

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

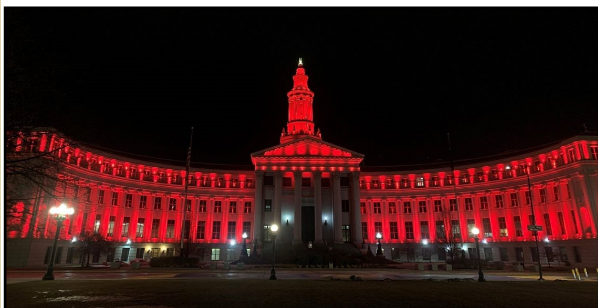


Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with
Children's Hospital Colorado

BLEEDING DISORDERS AWARENESS MONTH



The Denver City and County Building lit up red for Bleeding Disorders Awareness Month. Picture: NHF Colorado.

March is Bleeding Disorders Awareness Month! The past couple of years have made it hard to advocate and find ways to support those in our community, but this year NHF Colorado led the way with many activities to bring awareness!

President Ronald Reagan designated March as Hemophilia Awareness Month in 1986, and in 2016 the US Department of Health and Human Services officially

broadened this month to include all bleeding disorders. Over the years there have been many ways to bring awareness, and both the National Hemophilia Foundation and the Hemophilia Federation of America have shared large national campaigns to make a difference.

This year, our local NHF Colorado chapter has encouraged many of our community to come together to support those with bleeding disorders through advocacy. In early March, a group of NHF Colorado members were able to attend the Colorado State Advocacy Day.

NHF Colorado families know firsthand the impact legislation can have on their healthcare needs. They met with many local legislators from around Colorado and spent the day at the Colorado State Capitol bringing awareness to the needs of those with bleeding disorders. We applaud all who were able to attend and help bring a personal face to the challenges faced by all with bleeding disorders.

Nationally, the National Hemophilia Foundation held their annual Washington Days on March 1-2, 2022, to meet with national legislators virtually. In addition, the Hemophilia Alliance will be hosting a virtual Hill Day on April 5th to help educate national lawmakers as well.

This year the Denver City and County Building lit up their building red in honor of Bleeding Disorders Awareness Month. Other bleeding disorder community events have begun now that the pandemic restrictions are beginning to ease, and events this year will hopefully allow more support to those touched by these disorders.

Our HTC and NHF Colorado are planning both Family Camp and Mile High Summer Camp as in-person activities. Mark your calendar to attend the Unite for Bleeding Disorders Walk on [August 13th in Denver](#), or on [September 10th in Montana](#) to support both NHF Colorado and the RMHBDA in Montana. We thank all who are getting involved and encourage everyone to find ways to share awareness and participate in these programs to support those with bleeding disorders.



NHF Colorado met with local legislators at the State Capitol this month. Picture NHF Colorado.



The 2022 NHF Colorado group that visited the State Capitol for Colorado State Advocacy Day. Picture: NHF Colorado.

INSIDE THIS ISSUE

- Bleeding Disorder Awareness Month
- Meet Desi Hill, Pharmacy Manager
- Outreach Clinic Update
- Pediatric Stroke Parent Support Group
- Camp and Ed Days
- Upcoming Events
- News

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

SPOTLIGHT: DESI HILL, PHARMACY MANAGER



As you may know, our pharmacy has recently undergone several changes in staff. This month we welcome Desiree Hill, PharmD, RPh as our new Pharmacy Manager! Desi has been working with our HTC since 2010 as a pharmacist and has played an integral role as a part of our pharmacy team.

Desi grew up in rural Wyoming and was always interested in science and math. She attended Ricks Junior College in Rexburg, Idaho for her undergraduate degree and later attended the University of Wyoming School of Pharmacy. She pursued pharmacy in looking for a career in which she could help others but that would also allow her to spend time as a mom. She always envisioned herself working in a pharmacy in a small town in Wyoming, but followed her boyfriend (now husband) to Denver and worked in retail pharmacy for ten years before joining the HTC pharmacy.

She began working with our center only once a week as a contractor, but soon realized she had an immediate connection with both patients and co-workers.

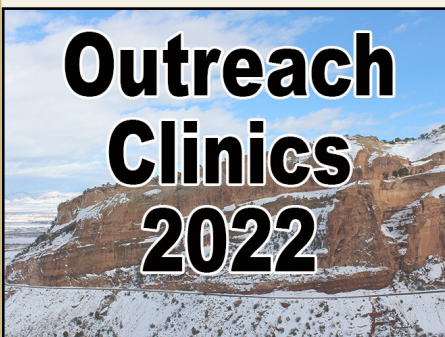
“I became a pharmacist because I love to take care of people, the HTC was a perfect fit for me. I love that we take care of people from birth to grave; it is so satisfying for me to see our patients grow and thrive. I love our patients, and I love our team!” – Desi Hill

One of the things Desi appreciates about working at the HTC pharmacy is that we are a non-profit 340B pharmacy, which allows our pharmacy staff to work with our clinic and base their decisions on what is best for the patient. She enjoys being a part of a multi-disciplinary group that takes care of a specific type of patients and addresses more than just their pharmaceutical needs. Being a part of a team with nurses, social workers, physical therapists, and medical providers at the HTC gives Desi a lot of satisfaction because of the well-rounded approach to care.

Desi works hard to maintain a work/life balance and enjoys traveling, riding roller coasters, and being with her two boys. As they are busy with teenage activities like golf and basketball, a lot of her extra time is spent driving them around and watching them participate in their activities. She is a very accomplished baker and has shared many of her delicious treats with our HTC staff, for which they are all appreciative! She also enjoys shopping and calls herself a ‘documentary dork’, enjoying shows such as the “That Built America” series on the History Channel.

As she steps into the role of Pharmacy Manager she considers Paul Limberis, who has just retired, to be her mentor and she plans to follow in his big footsteps. Desi will continue to work to keep our pharmacy fully accredited, which is a project she helped and supported the entire pharmacy staff achieve over the past several years. In addition, she is working with the Leadership for Innovative Team Science (LiTES) program investigating the future of gene therapy in hemophilia. This new frontier of care for patients will take much planning and skill to fully implement for use once approvals begin.

We at the HTC are thrilled to continue to work with Desi and are excited to see her advance and lead in this new role as our Pharmacy Manager.



OUTREACH CLINICS SCHEDULED FOR 2022

Outreach Clinics are an opportunity for our patients who do not live close to our clinic in the Denver area to meet in person with our clinical staff closer to their homes.

These clinics were cancelled during the pandemic due to travel restrictions for our staff as well as safety concerns. After two years of stops and starts, the HTC has several scheduled Outreach Clinics for 2022!

Of course, these are subject to change, but we are hopeful that we will be able hold them this year. Each of our Outreach Clinics will be scheduled through our front desk, and our staff will be sending out letters to those who live in these locations as we approach each date. Some of these clinics we will not yet be scheduling.

Save the Date:

May 18-20, 2022: Grand Junction, Colorado

June 22-24, 2022: Billings, Montana

Sept 28-30, 2022: Missoula, Montana

Oct 26-27, 2022: Billings, Montana

If you have questions, please [contact our front desk](#), or see our [Outreach Clinic website page](#) for more information.

PEDIATRIC STROKE PARENT SUPPORT GROUP

Pediatric Stroke Parent Support Group

VIRTUAL ZOOM Meeting

Monday
Apr 11, 2022
6:30-7:30 pm

Our next Pediatric Stroke Parent Support Group will be on **Monday, April 11, 2022 at 6:30 pm** on Zoom. This group invites parents of children who survived a stroke to meet with one another and our stroke team each month.

Normally we meet in person, but with the COVID-19 pandemic restrictions we are continuing to have these meetings on Zoom until things improve.

We are meeting on the second Monday of the month from 6:30 to 7:30 pm. Meetings are open to families of children of all ages and all types of stroke. Your child does not need to be seen at our stroke clinic to join our meetings.

[For more details, see our website](#), or [follow us on Facebook](#). To join our meeting, please RSVP to strokesupport@ucdenver.edu or call 303-724-8520.

CAMP AND EDUCATION DAYS COMING SOON!

We are excited to share some fun opportunities coming up this year! Please be aware that these are subject to change. These events likely will require abiding by COVID-19 safety protocols, so please check carefully what restrictions are in place. In addition, some events will have capped attendance, so please register early. We also recommend scheduling your HTC comprehensive visits and physicals now for those planning on attending summer camp.



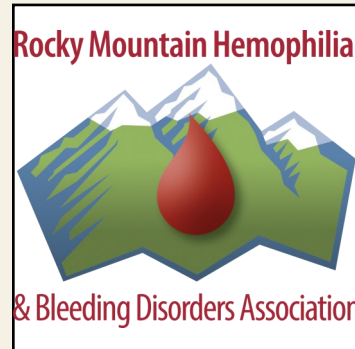
NHF Colorado Education Empowerment Days— Spring Series

April 24-29, 2022

**Registration Deadline:
April 14, 2022**

This will be a hybrid event, with some virtual and in-person activities across the

days of the event. Those attending one or more of the four education opportunities will receive a ticket to the Rockies Baseball Game on Friday. [Learn more at cohemo.org](#) or contact Hanna Beary at hbeary@hemophilia.org.

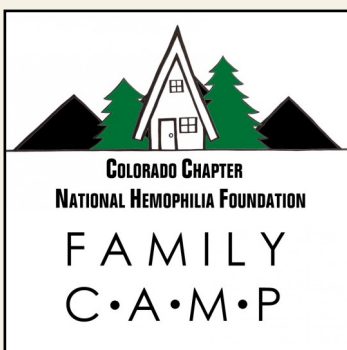


RMHBDA Education Weekend—Fairmount Hot Springs, Fairmount, MT

April 29-May 1, 2022

**Registration Deadline:
Until space is filled**

Bleeding disorder families in the Montana area are invited to attend a weekend of learning, fun, and the chance to connect with others. Lodging and meals are provided. [Learn more at rmhbda.org](#) or contact Brad Benne at brad@rmhbda.org. Fill out [this form for registration](#).



NHF Colorado Family Camp

May 21-22, 2022

**Registration Deadline:
May 1, 2022**

This is designed for individuals, families, and children living with a bleeding disorder. The focus

is on fun, relaxation, support, community, as well as education to help those with bleeding disorders learn to self-infuse.

[Learn more about this event at cohemo.org](#) or contact Hanna Beary at hbeary@hemophilia.org.



Mile High Summer Camp

Ages 15-17 only-

July 15-17, 2022

Ages 7-14 only-

July 17-21, 2022

**Registration Deadline:
June 13, 2022**

Mile High Summer Camp is scheduled as an in-person event in 2022!! Registration opens in **mid-April** and the number of campers will be capped, so register early! Priority will be given to those with diagnosed bleeding disorders.

[Learn more at cohemo.org](#), or contact Hanna Beary at hbeary@hemophilia.org.

RECENT HEADLINES

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

Gene Therapy Roctavian Safely Raises FVIII Levels for Hemophilia A Patients in Trial

Sobi and Sanofi Announce Positive Data for Efanesoctocog Alfa to Treat Hemophilia A

Joint Damage Still Evident in Hemophilia A Patients with Milder Disease

Vibrating Microbubbles May Improve Gene Therapy Delivery for Hemophilia A

The Legacy of HTC's: Article from HFA's Dateline Federation

Bleeds, Physical Limitations, Affect Severe Hemophilia A Patients Despite Prophylaxis

We maintain a newsroom page at our website with a list of the news we feel 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.

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 9: Backpacks + Bleeders: Beyond Boulder Cycling Event

Apr 11: Pediatric Stroke Parent Support Group-virtual

Apr 17: World Hemophilia Day

Apr 20-23: HFA Symposium—San Antonio, TX

Apr 24-29: NHF CO Education Empowerment Days-Spring Series—virtual and in-person

Apr 29-May 1: RMHBDA Education Weekend—Fairmount, MT— in-person

May 7: Backpacks + Bleeders: Garden of the Gods Climbing Event

May 21-22: NHF CO Family Camp-Allenspark, CO

See more at our Events Page on our website:

medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar

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