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

ENJOYING COLORADO'S FALL COLORS



Scenic drives, like along Guenella Pass in the autumn, offer plenty of chances for admiring the colors of Colorado. Photo: Merilee Ashton

Fall has arrived and there is just a short window to take in the colors! The weather is turning cooler and it's a great time to plan a walk, hike, bike ride, or drive to enjoy the scenery. Hiking, biking, and even just getting outside to walk around while on a scenic drive can be beneficial for our physical and mental health.

If you've been in Colorado all your life or just moved here, make sure you plan a hike with safety in mind. Even with cooler temperatures, sunscreen is a must. The lowest point in

Colorado (3,317 feet) is higher than any part of eighteen states in the country, and our highest peaks include 58 above 14,000 feet. The sun at high elevations is powerful year round; so hats, long sleeves, sunglasses, and sunscreen are necessities.

Just being up high can lead to dehydration. For those from lower elevations especially, suddenly going up in elevation can even make you feel sick, especially if you are dehydrated. If you have visitors from lower climes, be sure to take a day or two to acclimate before heading out on a high-altitude hike. Be prepared to carry at least a liter of water per every two hours you intend to hike, and plan on carrying extra. It's easy to go through your water with our high, dry climate.

Experienced hikers know that it is always best to hike with a buddy, to let others know where you are going, and to bring food and back up supplies in case something goes wrong. Many people have experienced a beautiful morning of hiking, followed by the sudden arrival of a serious rainstorm, hail, lightning, and even snow. Make sure you have the right shoes to hike, the right gear for your hike, and plan on layers to both cool down, or warm up when needed.

But where to go? It's a smart idea to do some research online on where you want to go or navigate with one of the hiking apps you can get on a smart phone like <u>All Trails</u>,

Rocky Mountain National Park has many scenic drives and miles of trails to enjoy the views. Photo: Merilee Ashton

<u>COTREX</u> (Colorado's trail explorer app), <u>The Hiking Project App</u> (Crowdsourced REI app), or others.

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Plan a hike or scenic drive and take in the fall colors, like aspens near Aspen, CO. Photo: Merilee Ashton

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



Website: Go to

medschool.cuanschutz.edu/ hemophilia-thrombosis



Email:

HTC.Newsletter@ucdenver.edu

BACK TO SCHOOL SUPPORT IS AVAILABLE



School is back in session for most families, and kids with bleeding disorders often face additional hurdles to manage their health during the school year. If you haven't yet had a chance to connect with your school about your child's bleeding disorder now is the time to get started. Even if your child attended the school last year, it's always good to connect and make sure teachers and administrators are aware of their needs and have clear plans in place to provide support.

Many resources are available for families to help educate school staff of what they will need to know about your child's bleeding disorder. Education is one of the more effective tools to help others know how to handle a bleed and

knowing what accommodations your child might need. Some kids with severe disorders may qualify for an IEP or a 504 plan (depending on their disabilities) and others may just need additional accommodations that don't require a formal plan. This can be simple things like extra time to get to class or additional support if they need to stay home because of a bleed.

Our nursing team can help create an Individualized Health Plan (IHP), and provide any forms needed for schools-whether or not they need additional IEP or 504 documentation. If you would like some help in setting up the right plan for your child at school, please reach out to our nursing team. You can contact them at our main number **303-724-0724** or at our nursing line **303-724-0364**. They are happy to answer questions about how to set up the best options for your child.

Be sure to also check out some of the many online helps at bleeding.org, including the NBDF's Back to School Highlights article, or their Steps for Living: School section. The Hemophilia Federation of America has some great Back to School Toolkit resources that explains IHPs, 504 plans, and IEPs and has a lot of other helpful information as well. Good luck with the new year and we hope it is a safe and fun year ahead.



PAY YOUR PHARMACY BILL ONLINE

Did you know that you can now pay your pharmacy bill online? Our HTC pharmacy is now able to accept payments for prescriptions using a debit or credit card right from our website. You can pay by going to our website's Pay My Bill page, or you can pay on your phone by using the QR code below.



In order to pay, you will need the **claim number** from your invoice, and the **patient's initials**.

If you have any questions about how to pay your pharmacy bill, details can be found at our website at:

medschool.cuanschutz.edu/

hemophilia-thrombosis/pay-my-bill, or you can contact our HTC pharmacy by phone at **303-724-0168 or 1-888-297-0724**, or email us at hemophilia@ucdenver.edu.

DROPS OF LOVE PROGRAM

Our HTC has a fun program called "Drops of Love" to celebrate our staff. 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!

Just scan the QR code (below) or find 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!



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Depending on the dates you are able to go, check out a map such as this dynamic one at <u>explorefall.com</u> to anticipate peak fall foliage.

Some popular destinations, like Rocky Mountain National Park, are so busy they require reservations to drive in to visit. Several others, including a couple of state parks and popular hikes with minimal parking require taking a shuttle to visit. Be flexible, do your homework, and realize that traffic is heavier on weekends-and it can pay off to find less traveled trails.

Here are a few places to look into:

Rocky Mountain National Park

Located just a couple hours north of Denver, it is a popular location and can be busy this time of year. RMNP has timed entry requirements to enter the park between May and October.

Golden Gate Canyon State Park

Golden Gate Canyon State Park is a wilderness area only 13 miles west of Golden. This park is included in the <u>Keep Colorado Wild Pass</u> (if you purchased one when renewing your vehicle's registration) or has daily entry fees.

Steamboat Lake and Pearl Lake State Park

Steamboat Lake State Park is located near Steamboat Springs, and close by is Pearl Lake State Park. Both have miles of beautiful trails and fall under the Keep Colorado Wild Pass or have an entrance fee.





Maroon Bells (top) is worth the trouble to get reservations for the shuttle. Kenosha Pass has one of the larger stands of aspen in Colorado, but can be crowded. Photos: Merilee Ashton

Maroon Bells

A true icon of Colorado, taking in Maroon Bells in the fall is an unforgettable experience. Located near Aspen, it has many popular trails and stunning views. It is also a very busy area but worth the reservations on the shuttle to get there.

Of course, just finding a hiking trail with a trailhead can do the trick without visiting a park or getting a shuttle. Scenic drives abound in Colorado, just make sure you are aware of weather, road closures, the type of roads you may be driving on, and what your car can safely manage.

Here are a few other beautiful areas to check out: <u>Mount Galbraith Park</u>; <u>Kenosha Pass</u>; <u>Nederland</u>; <u>Guanella Pass</u>; <u>Garden of the Gods/Pikes Peak</u>; <u>Silverton-Ouray-Durango</u> (the Million Dollar Highway); <u>Telluride</u>; and <u>The Grand Mesa</u>. Drive safe, hike safely, and enjoy the colors of the season.

UNITE WALKS BRING SUPPORT AND COMMUNITY



A few of our team members join other top fundraisers at the Unite Walk in Denver this year. Photo: NBDF Colorado.

In late August, our HTC team Chill Factor was able to participate in the annual Unite for Bleeding Disorders Walk at Sloan's Lake Park. This was a fun opportunity for our staff to connect in a different way with patients, families, and friends who were there to raise funds for and awareness of those with bleeding disorders. The Colorado Chapter of the National Bleeding Disorders Foundation hosts this event every year and our team is happy to share that we met and exceeded our goal of \$5,000 and are one of the top HTC teams in the country.

We also provide fundraising support to the Unite walk for the Rocky Mountain Hemophilia and Bleeding Disorders Association located in Montana. They held their walk in Billings, MT early September and our team was able to raise \$1400, with donations and a silent auction.

If you didn't get a chance to participate or donate, you can still make a difference by going to <u>uniteforbleedingdisorders.org</u>, look up a walk, and make a donation.

We thank all who participated to help these organizations raise funds for the coming year. Both are able to provide education, community, and opportunities for families with bleeding disorders.



RECENT HEADLINES

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

Gene Therapy Data for Roctavian Shows Most Remained Off Preventative Therapy after Seven Years

Gene Editing Therapy Shows Promise in Pre-Clinical Study in Animals

Survey Finds Most Men with Hemophilia Continue to Have Joint Problems Even with Prophylaxis

Prophylactic Treatment of Hemophilia Linked to Less Disability-Related Unemployment

Pfizer Shares Positive Trial Data for Hemophilia A Gene Therapy

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!



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.

Oct 4-6: NBDF Colorado Women's Wellness Retreat

Oct 8-10: HTC Outreach Clinic—

Grand Junction, CO

Oct 17: RMHBDA Education & Dinner Seminars—

Kalispell, MT

Oct 22-23: ATHN Data Summit—Atlanta, GA

Oct 31: Happy Halloween

Nov 1-3: RMHBDA Women's Retreat—Chico Hot

Springs, Pray, MT

Nov 3: Daylight Saving Time Ends

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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