

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

UNITE FOR BLEEDING DISORDERS WALKS



The Billings Montana Walk will be on Sept 11th at Zoo Montana. Photo: RMHBDA

Can you join us for a walk!? It's almost time for the Unite for Bleeding Disorder Walks once again! The NHF Colorado chapter is hosting their annual [Unite for Bleeding Disorders Walk](#) on **Saturday, August 28th at Sloan's Lake Park**. Check-in begins at 8 am and the walk starts at 9 am. This walk is vital to help the chapter fund the many activities and educational programs throughout the year, including camp. While the pandemic has put a damper on many things in the past year or so, NHF Colorado continues to reach out to families in the bleeding disorder community and strives to offer support.

This year you are welcome to join us virtually as well as in person! The Denver walk has a [new location for 2021!](#) The walk is still at Sloan's Lake but because of some construction we are meeting at the northeast side, also called the North Central Area. This is located near 22nd Street and Stuart Street. Parking for general participants is available along West Byron Place between Vrain Street and Stuart Street on the north side of the lake, or you can park in the neighborhoods surrounding the walk site. VIP parking for Elite Grand Champions is located right near the start at 22nd and Stuart. [Check out the cohemo.org website for details on how to become a VIP!](#)



Meet us at our new location at Sloan's Lake on the northeast side this year!

NHF Colorado will have a camper reunion area that is just for our campers to reconnect, hang out, and enjoy donuts together. Precautions will be in place to keep things as distanced and sanitized as possible. For those who want to participate virtually, you can check in with NHF Colorado on their [Facebook page](#) for a livestream broadcast. [More details and maps to parking are available at the NHF Colorado website \(scroll to the bottom for maps\).](#)



Walkers make their way around Sloan's Lake in 2017. Photo: Merilee Ashton

If you are one of our Montana or Wyoming bleeding disorder patients, the [Rocky Mountain Hemophilia and Bleeding Disorders Association's Unite for Bleeding Disorders Walk](#) is coming up soon as well. The Montana walk will be on **Saturday, September 11th** starting at 9 am **at Zoo Montana** in Billings, MT. This is a great opportunity for Montana and Wyoming locals to support RMHBDA and their incredible resources. The Montana walk will also have a climbing wall, an ice cream truck, and a bouncy house for participants to enjoy.

Whether you can join in person, or walk from afar, take this opportunity to support those in the bleeding disorder communities and [Unite](#) with us! Thank you for your support and we hope to see you walking!



HTC Program Director, Angie Blue (right) walks with community members at the 2018 walk. Photo: Merilee Ashton

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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

SPOTLIGHT: CLAIR KAISER PHARMACIST



Clair Kaiser stands in Muir Woods in Northern California, one of her favorite places to travel. Photo: Clair Kaiser

This past year has brought a number of changes, and our pharmacy is no exception. We have added two new pharmacists to our pharmacy team in the past several months. One of them is Clairah Kaiser, who goes by Clair. She started here at the HTC just two months ago, after working in retail pharmacy for fifteen years.

As a child, Clair and her family moved multiple times and had lived in five states by the time she graduated from high school. She graduated from the University of California at Irvine, did her pre-pharmacy work in Atlanta, and got her Pharmacy degree at the Massachusetts College of Pharmacy and Health Sciences in Boston. She has experience with routine and travel vaccination programs, medication management therapy, women's health initiatives, and even worked at COVID vaccine clinics.

Clair loves music and has collected over 1,000 vinyl records! She and her family love going to concerts and comedy shows. She loves to read and used to read much more often, but as a mom of young kids, she does admit that her reading lately has been limited to news articles and Dr. Seuss! She loves exploring all kinds of foods and considers herself an adventurous eater who loves variety and flavor. She loves to travel and enjoys experiencing new cities, landscapes, and cultures. Clair finds particular joy when she can include her kids in her travels and watch them discover the world.

Clair is excited to be working with our pharmacy team and is gratified to be helping our patients with their needs. She is a delight to work with and our team loves her energy and willingness to learn new things.

She and all our pharmacy staff work together to keep our HTC pharmacy operating at the highest standards of practice. We at the HTC are grateful for Clair's expertise and welcome her to our pharmacy team where we know she makes a difference daily!

AMY COWELL HONORED WITH MARY M. GOOLEY HUMANITARIAN OF THE YEAR AWARD

Many of you know Amy Cowell who works as a Senior Medical Assistant in our clinic, helping and supporting patients nearly every day.

Amy was just awarded the National Hemophilia Foundation's Mary M. Gooley Humanitarian of the Year Award! This is an incredible honor and for any who know Amy, they know it is well deserved! Amy was nominated by Jenny Bender, one of our Professional Research Assistants.

The award "honors a non-provider HTC staff member who is dedicated to the families at their HTC and demonstrate a commitment to their care. This person has shown a caring and humane spirit in their work to improve the quality of life for patients and their families."

Amy has been working at the HTC for seven years, starting in 2014. She shared, "I came to the HTC so nervous to make such a new change in my career. Now, I could never imagine not working here. I keep saying 'This is where I will end up retiring from.' The great bond that has built, not only with the HTC family, but also the patients and families is the most valuable part of my job. I appreciate every day that we as a team, provide the best of care to each individual patient as they deserve."



Amy Cowell holding her NHF Mary.M. Gooley Humanitarian of the Year Award in clinic. Photo: Kristi Norton

Congratulations to Amy for this well-deserved achievement! Our HTC staff members are grateful for Amy and her kindness and dedication to our patients!

LAST CHANCE TO TAKE THE PATIENT SATISFACTION SURVEY!



The Third National Patient Satisfaction Survey will end on **August 31, 2021**. Have you had a chance to take it? Paper versions were mailed out to our bleeding disorder patients in March, but all bleeding disorder

patients who received care at any HTC in the country during 2020 can participate. [Simply go to htcsurvey.com](https://htcsurvey.com), click on the 'Take the Survey' button, and find the HTC that provided care for you or your child in 2020.

HTCs had to make major adjustments in 2020 due to the COVID-19 pandemic. In response, questions have been added to this survey asking patients for feedback on telehealth as well as in-person care. You can respond to this survey whether or not you were seen in person, via telehealth, or sought support over the phone, as long as you received care during 2020.

We encourage our bleeding disorder patients who have not yet done so, to take this survey online so results can be immediately included. The survey is available in both English and Spanish. We ask that parents of young children fill out one survey per child, and patients who are 18 and up fill out their own survey.

For questions, or to learn more, please go to htcsurvey.com. Don't miss this chance to let us know how we are doing!

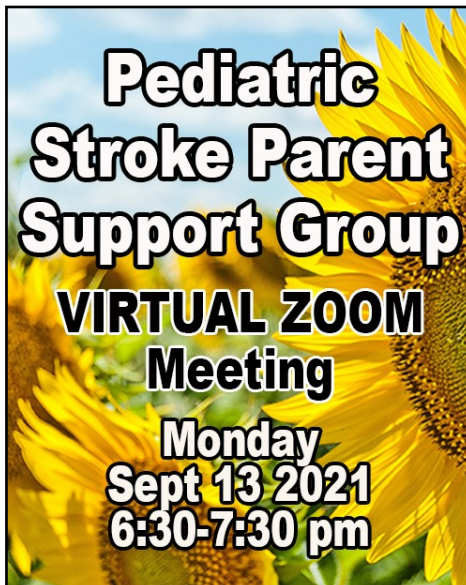
PEDIATRIC STROKE SUPPORT GROUP RESUMES IN SEPTEMBER

We will resume our Pediatric Stroke Parent Support Group on **Monday, September 13, 2021 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.

We usually have a formal presentation about topics that can help our pediatric stroke families and then have a chance to socialize. 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 have changed the date of our meetings to 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 here.](#) To join our September meeting, please RSVP to strokesupport@ucdenver.edu or call 303-724-8520.



NEW APP TO TRACK YOUR BLEEDING DISORDER

How to get started...

1. Download the app from the Apple store:



2. Let a member of our team know you are interested and we will send you an email with further information.

For more info contact:

Hana Durkee
Email: hana.durkee@cuanschutz.edu
Phone: 303-724-0422

Track bleeding events, medications, & activities that may have contributed to bleeding.

Currently available on iPhone or iPad.

[Android development is in process!]

UPCOMING OPPORTUNITIES

Sept. 11-12: Women's Wellness Retreat—Glenwood Hot Springs, CO NHF Colorado invites all women in the bleeding disorder community ages 18 and up to join us for an overnight retreat. COVID protocols will be in place for this chance to connect with others across the state.

Sept 25: Backpacks + Bleeders will be hosting a hike at Evergreen Lake. This family friendly 1.4 mile loop is a great chance to get out and enjoy the great outdoors as we move into fall weather! Dogs are welcome and parking is free!

Oct 8-10: Education Empowerment Days—Hyatt Regency DTC NHF Colorado Education Days is a two-day conference for those affected by bleeding disorders and their families. This will be both in-person and virtual and registration is free for those directly impacted by bleeding disorders.

For more details on these and other upcoming events please go to cohemo.org and [find their event calendar](#).



RECENT HEADLINES

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

Emicizumab (Hemlibra) May Improve Outcomes for Acquired Hemophilia A

Phase 2 Study Shows Monoclonal Antibody Marstacimab Appears Safe and Effective

Spark Therapeutics Shares Update for Gene Therapy SPK-8011 Trial

New Data for BioMarin's Valoctocogene Roxaparvovec, Gene Therapy for Hemophilia A shared at ISTH

ASC Therapeutics to Begin Phase 1/2 Gene Therapy Clinical Trial for Hemophilia A

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.

Aug 28: Unite for Bleeding Disorders Walk-Denver

Aug 28-29: NHF Colorado Family Camp

Sept 6: Clinic, Pharmacy, and Admin offices closed for Labor Day

Sept 11: Unite for Bleeding Disorders Walk-Montana

Sept 11-12: NHF Colorado Women's Retreat-Glenwood Springs

Sept 13: Pediatric Stroke Parent Support Group

Sept 16: NHF Colorado Gene Therapy Jeopardy

Sept 25: Backpacks & Bleeders Hike at Evergreen Lake

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

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