

# The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

January 2023  
Volume 13, Issue 1



Hemophilia and Thrombosis Center  
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with  
Children's Hospital Colorado

## DIRECTOR'S CORNER



Dr. Mike Wang, our HTC Director shares his thoughts as we begin a new year.

Many of us started 2022 with hope for a year of renewal. We planned on consistent in-person activity from clinics, outreach and education, and camp. While that happened without significant setbacks, we also sensed a weariness with our communities and ourselves. The successes of 2022 may be rooted in perseverance.

2023 has many advancements that will keep all of us engaged. We hope for no more clinical changes except for consistent access to the care patients want. Many of the delays in implementation will now become realities as we can program and plan around more robust clinic staffing. You will meet several staff possibly for the first time in person this year. During the pandemic we said farewell to many, but also

welcomed many new people into the HTC. Physical therapy, psychosocial, nursing, advanced practice providers, administrative and finance staff, pharmacy, and the clinical and laboratory science programs all saw staffing changes. 2023 feels like the time where our enhanced staffing can make our teams thrive. Currently we see patients in Hemostasis, Thrombosis, Women's Bleeding Disorder, Pain, Outreach, and Stroke clinics with additional Psychosocial, Research, Nursing, Physical therapy, and Laboratory visits.

New construction next to our clinic will begin and end by the end of the summer. This is a massive undertaking by the HTC to look at care beyond today, and to envision what our patients will need in the near and long-term future. This will allow us to open a new gait and motion lab to support ongoing research by Dr. Beth Warren. There will also be a new PT treatment area/gymnasium where we will use the individual expertise of our three physical therapists to offer care much beyond evaluation. Construction will also bring a new clinical and clinical research area that can support infusion, possibly even gene therapy.

We will be building a clinical coagulation laboratory on site that has the potential of same-day results as well as novel assays never consistently offered on the CU Anschutz Medical campus. This new resource will also be a place where the translation of laboratory evaluation and techniques may translate into improved patient care. One key part that that effort will be a clinical platelet laboratory directed by Dr. Pavel Davizon-Castillo. While this will be where we start, we plan on expanding our laboratory program to fit the needs of our patients. Finally, a much-needed expansion of pharmacy space, and a refresh of some of the clinic will wrap up the projects for the year. Please feel free to ask about how these projects are progressing when you visit.

[Continued on page 3]

# Happy New Year!

We are excited to head into 2023 and are grateful for both patients and staff who have dealt with so much in the past few years.

### INSIDE THIS ISSUE

- Director's Corner
- HTC Staff Share Joy With Holiday Project
- Sign Up Now for Co-pay Assistance Programs
- NHF Winter events coming soon
- Event Calendar
- News & More

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



Go to [facebook.com/ColoradoHTC](https://facebook.com/ColoradoHTC)



Go to [twitter.com/HTCColorado](https://twitter.com/HTCColorado)



Website: Go to

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



Email:

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

# HTC CELEBRATES WITH HOLIDAY PROJECT



Our HTC staff was excited to participate in our second annual holiday project last month. This was a lovely opportunity for us as co-workers and friends to give back to families in the bleeding disorder community. Every child deserves a magical holiday season, and every parent deserves the dignity of creating that magic. Our HTC team was grateful to be able to partner with some parents and families from our bleeding disorder and stroke program to create a meaningful and lasting memories for a happy holiday season.

Through our HTC and in partnership with Children's Hospital Colorado, we were able to help support several families who needed a little extra love. Generous donations from our staff members made it possible to help out, and our team was delighted to have the chance to wrap and prepare gifts to send. We thank all who participated and supported this project that allowed us a chance to share in the enchantment of the holiday season.

Our clinic, pharmacy, research, and admin staff were delighted to have the chance to come together and help make the holidays special for a few families that needed some extra care. We thank all of our staff who so generously gave of their time, donations, and kindness to make a difference.

Photos: Kristi Norton and Laura Singer-Fox.



## NHF COLORADO UPCOMING WINTER EVENTS

### February 2023: Indoor Climbing Clinic Series (4 dates)



Each Friday in February, Backpacks + Bleeders will host a special Indoor Climbing Clinic at Movement Gym in Englewood. Each week in the series will focus on different topics, but you can attend any clinic you are able to. This special series is available for those with a diagnosed bleeding disorder, a carrier, or caregiver of a minor with a blood disorder.

There are 15 spots available for each week's climb and you are invited to sign up for as many weeks as you can attend. See more information on and register for this exciting program at [cohemo.org](https://cohemo.org).

### February 7, 2023: Men's Game Night Party

NHF Colorado will host a Men's Game Night Party at The Viewhouse in Littleton, located at 2680 W. Main St. in Littleton. The event is open for all men in the bleeding disorder community, either directly impacted or caregivers. Registration includes dinner and game time. To register for this event, or for more information, go to [cohemo.org](https://cohemo.org) or contact Hanna Beary at [hbeary@hemophilia.org](mailto:hbeary@hemophilia.org).



### March 4, 2023: Connections, Coffee, and Conversations: Bleeding Basics

Newly diagnosed, or new to town? The NHF Colorado Connections program is designed to help connect, welcome, and support newly diagnosed families of infants and young children with bleeding disorders. Join our HTC experts and NHF Colorado at the Children's Museum of Denver for the opportunity to connect and learn with others in the bleeding disorder community. Registration and more information can be found at [cohemo.org](https://cohemo.org).

[Continued from page 1]

Advances in science and medicine will be noticeable in 2023. Lead by Dr. Manco-Johnson, the research effort at the HTC looks for advancement in all areas- laboratory (Drs. Ng, Davizon-Castillo, Manco-Johnson, Neeves), clinical research and sponsored programs (Drs. Warren, Buckner, Moyer, Wheat, Manco-Johnson, Wang), and investigations in patient outcomes (everyone!). In the clinic, we will be confronted with gene therapy for hemophilia A and B. The translation of this technology to patient care will be a focus at the HTC involving the clinic staff, clinical research, psychosocial assessment, and education.

Supporting patients and their families through this will be novel coagulation molecules that resemble human coagulation factors and those that work by completely different mechanisms. All these holds promise beyond what we currently use today.

2023 is 50 years since the HTC was first created as a small clinic in 1973. It is a lot to look back upon, much to be thankful for, and so much more to be excited about for the future- the next 50 years and beyond. We look forward to seeing you in a variety of venues and sharing what progress and optimism has emerged from the pandemic. Please use



We are excited to share that in 2023 the space on the first floor, that we previously used for offices, will be transformed to provide space for PT, research, laboratory, and other clinical needs.

this start of the new year as an invitation to let us know how we are doing, and what we can do to best support all of you. We look for continued and strengthened partnership with our patients and the bleeding and clotting disorder communities. We want to know how you are doing, and what the HTC can do to improve the lives of our patients and families.

With eagerness and hope,

*Mike Wang, MD*

HTC Director

## ENROLL NOW IN CO-PAY ASSISTANCE PROGRAMS

Programs created by drug manufacturers can help cover your out-of-pocket expenses for bleeding disorder factor products this year! These programs are called Co-pay Assistance Programs (or CAPs).

### What are Co-pay Assistance Programs (CAPs)?

CAPs are programs designed to essentially make medication much less expensive for you. Depending on the program, they may cover out-of-pocket expenses NOT covered or PARTIALLY covered by insurance up to \$20,000 per calendar year.

### When do I apply?

You can apply anytime, but the renewal period starts annually in January. Patients **must sign up** each year for the program and coverage is for the entire year Jan-Dec. So, if you were on this program last year, you must sign up again for 2023.

### Do I qualify?

These programs are available to patients who have private insurance and are using Hemlibra or factor products. They are **not** income dependent. Note that the following are exclusions from the programs: Medicaid, Medicare, Medigap, VA, DOD, TRICARE, or any other federal or state healthcare programs.

If there are multiple people in your family that require assistance that is still okay! Assistance is awarded for each



individual patient, meaning that multiple members of the same household can apply for these programs. One important thing to note is that most programs require commercial (private or non-governmental) insurance.

If you have any more questions or for more information, please refer to the National Hemophilia Foundation's (NHF) website for a list of programs and details: [Patient Assistance Programs | National Hemophilia Foundation](#)

Our HTC Pharmacy and social workers understand these programs and can provide support if you have questions. Please contact us if you have questions or need some guidance in signing up.

## RECENT HEADLINES

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

**Roctavian Trail Update Shows Most Patients Bleed-free at 3 Years**

**FDA Clears Test to Monitor Effectiveness of Hemophilia B Treatments**

**Pfizer Announces Updates for Investigational Gene Therapy for Hemophilia B**

**Data Shows SerpinPC Reduces Bleeds for All Hemophilia Types**

**Study Shows Durability of Investigational Gene Therapy in Patients with Hemophilia A**

**FDA Approves First Gene Therapy for Hemophilia B**

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](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) and fill out the form!

## UPCOMING EVENTS

### Mark Your Calendars:

**Please note. These dates may be tentative and subject to change. Please check appropriate websites for confirmation of events.**

**Feb 3:** Backpacks + Bleeders Climbing Clinic

**Feb 7:** NHF CO Men's Game Night Party

**Feb 10:** Backpacks + Bleeders Climbing Clinic

**Feb 17:** Backpacks + Bleeders Climbing Clinic

**Feb 20:** Clinic, Pharmacy, and Admin offices closed for Presidents Day

**Feb 24:** Backpacks + Bleeders Climbing Clinic

**Feb 28:** Rare Disease Day

**March is Bleeding Disorders Awareness Month**

**Mar 4:** NHF CO Connections, Coffee & Conversations: Bleeding Basics

**Mar 8-10:** NHF Washington Days—Washington D.C.

**Mar 16:** NHF Colorado Advocacy Day—Denver, CO

**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)

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

PLEASE  
PLACE  
STAMP  
HERE