

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS

MAY IS NATIONAL NURSES MONTH



Our nurses include (from left) Kate Hoeft, Julie Sweeney, Samantha Stalcup, Nancy Spomer, Nancy Workman, Erin Etcheverry, Michele Schnoor, Jenn Brown and Kim Hurdstrom. Photo: Merilee Ashton

Did you know that May is National Nurses Month? May also includes National Nurses Week and Nurses Day, all of which focus on how much nurses make a difference! In 2025 the American Nurses Association announced their theme for Nurses Month as “The Power of Nurses to Transform Health.” We know here at the HTC that our nurses are vital in transforming the health of our patients!

All year long our nurses assist patients during comprehensive visits, answer triage calls for injuries, refill requests, support surgical planning, and prepare

prior authorization work. Our nurses care for patients with injuries, perform lab draws, and administer factor and other medications. Additionally, they educate patients and families regarding the management of central lines while assessing ongoing medical needs. Our nursing team communicates with patients and families via phone, telehealth visits, in-person, and they work with many other providers to ensure our patients get the treatments they need.

Our nursing team is dedicated to supporting patients and families to increase their knowledge about their medication and bleeding disorder. This team teaches patients and caregivers how to mix and properly administer medication, which helps increase their confidence managing their treatment plans. Additionally, there is a strong emphasis on empowering patients to self-infuse when possible. The HTC would simply not function without all the work our nurses do!

Patients with bleeding disorders are rare, so our HTC nurses have a special niche and knowledge. They understand the unique problems that arise, the issues to anticipate, and the need to collaborate with outside providers to help patients with all their bleeding and clotting disorder needs. Our nurses take the time to listen to patients in a genuine and understanding way that makes a real difference.

Our nursing team can be reached directly on our nursing line at **303-724-0364** during our normal business hours. Voice messages are monitored frequently throughout the day, so we encourage patients to leave a message and share their name, number, and reason for calling. Our nurses will return these calls as soon as they are able throughout the day.

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You may find our nurses attending education events, camp, and the Unite for Bleeding Disorders Walk (above). Photo: Kim Hurdstrom



Our nurses, like Jenn Brown (above), teach and support kids at Mile High Summer Camp. Photo: NBDF Colorado

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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

Voices of Females with Bleeding Disorders and HTC Satisfaction

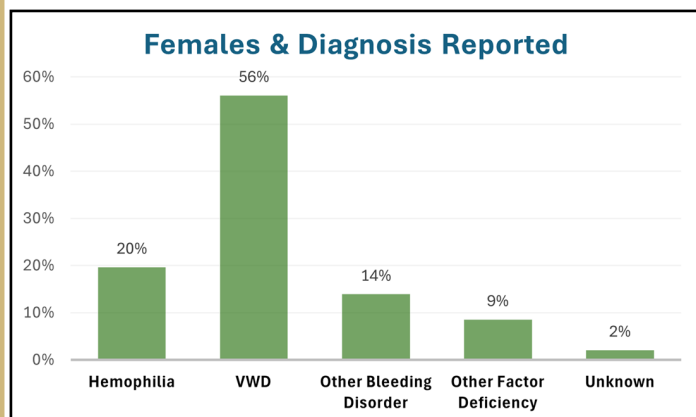


The Fourth National HTC Patient Satisfaction Survey (PSS 4) asked patients about the care they received at their HTC in 2023.

Bleeding disorders impact about 1% of females in the US¹. These individuals are more likely to have heavy menstrual bleeding, high rates of maternal mortality during pregnancy and delivery, and higher incidences of postpartum hemorrhage.¹ The number of females with a bleeding disorder seen at a Hemophilia Treatment Center (HTC) has greatly increased over the last 30 years.^{2,3}

How many females completed the PSS 4?

For this survey, 1,931 (37%) of the responses were from females. Of females completing the PSS 4, more than half (56%) reported a diagnosis of von Willebrand disease (VWD) and 20% had hemophilia.



The reported age of females ranged from 0 to 93 years, which did not differ from males. The median age of females was 34 years, compared to a median age of 29 years for males.

On average, females had (47%) 2 to 4 total HTC contacts in 2023. This was similar to males (43%) who had 2 to 4 total HTC contacts.

How satisfied were females with their HTC?

Participants were asked how satisfied they were with the overall care received at their HTC (Always/Usually/Sometimes/Never).

Participants were asked to indicate how satisfied they were with the HTC Team and the care and services provided. Most female respondents indicated they were Always or Usually satisfied with the HTC team.

95% of Females were Always/Usually Satisfied with their HTC care.

Hematologist	97%
Nurse	98%
NP/PA	97%
Social Worker	96%
Physical Therapist	98%
Genetic Counselor	96%
HTC Pharmacy	97%

There was no significant difference in satisfaction with overall HTC care or satisfaction with the HTC Team compared to male respondents.

What problems did females report?

The PSS 4 asked participants how often Insurance, Language, COVID-19, and Distance were a problem in accessing the HTC services. Five percent of female respondents Always, Usually, or Sometimes had problems with Insurance and Distance. Barriers to care faced by males and females were not significantly different.

How does this survey help HTCs?

Each HTC that participated received anonymous feedback and data for the patients at their center. This information helps HTCs understand their patients' experience and improve the quality of their care. This feedback from females on how they felt about their care can guide HTCs to improve options that may best support females in their care. The PSS 4 committee thanks all who participated.

For more information and additional articles about the results of this survey go to: www.htcsurvey.com

¹Byams et al., 2022, "Bleeding Disorders in Women and Girls."

²Haley et al., 2020 "A Cross-Sectional Study of Women and Girls with Congenital Bleeding Disorders."

³Baker et al., 2013, "US Hemophilia Treatment Center Population Trends 1990-2010."

[Continued from page 1] Our nurses participate in many off-site activities that our HTC is affiliated with throughout the year. This includes attending Outreach Clinics, infusion sessions at various NBDF events—including Education Days, Family Camp, and Mile High Summer Camp. Our nurses walk with patients and families at the NBDF Unite for Bleeding Disorders Walk each year and help fundraise for the RMHBDA Unite for Bleeding Disorders Walk as well. Our nurses participate in research efforts and attend conferences and regional meetings where they have shared insights with other nurses throughout the United States.

Our HTC nursing team is led by our Director of Clinical Services, Kate Hoeft. Kate has been a registered nurse for nearly 25 years. She brings pediatric and adult experience to the team. She states, ***“I am so proud to work alongside such an incredible team of nurses. They demonstrate true passion and pride in the work that they do.”***

Kate is pleased to work with all our nurses, who include Jennifer Brown, Erin Etcheverry, Kimberly Hurdstrom, Michele Schnoor, Nancy Spomer, Samantha Stalcup, Julie Sweeney, and Nancy Workman.

They are all skilled in providing for the needs of our patients and spend many hours improving the lives of patients with bleeding and clotting disorders. We are so grateful for our nursing team and wish each of them a Happy Nurses Month! Thank you for all you do all year long! Don’t forget that you can share a great experience with any of our nurses by using our Drops of Love program (below).

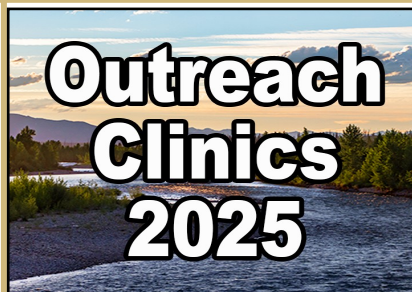


Our nurses travel to conferences (above left), take selfies (center), and even love eating s’mores (right). Photos: Kim Hurdstrom

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 (right) 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.

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

We have four Outreach Clinics in 2025:

July 29-31, 2025—Billings, MT

Aug 26-28, 2025—Billings, MT

Sept 9-11, 2025—Grand Junction, CO

Oct 7-9, 2025—Missoula, MT

Forms and details are mailed to our regular patients in these areas 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, please contact our front desk team at 303-724-0724 or toll free at 888-297-0724. [Details on our website.](#)

RECENT HEADLINES

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

Study Finds Little Genetic Testing Done for Girls at Risk of Being a Hemophilia Carrier

Study Finds Blood Group O is Not Tied to Inhibitor Risk in Kids with Severe Hem A

Scholarships Available for those with Bleeding Disorders at bleeding.org

FDA Approves Qfitlia (fitusiran)- a Subcutaneous Therapy for Hemophilia A & B

Paper Looks at Bone Health Screening Rates at HTC's Nationwide

Takeda Will Discontinue Two Treatments for Hemophilia

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!



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 17-18: NBDF Colorado—Colfax Marathon Relay

May 19: RMHBDA Montana—Education Dinner

May 26: Clinic, Pharmacy, and Admin offices closed for Memorial Day

May 29: Ruby Connections: NBDF Colorado Women's Program

June 3: NBDF Colorado Coping with Anxiety and Depression-Dinner Program

June 7-8: NBDF Colorado Family Camp—Allenspark, CO

June 15: Happy Father's Day!

June 16: NBDF Colorado—Painting Your Story

June 19: Juneteenth (our offices are open)

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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or toll free at 888-297-0724

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Web page:

medschool.cuanschutz.edu/hemophilia-thrombosis

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