

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with
Children's Hospital Colorado

MARCH IS BLEEDING DISORDERS AWARENESS MONTH



Some of the volunteer advocates who attended Washington Days in Washington DC to share their experiences with legislators this month. Photo: NBDF Colorado

went to Washington DC on March 6-8, 2024 to advocate for those with bleeding disorders. Hundreds of volunteer advocate members from all over the country met with legislators and staff. This was an opportunity to share their stories, the impact of policies and funding programs, and offer ideas to increase affordability and access to medical care. Perry Jowsey, Executive Director of the Colorado NBDF Chapter, joined other Coloradans to advocate for those with bleeding disorders. They discussed specific topics, such as current insurance practices, copay accumulator adjustor programs, copay maximizers, and the negative impact narrow formularies can have on our patients.

The NBDF Colorado chapter also went to the Colorado State Capitol on March 22, 2024 to speak with local representatives about these issues on a state level. Volunteers from NBDF focused on advocating for quality, comprehensive, affordable care for patients. Specifically, our volunteers shared a need to improve ease of access to care via insurance, problems arising from a need for repeated prior authorizations for patients with chronic conditions even after they have been approved—and asked to find ways to extend prior authorizations to last longer. They also encouraged legislation that would protect patients from denials for approved care that currently requires additional or different medically necessary care. In addition, they

Did you know that March is Bleeding Disorders Awareness Month? In 1986 Ronald Reagan designated March as Hemophilia Awareness Month, and in 2016 the US Department of Health and Human Services officially broadened the title to include all bleeding disorders.

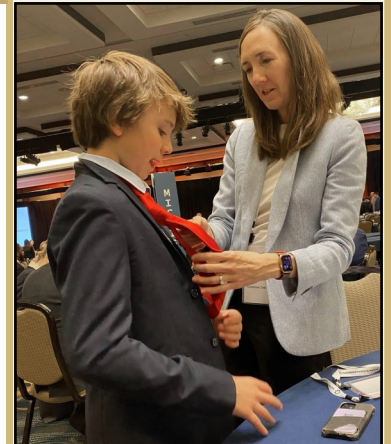
Over the years the National Hemophilia Foundation, now known as the National Bleeding Disorders Foundation (NBDF), the HTC, and many other organizations have worked in a variety of ways to raise awareness about the needs of those with bleeding disorders.

This year chapters from the NBDF



NBDF volunteers visited the Colorado State Capitol to advocate for families with bleeding disorders. Photo: NBDF Colorado

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Advocates from Colorado went to Washington DC to share their stories and talk with legislators about bleeding disorders and healthcare. Photo: NBDF Colorado

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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



Website: Go to

medschool.cuanschutz.edu/hemophilia-thrombosis



Email:

HTC.Newsletter@ucdenver.edu

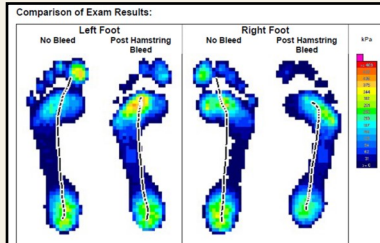
NBDF CO EDUCATION EMPOWERMENT DAYS A SUCCESS



On March 22-24, 2024, NBDF Colorado hosted their annual Education Empowerment Days. This was an event for bleeding disorder community members to connect, learn, and provide support for one another. The event took place at the Hyatt Regency, Denver Tech Center in Denver, and offered exhibits, including sessions on gene therapy, joint health, communication, insurance, and mental health.

This year about 250 participants gathered to network, learn, and provide support for others with bleeding disorders. Our HTC provided some of the programming by offering an infusion clinic and social work support. Our PT/Motion Lab team gave a presentation and did data collection throughout the conference. The PT/Motion Lab team members were excited to get to work with so many patients and to use their equipment to measure and collect data that can be used in future analysis.

There was an entire learning track for teens, including fun ice breaker events, a field day, pool time, group games, special youth learning sessions and a science fair. Childcare was included for all families and everyone had a lot of fun!



Our HTC team wore red to honor Bleeding Disorders Awareness Month. (top left) Photo: Kim Hurdstrom

Some of our nursing team worked with families to teach at an infusion clinic during Education Days. (above) Photo: NBDF Colorado

Colorado bleeding disorder families should mark their calendars for some fun, upcoming events sponsored by NBDF Colorado in the next few months. This includes a Pickleball Learning Event/Dinner, Family Camp, Family River Rafting with Backpacks + Bleeders, and of course, Mile High Summer Camp. Go to their website at cohemo.org for details.

Our PT/Motion Lab collected data from many of the attendees. (left) Data graphic: Joseph Mah

We thank all who were involved in helping NBDF Colorado's 2024 Education Empowerment Days be a powerful and education experience for all.

NBDF COLORADO UPCOMING EVENTS



June 7-9: NBDF CO Family Camp: Highlands Presbyterian Camp and Retreat Center in Allenspark, CO

Register now for Family Camp! This is a great opportunity for families to learn and have fun with others in the bleeding disorder community. Family camp is tailor-made for families with young children with a bleeding disorder, families wanting to connect with others, and individuals or children who want to take first steps toward self-care and self-infusion. Registration deadline is **May 26, 2024**— go to cohemo.org.

June 22: Families on the River with Backpacks + Bleeders (tentative date)

Join Backpacks + Bleeders for a fun Families on the River whitewater rafting trip. The tentative plan is to have a half-day full of exhilarating adventure, including a lunch. The trip will be open to those ages 6 and up who weigh over 50 pounds and reside in a household with a diagnosed bleeding disorder patient. This event is still being planned, so check back with cohemo.org to confirm dates and location. Be aware that wetsuits and splash jackets are not included in the package but are available for separate rental. For more info go to cohemo.org.



Mile High Summer Camp: Registration opens April 15, 2024

July 12-14: Teen Leadership Weekend

July 14-18: Mile High Summer Camp—Empire, CO

Mile High Summer Camp is coming soon! Registration will tentatively open on April 15, 2024 for kids ages 7-17 to have a fun, learning experience with others in the bleeding disorder community. The older kids can get involved with the teen leadership weekend and all will have a fun adventure in a safe and beautiful environment. Learn more and stay up to date on registration dates/updates at cohemo.org.

FOURTH NATIONAL HTC SATISFACTION SURVEY OPEN

Our HTC is participating in the Fourth National HTC Patient Satisfaction Survey. A paper survey was sent to our bleeding disorder patients if they were seen in our clinic or visited with us via phone or tele-health in 2023. The survey is a way for patients to share feedback about how we are doing.

The survey is anonymous but asks participants to identify the center where they received care. This allows our patients or caregivers to candidly share the things we are doing well and areas where we could improve. If you or someone you care for had contact with our HTC in 2023, we want to hear from you!

The easiest way to take the survey is online at www.htcsurvey.com, or fill out and return the paper survey that should have arrived in the mail. If you did not receive one but were seen at our clinic last year, we ask you to go online to take the survey. You can also use the QR code and take the survey on your phone!



It only takes a few minutes to complete but the feedback we receive is very helpful! The survey is available in both English and Spanish and we ask parents of young children to fill out this survey on their behalf. If you have more than one member of your household who was seen at our HTC, please use the online options to fill out one for every patient.

This year, the survey results will be collected and managed at our region's administrative offices at the Oregon Health & Science University in Portland, OR. Once they receive your digital or paper survey the information will be organized and shared with our center.

The input from patients in the past three surveys helped us identify areas where we may have strengths and where we need to improve. Your voice can again help our HTC learn and improve.

All surveys must be completed by May 31, 2024.

Pediatric Stroke Spring Event
April 20, 2024
9am-1pm
13199 E Montview Blvd. Aurora, CO
Breakfast, Lunch, Childcare included

Join us in-person Saturday, **April 20, 2024** from 9 am-1 pm at our HTC for a half-day of learning and connecting.

This spring seminar for families of a child who has experienced a stroke will include a panel discussion, a presentation on education after stroke, a support group breakfast and luncheon, and childcare is provided. This event is free to attend, but you must RSVP to join us. Our building will be locked, but we will have staff to let participants in on the day of the event.

Contact us at strokesupport@ucdenver.edu, to RSVP or for any questions. For more information, see our flier and event info at our website: <https://medschool.cuanschutz.edu/hemophilia-thrombosis/resources/pediatric-stroke/support-group>.

We hope to see you there!

[Continued from page 1] asked for more transparency with the way insurance companies manage their processes of approval for care.

We thank all who participated in advocacy during Bleeding Disorders Awareness Month this year. The NBDF Colorado and RMHBDA in Montana provide community and educational events throughout the year. They support events such as camps, men's and women's retreats, educational events, and fun recreation such as Backpacks + Bleeders hikes and other community activities. Reach out to either of these chapters if you want to get involved in supporting advocacy, or simply to connect with others in the community through their events.

Mark your calendars to support one or both chapters to join in their Unite for Bleeding Disorders Walks later this year. Colorado's walk is **August 24, 2024**, at Sloan's Lake Park in Denver, and the Montana walk is on **September 7, 2024**, at Zoo Montana.

These fundraisers help make all the advocacy and great events possible throughout the year. Learn more about each of these organizations by going to cohemo.org or rmhbda.org.

RECENT HEADLINES

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

ReCiBioPharm Teams Up with GeneVentiv to Develop Gene Therapy for All Hemophilia Patients

FDA Approves First Human Study of CRISPR/Cas9-based Factor 9 Gene Editing Therapy

Muscle Loss Common in Hemophilia A Patients with Joint Bleeds

Trial Shows Roctavian, Gene Therapy, Maintains Effectiveness after Seven Years

NBDF Names Phil Gattone, M.Ed, as Next CEO

We maintain a newsroom page at our website with a list of news articles that 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 or scan the QR code and fill out the form!



QR Code to Subscribe!

UPCOMING EVENTS

Mark Your Calendars:

Please note. These dates may be tentative and subject to change. Please check appropriate websites for confirmation of events.

Apr 4-6: THSNA 2024 Summit of North America—Chicago, IL

Apr 11-13: HFA Annual Symposium 2024—Indianapolis, IN

Apr 17: World Hemophilia Day

Apr 19-21: RMHBDA Education Weekend and Annual Meeting—Chico Hot Springs, Pray, MT

Apr 20: Pediatric Stroke Parent Support Group Annual Education Day

Apr 20: NBDF CO Industry Dinner + Pickleball

Apr 21-24: WFH World Congress 2024 Madrid, Spain

Apr 22: Earth Day

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

ME-WE-HTC We create hope.

Hemophilia & Thrombosis Center

13199 E. Montview Blvd., Suite 100
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

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