https://colorado.gov/PEAK)
- Use the [Health First Colorado app](#) on your phone
- CHP+ members can call 1-800-359-1991 (state relay: 711)
- Contact your [County Department of Human Services](#)

For Wyoming residents:

- Use the Client Web Portal at www.wesystem.wyo.gov
- Email wesapplications@wyo.gov (include your FULL name, DOB or case number)
- Call 1-855-294-2127
- Enroll Wyoming, at <https://enrollwyo.org/> or 1-888-425-7138, is a good source for WY residents

For Montana residents:

- Use the Montana portal at <https://apply.mt.gov/>
- If you do not have an email, use Montana Department of Public Health form: <https://bit.ly/DPHHSform>
- Call Montana Public Assistance Help Line at 1-888-706-1535
- Stop by your local Office of Public Assistance: <https://dphhs.mt.gov/hcsd/officeofpublicassistance>
- Cover Montana, at <https://covermt.org/> or 1-844-682-6837, is a good source for MT residents

We will be sharing more information about this change in coming months, but feel free to contact our social work team with questions.

Our social workers are Bryn Dunham bryn.dunham@cuanschutz.edu, and DeEtta Barnhardt deetta.barnhardt@cuanschutz.edu.

NHF COLORADO UPCOMING WINTER/SPRING EVENTS



March 4, 2023: Connections, Coffee, and Conversations: Bleeding Basics

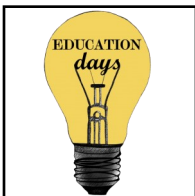
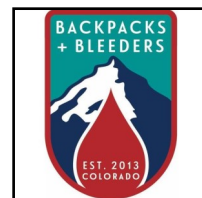
The NHF Colorado Connections program is designed to help connect, welcome, and support newly diagnosed families of infants and young children with bleeding disorders. Join our HTC experts and NHF Colorado at the Children's Museum of Denver for the opportunity to connect and learn with others in the bleeding disorder community. To register: cohem.org.

March 16, 2023: Colorado State Advocacy Day

Join NHF Colorado as they visit the Colorado State Capitol and meet with legislators to bring awareness about bleeding disorders. Registration includes a training program before you meet with local representatives. Sign up here: cohem.org.

April 1, 2023: Bleeders on the Slopes

Sign up now to get a spot to ski with Backpacks + Bleeders! For just \$15 a person, you will receive lift tickets, rentals and lunch. This is a great opportunity for skiers and snowboarders regardless of your skill to have fun with those in the bleeding disorder community. This event is for community members ages 4 and up. Spots are limited and registration is required at cohem.org.



April 14-16, 2023: Education Empowerment Days

Join us in-person this year for NHF Colorado's statewide Education Empowerment Days. This conference is a great opportunity to learn, connect, and celebrate with others in the bleeding disorders community. Registration includes hotel accommodations, food, and events. A variety of options are available for childcare, and teen programs are a part of the weekend. Learn more and register now at cohem.org.

[Continued from page 1] Other ways to celebrate and bring awareness include the opportunity to see buildings lit up red in honor of Bleeding Disorders Awareness and/or World Hemophilia Day! Keep an eye out this year for [Meow Wolf](#) to be lit up between **March 13-16, 2023**. This exciting addition to our local light up venues, coincides with our NHF Colorado State Advocacy day, so take the chance to snap a photo! Tag Meow Wolf at Facebook [@MeowWolfDenver](#), Twitter [@meowwolf](#), or Instagram [@meow_wolf](#).

[The City and County of Denver building](#) will be lit red for Bleeding Disorders Awareness on **April 15-19, 2023** during the week of World Hemophilia Day (the 17th). Tag the City and County of Denver by using [@CityandCountyofDenver](#) on Facebook, [@CityofDenver](#) on Twitter, or [@therealcityofdenver](#) on Instagram when sharing.

[The Fitzsimons Building in the heart of the CU Anschutz Medical Campus](#) will also be lit up this year for World Hemophilia Day, during the week of **April 14-19, 2023**. We'd love to see those pictures too! When snapping pics of any of these lit up buildings, or any of your Bleeding Disorder Awareness photos, we'd love it if you tag us. Find us at [@ColoradoHTC](#) on Facebook or [@HTCColorado](#) on Twitter, and remember to tag NHF Colorado on Facebook at [@NHFColorado](#) or Instagram at [@colorado.hemophilia](#).

Sharing on your favorite social media platform is a great way to let people know about bleeding disorders. You can use #BDAM or #BleedingDisordersAwarenessMonth when posting or [find other creative ways to get the word out](#).

The [HFA also has some great resources to advocate](#) for



The City and County Building of Denver will be lit up with red lights for Bleeding Disorders Awareness during the week of World Hemophilia Day, April 15-19, 2023. Be sure to check it out!

those with bleeding disorders. Be creative in 2023, and use the resources available online, both from websites and social media to let others know what hemophilia, or vWD are, or even [learn more about the history of bleeding disorders](#). Consider finding items that mean something to you and sharing with friends and family online, at school, or wherever you are.

Remember that local NHF Chapters, national programs like NHF or HFA, and centers like our HTC all have options for donations if you feel inclined to provide financial support. If you haven't already, sign up for our [HTC monthly newsletter here](#), and we encourage you to sign up for newsletters or event notices from your local [NHF Colorado chapter](#), or the Montana based [RMHBDA](#) and learn about upcoming events. Don't forget to save the dates for Unite for Bleeding Disorders Walks in 2023 as well. [NHF Colorado](#) is **August 26, 2023** and [RMHBDA](#) is **September 9, 2023**. Make this March a month to share and be an advocate for bleeding disorders and make a difference in 2023!

PEDIATRIC STROKE EDUCATION DAY

We invite all families of a child who has survived a stroke to join us for our Pediatric Stroke Education Day, a half-day seminar on **April 29, 2023 from 10 am to 2 pm**. This event is designed to provide connection and education to stroke patients and families. Topics during this half day program will focus on cognitive compensation strategies, allied therapies, and stress management.

We will have experts on hand to instruct and provide support to families in attendance. The entire family is invited to take part to learn and connect with others who have similar experiences.

This educational program is free to all who want to attend, but please RSVP at strokesupport@ucdenver.edu or at 303-724-8520 so we can send you a calendar invite via email and know how many to plan for. Childcare will be available by volunteers from Children's Hospital Colorado, and food will be included.

Join us at the Hemophilia and Thrombosis Center, located at 13199 E Montview Blvd., Aurora, Colorado 80045. Free

parking is available in the visitor's parking in the adjacent garage on the corner of Montview and Victor Streets (enter on the North side of the parking garage).

Check in begins at **9:45 am**, and the program will begin at 10 am and run through 2 pm.

Be aware that our building is locked, but access will be provided with staff to check families in at our main entrance. We look forward to connecting and learning with you!

A graphic for Pediatric Stroke Education Day. It features a large, vibrant orange flower with yellow centers, set against a dark background. The text is overlaid on the flower in white and yellow. The text reads: "Pediatric Stroke Education Day", "In-Person Half-Day Seminar for Families", "Saturday Apr 29, 2023", and "10 am-2 pm".

Pediatric Stroke Education Day
In-Person Half-Day Seminar for Families
Saturday Apr 29, 2023
10 am-2 pm

RECENT HEADLINES

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

Emicizumab (Hemlibra) Appears Safe, Effective in Mild or Moderate Hemophilia

Study Shows Efanesoctocog Alfa Prophylaxis Effective in Hemophilia A

Changes Coming to State Medicaid and CHIP Programs

Roctavian Trail Update Shows Most Patients Bleed-free at 3 Years

FDA Clears Test to Monitor Effectiveness of Hemophilia B Treatments

Pfizer Announces Updates for Investigational Gene Therapy for Hemophilia B

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.

Sign up to get this newsletter delivered directly to your email box each month! Just go to 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.

Feb 28: Rare Disease Day

March is Bleeding Disorders Awareness Month

Mar 4: NHF Colorado Connections, Coffee & Conversations: Bleeding Basics

Mar 8-10: NHF Washington Days—Washington D.C.

Mar 16: NHF Colorado Advocacy Day—Denver, CO

Mar 23: NHF Colorado Von Willebrand Disease Dinner Program

Apr 1: NHF Colorado Backpacks + Bleeders on the Slopes

Apr 14-16: NHF Colorado Education Empowerment Days—Denver, CO

Apr 21-23: RMHBDA Education Weekend—Fairmont Hot Springs, Fairmont, MT

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

Hemophilia & Thrombosis Center

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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