The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



Hemophilia and Thrombosis Center

UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS

2025 NBDF ANNUAL BLEEDING DISORDERS CONFERENCE



Nurses Nancy Workman and Julie Sweeney attended the conference to learn and connect. Photo: Julie Sweeney

The National Bleeding Disorders Foundation hosted their 77th Annual Bleeding Disorders Conference (BDC) from August 21-23, 2025 in Aurora, Colorado. The conference was held at the Gaylord of the Rockies and hosted approximately 2,200 people during the event. Because the BDC was close to our HTC this year, many of our staff participated and attended the conference. Beth Warren and Jenna Moyer were selected to help introduce the conference at an opening session on the first night. They spoke in a panel-type discussion and addressed where research is leading us in treating bleeding disorders.

Dr. Tyler Buckner, our HTC director, participated in a session talking about novel therapies, our social workers DeEtta Barnhardt and Bryn Dunham both spoke and participated in several sessions, Kim Hurdstrom, Kaylee

Dollerschell, Joanna Roybal, and Emily Wheat all spoke or led discussions during the conference. We've included in this month's newsletter (on pages 2-3), pictures and details on how the conference went for our team.

The conference coincided with the annual Unite for Bleeding Disorders Walk that was held at Sloan's Lake for the Colorado NBDF chapter. Some of our HTC team were able to participate virtually in the annual Unite for Bleeding Disorders Walk as they were attending the conference the same weekend. Our HTC team raised \$5840 for the Colorado walk and \$1100 for the RMHBDA in Montana that took place Sept 9th. It was a lovely morning for those at the BDC to walk around the Gaylord Hotel to show support for the walk.

The Colorado Chapter of the NBDF held their walk at Sloan's Lake Park the same day and more than 200 people attended. If you were unable to attend but would like to help support either the Colorado or Montana chapters, you can still donate and make a difference. See the Colorado page or the Montana page at the Unite For Bleeding Disorders website for details.

We are grateful for all who participated at the conference and the walks. The NBDF is a huge support to our patients, and this conference provides a great learning environment for families and providers alike.





Top: Dr. Jenna Moyer and Dr. Beth Warren spoke at the opening session of the conference and shared how their research fits in to where we are going with the treatment of bleeding disorders. Bottom: Some of the HTC staff who walked virtually at the conference. Photo: Merilee Ashton



Bryn Dunham spoke in a session about underserved populations in the bleeding disorders community. She spoke about patients in rural areas. Photo: Merilee Ashton

INSIDE THIS ISSUE

- 2025 NBDF Bleeding Disorders Conference
- Photos from the Bleeding Disorders Conference
- Drops of Love
- Outreach Clinics
- Upcoming Events
- News & More

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



Go to <u>facebook.com/</u> ColoradoHTC



Go to <u>twitter.com/</u> <u>HTCColorado</u>



Website: Go to

medschool.cuanschutz.edu/ hemophilia-thrombosis



Email:

HTC.Newsletter@ucdenver.edu

HTC STAFF PARTICIPATE IN THE 2025 BDC



Dr. Emily Wheat was one of four speakers who spoke at a session moderated by Kim Hurdstrom that focused on the needs and behavior of adolescents in the bleeding disorders community. Drawing on her training as a pediatric psychologist, Dr. Wheat discussed developmental considerations in adolescence. how milestones may unfold differently for teens managing chronic illness, and how healthcare teams can best support youth with bleeding disorders. She also highlighted her current work leading clinical quality improvement initiatives at our HTC,

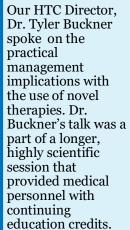
including efforts to optimize the transition from pediatric to adult care. Photo: Merilee Ashton

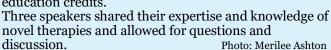
Dr. Beth Warren, Physical Therapist Laura Singer-Fox, and one of our medical students were a part of a poster session that explored joint health in Von Willebrand

Disease. The

study found (unexpectedly) that joint exam scores in females with VWD were similar to joint exam scores in females with mild hemophilia. This discovery will lead to more research on this important group of patients.

Photo: Laura Singer-Fox







Physical Therapist, Joanna Roybal spoke at one of the physical therapy education sessions. She focused primarily on gait and pediatric orthopedic conditions. She discussed how physical therapists assess gait in our patients at all ages, highlighted common pediatric orthopedic conditions, and offered treatment strategies. She introduced trends in gait patterns specific to patients with bleeding disorders, and discussed the ways physical therapists can make a

difference. She also presented some of the biomechanics research being done in our HTC motion lab. Led by Dr. Warren and the biomechanics team, this research will continue to guide future bleeding disorder physical therapy practice. This was also a course that provided continuing education credits for physical therapists from around the Photo: Merilee Ashton



As a part of the NBDF Nurse Work Group, nurse Kim Hurdstrom was very involved at the conference, helping guide discussion in two sessions. She presented in a session focused on the health and wellness of an aging population in the bleeding disorders community and moderated a session that focused on adolescents. Kim also led our HTC fundraising walk efforts for 2025 and organized our HTC team to walk virtually on the last day of the conference.

Photo: Merilee Ashton

Kaylee Dollerschell, our HTC's genetic counselor, spoke in two sessions. The first was an Ask the Experts panel

on Ultra Rare Bleeding Disorders where she reviewed unique aspects and considerations of living with a rare hereditary bleeding disorder. She also spoke in a small group discussion on Understanding and Managing Inhibitors where she reviewed genetic risk components involved in inhibitor development risk.

Photo: Merilee Ashton





Bryn Dunham, one of our HTC social workers, joined together with other speakers to discuss challenges and approaches to working with underserved populations.

Bryn's presentation discussed rural communities, unique barriers encountered by

this population, and ideas and strategies for working with patients and families who reside in rural areas. Bryn also moderated a session featuring DeEtta Barnhardt, HTC social worker, and other speakers discussing creative social work ideas. DeEtta spoke on the success of the Poke Comfort Kit project at our HTC.

Photo: Merilee Ashton

One of our social workers, DeEtta Barnhardt, led a small group session that focused on Discovering Your Path to Mental Wellness. In that session attendees were divided up into small groups that rotated, having the opportunity to speak one-on-one with mental health professionals who shared insights on everything from mental health resources at your HTC, substance use, and coping with depression and anxiety.

DeEtta was also a presenter at the Creative Social Work session. In

this session DeEtta presented on an innovative social work project. She provided details on a grant received through the Hemophilia Alliance for Poke Comfort Kits. The grant allowed the HTC to purchase supplies for patients between the ages of 3 to 18 to help them with comfort and distraction when receiving a poke at the HTC. DeEtta shared what was learned from the grant process and what steps the HTC has taken to expand the program since the grant ended.

Photo: Merilee Ashton

DROPS OF LOVE: CELEBRATE CARING HTC STAFF MEMBERS

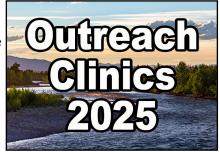


Our HTC has a program called "Drops of Love" to celebrate those who work at our HTC. Any patient, family member, caregiver, or visitor to our HTC can recognize

anyone at our center who went above and beyond with a simple scan on your phone! We know that even one great interaction with a clinical team member can make a visit to the HTC a positive experience and help patients improve their health. This is also a great way to thank the nurses and other providers who make a difference to your care.

Just scan the QR code (above) or scan the code in our office to send a "drop of love" to our staff members and let us know how they made a difference in their service to you! Thank you for sharing your feedback with us!

Our HTC team visits locations in our region to offer comprehensive care to patients who live in more distant areas from our main clinic. Each year we usually visit Missoula and Billings, Montana, and Grand Junction, Colorado.



These clinics give patients the opportunity to more easily visit with all our main providers in-person on at least an annual level.

Remaining 2025 Outreach Clinic:

Oct 7-9, 2025—Missoula, MT

Forms and details are mailed to our regular patients in the months before they take place. If you do not receive any information about an Outreach Clinic near you, or would like to schedule an appointment at one of these locations in the future, please contact our front desk team at 303-724-0724 or toll free at 888-297-0724. Details on our website.

CAMP PICTURES AVAILABLE!

We've been uploading pictures to our website camp page. We will continue to update and add to this page, but you are welcome to go and check out some of the fun pictures from camp 2025! Go to the QR code (right) or head to our website and find the camp page at our website:

<u>medschool.cuanschutz.edu/htc</u> find the camp page under Resources/Bleeding Disorders.



RECENT HEADLINES

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

Study Shows Spinal Stenosis May be a Complication in Older Hemophilia Patients

Discovery of F8 Mutation May Lead to Better Bleeding Control for Hemophilia A Patients

FDA Approves Alhemo for Hemophilia Patients without Inhibitors

Study Shows Higher Rates of Depression, Anxiety for Hemophilia Patients

Study Indicates Immune Markers May Predict ITI Response in Hemophilia A

Trial Shows Hympavzi Lowers Bleeding Rates for Hemophilia Patients w/Inhibitors

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 X/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!



UPCOMING EVENTS

Mark Your Calendars:

Please note. These dates may be <u>tentative and subject to change</u>. Please check appropriate websites for confirmation of events.

Sept 25: NBDF CO Ruby Connection: Cooking Class

Sept 28: NBDF CO Community BBQ lunch—Fox

Run Park, Colorado Springs, CO

Oct 7-9: HTC Outreach Clinic-Missoula, MT

Oct 11: NBDF CO El dolor importa: Cena educative

en Espanol

Oct 12: Backpacks + Bleeders Disc Golf Clinic—

Arvada, CO

Oct 17-19: Women's Wellness Retreat 2025—

Glenwood Springs, CO

Oct 31: Happy Halloween

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

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Web page:

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