

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
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NHF CO EDUCATION DAYS A SUCCESS



Many of those attending Education Days in 2023 were able to go downtown to see the Denver City and County Building lit up red in honor of those with bleeding disorders. Photo: Hanna Beary

NHF Colorado and the HTC joined forces in April to support NHF Colorado Education Days. This annual gathering allows families with bleeding disorders to connect, learn, and support one another. Our HTC staff was very happy to have been able to participate and help our bleeding disorder families in this fun and engaging event.

This year, Education Days was held at the Hyatt Regency Hotel in the Denver Tech Center from April 14-16th and provided a chance for families

to meet together for a weekend of learning and connection free of charge. The event provided childcare during the conference which allowed kids to play together while letting adults fully engage in the programs. Many of our HTC staff, including physical therapists, nurses, doctors, and our psycho-social team were involved, and shared that it was a wonderful event.

Our nursing team worked with patients in an infusion session that was well attended. Nurse Kim Hurdstrom and physical therapist Laura Singer-Fox helped teens to create a “go bag”, which contained everything that they may need (except the actual factor medication) to infuse if something came up when they were far from home. Nurse Nancy Spomer was a part of a question-and-answer session and provided support during the infusion session as well.

Joanna Roybal, one of our physical therapists, led a session on Practical Mindfulness in which she shared ways to use your body to calm your mind. She provided specific resources for our younger patients to manage stress by using physical activity, and she provided practical tips for anyone to use mindfulness to relieve stress throughout the day.

The psycho-social team from the HTC were also involved with several fun activities at the event. Our social workers, Bryn Dunham and DeEtta Barnhardt, and one of our psychologists, David Hayduke, managed a



Dr. Marilyn Manco-Johnson speaks at the NHF Colorado Education Days. She introduced our two Fellows who have been working at the HTC for the past few months. Photo: Perry Jowsey

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HTC Director Dr. Mike Wang spoke about upcoming therapies at NHF Colorado Education Days. Photo: Perry Jowsey

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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

VERIFY YOUR INSURANCE COVERAGE NOW



Many people who have Medicaid, including those whose children may qualify for the Child Health Plan (CHP) in various states, may lose eligibility for these programs due to changes in federal funding starting in May 2023. Those who do still qualify need to confirm contact information with these programs, and check to see if there is a need to make any changes for health plan coverage going forward.

To update or check your contact information, see the following resources.

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](#)
- Connect for Health Colorado at connectforhealthco.com or 1-855-752-6749 is a good resource for CO residents to navigate the Health Insurance Marketplace and options on lowering costs of private insurance

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 to navigate the Health Insurance Marketplace and options on lowering costs of private insurance

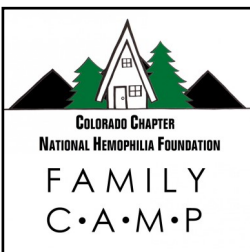
For Montana residents:

- 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 MT 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 to navigate the Health Insurance Marketplace

Our HTC staff are aware of this change and how it may impact patients. If you need a new insurance plan, our HTC can help you understand which plans work with our center and provide the coverage and medications you need.

Please contact us if you have questions and need some help in verifying your coverage or if you will need to enroll in a private program. Reach out to our social workers, Bryn Dunham bryn.dunham@cuanschutz.edu, and DeEtta Barnhardt deetta.barnhardt@cuanschutz.edu, or contact our pharmacy at 303-724-0168 or our main clinic at 303-724-0724 for information and support.

NHF COLORADO UPCOMING EVENTS



June 10-11, 2023

NHF Colorado Family Camp: Highlands Presbyterian Camp and Retreat Center—Allenspark, CO

Sign up before May 1, 2023 to attend NHF Colorado's Family Camp. This is a great opportunity for families with young kids with a bleeding disorder to connect and spend time with others in the bleeding disorder community. It's also a fun and relaxing time for families to help their kids as they learn to take their first steps toward self-care and self-infusion. Register at cohemo.org or contact Hanna Beary at hbeary@hemophilia.org.

June 24, 2023

Backpacks + Bleeders: Whitewater Rafting the Cache la Poudre

Sign up today to join Backpacks + Bleeders as they take a half-day whitewater rafting trip down the Lower Poudre near Fort Collins, CO. This adventure is facilitated by Rocky Mountain Adventures and will take place on Saturday, June 24, 2023 from 11-2 pm. To sign up or for more information, go to cohemo.org or contact Hanna Beary at hbeary@hemophilia.org.



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booth with a spinning wheel to have kids answer questions, as well as providing handouts for financial resources, sharing our newsletter, and Medical ID forms or applications. They also helped our teens with a BINGO game, where those in attendance could interact with various tables to get their cards signed.

Dr. Michael Wang, our HTC Director, was honored to be able to speak about new therapies in the pipeline that may provide positive impacts on our patients' lives. His expertise in novel therapeutics provided an informative and encouraging view on how these potential therapies could be used to help patients.

Many other speakers and discussion groups were offered throughout the weekend event, including a spotlight on visiting HTC Fellows Rebeca Gutierrez Telica, and Andrea Odonez Cuetto. They have both been working with our HTC and Children's Hospital over the past two months studying hematology. Dr. Ordonez Cuetto was a pediatric resident in Mexico City and Dr. Gutierrez Telica was a pediatric resident in Guatemala.



Our HTC was happy to have been able to be a part of the 2023 Education Days and that so many of our patients and families were able to join us in learning and connecting. We thank NHF Colorado for their efforts in putting together so many informational sessions and presentations to help our bleeding disorder community.

NHF Colorado Education Days had a great turnout with those in attendance having many opportunities for learning and connections with others in the bleeding disorder community. Photo: Perry Jowsey

MILE HIGH SUMMER CAMP 2023—SIGN UP SOON!



Mile High Summer Camp will be here before you know it! NHF Colorado is working hard to get 2023 camp ready to go and is excited to have several new changes in camp this year.

Mark your calendar for some important upcoming dates for camp this year. NHF Colorado expects to open registration for all campers starting on **May 1, 2023**. **The last date to apply will be June 15, 2023, no exceptions.**

Sun-Thurs., July 23–27, 2023: Main Mile High Summer Camp for kids ages 7-13

Fri-Sun., July 21–23, 2023: Teen Leadership Weekend for teens ages 14-17 (teens ages 14-15 will then attend Mile High Summer Camp with the main camp)

Teens ages 16-17 are invited to apply to be a part of the **Bleedership in Training program (BITs)**. These teens would attend the Teen Leadership Weekend and then spend the rest of camp expanding leadership skills helping younger campers.

NHF is also recruiting young adults ages 18 and up who are willing to guide our younger campers and gain leadership skills as one of our **Bleedership Counselors**. These young adults will provide support for campers in all activities and must be available July 21-27, 2023. Applications for this program will also open when camp registration begins May 1st.

For info and details about these programs, please see the camp pages at cohemo.org, or contact our camp director Hanna Beary at hbeary@hemophilia.org or 646-499-0684.



RECENT HEADLINES

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

Survey of HTC Clinicians Shows Changes in Treatment Trends over 22 Years

Sanofi Announces Results from Two Phase 3 Trials of Fitusiran

Dr. Beth Warren Discusses Differences in Factor and Non-Factor Prophylaxis in ASH Publication

New Data: Hemgenix Reduces Bleeds in Hemophilia B Better than Standard Replacement Therapy

FDA Extends Review of Gene Therapy Roctavian for Hemophilia A

FDA Approves Efanesoctocog Alfa (Altuviiio) to Treat Hemophilia A

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 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.

May 6: NHF Colorado Women's Group, Teatime

May 29: Clinic, Pharmacy, and Admin offices closed for Memorial Day

June 10-11: NHF Colorado Family Camp—Highlands Presbyterian Camp, Allenspark, CO

June 24: NHF Colorado Backpacks + Bleeders Rafting Event

July 4: Clinic, Pharmacy, and Admin offices closed for Independence Day

July 21-23: Teen Leadership Weekend

July 23-27: Mile High Summer Camp

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

ME-WE-HTC We create hope.

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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

PLEASE
PLACE
STAMP
HERE