

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

August 2023
Volume 13, Issue 8



Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with
Children's Hospital Colorado

MILE HIGH SUMMER CAMP 2023



Dr. Wang helps one of the campers at camp.
Photo: NHF Colorado

In July, NHF Colorado and the HTC joined forces to host Mile High Summer Camp at Easterseals Rocky Mountain Village in Empire, Colorado. This annual camp combines a separate leadership weekend, where older campers have their own adventure, and then work with younger campers (ages 7-14) for their time at camp. This year our leadership weekend was held from July 21-July 23; the main Mile High Camp ran from July 23-July 27, 2023. Campers came to participate in Mile High Summer Camp from all over Colorado, Wyoming, and Montana. Siblings were also invited to join, connecting them to others in the bleeding disorders community. This year our camp welcomed around 45 campers who enjoyed a successful week of fun and learning.

including archery, horseback riding, swimming, fishing, crafting, and even a zip-line! It is a great way for these kids who face the challenges of a bleeding disorder in their lives to make new friends, learn leadership, gain new skills, and take steps toward managing their own health. Our HTC nursing staff, doctors, psychosocial workers, and physical therapists participate to teach and provide support for campers.

We had a great group of kids this year, and one of our social workers, Bryn Dunham shared:

“At camp this year, I watched the teenage and young adult Leadership group share their knowledge and skills in infusion and injections with younger campers. The teenagers also provided unending, consistent support for the younger campers throughout all camp activities, both hemophilia-related as well as general camp fun. This mentorship is essential for young campers and I am excited to watch this process continue to blossom and grow in future years.”



NHF Colorado Program Manager Hanna Beary (right) joins some campers for some fun smiles. Photo: NHF Colorado

We are grateful for all the support from our HTC staff and NHF Colorado to make Mile High Summer Camp a wonderful experience. A few pictures from camp are on page 3; these and other pictures from camp can be found at our website camp page here: <https://medschool.cuanschutz.edu/hemophilia-thrombosis/resources/bleeding-disorders/camp> Scroll down to see photos from 2023 and 2022. For more information about Mile High Summer Camp and what NHF Colorado offers, go to cohem.org.



Mile High Summer Camp was held in late July up at Easterseals Rocky Mountain Village in Empire, Colorado. Photo: NHF 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



Go to twitter.com/HTCColorado



Website: Go to

medschool.cuanschutz.edu/hemophilia-thrombosis



Email:

HTC.Newsletter@ucdenver.edu

MARK YOUR CALENDAR: UPCOMING EVENTS



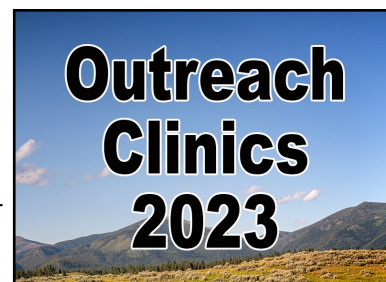
August 26, 2023: NHF CO Walk—Sloan’s Lake Park, Denver, CO

Sept 9, 2023: RMHBDA Walk—Zoo Montana, Billings, MT

NHF Colorado’s Unite Walk is will be on August 26th at Sloan’s Lake Park in Denver. Please join us as we walk to raise funds and awareness to those with bleeding disorders. You can sign up just to walk, join a team, make your own, and even walk virtually. If you are in Montana, sign up to support the RMHBDA Unite walk in Billings on Sept 9th. Both walks are the only major fundraisers for these powerful programs supporting those with bleeding disorders. If you can’t make it, consider donating! Learn more and sign up for the [NHF CO walk on Aug 26, 2023 at Sloans Lake Park, Denver, CO](#) or the [RMHBDA walk on Sept 9, 2023 at Zoo Montana, Billings, MT](#) by going to uniteforbleedingdisorders.org.

Sept 12-14: Outreach Clinic—Grand Junction, CO

We will be holding an outreach clinic in Grand Junction, CO next month from Sept. 12-14th for patients who live in and around the Grand Junction area. Letters have been sent to local patients, but give us a call if you do not receive one or would like to make an appointment for this clinic. **Be aware that we have moved locations for this clinic.** To schedule or answer questions about this clinic, contact us at our front desk: 1-888-297-0724 or 303-724-0724. See details at our website: medschool.cuanschutz.edu/hemophilia-thrombosis/clinic/clinics/bleeding-disorders/outreach



UPDATES AND CHANGES FROM THE NHF/NBDF BLEEDING DISORDERS CONFERENCE



Nikki Clark, PT, and Bryn Dunham, LCSW, at the NBDF Bleeding Disorder Conference. Photo: NHF Colorado

The NHF Bleeding Disorders Conference was held August 17-19, 2023 in National Harbor, Maryland. There it was announced that the National Hemophilia Foundation is changing their name to the National Bleeding Disorders Foundation (NBDF). This change is to reflect the wider group of bleeding disorders they have been serving for many years. You can learn more about their name change at their website hemophilia.org. Watch for changes to local chapters and branding over the next year or so as NHF shifts to NBDF and continues to serve all our bleeding disorder patients.

Several members of the staff at our HTC were able to attend the and participate in the bleeding disorders conference. Bryn Dunham, social worker, Kim Hurdstrom, nurse, Nikki Clark, physical therapist, Tyler Buckner, MD, Beth Warren, MD and Mike Wang, MD, were each involved as speakers, advisory board members, moderators, or panelists at the conference.



We also want to congratulate several people in our HTC circles that received special recognition at the conference.

Kaylee Dollerschell was awarded Genetic Counselor of the Year.

Joanna Roybal was awarded a NBDF Research Grant for upcoming work she will be starting in the motion lab-Laser labyrinth proprioception training (LLPT).

Hanna Beary of the local NHF Colorado chapter accepted on behalf of the chapter the Ziggy Douglas Innovation in Youth Programming Award, which recognizes youth programming that fosters development of leaders.

Chris Bombardier, which many of you may know as both a patient and former HTC employee, received the Humanitarian of the Year Award for his successful leadership of Save One Life.

Dr. Donna Di Michele was honored as Researcher of the Year-Donna was a resident and fellow here at CU and trained with Dr. Hathaway.

Congratulations to all and thank you for all you do in support of bleeding disorders! Whether under the NHF or NBDF banner, it all makes a huge difference in the lives of those with bleeding disorders.



Kim Hurdstrom, presents in a panel at the BDC. Photo: Kim Hurdstrom

Director Mike Wang, MD, accepts an award at the BDC. Photo: NHF Colorado.

MILE HIGH SUMMER CAMP 2023



See more pictures at our website: <https://medschool.cuanschutz.edu/hemophilia-thrombosis/resources/bleeding-disorders/camp> Scroll down to view the gallery.

RECENT HEADLINES

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

Small Number of Young Patients Experience Severe Bleeds on Hemlibra

Gene Therapy Roctavian Likely to Arrive in US in August 2023

Roche's Gene Therapy Trial of SPK-8011 Moves Forward to Phase 3

Recent Studies Show Fitusiran Could Treat Women's Bleeding Disorders

In Non-Severe Hemophilia A, Hemlibra is Not as Cost-Effective as Standard Care

FDA Approves First Gene Therapy for Adults with Severe 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 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 26: Unite for Bleeding Disorders Walk—Denver CO

Sep 4: Clinic, Pharmacy, and Admin offices closed for Labor Day

Sep 9: Unite for Bleeding Disorders Walk—Billings, MT

Sep 12-14: Outreach Clinic—Grand Junction, CO

Oct 6-8: NHF Colorado Women's Wellness Retreat, Glenwood Hot Springs, Colorado

Nov 3-5: RMHBDA Women's Retreat—Chico Hot Springs, Pray, MT

Nov 23-24: Clinic, Pharmacy, and Admin offices closed for Thanksgiving Holiday

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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