The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



Hemophilia and Thrombosis Center

UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS

REGISTER NOW FOR MILE HIGH SUMMER CAMP



Camp is all about fun, friendships, and learning together. Photo: NBDF Colorado

Every summer the Colorado Chapter of the National Bleeding Disorders Foundation (NBDF), and our HTC work together to plan and run a week-long summer camp for children with a bleeding disorder. Mile High Summer Camp is held at <u>Easterseals Rocky Mountain Village</u> in Empire, Colorado, and this year will be from **July 13-17**, **2025**.

Children ages 7-17 with a bleeding disorder (or who has a family member with a bleeding disorder) are eligible to attend Mile High Summer Camp, and costs are covered by NBDF and the HTC. This year all our Campers will start out at Rocky Mountain Village and the older kids (ages 13-17) will leave from camp mid-week to attend their own offsite

adventure with Breckenridge

Outdoor Education Center. These older kids will be returning to Rocky Mountain Village before pick-up on Thursday.

This fun-filled camp is a great opportunity for kids with a bleeding disorder to learn, make new friends, and take steps toward independence. Mile High Summer Camp gives kids with a bleeding disorder the chance to try new things and have a lot of fun in a safe environment. Our HTC provides nurses, pharmacists, social workers, physical therapists, and physicians on site to teach and provide medical support throughout the week. Kids attending can participate in crafts,



Cultivating creativity and a chance to relax is a big part of Camp. Photo: NBDF Colorado

swimming, zipline, fishing, creative activities like skits and songs, as well as classes to help them learn.



Learning and practicing selfinfusion is a milestone that many of our campers work on during camp with the help of our medical staff. Photo: NBDF Colorado

Many campers have learned to infuse their own medication at Mile High Summer Camp, and we have a nursing team as well as older mentors there to help guide young campers through infusions.

New this year: The HTC team will be hosting an Education Fair on the first night of camp, where each discipline will have activities to help our campers learn about their bleeding disorder through hands-on fun. Don't miss this chance for a powerful camp experience this summer!

Registration is now open, and space is filling up fast. Go to <u>co.bleeding.org</u>, or contact Anna Cheshire at <u>acheshire@bleeding.org</u> for more information, or go to their registration page directly at https:// hemophilia.campbrainregistration.com/.



Mile High Summer Camp is full of fun, creativity, even bubbles! Photo: NBDF Colorado

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



Go to <u>facebook.com/</u> <u>ColoradoHTC</u>



Go to <u>twitter.com/</u> HTCColorado



Website: Go to

medschool.cuanschutz.edu/ hemophilia-thrombosis



Email:

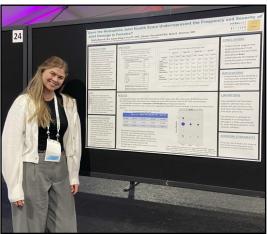
HTC.Newsletter@ucdenver.edu

HTC TEAM MEMBERS ATTEND HTRS SYMPOSIUM

Last month, several of our HTC team members attended the Hemostasis and Thrombosis Research Society (HTRS) Scientific Symposium that was held in Coronado, California. This is the largest conference HTRS hosts and is focused on both research and clinical care related to hemostasis and thrombosis. This year their theme was "Bring Your Team" and well over seven hundred people attended. The symposium incorporated time to collaborate with team members from numerous HTCs to learn how they work together to improve care.

Our HTC sent Scientific Director Keith Neeves, Dr. Beth Warren, who was mentoring Mia Barrett—a medical student who was presenting a poster, and Tim Schardt, our Clinical Pharmacist. One of our Physician Assistants, Elizabeth Gibson, also attended the symposium to participate and learn from the sessions there.

Keith Neeves was a speaker in a session called "AI in Science and Medicine: Hype or Hope? A Debate on Machine Learning's Role in Shaping the Future." He spoke and



Mia Barrett, a medical student at CU Anschutz, presented her first poster at the HTRS Symposium. Her mentor, Dr. Beth Warren, also attended. Their poster looked at the way joint damage is analyzed to see if it underrepresents joint damage in females with bleeding disorders. Photo: Beth Warren

poke and presented the viewpoint of how AI and Machine Learning is advancing research and its impact on basic and translational

A poster
presentation
entitled "Does
the
Hemophilia
Joint Health
Score Under-

science.



Timothy Schardt (left end of table) participated on a panel discussion about a pharmacist's role in providing education and improving medication management at HTCs. Photo: Tim Schardt

represent the Frequency and Severity of Joint Damage in Females?" was presented by CU Anschutz medical student Mia Barrett. This represented work by Drs. Beth Warren (pediatric hematologist), Laura Singer-Fox (physical therapist), and Dianne Thornhill (statistician). Results suggested that the way we are currently calculating joint damage in women with hemophilia may be underestimating the amount of damage - and it proposed a plan to be more accurate.

Timothy Schardt works at our HTC in a clinical pharmacist role, doing research and supporting patients, especially those dealing with thrombosis. He presented during a panel discussion on a pharmacist's role in improving medication management and education for patients who attend the HTC. Tim shared that he especially enjoyed the clinical conundrums session which discussed complex issues encountered when treating patients with thrombosis and bleeding disorders.

We congratulate all our staff members who participated and attended this conference to share research results and learn from one another. Attending this and similar meetings are just one way our HTC team members work to improve the outcomes of patients managing bleeding and clotting disorders.

DROPS OF LOVE: CELEBRATE CARING HTC STAFF MEMBERS



Our HTC has a program called "Drops of Love" to celebrate those who work at our HTC. Any patient, family member, caregiver, or visitor to our HTC can recognize anyone at our center who went above and beyond with a simple scan on your phone! We know that even one great interaction with a clinical team member can make a visit to the HTC a positive experience and help patients improve their health.

Just scan the QR code (left) or scan the code in our office to send a "drop of love" to our staff members and let us know how they made a difference in their service to you! Thank you for sharing your feedback with us!

PAY YOUR PHARMACY **BILL ONLINE**



Did you know that you can now pay your pharmacy bill online? Our HTC pharmacy is now able to accept payments for prescriptions using a debit or credit card right from our website.

You can pay by going to our website's Pay My Bill page, or you can pay on your phone by

using the OR code (below)!

In order to pay, you will need the **claim number** from your invoice, and the patient's initials.

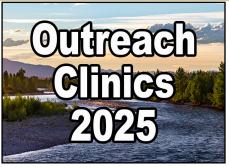
If you have any questions about your pharmacy bill, or are

having any issues with paying your pharmacy bill online, details can be found at our website at:

medschool.cuanschutz.edu/hemophiliathrombosis/pay-my-bill, or you can contact our HTC pharmacy by phone at 303-724-0168 or 1-888-297-0724, or email us at

hemophilia@ucdenver.edu.





Our HTC team visits locations in our region to offer comprehensive care to patients who live in more distant areas from our main clinic.

This gives patients the opportunity to more easily visit with all our main providers in-person on at least an annual level.

We have four Outreach Clinics in 2025:

July 29-31, 2025—Billings, MT Aug 26-28. 2025—Billings, MT Sept 9-11, 2025—Grand Junction, CO Oct 7-9, 2025—Missoula, MT

Forms and details are mailed to our regular patients in these areas in the months before they take place. If you do not receive any information about an Outreach Clinic near you, or would like to schedule an appointment at one of these locations, please contact our front desk team at 303-724-0724 or toll free at 888-297-0724. Details on our website.

SAVE THE DATE FOR OPPORTUNITIES IN 2025



Mark your calendar for the Unite for Bleeding Disorders walks that provide support and community for families with bleeding disorders. This is one of the main fundraisers for chapters of the National Bleeding Disorders Foundation, including Colorado and Montana/Wyoming. The funds raised go directly to each chapter and provide support for education, awareness, for Bleeding Disorders advocacy and research. Don't miss this chance to be a part of this opportunity to make a difference. If you are unable to attend, consider donating directly to their walk online.

NBDF Colorado Walk: Saturday, August 23, 2025—Sloan's Lake Park 9 am

RMHBDA Montana Walk: Saturday, September 6, 2025-Zoo Montana 9 am



Sign up now to participate in the 77th **NBDF Bleeding Disorders** Conference. This year the conference will be held here in Aurora, Colorado from Aug 21-23, 2025 at the Gaylord **Rockies Resort and Convention** Center. All sessions, symposia, social events and exhibits will be located in

the hotel's convention center. This is a chance for patients and families of those with bleeding disorders to learn and connect with researchers and medical professionals sharing the latest advancements in patient care and research. There is a program for kids under 12, and a teen track, as well as tracks for NBDF chapters, consumers and health care providers. Many of our HTC staff will be in attendance, we would love to see you there. **Registration is open now**. Learn more at bleeding.org/events.

RECENT HEADLINES

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

FDA Approves Qfitlia (fitusiran)- a Subcutaneous Therapy for Hemophilia A & B

Paper Looks at Bone Health Screening Rates at HTCs Nationwide

Takeda Will Discontinue Two Treatments for Hemophilia

Study: Children with Hemophilia Have Problems with Dynamic Balance & Falls

Pfizer Discontinues Hemophilia B Gene Therapy Beqvez

CSL Reports on Four Years of Data for Gene Therapy Hemgenix

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 X/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!



UPCOMING EVENTS

Mark Your Calendars:

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

Apr 24: NBDF Colorado—Journey Through von Willebrand Disease Dinner Program

May 10: NBDF Colorado—Women's Luncheon, Manitou Springs, CO

May 11: Mother's Day

May 15: RMHBDA Montana—Education Dinner

May 17-18: NBDF Colorado—Colfax Marathon Relay

May 19: RMHBDA Montana—Education Dinner

May 26: Clinic, Pharmacy, and Admin offices closed for Memorial Day

June 7-8: NBDF Colorado Family Camp—Allenspark, CO

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

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Web page:

medschool.cuanschutz.edu/ hemophilia-thrombosis PLEASE PLACE STAMP HERE