

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

September 2020
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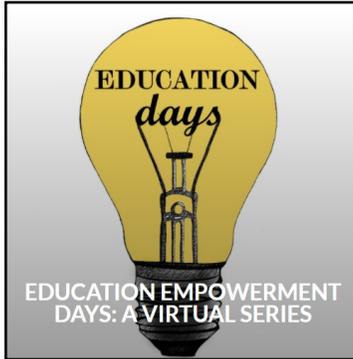


Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with
Children's Hospital Colorado

EDUCATION DAYS GOES VIRTUAL



Every year, NHF Colorado and the HTC join forces to put together an educational forum that brings families in the bleeding disorder community together for a weekend of learning, interaction, and fun. This year the COVID-19 pandemic hit just weeks before Education Days was planned in Colorado and it had to be postponed.

We are happy to share that NHF Colorado and the HTC will be involved in the **2020 Virtual Education Days** that will be held on three

consecutive Saturdays in online formats. These events will be online **October 10th, 17th and 24th**, each day with special learning sessions. Complementary GrubHub gift cards will be sent to all participants to provide lunches as well as dinner on select days.

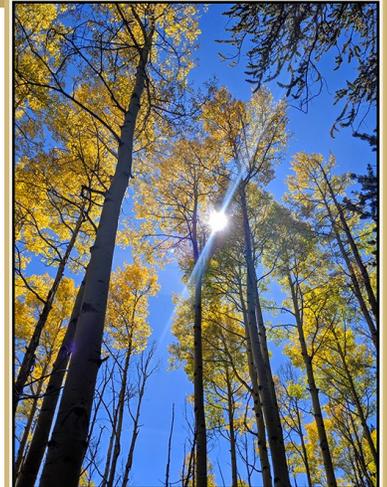
Many educational and interactive programs will be available on each day, including special programs for teens, ages 14 and up, that will be presented by Gut Monkey. While several presentations are still being finalized, we can share that our Co-Director, Dr. Mike Wang, is scheduled to present “Gene Therapy Preparedness and New Therapies” on Oct 17th in the 4 pm slot.

Our HTC staff will be presenting and also involved in many other ways; we look forward to the opportunity to interact with our bleeding disorder families. NHF Colorado will host a celebration of the 2020 Unite for Bleeding disorders Walk, present Member Awards, and award prizes for the Walk Across Colorado program (see page 2 for more information).

There will be interactive sessions, several Spanish Language programs (presented in Spanish), the Leading Edge Program for teens, and a networking reception allowing families to interact. Several time slots will be dedicated to Interactive Exhibits, where a program isn't being presented but viewers can browse at their leisure to learn about new research and findings. A community movie night will allow everyone the chance to watch *Bombardier Blood*. This is an incredible documentary featuring Colorado's own Chris and Jessica Bombardier and their experiences as Chris worked to climb the Seven Summits, including Mount Everest.

Though this Education Days will be very different than in the past, it will provide many opportunities to gather, learn, share, and connect with those in our community. The program is free, but you must register to be able to log in and receive the items that come with registration.

Go to cohemo.org to register and to learn more about this great upcoming opportunity!



Get your steps in by walking trails this Fall. Image by Merilee Ashton.

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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

WALK ACROSS COLORADO WITH NHF



Did you miss attending the NHF Colorado Unite for Bleeding Disorders Walk in person this year? We missed seeing you!

As a part of the upcoming NHF Colorado Education Days, NHF Colorado has a fun new program that allows you to keep walking for a purpose! Join us for the [Walk Across Colorado](#) program, that encourages our same Unite for Bleeding

Disorders teams to unite in their efforts to walk “across” Colorado virtually!

How does this work? There’s an app of course!

The app will allow you to connect to a variety of health apps, such as Fitbit, Apple Health or Google Fit (to mention just a few) that will help keep track of your steps and miles. You will be able to sign up for a team or walk on your own. Each team or participant has a chance to earn rewards along the way as we include our steps as an effort to go the distance before Education Days wraps up!

Working as a team, or individually, your goal is to walk ‘across’ Colorado (or 280 miles) by the end of Education Days on October 24th. Prizes will be awarded to members who are able to walk 50 miles, 100 miles, and to each team who completes the 280 miles.

While 280 miles sounds like a lot, by joining forces with other team members, you don’t have to do it alone. Even better, you can share your progress with friends and family, and encourage those who would have donated or attended our walk to instead

walk with you and donate online to NHF Colorado. [Donation to NHF Colorado is still open here.](#)

Walking and hiking are incredible ways to keep fit, keep joints healthy and enjoy the sunshine. We know that exercise can help strengthen muscles and help with recovery for those who may have bleeds.

Our physical therapist, Dr. Laura Fox, recommends that you carefully consider your level of current physical activity when engaging in any kind of new exercise. Start gradually, take it slow, and listen to your body so you don’t overdo it. She recommends warming up before a walk, cooling down at the end with slower pacing, and including stretches ([upper and body stretches are available on our website](#)). Be sure to wear supportive shoes and drink lots of water but have fun!

We’d love to see you go the distance, and each step counts! Walking the dog, walking at the store, walking around the block, all of it counts toward your own Walk Across Colorado!

To sign up to join us, you will need to:

- Download the Walk Tracker App from iTunes or the Android Google Play store
- Choose “create new account”
- Enter the URL: <https://nhfcolorado.walkertracker.com>
- On the registration page, enter your name, email, and choose a password.
- Scroll down and select your team!

You can choose which step tracking device you want to use with the app. If you have trouble connecting your apps on your phone, you can also connect your devices on the website version of the app.

The Walker Tracker team is very responsive, so if you have trouble, reach out to them for technical support. Get out and Walk Across Colorado!

**Pediatric
Stroke Parent
Support Group**
**VIRTUAL ZOOM
Meeting**
**Tuesday
Oct 13, 2020
6:30-7:30 pm**

PEDIATRIC STROKE SUPPORT GROUP

Our Pediatric Stroke Parent Support Group is now meeting online! We’ve missed visiting with our pediatric stroke families in person, but to stay safe we’ll be meeting online for a while longer.

Please join us for our next online meeting on **Tuesday, October 13th from 6:30-7:30 pm on Zoom.**

This group meeting welcomes everyone in the family to join. Your child does not need to be treated at our center to attend.

To join, please RSVP by contacting us at strokesupport@ucdenver.edu or (303) 724-8520. We’ll send a calendar reminder with the zoom link to all who RSVP. Follow us on Facebook for the latest on our meetings at www.facebook.com/Colopedsstroke. We hope to ‘see’ you on October 13th!

FIVE EASY FALL HIKES TO GET IN YOUR STEPS

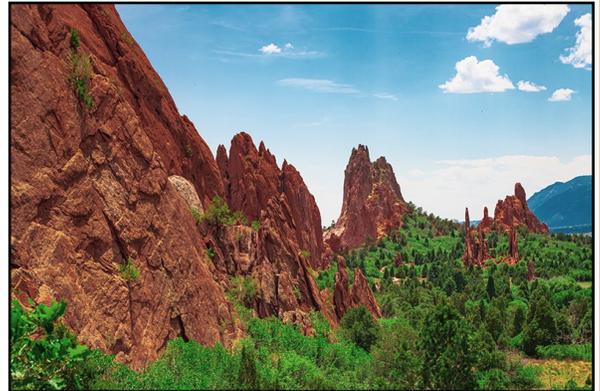
Fall is here and it is the perfect time to get out and hike! You can add steps to your Walk Across Colorado Challenge, spend time with family (or socially distanced friends), and enjoy the changing of the seasons. We've found a few easy hikes to get you started, but there are so many options! Be creative and explore! Be prepared for all kinds of weather, use sunscreen, bring food and water, and be aware of any restrictions due to COVID-19 and the recent wildfires in our state. Get out and enjoy!

Alberta Falls, Rocky Mountain National Park

This trail is just one of the park's beautiful views and hiking opportunities. With the COVID-19 restrictions and recent fires closing parts of the park, be sure to check their website for updates. You must book a time slot in advance in order to enter the park so plan ahead by going to [nps.gov](https://www.nps.gov).

Garden of the Gods Loop Trail

Located near Colorado Springs, Garden of the Gods is a "must-visit" site for newcomers, visitors, and longtime locals. Many beautiful red-rock formations are visible on a 3.7 mile loop that is paved and maintained. It's a great place to enjoy fall weather and the scenery at any time of year. Find details at [gardenofgods.com](https://www.gardenofgods.com)



Garden of the Gods. Image by Jude Infantini, unsplash.com.

Meyer Ranch Open Space Hikes

There are three easy to moderate hikes with beautiful views, wildlife, and easy access found in the Meyer Ranch Open Space near Conifer. Only about a half hour from Denver, these trails are a nice getaway without the long drive. Bring sunscreen and water, but get some fun steps in just outside of town. More details can be found at [dayhikesneardenver.com](https://www.dayhikesneardenver.com).



Mesa Lakes Trail. Image by Alltrails.com

Mesa Lakes Trail

If you're on the Western Slope, consider exploring Grand Mesa National Forest. The Mesa Lakes Trail is a kid-friendly, 2.8 mile loop that offers scenic views and may be less crowded than the more popular trails. Learn more about this and other nearby trails at [fs.usda.gov](https://www.fs.usda.gov).

Trollstigen Trail

Did you know there's a troll in Colorado? There's actually more than one! Isak Heartstone is an art piece installed near Breckenridge and is at the end of a very short trail made just for him. The trailhead is right next to the Illinois Gulch trailhead and is easy to access with Breckenridge's free transportation system. Learn more at [gobreck.com](https://www.gobreck.com). Another troll in Colorado, [Halvor Flowstone](#), can be found near Glenwood Springs.



Isak Heartstone Troll near Breckenridge. Image Merilee Ashton.

There are so many more trails in Colorado and nearby states to choose from. Explore online to find the one that is right for you and your family. Be prepared with water, snacks, sunscreen, and medical supplies. Don't overdo it, but get out and have some fun enjoying fall with a hike!

RECENT HEADLINES

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

CSL Behring Will Discontinue Mononine for Hemophilia B

Genentech Provides Update on Particles in Hemlibra

Sanofi's BIVV001 Phase 1/2 Trial Results Show Promise

FDA Rejects BioMarin's Gene Therapy for Hemophilia A

CSL Behring and Ferring Issue Recall of Stimate

We maintain a newsroom page at our website with a list of the news we feel 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.

UPCOMING EVENTS

Mark Your Calendars:

Please note. These dates may be tentative and subject to change due to the COVID-19 pandemic and restrictions. Please check appropriate websites for confirmation of events.

Oct 10, 17, 24: NHF CO Virtual Education Days

Oct 10: RMHBDA Unite for Bleeding Disorders VIRTUAL Walk (see rmhda.org for updates)

Oct 13: Pediatric Stroke Parent Support Group-Virtual Meeting

Oct 27-30: THSNA 2020 Summit—VIRTUAL

Nov 6-8: RMHBDA Women's Retreat—Chico Hot Springs, Pray, MT

Nov 26-27: HTC Clinic, Pharmacy, and Admin Offices Closed for Thanksgiving Holiday

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

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or toll free at 888-297-0724

Pharmacy Main: 303-724-0168

or toll free at 888-724-7427

Web page:

[medschool.cuanschutz.edu/
hemophilia-thrombosis](https://medschool.cuanschutz.edu/hemophilia-thrombosis)

PLEASE
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