

# 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

## NHF CO HOLDS VIRTUAL AND IN PERSON EVENTS FOR SUMMER CAMP FUN



Mile High Summer Camp was held in a three day virtual event.

With the COVID-19 pandemic still causing significant disruptions in most of our lives, NHF Colorado held a hybrid of fun events in July to support our summer camp kids and bleeding disorder families. To keep our families safe, we held Mile High Summer Camp in a three-day virtual format this year.

Over 20 of our local campers registered and we were joined by campers from the Hemophilia Foundation of San Diego as well. The theme for our campers was "Galaxy Camp-Saving the Universe from the Weepuls"! This involved three days of campers creating weepul homes, catapults, and various robots!

What are weepuls you ask? Well, many adults may remember them from childhood, kids may remember them from school events, but they are fun, little, fuzzy critters with googly eyes and goofy paper feet. But for camp this year, they were the focus of a fun-filled three days of silly adventures.

All our campers participated in the Space Jam Relays, making new friends from different cabins and ages. On our last day we had a variety show where over 10 campers and counselors had something fun and unique to share. We thank all who participated in our 2021 virtual camp this year! See some fun pictures from virtual camp on page 2!

In addition, NHF Colorado's in-person Beach Day was a huge success as well! Over 20 families and over 60 people attended this event held at Bear Creek Lake. Kids of all ages had fun playing with water balloons and yard games, enjoying treats and spending time outside.

NHF Colorado and RMHBDA both have a series of upcoming events that look amazing. These include:

- Aug 7-8:** NHF Colorado Teen overnight camping trip-Wellington Lake
- Aug 7:** Middle Schoolers invited to join for day program-Wellington Lake
- Aug 11-13:** Montana Teen Retreat- Flathead Lake Camp
- Aug 28:** NHF Colorado Unite for Bleeding Disorders Walk- Sloan's Lake, Denver
- Aug 28-29:** NHF Colorado Family Camp- Highland's Camp, Allenspark
- Sept 11:** RMHBDA Montana Unite for Bleeding Disorders Walk, Billings Zoo

To register or find out more information on any of these upcoming events and other future events not listed, please go to the websites for [NHF Colorado](#) or [RMHBDA](#).



Were you there for the weepuls!? 2021 Camp was filled with fun!

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Campers shared talents, creations, and fun games.

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



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

# SUMMER CAMP SHENANIGANS 2021



# Save the Date!

**Billings, Montana  
Outreach Clinic  
Sept 27- Oct 1  
2021**

**More details to come!**

After more than a year, the HTC will now begin to offer in-person Outreach Clinics! Our first scheduled clinic will be in Billings, Montana on Sept 27-Oct 1st. Stay tuned for details on how to sign up! Check with our [Outreach Clinic website page](#) for upcoming information.

## 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!]

## TAKE THE NATIONAL PATIENT SATISFACTION SURVEY!



The Third National Patient Satisfaction Survey is set to close on **August 31, 2021**. Have you had a chance to return your survey? Paper versions were mailed out to our bleeding disorder patients in

March, but all bleeding disorder patients who received care at any HTC in the country during 2020 are welcome to participate. [Simply go to htcsurvey.com](http://htcsurvey.com), click on the Take the Survey button, and find the HTC that provided care for you or your child. This survey is designed to help all HTCs in the United States get feedback from patients to find out what things are working, and what things may need changes.

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.

We encourage our bleeding disorder patients to take this survey online as it is easier for processing; it is available in both English and Spanish. We ask that parents of young children fill out one survey per child, and patients who are 18 and up fill out their own survey. For questions, or to learn more, please go to [htcsurvey.com](http://htcsurvey.com). Don't miss this opportunity to let us know how we are doing!

## DENVER UNITE FOR BLEEDING DISORDERS WALK IS AUG 28, 2021

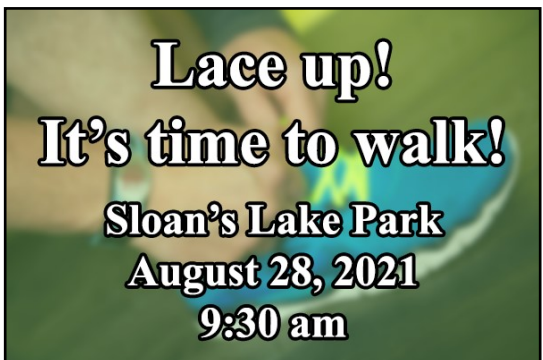
The Denver Unite for Bleeding Disorders Walk will be held on **Saturday, August 28, 2021 at Sloan's Lake in Denver**.

This is an updated date but same location and start time at 9:30 am (check in begins at 8:30 am). The event will be in person but also has the option for virtual participation.

You can [register now](#) to join us as we walk to support NHF Colorado and families with bleeding disorders. The walk is an important fundraiser for NHF Colorado and provides most of the funds for the activities they host throughout the year, including camp, education days, family events and more.

Our HTC participates in the walk and we would love to walk with you! Anyone signing up can either join our team "Chill Factor", join another team, or create their own. All teams help us unite as a community in helping families learn and grow.

Check out the [NHF Colorado website](#) to learn more or go here to [register for the walk directly](#). We hope you can join us and make a difference.



## RECENT HEADLINES

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

**New Data for BioMarin's Valoctocogene Roxaparvovec, Gene Therapy for Hemophilia A shared at ISTH**

**ASC Therapeutics to Begin Phase 1/2 Gene Therapy Clinical Trial for Hemophilia A**

**FDA Puts Hold on Sigilon's Hemophilia Cell Therapy Trial**

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

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

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.**

**Aug 7-8:** NHF CO Teen Overnight Camping Trip– Wellington Lake

**Aug 8:** Middle Schoolers Day Program– Wellington Lake

**Aug 11-13:** Montana Teen Retreat-Flathead Lake

**Aug 28:** Unite for Bleeding Disorders Walk-Denver

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

**Sept 11:** Unite for Bleeding Disorders Walk-Montana

**Sept 11-12:** NHF Colorado Women's Retreat-Glenwood Springs

**Sept 25:** Backpacks & Bleeders Hike at Evergreen Lake

**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