

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



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GRATITUDE FOR PATIENTS AND STAFF



As we begin a new year and soon will arrive at two years since the COVID-19 pandemic began, our HTC would like to thank our clinic, pharmacy, and administrative staff members for their efforts in keeping things running smoothly. We thank our patients for their patience and flexibility as we have implemented protocols that may have been difficult as they have sought care.

Since March of 2020, we've been through total lockdowns, limited access to care, varying health screening requirements, the opportunity to receive vaccines and boosters, multiple variants of the virus, and many barriers to providing care and connecting with patients. Many of our staff have managed much of their work remotely, while others have become masters of

using PPE and risk assessment. Some of our staff even moved offices as we've vacated space to expand our usable clinic area to include some much-needed upgrades and resources for patients.

We've seen the addition of tele-health and faced the struggle of getting access for all our families. We have seen both patients and co-workers deal with illness, financial struggle, emotional strain, death of loved ones, uncertainty, and the many other stresses of this pandemic. We have perhaps all wondered about many of the issues that came with this virus, and possibly have been overwhelmed by the overload of confusing information available to us. However, in view of the challenges, we also have seen many rise above their challenges to help others, lift and support their families, co-workers, or total strangers.

We continue to maintain very high standards of care in our clinic and have strict protocols in place to keep the HTC as safe for both patient and staff as possible. Our staff meetings involve communication about needs of patients and staff, as well as clear instruction on procedures to help all who enter maintain their health and safety. Our internal emails and group sharing opportunities have allowed us to support one another during times of joy and grief.

Our clinic remains open from 8 am to 4:30 pm Monday through Friday, though appointments are required, and we ask that anyone with symptoms either reschedule or check with our front desk about their options. The building remains locked, so we encourage you to communicate with our staff on how to check in for in-person appointments. We welcome questions and are happy to assist patients in learning about how to use tele-health tools to gain access to care when unable to visit us in person. This tool is likely to become a helpful asset in the future, far beyond this current crisis.

Again, thank you for your patience as we work together to support one another through this stressful time. We express gratitude to all who have shown kindness, and we hope to continue to work with all our patients as we step into a new year and a bright promise of improved health and happiness for all.



Research Manager Kristi Norton spent time in December wrapping gifts for families in need—with some support from the antics of “Home Alone”. Photo: Kristi Norton.

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



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



Go to twitter.com/HTCColorado



Website: Go to

medschool.cuanschutz.edu/hemophilia-thrombosis



Email:

HTC.Newsletter@ucdenver.edu

HTC HOLIDAY PROJECT SPREADS JOY

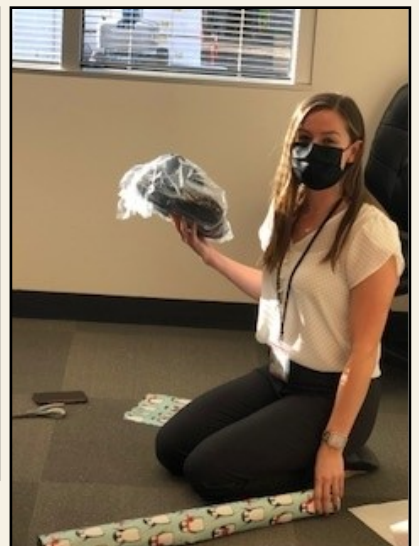


We are delighted to share that our HTC staff were able to participate in a holiday project in December that was inspiring and helped spread joy throughout our office. Many of our employees joined forces and provided gifts to a few families who needed some extra help this past holiday season. All in all, generous donations to this cause provided over 150 gifts that were purchased and wrapped and shipped out to three families.

Through our staff's donations, we gathered all the items and any team member in the office could take a few minutes out of their day and go wrap presents while Christmas movies were playing in our conference room.

Over two days we used 14 rolls of wrapping paper, fit all the gifts into 10 big shipping boxes, and felt the joy of giving back. Rumor has it that "Home Alone" was played on repeat, there were many smiles, and no paper cuts reported.

We are so grateful for our generous HTC staff. They are energized by finding ways to make life better for others throughout the year. This is just one example of our caring HTC staff, and it was a fun experience for all of us.



Our clinic, pharmacy, research, and admin staff were all thrilled to get the opportunity to come together to make the holidays special for a few families who needed a little extra love. We thank all our staff who so generously gave of both gifts, donations, and time to make a difference to others.

Photos courtesy Kristi Norton.

PEDIATRIC STROKE PARENT SUPPORT GROUP

**Pediatric
Stroke Parent
Support Group**
**VIRTUAL ZOOM
Meeting**
**Monday
Feb 14, 2022
6:30-7:30 pm**

Our Pediatric Stroke Parent Support Group will be on **Monday, February 14, 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. This month we will have a special Valentine's Day party-virtually!

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

NEW APP TO TRACK YOUR BLEEDING DISORDER

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

Currently
available on
iPhone or
iPad.

[Android development
is in process!]

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

ENROLL IN CO-PAY ASSISTANCE PROGRAMS NOW

By Jonathan Truong, Pharmacy Intern

Did you know that there are programs created by drug manufacturers designed to help cover your out-of-pocket expenses for bleeding disorder factor products?

What are Copay Assistance Programs (CAPs)?

CAPs are programs designed to essentially make medication way 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.

Who qualifies?

These programs are available to patients who have private insurance and are using a factor product. 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, do not worry! Assistance is awarded for each individual patient, meaning that multiple members of the same household can apply. One important thing to note is that most programs require commercial (private or non-governmental) insurance.

When do I apply?

You can apply anytime, but they renew period starts



Out of pocket pharmaceutical costs can add up. Help keep your expenses in check by finding the right Copay Assistance Program for you.

annually in January. Patients must sign up each year for the program and coverage is for the entire year Jan-Dec.

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](#)

More information can be found at <https://creakyjoints.org/advocacy/understanding-copay-assistance-programs/>

Our HTC pharmacy and social workers are well versed in these programs. Please contact us if you have additional questions.

RECENT HEADLINES

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

Study Shows Low Dose ITI Partially Successful in 80% of Children with Hemophilia A

BioMarin Announces Positive Results in Gene Therapy Study for Hemophilia A

NHF Mourns the Loss of Longtime CEO and Advocate Val Bias

Update for Hemophilia B Gene Therapy Trial from uniQure and CSL Behring

Hemophilia A Patient Develops Complications in SIG-001 Clinical Trial

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.

Feb 3: NHF CO Connections, Coffee, and Conversations—Virtual

Feb 9: Bleeders and Blades, a Women's Event—In Person

Feb 14: Pediatric Stroke Parent Support Group—Virtual

Feb 21: Clinic, Pharmacy, and Admin offices closed for Presidents Day

Feb 26: Backpacks + Bleeders Ice Skating at Evergreen Lake—In Person

March is Bleeding Disorders Awareness Month

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

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Pharmacy Main: 303-724-0168

or toll free at 888-724-7427

Web page:

medschool.cuanschutz.edu/hemophilia-thrombosis

PLEASE
PLACE
STAMP
HERE