

# 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

## THE HEMOPHILIA ALLIANCE AND HTCS



Did you know that 2024 marks the 25<sup>th</sup> anniversary of the Hemophilia Alliance? If not, you may also wonder what the Hemophilia Alliance is! The Hemophilia Alliance is a not-for-profit organization that has Hemophilia Treatment Centers (HTCs) as members, and their purpose is to provide support for the common interests and sustainability of HTCs. There are approximately 140 federally recognized HTCs in the United States, and they treat and provide care for rare bleeding disorders like hemophilia A and B, Von

Willebrand Disease, and other rare bleeding and clotting disorders.

Treating bleeding disorders can cost a lot of money and may require a lot of medical care. Because bleeding disorders are rare, the prescription medications needed to treat them can cost much more than other medications. This means the financial burden for treating a condition that a patient was just born with can become unattainable.

In 1992, George H. W. Bush signed Section 340B of the Public Health Service Act into law. This required drug companies to discount the prices of their medications as a condition for including them in Medicaid and Medicare. This allowed providers who cared for vulnerable populations, including bleeding disorder patients, to qualify for these discounts and pass along savings to patients. The costs saved can be used for specific purposes, one of which is to fund the additional care needed for patients at HTCs.

The problem that HTCs faced when the program began was that there were confusing legal requirements that needed to be completed to secure the discounts. HTC pharmacies across the country were not quite sure they were complying with all the rules and did not want to make mistakes that could cost them their entire business plan. In 1999, about seven years after the 340B program began, leaders at five HTCs discussing these problems realized they each had a different understanding of how these rules applied. These five HTCs joined together in securing a lawyer and the Hemophilia Alliance began. The University of Colorado Hemophilia and Thrombosis Center was one of the first five members that helped start the Hemophilia Alliance and our membership has provided much needed help to our HTC.

From the beginning, the Hemophilia Alliance was not something most patients would know was working in the background to help their HTC. It became clear that it was not just a few HTC pharmacies that were unsure of legal matters; they found others that needed support and many HTCs began to join. The Hemophilia Alliance takes membership fees and applies them to provide services to help HTCs run smoothly.

Twenty-five years later, the Hemophilia Alliance is supported by the membership of most of the HTCs across the country. The members now receive not just legal advice on 340B questions, but group purchasing discounts, contracting support with insurance companies, development of policies and procedures for HTCs, help setting up pharmacies for bleeding disorder care, advocacy support and opportunities, outreach materials, educational opportunities for HTC staff, and more.

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April 2024  
Volume 14, Issue 4



Advocates from Colorado and Utah joined more than 100 others from HTCs around the country to support the Hemophilia Alliance Hill Day in Washington DC.  
Photo: Steve Powell

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Find us on Facebook, Twitter, and our website for frequent updates on news and events.



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Website: Go to

[medschool.cuanschutz.edu/hemophilia-thrombosis](https://medschool.cuanschutz.edu/hemophilia-thrombosis)



Email:

[HTC.Newsletter@ucdenver.edu](mailto:HTC.Newsletter@ucdenver.edu)

# PEDIATRIC STROKE SUPPORT GROUP SPRING SEMINAR



The Pediatric Stroke Support Group hosted a Spring Seminar here at our HTC. Photos from top: Our stroke survivors panel shared their experiences; Our HTC Support Group team included DeEtta Barnhardt, Bryn Dunham, Lia Thompson, Emily Wheat, and Joanna Roybal; Keynote Speaker Jodi Krouse shared valuable information to families.

All photos: DeEtta Barnhardt.



Childcare was provided through Children's Hospital Colorado volunteers. Photos: DeEtta Barnhardt.

On April 20, 2024 our Pediatric Stroke Support Group hosted an Education Seminar designed to allow families of children who have survived a stroke to connect and learn together. This half-day event had a great turnout of more than 30 adult participants. The event hosted a panel, including a teenager who had a stroke last fall and two parents of children who have had strokes, who were able to share their challenges and successes with the group.

The event also included a presentation from Jodi Krause, a Clinical Learning Specialist and Educational Coordinator at Children's Hospital Colorado. Her helpful presentation was well received, and families appreciated her knowledge about school services and resources available to stroke survivors.

The event included both breakfast and lunch, along with a "Rose, Bud, Thorn" support group luncheon where patients and families had the opportunity to share what is going well, what they are working on, and what concerns they have for the future.

We are grateful to our staff and the families who participated in this educational program! The support group will take a break over the summer and hopes to return to meet again this coming fall. Please watch for details on our [website](#) and [social media](#) pages.



**Mile High Summer Camp**  
Registration opens  
May 1, 2024

## MILE HIGH SUMMER CAMP

Mark your calendars! Mile High Summer Camp registration is set to open on **MAY 1, 2024!**

Camp is a great opportunity for kids ages 7-17 to have a fun learning experience with others in the bleeding disorders community. Older kids have a chance to participate in teen leadership weekend and then help younger kids during main camp.

**May 1: Registration opens**  
**July 12-14: Teen Leadership Weekend**  
**July 14-18 Main Mile High Summer Camp**

**Go to**  
**[cohemo.org](http://cohemo.org) for**  
**details.**



## HTC MEMBERS SUPPORT HILL DAY



Steve Powell, Hannah Geisman of Sen. Hickenlooper's office, Ashley Bowen, Penni Smith, Karla Pamer from Utah, and Mark Plencner from the Hemophilia Alliance meeting at the Hemophilia Alliance Washington DC Hill Day. Photo: Steve Powell

Steve Powell, our Finance Manager at the HTC and current treasurer of the Hemophilia Alliance Board of Directors, was able to attend Hill Day April 15-18, 2024. He met with members of Colorado's senators and representatives in Washington DC, and joined colleagues from Utah and met with their representatives as well.

He also met with Senator Thune from South Dakota who has drafted bi-partisan legislation with other senators called the Sustain 340B Act.

For more information on the events and details from Hill Day see the [Hemophilia Alliance newsletter from April 2024](#).

How is your HTC doing?

Take the survey!

PSS National HTC Patient Satisfaction Survey

Our HTC is participating in the Fourth National HTC Patient Satisfaction Survey. The survey is a way for patients to share feedback about how we are doing.

If you or someone you care for had contact with our HTC in 2023, we want to hear from you!

The easiest way to take the survey is online at [www.htcsurvey.com](http://www.htcsurvey.com), or fill out and return the paper survey that should have arrived in the mail. If you did not receive one but were seen at our clinic last year, we ask you to go online to take the survey. You can also use the QR code above and take the survey on your phone!

It only takes a few minutes to complete but the feedback we receive is very helpful!

**All surveys must be completed by May 31, 2024.**

[Continued from page 1] The Hemophilia Alliance allows hemophilia treatment centers across the country to meet, collaborate, and learn from each other. They provide specialized educational programs for social workers, physical therapists, nursing, and pharmacists. In fact, the Hemophilia Alliance will be hosting a Physical Therapists Continuing Education Conference in Aurora, Colorado next month.

The Hemophilia Alliance recently expanded their Hemophilia Access Network, which works with HTCs to help market the HTC pharmacy programs to third party insurance companies and negotiate contracts with large self-funded insurance plans. This is important to HTCs as more and more patients have insurance plans that do not contract with the HTC 340B pharmacies and force patients to use one specific specialty pharmacy. The 340B pharmacy programs financially support hemophilia treatment centers by investing any profits into patient services and education, such as social work and physical therapy.

One of the newest employees of the Hemophilia Alliance is Angela Blue, who worked at our HTC for five years and joined the Hemophilia Alliance's Directors of Member and Community Relations in 2023. She shared how the work of the Hemophilia Alliance provides not just support to pharmacies and patients with insurance coverage, but through the Hemophilia Alliance Foundation, they also provide grants to NBDF Chapters, HTCs, and support for other costs. Over \$9 Million has been distributed over the years to the bleeding disorders community through Hemophilia Alliance Foundation grants. One of our Physical Therapists, Joanna Roybal, received a grant from the Hemophilia Alliance foundation last year to fund research for a physical therapy program in our new PT motion laboratory.

Steve Powell, our HTC Finance Manager, is currently serving as Treasurer of the Hemophilia Alliance Board of Directors. Steve and others have been closely involved with the Hemophilia Alliance over the years, continuing the longstanding participation of the University of Colorado HTC with the organization.

We have seen many changes in the bleeding disorders community over the past 25 years, and we are grateful that the Hemophilia Alliance is working with HTCs across the country to continue to improve the care and services available to our bleeding disorder patients. For more info, see the [Hemophilia Alliance's Website](#).

## RECENT HEADLINES

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

**New Long-Term Data Shows Emicizumab Safe, Effective in Hemophilia A Patients**

**Study Shows Wristband Tracking Activity Improves Quality of Life in Severe Hemophilia Patients**

**FDA Approves IXINITY for Use in Children 12 and Under with Hemophilia B**

**ReciBioPharm Teams Up with GeneVentiv to Develop Gene Therapy for All Hemophilia Patients**

**FDA Approves First Human Study of CRISPR/Cas9-based Factor 9 Gene Editing Therapy**

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](https://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](http://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.**

**May 1:** Registration for Mile High Summer Camp Begins

**May 4:** Backpacks + Bleeders Hike: NCAR Trailhead, Boulder

**May 27:** HTC Clinic, Pharmacy, and Admin offices closed for Memorial Day

**Saturdays beginning in late May:** NBDF Colorado Weekly Golf Group-Free Lessons

**June 7:** NBDF Colorado Family Camp– Allenspark, Colorado

**June 22:** Families on the River with Backpacks + Bleeders

**See more at our Events Page on our website:** [medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar](https://medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar)

**ME-WE-HTC** We create hope.

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