The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



Hemophilia and Thrombosis Center

UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS

UNITE FOR BLEEDING DISORDERS WALKS



Join us for a walk at Sloan's Lake Park, Aug 23rd! Photo: NBDF Colorado

The Unite for Bleeding Disorders Walks are coming right up! The Colorado Chapter of the NBDF is hosting their annual walk on Saturday, August 23, 2025 at Sloan's Lake park. This year they will be meeting on the south side of the park, near 17th and Utica. This important fundraiser is how NBDF Colorado provides education, community events, and even Mile High Summer Camp. Their goal this year is to raise enough to be able to add an additional night to their annual Family Camp next vear.

Because the Colorado walk coincides with

the NBDF's Bleeding Disorders Conference in Aurora that same weekend, we encourage all who participate in that to also register and donate-even if you can not attend in person. If you are going to attend in person, NBDF Colorado asks that you register now (join any team) so they have a good idea of how many breakfast burritos to provide! Your \$25 donation gets you a tee-shirt as well as free food! (including donuts and coffee!) We encourage any attending at the conference in Aurora to carpool to Sloan's Lake and/or share an Uber/Lyft. Check out details at their Facebook account and website for specifics.

In addition, the RMHBDA, supporting Wyoming and Montana. will hold their walk coming up on Saturday, September 6, 2025 in Billings, Montana at Zoo Montana. This chapter also supports many of our patients and we encourage any to donate and participate if possible.



One of our "fun" draisers at the HTC: a popcorn bar to make

Each of these walks are a great opportunity to connect and encourage, as well as raise funds and awareness about the challenges facing those who have a bleeding disorder. Most NBDF chapters, including the Colorado chapter and the RMHBDA chapter, are non-profit organizations that rely on these funds to provide the educational and community activities throughout the year. This includes Mile High Summer Camp, which is such a powerful part of helping children with bleeding disorders learn, connect, and have fun in a safe environment.

Can't attend in person? Consider taking the time to contribute to one or both of these walks by donating online. Fun fact, for most of August, our HTC has held creative fundraising events to contribute to these organizations. We've had an ongoing "snacks for a cause" events, special lunches, pizza, popcorn, lemonade, and raffle events, all for our staff to be able to contribute, one snack at a time! We look forward to seeing you at one of these walks or at a future NBDF event.

You can make a difference by donating to these organizations who both work all year to make a difference to families with bleeding disorders. Thank you for your support!



Join us for the Unite for Bleeding Disorders walks! NBDF Colorado-Aug 23rd, or RMHBDA-Sept 6. If you can't join, consider donating to support those with bleeding

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



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



Go to twitter.com/ HTCColorado



Website: Go to

medschool.cuanschutz.edu/ hemophilia-thrombosis



Email:

HTC.Newsletter@ucdenver.edu

BACK TO SCHOOL TIPS AND TRICKS



For many children and young adults, the fall semester has begun! Others will be starting in the next few weeks, and getting back into the school schedule can be a struggle. Now is a good time to review your routine and think about ways to set good habits for the new school year.

Chat about schedules. Take time to have a discussion to review what everyone's schedule looks like. This can be weekly, monthly, even via text or a calendar if that works easier for you. Depending on the ages of your kids and their activities, simply touching base can help make sure no major conflicts are coming up. Having a regular check-in with everyone is also a great time to get a feel for how they are doing with their schedules, homework, and determine if some activities may need to be dialed back. Planning logistics for everyone's schedule can help kids and parents keep track of the items they need to attend to, and avoid surprises — most of the time. Some ideas on planning schedules with kids can be found at tryingtogether.org.

Make a meal plan with healthy choices. Studies show that sharing a meal with your family can provide many benefits including communication skills, healthier habits, preventing mental health disorders, growing self-esteem, and fewer problems



with being bullied. When planning your weekly schedule, you could also incorporate your plans for meals. If you are able to have a regular dinnertime, even if it's a few times a week, include the kids in planning and cooking healthy meals. Cook what you and your kids will eat and encourage children to suggest ideas for new things to try together. Cooking at home also can save a lot of money over time — on average it is nearly three times more expensive to eat out

than eating at home. Many apps offer recipes, planning guides, and ideas for family friendly meals. Read more about planning meals together at <u>parents.com</u>.

Find a good bedtime routine.

Everyone needs a good night's sleep, no matter the age or challenges throughout the year. But it isn't always easy to get in a good pattern, and sometimes we forget just how much sleep should be prioritized. Set a bedtime and create a regular



pattern that allows your kids time to wind down and get enough rest. Each age group may need different routines, but even young children connect with simple routines like brushing teeth, taking a bath, and reading a book together before bed. Try not to have other activities running into your bedtime routine to keep things on track. If you feel like this time is chaotic, find one thing to adjust to your routine at a time. See a few great ideas at sleepfoundation.org.

Reduce technology and screen time. The research is pretty solid now that exposure to TV, computers, phones, games, and other screens stimulate the brain so it's hard to settle down or make it harder to focus on needed tasks. The saturation of digital tools and toys is impacting everything from development of language skills, social interactions, sleep, physical health, self-esteem, and mental health. Talk with your kids honestly, and in an age appropriate way, about the use of technology and screens; what they can be good for, but also their drawbacks. As the parent, you set rules about screen time, but adults and kids alike struggle with too much screen time. Work together as a family to set your own limits and encourage other ways to spend time together, such as playing outside, interactive games, or learning a craft or skill — that isn't on a screen. If your kids are struggling with controlling impulses with tech, set a time when these items are off limits, such as during dinner. or as part of a bedtime routine. For some helpful ideas and good management of tech for families, check out discoverymood.com.

Look for opportunities to connect and have family fun. No matter what age your kids are, spending time together doesn't have to be a large event to be meaningful. Small activities over time create a safe space at home and opportunities to connect and build healthy relationships. Schedule a regular family board game night or go on regular outings like a walk or bike ride together. Connection with your family is one of the most powerful joys in life, and a



[Continued from page 2] strained relationship can cause stress. Actively working to connect with your family, large, small, old or young can improve life overall. For some insight on how to build strong family connection, see raisingchildren.net.au.

Families with bleeding disorders may need extra connection. If you have a child with a bleeding disorder, you know that an unexpected bleed or injury can throw a wrench into any routine, even if they're well planned. Include in your planning things that you may need in case of a bleed during school, activities, and on weekends. Do you have the supplies you need? Do you know how to contact your HTC after-hours? Have you bookmarked our <u>Contact Us</u> page, for after-hours details?

Do you have protocols for your school to follow on what to do and who to call? Does your school have a nurse on staff that is aware of your child's disorder and the emergency care they could require? It is important to schedule a meeting with school principals, nurses, and teachers to inform them of your child's condition, and what steps they need to take if there is an injury or a bleed. This can be an in-person chat at a back-to-school night, or informative details shared via email. If you are struggling to find resources and support from your school, contact our nursing team at 303-724-0364 for some ideas and support. You can also check out the wealth of resources available at stepsforliving.bleeding.org.

This time of year can be chaotic and busy, but you can take steps to make things easier by simply planning and connecting. If life is feeling overwhelming, just start with one thing that you think you can do, and do your best! All families are unique but healthy routines and planning family time can make a things run a little smoother. See a few more great ideas on routines and fun family activities at raisingchildren.net.au and at parents.com. All photos Adobe Stock.

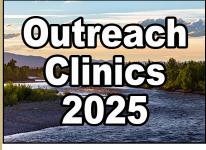
DROPS OF LOVE: CELEBRATE CARING HTC STAFF MEMBERS

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 anvone 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.

This gives patients the opportunity to more easily visit with all our main

providers in-person on at least an annual level.

Remaining 2025 Outreach Clinics:

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.

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:

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

Study Shows Gene Therapy Benefits for Hemophilia B Last More than a Decade

FDA Approves Jivi for use in Children with Hemophilia A as Young as 7 years-old

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.

Aug 21-23: NBDF Bleeding Disorders Conference—Aurora, CO

Aug 23: NBDF Colorado Unite for Bleeding Disorders Walk—Sloan's Lake, CO

Aug 26-28: HTC Outreach Clinic—Billings, MT

Aug 30: RMHBDA Montana 2nd Annual Pickleball Fundraiser—Jackson, WY

Sept 1: Clinic, Pharmacy, and Admin offices closed for Labor Day

Sept 5: RMHBDA Montana Golf Clinic and Dinner—Billings, MT

Sept 6: RMHBDA Montana Unite for Bleeding Disorders Walk—Billings, MT

Sept 9-11: HTC Outreach Clinic-Grand Junction, CO

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

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:

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