

# BLOODLINE

**news from your local nonprofit for all bleeding disorders**  
**Quarter One Newsletter**  
**May 6th, 2021**

[VISIT WEBSITE](#)

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## **A Note from Your Executive Director**

Colorado continues to make great progress in the fight against COVID-19. As of this writing, nearly 2 Million Coloradans have been fully vaccinated, and more than 500,000 have confirmed positive since the pandemic began, offering hope that we can begin returning to more familiar activities later this summer. You may have seen in the news recently the state's decision to bring the MLB All Star game to Denver as a high-profile indication that gathering in large groups is something that will resume soon.

Our Chapter is eager to bring the community together in a safe and socially responsible way. After much analysis, we have concluded that it will not be possible to implement Mile High Summer Camp in a manner that can ensure health protections for all participants at the strictest levels that are essential. This is consistent with decisions of bleeding disorders organizations across the country and other chronic condition groups in our state. The close proximity of campers, interactive activity, multiple day/night stays, and challenges in providing a full medical team are unique variables that prevent us from moving forward. However, we are diligently exploring offering a one-night Family Camp June 12-13 and possibly again in late August, as well as a potential overnight teen experience in mid-July. This requires a great deal of work to coordinate logistics and develop safety protocols, so look for an official announcement later this month. And join us on Wednesday, May 12 for a Community Town Hall with the HTC where we will discuss the state of operations as well as COVID-related information.

We have so valued your engagement with our virtual activities and your determination to overcome the pandemic. We will be able to celebrate these efforts together in person soon!

Alongside,

Perry Jowsey, Executive Director

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## EDUCATION SERIES

### TOWN HALL

MAY 12TH AT 6:00PM



The Hemophilia Treatment Center in conjunction with NHF Colorado will be hosting a virtual Town Hall Thursday, May 12th. Join us at 6:00 PM to hear how both entities have been handling COVID-19 and future plans. Dr. Mike Wang will provide an update on COVID-19 pandemic, specifically regarding vaccines. You will also discover the process that new drugs go through during clinic trials from pharmacist Kristi Norton. HTC and Chapter Staff will be available to answer any questions afterwards.

Community members who stay for the entirety of the session will receive a \$50 GrubHub gift card to enjoy.

[Register Today!](#)

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### GENE THERAPY JEOPARDY

THURSDAY, MAY 20TH 6:00 PM



Expand your knowledge on Gene Therapy Research! You are invited to join a fun new experience to make the science behind gene therapy research memorable and entertaining. Whether you're already a whiz or are just starting to explore, you and your friends can learn together and earn points to win bragging rights! Will you become the next Jeopardy gene-ius?

It's FUN, EDUCATIONAL, AND EASY TO PLAY!

Buzz in answers to clues on the topic of gene therapy research across 4 unique categories, including "Nuts and Belts" and "Knowledge is Power". You'll have a chance to wager your points against friends in a Final Jeopardy to be the next champion.

All attendees will receive a \$50 GrubHub gift card to enjoy dinner after this fun event!

Who's Ready To Play?!



### **NEW APPLICATION PROCESS!**

NHF Colorado is proud to award two scholarships annually to those in the bleeding disorder community to help further secondary education. This year the Scholarship Committee is excited to announce there is a new application! The new condensed PDF application will provide a sense of ease while completing and submitting the form. This will help you as the applicant to make the most of your time as you are preparing for the next steps. By completing one application you will be considered for both scholarships.

The two scholarships are available to anyone who meets the criteria listed, to [find out more about the criteria visit our website](#). Preference will go towards first time applicants - though that does not mean a returning applicant cannot receive the scholarship as well.

We encourage graduating seniors as well as anyone who is pursuing secondary education to apply for this scholarship!

Apply Today!

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### **2020 MILE HIGH SUMMER CAMP RECAP**



Mile High Summer Camp in the year 2020 looked much different than it had in past years.

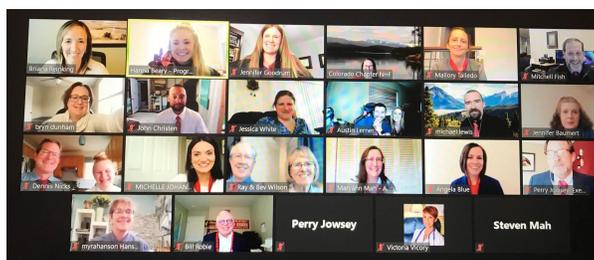
When it became obvious that we were not going to be able to safely gather the usual 80+ campers together for a week full of camp fun, we decided to take camp to them. We pivoted and turned all our efforts into providing a meaningful space for our campers to gather every Wednesday throughout the month of July. For the two hours that we signed on to engage face-to-face with each other through All Camp activities like Dance Parties and a Variety Show. Cabin groups were able to connect with one another on a more personal level racing through space with one another or discovering dino eggs. We were over the moon for the opportunity to work with the award-winning experiential group, GutMonkey to provide such meaningful activities. Though we were not able to be in person for Mile High Summer Camp 2020, the camp spirit lived on and grew a little brighter within our virtual campers.

Thank you to all of the campers who joined us last summer for this virtual camp experience!

## ADVOCACY - 365 DAYS



Teen Advocacy Summit hosted with teens from Nebraska and Montana



State Advocacy Day hosted on Thursday, April 22nd

Throughout the month of March and April bleeding disorder advocates ramped up their efforts to bring awareness for the community. In the Colorado Legislature, Representative Mullica announced March as Bleeding Disorders Awareness Month in a tribute to the house floor. During the month of March teen advocates from across 3 different states gathered virtually to learn how they can use their voice to advocate everyday in a great display of interstate collaboration. During April we celebrated World Hemophilia Day as Senator Ginal spoke on behalf of the bleeding disorder community, announcing the tribute to the senate floor while inviting the legislators to join us for State Advocacy Day. It was amazing to have the dedicated time for constituents to speak directly with elected s to raise awareness for bleeding disorders and express our healthcare concerns.

## CALL TO ACTION

NHF Colorado alongside other concerned patient disease groups like the Chronic Care Collaborative have been closely monitoring [House Bill 21-1297 Pharmacy Benefit Manager And Insurer Requirements](#). This bill will ensure Colorado pharmacies and their patients are treated fairly and equitably; patient access to pharmacy services is preserved; patients have access to affordable, life-saving medications; and transactions between PBMs, patients, and pharmacies are transparent. This bill also includes important non-medical switching and patient protections.

If you or someone you know has had trouble with mid-year formulary changes or problems with mail order prescriptions, your voice could make a vital impact in the passing of this bill. We would greatly appreciate your help raising awareness by sharing your story either through virtual oral or written testimonies. We can assist with helping to craft personal stories. Please contact Hanna with the chapter if you are interested in helping!

ASK YOUR LEGISLATORS TO SUPPORT HB21-1297

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## LOOKING FOR DIFFERENT WAYS TO FUNDRAISE?

You can also help raise critical funds for your local Coloradoans by as a few click of the keys through [Facebook Fundraisers](#). Another fundraising tool possibility is to [use the Unite Your Way](#) site to turn your passion into funds and awareness.



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## BACKPACKS + BLEEDERS

Are you looking to get you and your family outdoors? Through Always Choose Adventure you can gain access to almost any type of gear needed! From paddle boards, camping gear, or even climbing clamps to take you up the side of a mountain - ACA has the gear for it!

To continue to help empower the members of the community Backpacks + Bleeders have partnered with ACA to provide Backpacks + Bleeders an opportunity to CHOOSE ADVENTURES! Bypass the annual membership fee by signing up through Backpacks + Bleeders when you complete this form. With your FREE membership you'll gain access to gear rental at low or now cost, guided activities like ice climbing and meeting individuals with different chronic diseases.

Backpacks + Bleeders is excited for the opportunity to get back to trailblazing with the community for in-person experiences soon!

**SAVE THE DATE FOR THESE FUN ADVENTURES AHEAD!**



**Community Cycle Event: RESCHEDULED TBA**



**Hike a 14ner: August 7-8th**



**Fly Fishing Clinic: Boxwood Gulch September 25**

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# NHF

## Community Voices in Research

### COMMUNITY VOICE RESEARCH

Are you interested in being apart of a community-powered registry? The Community Voice Research program will help researchers understand what it really means to live with a bleeding disorder and how current treatments, therapies, and policies affect the community. Your participation could make a huge impact.

[Enroll Today!](#)

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### BOARD OF DIRECTORS

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Vice Chair - Mitch Fish  
Secretary - Salome Aguilar  
Treasurer - Briana Reinking

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Angie Blue (ex-officio)

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