

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

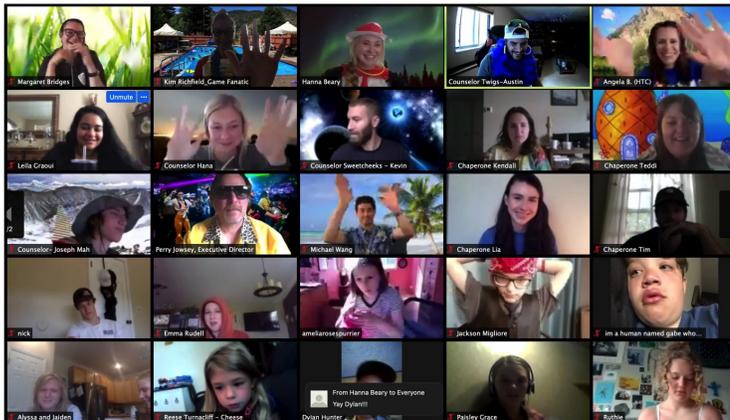


Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Affiliated with
Children's Hospital Colorado

VIRTUAL CAMP BRINGS FUN & SMILES



Kids and teens from all over Colorado, Montana, Wyoming and beyond have been joining weekly “Virtual Mile High Camp” online sessions each Wednesday in July. The Colorado Chapter of the National Hemophilia Foundation, along with Gutmonkey, an outdoor experience company, and the University of Colorado Hemophilia

Each Wednesday in July our campers met online, complete with fun backgrounds, great interaction, and fabulous faces. Photo: NHF Colorado.

and Thrombosis Center with support from the Rocky Mountain Hemophilia and Bleeding Disorder Association have collaborated to continue the camp fun in 2020 even though we can't gather in person this year.

Online camp was a new idea for all of us, it has proved to be a fun way to connect with friends old and new. Each camper was sent a box full of supplies to participate in camp activities from home. Thanks to the NHF and HTC volunteers who spent extra time in June assembling each box for specific campers based on age and color team groups! Campers spend time each week in “cabin” groups doing fun, energetic activities such as

scavenger hunts and interactive games.

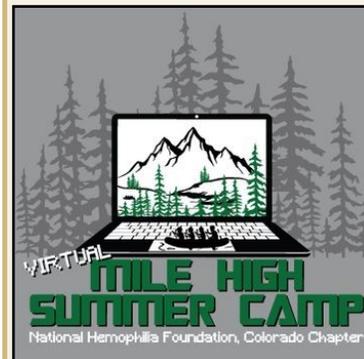


One of our young campers joining us at Mile High Virtual Camp. Photo: NHF Colorado.

Our youngest cabin, now self-named the Friendship Banana Bears, have been having a blast planting magic beans during Bug Day and creating Oreo moon phases for Solar Day. The middle cabin, now known as the Blood Gushers, have been having fun with the Space Game that they have created! Tackling individual and team challenges the group is roaming the universe conquering all! Lastly, our teenage cabin, or the Bleedership group, have been busy having fun with the Teen Olympics, recently tackling the ribbon dance.

In addition to cabin groups, campers are a part of a “color team”. Red, Yellow, Blue and Green teams are in a month-long competition to earn

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Hanna Beary, Program Manager at NHF Colorado, helped campers set the mood for fun. Photo: NHF Colorado.

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



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Website: Go to medschool.ucdenver.edu/htc



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NHF COLORADO AWARDS 2020 SCHOLARSHIPS

The Colorado Chapter of the National Hemophilia Foundation awards two scholarships each year. This June the chapter board met and chose the 2020



Kathleen Mah, recipient of the Jana Marie Lambert Scholarship

recipients of these annual scholarships from an incredible pool of applicants.

Kathleen Mah was awarded the Jana Marie Lambert Scholarship. This award is given to an individual in the bleeding disorder community who is pursuing higher education and shows optimism and hard work.

Kathleen plans to attend the Colorado School of

Mines where she plans to major in engineering.

Emily Fish was awarded the Colorado Chapter Scholarship. This award goes to an individual who has given back to their community and serves as a role model to their peers.

Emily is a graduating senior who plans to continue her education at the University of Minnesota and has been very engaged in our bleeding disorder community.

We congratulate both of these fantastic leaders and wish them well as they pursue bright futures that will make a difference!



Emily Fish, recipient of the NHF Colorado Chapter Scholarship.

UNITE FOR BLEEDING DISORDERS WALK GOES VIRTUAL



This year has turned out to be vastly different than almost anyone thought! Massive changes to schooling, work, and how we play and interact have all made big impacts to our daily lives. Even activities that give us the opportunity to help others have been impacted, such as the NHF Colorado Unite for Bleeding Disorders Walk.

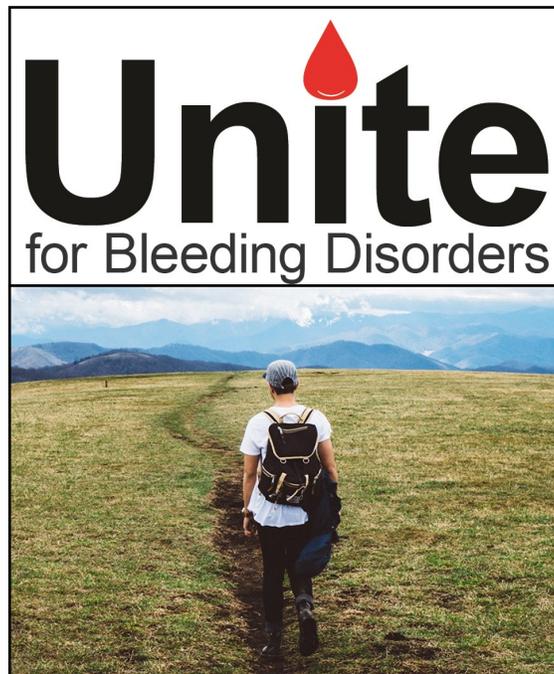
The NHF Colorado Chapter will host a “Virtual” walk on August 22, 2020, to encourage us to all get out and walk, raise funds, and yet stay physically distant enough to keep everyone safe amid this pandemic.

That doesn't mean you sit on the couch! This is a chance for you to recruit others near and far to donate and unite as we walk to support this great cause! This important

event provides nearly all of the funds to the Colorado chapter that provides so much to patients and families of those with bleeding disorders every year.

As a part of the activities, NHF Colorado is offering fun incentives to get walking and support families with bleeding disorders. In addition, Backpacks + Bleeders also is offering prizes for your outdoor hiking efforts this year. Learn more, sign up to support a team, create your own team, and find out about ways to support NHF Colorado Unite for Bleeding Disorders Walk this year at

www.cohemo.org.

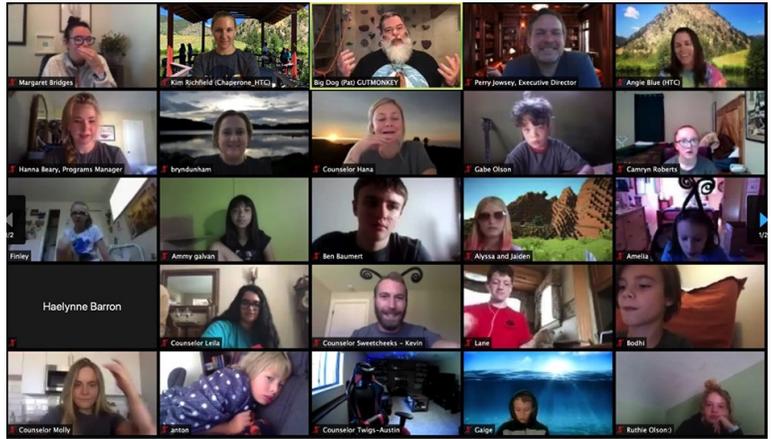


[continued from page 1] points through completing challenges throughout the month that earn points for their teams! HTC staff have been providing some fun educational sessions, just like we do during an in-person week at camp. Everyone has enjoyed seeing their camp friends on Zoom, and for those first timers, they will know some familiar friendly faces when they do come to camp in person in future years.

Besides cabin time and education sessions, we spend time each week with the entire group playing games, such as a color team challenge where kids had to complete several tasks as a team, like singing “Happy Birthday” to someone in their house and melting an ice cube in their hands in a timed competition. There was even a camp dance during week three where campers could bust a move in their living rooms, we were impressed with all of the dance decorations and creativity on display. Campers could also take a break from the dance to visit the ice cream and snack “room” (many took advantage of being able to eat ice cream at 10am!) and a game room!

Thanks to all of the campers and families who have helped keep the Colorado camp tradition alive this year! Your openness to trying something new and enthusiastic participation means the world to us here at the HTC! Camp continues through the end of July, and though it was a very different year for camp, we’ve had a great time being with campers online in 2020!

Campers participated in a variety of activities at home for the all-camp and color team challenges. The chalk challenge asked campers to go outside and draw something that would brighten someone’s day. For the Old Times Sake challenge, kids were asked to take a selfie with something that reminded them of last summer camp. Other challenges featured here include Copper Column; How’s This Look?; Safety First; and Book Club.



2020 Campers meeting in their online groups brought fun, silly antics, great backgrounds, and laughter each day they met! Photo: NHF Colorado.



RECENT HEADLINES

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

Roche Posts Update on Hemophilia A Gene Therapy Data

Data Shows Hemlibra Continues to Maintain a Favorable Safety Profile

Phase 1/2 Trial of Gene Therapy for Hemophilia B Shows Promise

Gene Therapy from BioMarin Could Be Most Expensive US Drug Ever

Data from Biopsy Study of BioMarin's Gene Therapy Shows Positive Results

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. [To see more go to: www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) then find the **RESOURCES** tab, and go to the **NEWSROOM** page. Find other stories at our Facebook page at www.facebook.com/ColoradoHTC/

UPCOMING EVENTS

Mark Your Calendars:

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

Jul 30: NHF Colorado hosts a Zoom for Women and Girls with Bleeding Disorders

Aug 1-8: NHF Annual Conference—A fully VIRTUAL Conference

Aug 21-23: RMHBDA Family Camp

Aug 22: NHF CO Unite for Bleeding Disorders VIRTUAL Walk (see cohemmo.org for updates)

Aug 24-29: HFA Symposium— Virtual Conference

Sept 7: Clinic, Pharmacy, and Admin Closed for Labor Day

Sept 12: RMHBDA Unite for Bleeding Disorders Walk —Billings, MT

See more at our Events Page on our website:

www.medschool.ucdenver.edu/htc find **RESOURCES** tab, go to **EVENTS**

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