

# The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

August 2024  
Volume 14, Issue 8



Hemophilia and Thrombosis Center  
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with  
Children's Hospital Colorado

## MILE HIGH SUMMER CAMP 2024



The Teen Leadership Group heading out on their retreat the weekend before Mile High Summer Camp. Photo: NBDF Colorado

Mile High Summer Camp was held July 14-18, 2024, at Easterseals Colorado at Rocky Mountain Village in Empire, Colorado. The Teen Leadership retreat began July 12<sup>th</sup> with the teens joining the main camp on the 14<sup>th</sup> when the younger campers arrived.

The teen group included eleven teens who went up to Kremmling, Colorado

with the Breckenridge Outdoor Education Center (BOEC). They camped for two nights, cooked their own meals, went rafting, and had a great time!

At the main camp, more than fifty campers attended this year, which was the largest group we have seen since 2019. We even had our first camper attend from Montana since 2019 as well. As always, our staff showed up with their incredible skills and kindness to help teach and provide support to all the campers throughout the week. Kids at camp have the chance to learn new skills, including learning to self-administer their medications via infusions. This is a challenging experience for many, and we saw beautiful exchanges when peers and older campers encouraged younger ones during this process.

Mostly, camp is for fun and community! This year provided ample opportunities for campers to have fun; from sharing talents, swimming, crafts, and fishing, to music & drama, and even a zip-line! Mile High Summer Camp is a place where kids who didn't even know each other can form new friendships that can last a lifetime.

Over forty of our campers completed the "Teachable Moments" curriculum this year. This is a program that campers could voluntarily seek out members of staff in various disciplines (social work, physical therapy, nursing, providers) to learn important things about bleeding disorders. It was a fun way to learn with each interaction earning them a bead. They could then find NBDF's Program Manager, Anna Cheshire, who had them "teach back" what they learned. This earned them their final bead. Those who completed this program earned five beads a day for three days.

Our HTC staff and the NBDF Colorado team shared some fun photos, just a few of which we have included in this newsletter. We are currently in the process of adding all our photos to our camp website page. Go to [medschool.cuanschutz.edu/htc](https://medschool.cuanschutz.edu/htc) and find our "Resources Tab", where you'll see "Bleeding Disorders" and a page for "Camp" to see more photos. We would like to thank all the HTC staff who supported camp, the NBDF Colorado team, and the wonderful staff at Rocky Mountain Village for their incredible dedication to making this a magical experience for these children in the bleeding disorders community!



Learning to self-infuse is a challenging experience at camp. Photo: Jenn Brown



Campers having fun peering in at our staff at Mile High Summer Camp. Photo: DeEtta Barnhardt

### INSIDE THIS ISSUE

- Mile High Summer Camp 2024
- Pictures from Camp
- Unite for Bleeding Disorders Walk-CO
- Pay your Pharmacy Bill Online
- Drops of Love
- Event Calendar
- News & More

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



Go to [facebook.com/ColoradoHTC](https://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)

# UNITE FOR BLEEDING DISORDERS WALK-DENVER



Join us at Sloan's Lake Park on **August 24, 2024**, to raise awareness and funds to support the bleeding disorders community! This is the major fundraiser for the National Bleeding Disorders Foundation (NBDF), and provides support for all their incredible programs including Education Days, retreats, Backpacks + Bleeders, and Mile High Summer Camp! There will be music, awards, coffee, and breakfast burritos! Come have some fun, take a walk and make a difference!

Sign up online at [uniteforbleedingdisorders.org](https://uniteforbleedingdisorders.org). Join our HTC team "**Chill Factor**", join a different team, or create your own! If you can't make it, you can still help by donating online.

Check in begins at 8 am, which will be followed by a brief opening ceremony at 9 am, with the walk beginning immediately after.

Be aware that this year, the walk will begin at a different location than the last couple of years.

Please find the start location, with all the booths and treats, at the SOUTH CENTRAL side of the park, just off 17th and Utica Street.

For more info see the NBDF website at [cohem.org](https://cohem.org).



**Unite**  
for Bleeding Disorders

## 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 QR code below.



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

You can still pay your bill by check by mailing your payment (along with the remittance statement included in your invoice) to:

University of Colorado Hemophilia Pharmacy  
P.O. Box 911969  
Denver, CO 80291

If you have any questions about how to pay your pharmacy bill, details can be found at [medschool.cuanschutz.edu/hemophilia-thrombosis/pay-my-bill](https://medschool.cuanschutz.edu/hemophilia-thrombosis/pay-my-bill), or you can contact our HTC pharmacy at **303-724-0168 or 1-888-297-0724**, or email at [hemophilia@ucdenver.edu](mailto:hemophilia@ucdenver.edu).

## DROPS OF LOVE PROGRAM

We have a new program at our HTC called "Drops of Love" to celebrate our staff.

We know that often our HTC team members do a great job but may not know that their efforts were appreciated. We would love your help!

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!

Just scan the QR code (below) 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!



# CAMP PICTURES



All photos are courtesy NBDF or HTC staff. See more at our website.

## RECENT HEADLINES

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

**Prophylactic Treatment of Hemophilia Linked to Less Disability-Related Unemployment**

**Pfizer Shares Positive Trial Data for Hemophilia A Gene Therapy**

**Small Study Shows Extended Half-life Using Experimental Treatment for Hemophilia with Inhibitors**

**Study Shows Hemlibra Safe, Effective in Older Patients**

**FDA Grants Orphan Drug Status to Biopharma's B-cell Treatment for Hemophilia B**

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](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) 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.**

**Aug 24:** NBDF Colorado Unite for Bleeding Disorders Walk—Sloan's Lake, CO

**Aug 27-29:** HTC Outreach Clinic—Missoula, MT

**Sep 2:** Clinic, Pharmacy, and Admin offices closed for Labor Day

**Sep 6:** RMHBDA Golf Clinic & Dinner—Billings, MT

**Sep 7:** RMHBDA Unite for Bleeding Disorders Walk—Billings, MT

**Sep 7:** Bowling with Backpacks + Bleeders—Lone Tree, CO

**Sep 12-14:** NBDF Bleeding Disorders Conference—Atlanta, GA

**Sep 17-19:** HTC Outreach Clinic—Billings, 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)

**ME-WE-HTC** We create hope.

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or toll free at 888-724-7427

Web page:

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

PLEASE  
PLACE  
STAMP  
HERE