

# 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

## 2021 SUMMER CAMP OPTIONS



2021 is nearly halfway through, and many are wondering if things will ever get back to normal. There are still a number of restrictions and adjustments, but the good news is that progress continues as more people are vaccinated, COVID numbers are improving, and rules are relaxing.

Many may be wondering if camp can return to normal yet, and the answer is: sort of! NHF Colorado is our partner in supporting families at camp and they have carefully navigated all the restrictions, suggestions, desires, logistics, and possibilities to come up with a hybrid summer camp. Camp this year is full of options and choices to allow families to choose what is right for them.

So, what will camp look like this year? NHF Colorado has set up a variety of fun possibilities to engage in safe and exciting ways. NHF Colorado's Family and Summer Camp Series includes a mix of family and individual, virtual and in-person events.

**July 16th-** Virtual Family Campfire. This is an evening where we gather virtually, but share camp traditions, like games, songs, and activities. This is an easy way for families across our region to connect and visit. Families who register will receive a Camp Box that will include goodies and resources to enjoy this fun night together.

**July 20-22nd-** Three-Day Virtual Mile High Summer Camp. We are excited to allow campers of all ages to gather online for a virtual camp experience. Last year we had over 40 campers and this year we will partner with the San Diego Chapter to have more campers connect in this fun way. All three days will be filled with adventure, connection, and opportunity.

**July 24th-** Beach Day at Bear Creek Lake. This is an in-person opportunity for families to connect and play! There will be a variety of family fun games, activities planned for certain age groups, and opportunities to learn new skills and connect with those you may have met online.

**Aug 7th-** Together in the Outback- This Teens Only leadership event is an in-person chance for our older campers to grow their leadership skills. A series of fun challenges will allow teens outdoor exploration, connection, and build lifelong relationships with their peers.

**Aug 21st-** Camp Reunion Tent at the Unite for Bleeding Disorders Walk, Sloan's Lake. The in-person walk is back, as well as opportunities to walk virtually, but more importantly, our camp reunion tent gives our campers a chance to connect again before the school year begins once more.

**Aug 28-29th-** Overnight Family Camp. Families have a chance to connect with others in a fun, all inclusive environment. Highland's Camp in Allenspark has a variety of fun, team-building activities for family members to choose from.

We hope you can take advantage of some or all of these fantastic opportunities this summer and enjoy the sense of community that can come with spending time with others with bleeding disorders. All camp activities require registration, which is open now. **Registration is open until July 2nd** at [cohemmo.org](http://cohemmo.org).



Join NHF Colorado for a hybrid of virtual and in-person fun for this year's Mile High Summer Camp! Register by July 2, 2021. Photo: Hanna Beary

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



Go to [facebook.com/ColoradoHTC](https://facebook.com/ColoradoHTC)



Go to [twitter.com/HTCColorado](https://twitter.com/HTCColorado)



Website: Go to

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



Email:

[HTC.Newsletter@ucdenver.edu](mailto:HTC.Newsletter@ucdenver.edu)

## NEW OPPORTUNITIES

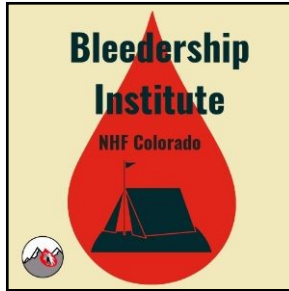


Backpacks + Bleeders is back! After a long hiatus because of the pandemic, we are embarking on some new adventures! Please join us for a fun and family friendly hike at Evergreen Lake on **Saturday, June 26, 2021 at 10 am.**

This is an easy 1.4 mile hike around Evergreen Lake. Bring your family, friends, or even your dog, but come

connect with others in the bleeding disorder community. Parking is free! For more information contact Hanna Beary at [hbeary@hemophilia.org](mailto:hbeary@hemophilia.org) or to [register go to cohemo.org](https://www.cohemo.org).

NHF Colorado's Mile High Summer Camp is a mix of virtual and in-person this year, but they still need help! Join our Bleedership Institute as a Camp Counselor to support both our virtual and in-person camp events. If you want to get involved, are 19 years or older, and are able to help supervise and care for campers, maybe being one of our counselors is for you!



Our Bleedership Institute is perfect for individuals pursuing non-profit careers, those who love working with kids, or as experience for future internships or college programs. See [NHF Colorado's Bleedership Program page](#) for information, qualifications, time commitments and how to apply.

## HTC PHARMACY RECEIVES ACHC ACCREDITATION



Congratulations to the HTC Pharmacy for achieving a new Specialty Pharmacy Accreditation from the Accreditation Commission for Health Care (ACHC) at the end of May. The ACHC accreditation process is highly detailed and requires our pharmacy to comply with strict policies and procedures. Our pharmacy team has already achieved Specialty

Pharmacy accreditation from URAC and continues to build practices into their daily protocols to keep patients and pharmacy workers safe, and provide excellence in all their services.

Our pharmacy is one of a select few HTC pharmacies in the entire country to have achieved both the URAC and ACHC accreditations. The process to gain accreditation is challenging and most of the work for the ACHC accreditation was done during the pandemic, adding an additional hurdle. We honor the hard work done by our incredible pharmacy staff to reach all the milestones to achieve both of these accreditations. You can count on our pharmacy to lead the way in quality and excellence.

## NEW APP TO TRACK YOUR BLEEDING DISORDER

### How to get started...

1. Download the app from the Apple store:



2. Let a member of our team know you are interested and we will send you an email with further information.

### For more info contact:

**Hana Durkee**  
Email: [hana.durkee@cuanschutz.edu](mailto:hana.durkee@cuanschutz.edu)  
Phone: 303-724-0422

Track bleeding events, medications, & activities that may have contributed to bleeding.

Currently available on iPhone or iPad.

[Android development is in process!]

## UNITE FOR BLEEDING DISORDERS WALKS

Save the date, find some shoes, warm up those walking muscles, the Unite for Bleeding Disorders Walk is just around the corner.



NHF Colorado's Event will be on **Saturday, August 21, 2021 at Sloan's Lake in Denver**, and Rocky Mountain Hemophilia and Bleeding Disorders Association (RMHBDA) will host their walk on **Saturday, September 11, 2021 at Zoo Montana in Billings, MT.**

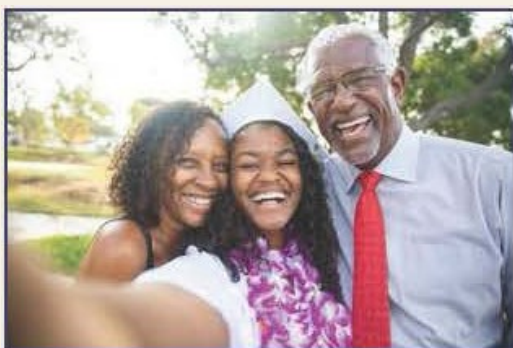
Both walks will have in-person and virtual options this year so you can walk whichever way is best for you! NHF Colorado and RMHBDA would love your help in reaching out to your friends, neighbors, family, and others to ask for their involvement and support. These walks are the main fundraisers to help both organizations provide advocacy, education, and connection for bleeding disorder families.

Check the [NHF Colorado](#) or [RMHBDA websites](#) for more details, and for information on how to sign up.

We hope you can join us at one of these events to enjoy a walk, connect with others in the bleeding disorders community, and make a difference.

**Unite**  
for Bleeding Disorders

## REGISTER NOW FOR 2021 EMPACT PARENTING PROGRAM



Do you have a teen with special needs or a medical condition? Are you looking for tools on how to be a better parent? You may be interested in a special parenting program that is uniquely designed to help parents of teens and young adults with serious medical conditions or special needs.

This Impact Parenting Program will be hosted by the Hemophilia and Thrombosis Center and is specifically targeted to parents with teens and young adults with bleeding disorders. It will be co-facilitated by Dr. Emily Wheat, PhD, who is our psychologist at the HTC and head of our Psychosocial Team. She will be joined by [Danna Merritt](#), author of the program, [Ruben Aguirre](#), a parent of a child with hemophilia, and [Ben Marth](#), a parent of a child with autism.

The Impact Parenting program is designed to help parents understand the teen brain and mindset through puberty, and how the changes teens are going through impact their decisions. Parents will learn about parenting attitudes, and discussions will cover topics like sex, tattoos, alcohol, bullying and career planning. This robust program encourages parental personal awareness, improves family health, viability, engagement, and interaction. It also connects parents with others going through the same thing, helping parents not feel so alone during this time of life with their teens.

This is a 12-week program that will be held on Tuesday evenings from 7-8 pm MT and held weekly on zoom. This program will begin August 10, 2021 and run through October 26, 2021. Parents will receive access to online educational videos and content, and hard copies of the parent handbook and materials. Normally a \$399 value, this program is **free** through Bayer Pharmaceuticals by using the QR code. To participate you must be a parent of a teen or young adult (ages 12 and older) and must have access to the internet and a computer or tablet with a camera. If you have questions or want more information about this program, [we have more details on our website here](#), or contact Dr. Emily Wheat at 303-724-7900 or at [Emily.Wheat@cuanschutz.edu](mailto:Emily.Wheat@cuanschutz.edu).

Scan to Register



This program is free by using this QR code to register. Contact us if you have questions about signing up.

# EMPACT

## THIRD NATIONAL PATIENT SATISFACTION SURVEY OPEN!

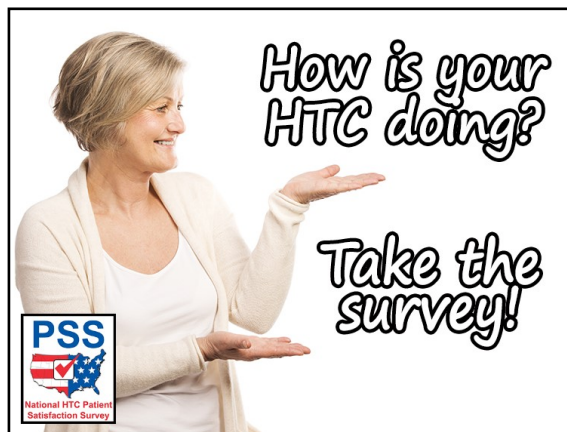
How satisfied are you with your HTC services? HTC bleeding disorder patients and caregivers throughout the US are invited to tell us by taking the Third National Patient Satisfaction Surveys (PSS). The survey is now open and available to all who were treated by an HTC during 2020 to let us know how your care was.

Our HTC sent out paper copies of this survey in March to all our bleeding disorder patients. We encourage our bleeding disorder patients to take this survey online as it is easier for processing, however we included a survey and a self-addressed, stamped envelope if sending by mail is easier for you. If you did not receive a paper copy, please just go to the website to fill out a survey at [htcsurvey.com](https://htcsurvey.com).

This survey is anonymous but both the paper survey and the online version allows a patient to identify the center at which they received care.

This helps our center by allowing us to get honest feedback from patients about their care in the past year. Nearly all HTCs had to make major adjustments in 2020 due to the COVID-19 pandemic. In response, questions have been added to this survey asking patients for feedback on tele-health as well as in-person care. You can respond to this survey whether or not you were seen in person, via tele-health, or sought support over the phone, as long as you received care during 2020.

The survey is brief and is available in both English and Spanish. We ask that parents of young children fill out one survey per child, and any patients who are 18 and up fill out their own survey. For questions, or to learn more about the earlier surveys, please go to [htcsurvey.com](https://htcsurvey.com). **The survey deadline has been extended to August 31, 2021.** Don't miss this opportunity to let us know how we are doing!



## RECENT HEADLINES

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

**Study Analyzes Risk of Inhibitors in Non-Severe Hemophilia A**

**Prophylactic Hemlibra May Lower Treatment Costs for Hemophilia A Patients**

**Book Contest for Hemophilia B Patients Ends June 30th**

**Gene Therapy Trial Data Suggests Efficacy in the Presence of Antibodies**

**Roctavian, Gene Therapy for Hemophilia A, Shows Potential from Early Data**

**First Patient Dosed in Marzeptacog Alfa (MarZAA) Phase 1/2 Study**

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](https://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. Please check appropriate websites for confirmation of events.**

**June 26:** Backpacks + Bleeders at Evergreen Lake

**July 5:** Clinic, Pharmacy, and Admin Offices Closed in honor of Independence Day

**July 16:** NHF CO Virtual Family Campfire

**July 20-22:** Virtual Mile High Summer Camp

**July 24:** NHF CO Beach Day at Bear Creek Lake

**Aug 7:** NHF CO Together in the Outback (Teens Only Leadership Events)

**Aug 21:** Unite for Bleeding Disorders Walk

**Aug 28-29:** NHF Colorado Family Camp

**See more at our Events Page on our website:** [medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar](https://medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar)

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or toll free at 888-724-7427

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

PLEASE  
PLACE  
STAMP  
HERE