

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

LET YOUR VOICE BE HEARD! THE FOURTH NATIONAL HTC PATIENT SATISFACTION SURVEY IS NOW AVAILABLE!



How satisfied are you with your HTC? Our HTC is participating in the Fourth National HTC Patient Satisfaction Survey. This survey is sent every three years to our bleeding disorder patients if they were seen in our clinic or visited with us via phone or tele-health in the previous year. This year, the survey is asking for your input if you were seen or had contact with us in 2023. The survey is a way for

patients to share feedback about how we are doing. The survey is anonymous but asks participants to identify the center where they received care. This allows our patients or caregivers to share with us the things we are doing well and areas where we could improve. If you or someone you care for had contact with our HTC in 2023, we want to hear from you!

You can take the survey online at www.htcsurvey.com, or fill out the paper survey that should be arriving in the mail soon. You can even use the QR code and take the survey on your phone! It only takes a few minutes to complete but the feedback we receive is very helpful! The survey is available in both English and Spanish and we ask parents of young children to fill out this survey in their behalf. You are welcome to send the paper survey that should arrive in your mailbox soon, however **we encourage our bleeding disorder patients to take this survey online or on their phone** as it is easier to process. If you have more than one member of your household who was seen at our HTC, please use the online options to fill out one for every patient.

This year, the survey results will be collected and managed at our region's administrative offices at the Oregon Health & Science University in Portland, OR. Once they receive your digital or paper survey the information will be organized and will be shared with our center.

The input from patients in the past three surveys helped us identify areas where we may have strengths and where we need to improve. Your voice can again help our HTC learn and improve. **All surveys must be completed by May 31, 2024.**

Please go to www.htcsurvey.com or use the QR code to take the survey. The survey only takes a few minutes of your time! Thank you for your valuable feedback!



Take the survey!



We will miss Julie Smith, who has been working at our HTC in research for 13 years. She bids us a fond farewell as she has taken a new position elsewhere (page 3).
Photo: Julie Smith

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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

BLEEDING DISORDER SUBSTANCE ABUSE AND MENTAL HEALTH ACCESS COALITION

A RESOURCE FOR THE BLEEDING DISORDER COMMUNITY

By Emily Wheat, PhD

Individuals with bleeding disorders, like most people with chronic conditions, are at an increased risk for mental health issues. In fact, up to 58.3% of individuals with bleeding disorder diagnoses experience significant symptoms of anxiety and as many as 63.6% experience significant symptoms of depression. Mental health has been connected to medical outcome and overall wellbeing for individuals with bleeding disorders. For example, higher anxiety and depression are associated with higher reports of bleeds and hospital visits due to bleeding disorder diagnosis, and increased numbers of joint problems. Because of the chronic pain associated with joint concerns, many in the bleeding disorder community find relief from pain through opioids and this increases the risk for substance use disorders. The increased risk of mental health concerns and substance use disorders means those with bleeding disorders need access to appropriate treatment. And without this access, the consequences can be disastrous and even fatal.

To address concerns about access to care for the bleeding disorder community, our HTC has partnered with the [Bleeding Disorder Substance Abuse and Mental Health Access Coalition](#) (BD SUMHAC). The coalition is dedicated to advocating for equal access to appropriate substance use and mental health treatment facilities, particularly focusing on inpatient and residential care, for all individuals with bleeding disorders. The need for this initiative became painfully evident when a young man with hemophilia was tragically denied access to residential substance use treatment and subsequently lost his life to a drug overdose.

Through our collective efforts, we've uncovered a deeply concerning statistic: Approximately 80% of providers attempting to refer a bleeding disorder patient to treatment reported facing denials. Denials frequently stem from fear and a lack of understanding. It's essential to recognize that individuals with stable bleeding disorders should not be declined access to behavioral health treatment. Obtaining

the essential support for your mental health or substance use challenges is vital for your overall well-being.

Currently, HTC Psychologist, Emily Wheat, PhD, and Social Worker, Bryn Dunham, LCSW, are working closely with BD SUMHAC and Rocky Mountain Bleeding Disorder Association Executive Director, Brad Benne, as part of the state advocacy program. This program is supported by the Hemophilia Alliance



Psychologist Emily Wheat, and Social Worker Bryn Dunham, are working with BD SUMHAC to find ways to increase mental health access for patients. Photo: Emily Wheat

Foundation Innovation Grant and is a year-long partnership aimed at identifying and building relationships with state agency contacts who can serve as champions in improving access to behavioral health treatment for individuals with bleeding disorders. Currently, five states are participating in this program, including the state of Montana. We hope the lessons learned from the efforts made to increase access in these five states can be packaged into a State Advocacy Playbook for other states to replicate this work.

If you or someone you care about is encountering denials for behavioral health treatment or is seeking resources, please don't hesitate to reach out to BD SUMHAC through the contact information listed on their website www.bdsumhac.org.

In addition, our Psychosocial Department has information on how to find a therapist and can provide this information as part of your next appointment in our Aurora-based clinics or outreach locations.

MARK YOUR CALENDAR: UPCOMING EVENTS!



Mar 2: Bleeders on the Slopes (NBDF CO)

—Granby, CO

Mar 22-24: NBDF CO Education Days—
Denver, CO

Apr 19-21: RMHBDA Education Weekend
—Pray, MT

June 7-9: NBDF CO Family Camp—Allenspark, CO

July 12-14: Teen Leadership Weekend—Empire, CO

July 14-18: Mile High Summer Camp—Empire, CO

Aug 8-9: RMHBDA Teen Retreat—Seeley Lake, MT

Aug 9-11: RMHBDA Family Camp—Seeley Lake, MT

Aug 24: NBDF CO Unite for Bleeding Disorders Walk—
Denver, CO

Sep 7: RMHBDA Unite for Bleeding Disorders Walk—
Billings, MT

Oct 4-6: NBDF Women's Wellness Retreat—Denver, CO

Nov 1-3: RMHBDA Women's Retreat—Pray, MT

To RSVP, confirm dates, or get more info on these events, go to: cohemmo.org and rmhbda.org.

RESEARCHER JULIE SMITH SHARES A FOND FAREWELL



Julie always went all out on Halloween!
Photo: Julie Smith

Our HTC has been very blessed with some extraordinary staff members that really make a difference with patients and co-workers. One of those delightful people is Julie Smith, our Research Program Manager, who has worked with patients at the HTC for more than a decade. Julie has just left our HTC family this month for a new opportunity in research.

Julie has been a dynamic and hard-working leader on our research team, and always had a smile to go with her dedication. She is crafty and creative, and full of spunk and kindness. Julie had a few words to share with you as she left! We wish Julie the best of luck, and much joy and success!

Dear HTC patients, families, and friends,

I would like to take this opportunity to thank you for the trust and confidence you have placed in me to be a part of your care at the HTC over the past 13 years. It is with heavy emotions that I announce that I will be leaving my position as Research Services Program Manager at the HTC effective February 16th. I have accepted a position to serve as the director of the Research Division for HCA/Swedish Medical Center.

As I look back over my time at the HTC, what a decade it has been! It has been such a privilege to have partnered with so many of you, through your research participation, to help us learn and bring cutting-edge therapies to market! For the bleeding disorder community- when I started back in 2011, many of you were on standard half-life products. Some of my first trials were looking at extended half-life products. Then we moved on to the subcutaneous injections, and now we're investigating gene therapy! For the clotting disorder community- Dr. Manco-Johnson and I worked very closely with many of you who have a history of lower extremity DVT to learn more about Post thrombotic syndrome (PTS). I have never measured so many legs in all my life! Thanks for lending me your lower limbs to measure for swelling and look for edema!

Across the whole bleeding and clotting disorders spectrum, it has really been an exciting and innovative time during my tenure at the HTC, and I feel extremely fortunate to have been a part of this season of scientific advancement with all of you! I hope you all know what a critical role you play in this! None of this is possible without your bravery and altruism! You, the patients, are the real heroes in this endeavor to advance science and healthcare! You

allow for hope; hope that today isn't as good as it gets. We've come a long way, but we still have more to learn!

The research team members I leave behind are fantastic people and they will continue to take great care of you. I assure you that you are in good hands, and they will provide the same gentle, friendly, FUNNY, and high-quality care that you so deserve!

Again, thank you, from the bottom of my heart, for trusting me with your care! Thank you for allowing me to be a part of your lives. I have loved serving you and I value the relationships and friendships we have created. I will miss you tremendously, but I plan to remain connected. This isn't a goodbye, just a see you later!

All my love,

Julie Smith, Research Services Program Manager



Join us in-person Saturday, **April 20, 2024** from 9 am-1 pm at our HTC for a half-day of learning and connecting.

This Spring Event will include:

- A panel discussion including pediatric stroke survivors and families
- A speaker presentation on education after stroke by Jodi Krause, a learning specialist at Children's Hospital Colorado
- A support group luncheon
- Both breakfast and lunch will be provided
- Childcare will be provided

This event is free to attend, but you must RSVP to help us plan for childcare and food/snacks. We will have volunteers from Children's Hospital for childcare.

Please **RSVP by March 19, 2024** to strokesupport@ucdenver.edu.

Please include in your RSVP:

- Number of adults attending
- Number of children attending
- Ages of children attending
- Any food allergies

For more information, see our flier and event info at our website:

<https://medschool.cuanschutz.edu/hemophilia-thrombosis/resources/pediatric-stroke/support-group>

If you have any questions, please reach out at strokesupport@ucdenver.edu. We hope to see you there!

RECENT HEADLINES

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

Muscle Loss Common in Hemophilia A Patients with Joint Bleeds

Trial Shows Roctavian, Gene Therapy, Maintains Effectiveness after Seven Years

NBDF Names Phil Gattone, M.Ed, as Next CEO

Jivi Safe, Effective for Hemophilia A in Long-term Study

First US Patient Treated with Hemophilia A Gene Therapy Outside a Clinical Trial

Three Year Study Shows SerpinPC is Safe and Reduces Bleeds in Hemophilia A & B

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 [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.

Feb 29: Rare Disease Day

Mar 2: NBDF CO Bleeders on the Slopes—Granby, CO

Mar 6-8: NBDF Washington Days—Washington, DC

Mar 22: NBDF CO Chronic Disease Awareness Day

Mar 22-24: NBDF CO Education Empowerment Days—Denver, CO

Apr 4-6: THSNA 2024 Summit of North America—Chicago, IL

Apr 11-13: HFA Annual Symposium 2024—Indianapolis, IN

Apr 17: World Hemophilia Day

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

ME-WE-HTC We create hope.

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medschool.cuanschutz.edu/hemophilia-thrombosis

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