

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

December 2023
Volume 13, Issue 12



Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with
Children's Hospital Colorado

REFLECTING ON 2023 AT THE HTC



Some of our HTC Staff at the Unite for Bleeding Disorders Walk in Denver during August of 2023. Our team raised over \$5000 for NHF Colorado this year. Photo: Merilee Ashton

With the end of 2023 upon us, it is a good time to reflect on the effort and events that our clinic and staff were involved in over the past year. Our newsletter tries to touch on and share some of the changes, victories, challenges, and opportunities that we witness and experience through our HTC. Here are a few things we talked about in 2023.

As pandemic numbers began to ease toward the beginning of the year, many things started feeling a lot more like normal. More events, traffic, travel, and in-person visits started shifting back to what we may have experienced before the pandemic. In the spring, the CU Anschutz Medical Campus officially lifted any mask mandates and our clinic did as well. Our clinic continues to ask patients who may have transmissible symptoms such as cough, fever, muscle aches, stuffy nose, vomiting, or diarrhea to either stay home and reschedule, or wear a mask if they are coming in. We still have limited access to our building for security, so if you are visiting our center, be aware you will still need to call us upon arrival to gain entry. Our HTC has been diligent in maintaining protocols to keep our clinic clean and safe to avoid the spread of any disease.

With the good news of things going back to normal came the challenge of the federally required emergency programs beginning to expire. The emergency status for federal programs like Medicaid, CHIP and other state health plan programs ended in May, and many patients who still qualified had to re-enroll or risk losing coverage. Our team collaborated with patients to help them understand their insurance coverage and navigate the changes and requirements needed. We spent several months including this important information in our newsletter, on our website, and social media platforms to spread the word about changes that might have affected some of our patients. Our staff continues to work with patients to find ways to help them qualify for care, special programs, discounts, and other opportunities to maintain their ability to seek medical care with us. If you need support understanding insurance issues for care or pharmacy coverage, reach out to our clinic or pharmacy.



Our Pediatric Stroke Parent Support Group held their First Annual Education Day in April of 2023. Photo: Cindy Nederveld

[Continued on page 2]



Hanna Beary of NHF Colorado with one of the campers at Mile High Summer Camp, in 2023. Camp this year was fully in-person and a fun adventure for all. Photo: NHF Colorado

INSIDE THIS ISSUE

- Reflecting on 2023 at the HTC
- Pediatric Stroke Group: Holiday Party & Update
- Event Calendar
- News & More

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

[Continued from page 1] In 2023, NHF Colorado also began



Mile High Summer Camp was a great success, full of fun and learning. Photo: NHF Colorado

offering more in-person events, including a return to their Education Empowerment Days Conference, which was held in April. Many on our HTC team were involved in this event. Our nurses hosted an infusion session, our physical therapists taught mindfulness, and our psycho-social team shared educational activities. Our Director,

Dr. Michael Wang, spoke about new therapies, and the event was well attended. In August, [it was announced](#) that the National Hemophilia Foundation (NHF) was changing their name to the National Bleeding Disorders Foundation (NBDF), allowing for more inclusive wording to reflect the patient group they already support. Going forward it is likely you will see less of the events and news from this group marked “NHF” and more noting “NBDF,” though you may still see some older materials still labeled NHF for a while as this change occurs.

At the end of April, our Pediatric Stroke Support Group initiated their first Annual Pediatric Stroke Education Day. This was a half-day seminar held at our HTC to promote connection and education for stroke patients and their



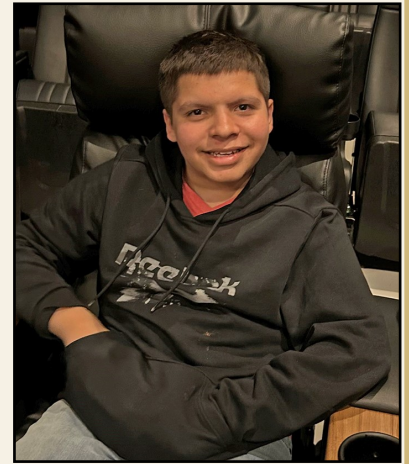
Our Pediatric Stroke Parent Support Group hosted a fun day at the park in August. Photo: DeEtta Barnhardt

families. It was an incredibly positive event and a wonderful opportunity for these families to learn and be with others in similar circumstances. The Pediatric Stroke Support Group is already planning the second annual version of this event to be held on April 20, 2024. This group also had a fun park outing in August, as well as a holiday party at the beginning of December. For more information on this group, see our [support group webpage](#).

In May we highlighted our stroke program during Pediatric Stroke Awareness month. We shared the experience of one of our patients, Izaiah Ornelas, who survived a stroke at school when he was twelve. Powerful stories of patients like Izaiah, who overcome so much, show resilience and give hope and courage to others going through similar experiences. We are blessed to be able to work with such

families and see their kindness and strength during their considerable challenges.

As we moved toward the summer, we began enrolling bleeding disorder patients for Summer Camp! 2023 brought a fully in-person camp with some changes to how our leadership and camp groups attended. Campers attended from Colorado, Wyoming, and Montana, with siblings invited, to join in a week of fun and learning. We had an excellent group of kids who supported one another in everything from learning infusion skills and dealing with injections to participating in fun activities like archery, swimming, crafting, and a zip-line. Mile High Summer Camp is a wonderful opportunity for these kids and our HTC staff are very involved in making it special. Our camp pictures can be viewed on our website on



Izaiah Ornelas survived a stroke and shared his experience with our readers in May. Photo: Cristi Ornelas

our [camp page](#).



At Mile High Summer Camp our team worked with kids to practice infusions, a challenging and rewarding accomplishment. Photo: NHF Colorado

In late summer, many of our staff walked or donated to support the NBDF Unite for Bleeding Disorders Walk at Sloan’s Lake in Denver, as well as providing the RMBDA Unite Walk that was held in early fall in Montana. The walks are the main fundraisers for these programs that offer education and community building opportunities to

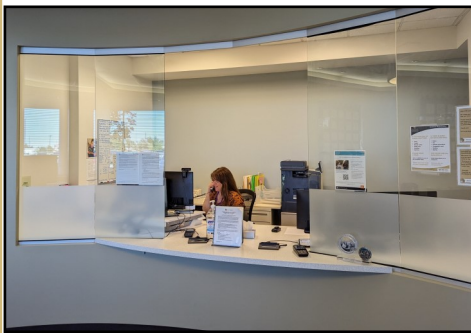
families with bleeding disorders in our region. Our HTC team surpassed our goal and raised over \$5,200 for the Colorado Chapter and \$1000 for the Montana team. The efforts by our staff made our HTC team one of the highest fundraising HTCs in the nation.

This year also brought more consistent [Outreach Clinics](#), which were held in-person in Billings and Missoula, Montana as well as Grand Junction, Colorado. Our HTC covers much of the mountain west areas, and these clinics are opportunities for our staff to meet with patients closer to where they live. The pandemic made it very challenging to get these back up and running, so it was a good sign to have our Outreach clinics functioning much closer to normal this year.

[Continued on page 3]

[Continued from page 2]

We had a lot of construction at our center during 2023, in both our clinic area, our pharmacy, and in new sections on the ground floor. Some of this construction is still ongoing, but a noticeable change was the layout of our front desk and reception area and some additional

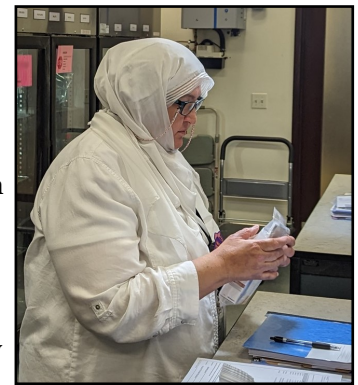


We made some changes to our front desk and waiting area in 2023. Photo: Merilee Ashton

clinic space. We also had some staff changes, so expect a few new faces welcoming you into the clinic or helping you during your visit. We miss and wish well those who have left to meet other challenges and welcome the staff members who joined us this year.

Our pharmacy continues to grow and improve, supporting patients in everything from their medication and supplies to helping families with tips on travel. Our 340B pharmacy makes it possible for a variety of helpful resources that our patients can access. The 340B program allows patients to get bleeding disorder medications at a lower cost, and our pharmacy staff can work with many insurance plans to help patients gain access to the comprehensive care that is

offered at our HTC. The pharmacy received full re-accreditation with URAC in 2023. This allowed us to maintain our dual specialty pharmacy accreditation, which in turn helps us with behind-the-scenes operations that improve care for patients. We encourage patients to reach out to our clinic and pharmacy staff with questions about current or new medications and what is the right fit for each patient individually.



Our pharmacists, such as Suzanne Kasim pictured here, continue to provide exemplary service to patients. Photo: Merilee Ashton

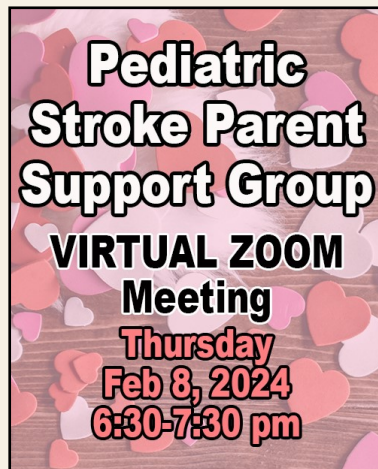
We hope that as the year comes to an end, that you will have the chance to reflect on the good things that happened this year. We look forward to working with you and helping with problems that may come your way. We hope your holidays have been wonderful and that the future ahead is bright! Keep up with what is happening at our HTC in 2024 by subscribing to this newsletter at eepurl.com/bnszoz or by scanning this QR code:



You can also follow us at our [HTC Facebook page](#), our [Pediatric Stroke Facebook page](#), or our [HTC X \(formerly Twitter\) account](#).

PEDIATRIC STROKE GROUP: HOLIDAY PARTY & UPDATE

In early December, our Pediatric Stroke Parent Support Group hosted a holiday party to meet and celebrate the year with our pediatric stroke families! Dr. Bernard gave an informal talk and spent a lot of time answering questions and discussing issues that parents were interested in.



The kids had a blast decorating cookies and playing “Freeze Dancing” together. The event was very interactive, and families enjoyed connecting with others who were on a similar journey navigating a life after a stroke in their family.

The Pediatric Stroke Parent Support Group will be meeting virtually for the first meeting in 2024. We invite all our pediatric stroke families to attend online with us on **February 8, 2024**, when we will have a discussion led by a psychologist from Children’s Hospital Colorado talking about managing difficult emotions. The group is also planning their 2nd Annual Education Day, to be held on Saturday, **April 20, 2024**. More details to come!



We thank all who were involved in our support group this year and all who help support these families! For more information on this program, see our [website](#) or [Facebook page](#).

A few photos from our Pediatric Stroke Support Group Holiday Party. Photos: DeEtta Barnhardt

RECENT HEADLINES

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

Gene Therapy Hemgenix Lowers Bleeding Rates and Rate of Replacement Therapy

Dosing Begins in Phase 1/2a Trial of Optimized Gene Therapy for Hemophilia A

FDA Grants Dual Designations for Investigational Hemophilia A Therapy

Novo Nordisk and Genevant Join Forces to Develop Gene-editing Treatment for Hemophilia A

Study Looks at Therapies for Women with VWD and Heavy Menstrual Bleeding

Over Half of Hemophilia Patients Hide Symptoms & Don't Share Negative Impacts

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.

Dec 25-26: Clinic, Pharmacy, and Admin offices closed for Christmas Holiday

Jan 1, 2024: Clinic, Pharmacy, and Admin offices closed for New Year's Day

Jan 13: NBDF Colorado Connections Event

Jan 15: Clinic, Pharmacy, and Admin offices closed for Martin Luther King Jr. Day

Jan 28: NBDF Colorado Men's NFL Championship Lunch

Feb 8: Pediatric Stroke Support Group Virtual Meeting

Feb 10: Backpacks + Bleeders Hike at Rocky Mountain Arsenal

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

ME-WE-HTC We create hope.

Hemophilia & Thrombosis Center

13199 E. Montview Blvd., Suite 100
Aurora, CO 80045

Clinic Main: 303-724-0724

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