

# COLORADO CHAPTER NATIONAL HEMOPHILIA FOUNDATION



MARCH 2022

## PROGRAMS UPDATE

[VIEW WEBSITE](#)

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## ACT NOW

EDUCATION EMPOWERMENT DAYS, CAMP REGISTRATION, BLEEDING DISORDERS AWARENESS MONTH, AND MORE!



You are invited to participate in the multi-day Spring Series for Education Empowerment Days where our theme is 'Blooming for Community'. Though we are unable to gather for a multi-day hotel conference, we are excited for the opportunity to connect over multiple virtual and in-person opportunities to gather and celebrate. We strive to bring the members of the bleeding disorders community together with a mix of virtual, hybrid and in person activities to promote connectivity, education, and awareness.

Throughout Sunday, April 24 to Friday April 29th there will be four separate opportunities – virtually or in person – to connect with the Bleeding Disorders Community. Those who attend 1 or more of the 4 activities will receive a ticket for the Final Night Celebration – a Rockies Baseball ticket for the Friday night game against the Cincinnati Reds!



### **MULTIPLE IN PERSON OPPORTUNITIES TO CONNECT**

#### **BLOOMING FOR COMMUNITY, SUNDAY APRIL 24**

**3:00 -7:00 PM**

#### **WASHINGTON PARK BOATHOUSE**

Blooming for Community is an in-person event for individuals and families alike. Join us at the Washington Park Boathouse on Sunday, April 24th to blossom with your bleeding disorders community. Check-in at the registration table located in front of the Boathouse at 3:00 PM to receive your name badge and welcome goodies! Before *Mac Shack Food Truck* arrives, everyone is asked to take a seat in the Boathouse to partake in the Blooming For Community Session. Throughout this 90-minute program you can look forward to a series of short updates, a parent panel, activities, and *fun surprises!* We will go live through Facebook to ensure access to all on the information to be shared.

Throughout the rest of the evening we invite all to enjoy activity areas around such as First Aid Survival with Trails to Healthy Living, yoga on the lawn, arts and crafts, and yard games. To participate in the Blooming for Community Session virtually be sure to follow the Chapter's Facebook page to catch the updates!

#### **TEEN OUTING – SUNDAY, APRIL 24, 1:00 - 3:00 PM**

For teens ages 13-17, take on an adventure with Trails to Healthy Living and learn first aid survival by making your own First Aid Kit. Hands on snacks, creativity, and fun is in store! Trails to Healthy Living is a wellness programs designed and led by two hemophiliacs that is intended to teach participants crucial lifestyle skills that align them with their own trail towards healthy living.

**Off site adventures:** 1:00 – 3:00 PM

**Drop off/Pick up:** Washington Park

### **MULTIPLE VIRTUAL OPPORTUNITIES TO CONNECT**

#### **PFIZER DINNER PROGRAM**

**WEDNESDAY, APRIL 27 via ZOOM beginning at 6:00 PM**

Virtual dinner program with Pfizer starting at 6:00 PM. Join us for an engaging presentation over a comprehensive overview of how caregivers can gain a better understanding and learn ways to effectively communicate with individuals living with bleeding disorders. Attendees will have the opportunity to participate through chat or video.

*Participants who join for the entirety of the event will receive a \$50 GrubHub Gift Card the following day (one per household).*

**SPONSORED BY: PFIZER**

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#### **CONNECTIONS, COFFEE, AND CONVERSATIONS**

**WEDNESDAY, APRIL 27 via ZOOM beginning at 7:30 PM**

New parents to the bleeding disorder community? Join us for this independent virtual event where you will have the opportunity to connect with other parents in the community and share similar experiences. Volunteer lead will kick

off this session sharing their experiences as a parent of a son with hemophilia. This is a safe space to share experiences or gather insight on what you may be going through. There is no scheduled program, instead a place for parents to gather, share, and connect with one another.

*Targeted towards connecting with new parents in the bleeding disorder community. Attendees will receive a \$10 Einsteins GiftCard to enjoy coffee during the conversations.*

**SPONSORED BY: NHF COLORADO**

***IN-PERSON DINNER PROGRAM, MAGGIANOS DTC  
THURSDAY, APRIL 28TH 6:30 – 8:30 PM***

**Gene Therapy Basics**

**SPONSORED BY: BIO-MARIN presented in ENGLISH**

Gather together with members of the bleeding disorders community for this in-person dinner presentation at Maggianos DTC. Learn about the basics of Gene Therapy with Bio-Marin through this interactive presentation.

**The Whole Tooth: Understanding the Importance of Oral Health**

**SPONSORED BY: TAKEDA presented in SPANISH**

There is a lot more to good oral health than brushing your teeth and it's especially important for people with bleeding disorders. Find out what you've been missing that may help you avoid bleeds. *This presentation will be presented in Spanish.*

***FINAL NIGHT CELEBRATION***

***FRIDAY, APRIL 29 at COORS STADIUM***

***ROCKIES vs CINCINNATI REDS, first pitch at 6:10 PM***

***BATTER UP!*** Celebrate with the bleeding disorders community on the final night of the Spring Series at the famous Coors Stadium! Enjoy a Friday night game against Colorado's beloved Rockies and the Cincinnati Reds! The community will sit together enjoying each others company and baseball. *To receive a game ticket individuals must attend 1 of the 4 (Blooming for Community, Virtual Dinner Program, Connections Coffee or Conversations, or In-Person Dinner Program) events.*

We hope that you can join us for The Education Empowerment Days Spring Series throughout April 24-29 for Blooming for Community!



**BLOOM FOR COMMUNITY and REGISTER TODAY!**

We are pleased to announce that we anticipate our 2022 Family Camp and Mile High Summer Camp will be held in-person this spring. NHF Staff and Camp Medical Team came to this decision after carefully reviewing data and guidance from the Centers for Disease Control (CDC), American Camp Association (ACA), and Association of Camp Nursing (ACN). Using guidelines from these organizations and our local partners, we have developed a series of protocols that will allow us to safely host both Family Camp AND Mile High Summer Camp in-person.



## **FAMILY CAMP**

**MAY 21 - 22**

**HIGHLANDS PRESBYTERIAN CAMP**

**1306 Business Highway 7 POB 66, Allenspark, CO 80510**

Family Camp is designed to prepare families with a child or individuals living with a bleeding disorder for an independent, overnight summer camp experience, and help them gain comfort in sending their child away to camp. Families spend the weekend together canoeing, hiking, arts and crafts, and sharing alongside campfires. They stay in comfortable retreat style rooms for each family.

Here **we focus on two key goals:** *increasing and enhancing self-infusion skills and building connections within our community.* Individuals and children develop confidence, independence and build life-long friendships and memories while they canoe, hike, and learn outdoor skills.

**FAMILY CAMP REGISTRATION**



**SAVE THE DATE - IT IS ALMOST CAMP SEASON!**

## **MILE HIGH SUMMER CAMP**

**JULY 17 - 21 at EASTERSEALS ROCKY MOUNTAIN VILLAGE**

In its over 40 years of existence, Mile High Summer Camp provides an opportunity to reach the youth in the bleeding disorder community. After two years of virtual camp we are ecstatic to have the opportunity to gather together again in-person at Rocky Mountain Village. Mile High Summer Camp will begin Sunday, July 17 and end on Thursday, July 21st for campers aging 7-14. Teens will have the opportunity to go on a wild adventure with Breckenridge Outdoor Education Center participating in familiar activities. Here are a few key details to know before registration goes *LIVE* in April, 2022.

- **Mile High Summer Camp:** For campers 7-14 living with a bleeding disorder, a known carrier, or sibling (*priority will go to those living with a bleeding disorder first*)
- **Teen Leadership Weekend:** Friday, July 15 - Sunday, 17th for teens ages 15 - 17
- **Camp Week:** Sunday, July 17th to Thursday, July 21st at Easterseals Rocky Mountain Village
- **COVID-19 Vaccination Required:** Chapter and Medical Staff are working in every capacity to ensure the utmost safety of our campers which is why a COVID-19 vaccination is required for all campers and Bleedership Counselors to attend

*Registration for the Teen Leadership Weekend and Mile High Summer Camp goes **LIVE NEXT MONTH!** For more information visit our [website!](#)*

**REGISTRATION WILL GO LIVE IN APRIL - KEEP AN EYE OUT FOR FURTHER INFORMATION!**

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## **BLEEDING DISORDERS AWARENESS MONTH AND YOU**

### **DID YOU KNOW ...**

Each March, NHF Colorado calls attention to inheritable blood and bleeding disorders during **Bleeding Disorders Awareness Month**. This month lets patients and families with hemophilia, von Willebrand disease, rare factor disorders, and more, share their lives, stories, struggles, and successes.

### **BDAM PHOTO SCAVENGER HUNT!**

Participate who complete the BDAM Photo Scavenger Hunt List and WIN PRIZES! Follow along the 2022 BDAM Photo Scavenger Hunt by documenting each item with a photo and your own caption. Each photo challenge completed and submitted you will receive an entry to win the grand prize! Getting involved is easy! Follow the steps below to get started:

- Download the BDAM Photo Scavenger Hunt card from [cohem.org](http://cohem.org)

- Complete as many photo challenges as you can!
- Submit your BDAM Photo Scavenger Hunt Card by emailing it and your captioned photos to [info@cohemo.org](mailto:info@cohemo.org)

### WIN PRIZES!

Participants who complete and submit their captioned photos will receive prizes! Complete 8 (50%) of the challenges to receive a red light bulb. Complete all 16 and get the bulb, tie, and shirt. (one prize per household).

Download your BDAM Photo Scavenger Hunt Card by clicking and downloading the image or at [www.cohemo.org](http://www.cohemo.org)

### BLEEDING DISORDERS AWARENESS MONTH PHOTO SCAVENGER HUNT

- Illuminate it Red! Take a picture of the City and County building lit red February 28-March 4 (located downtown Denver)
- Yum! Take a photo of your favorite red colored food
- Educate! Take a photo of you sharing BDA Education
- Wear Red! Take a photo of you wearing something red
- HTC Love! Share a picture and story about the professionals that help take care
- Clotting Cascade! Build a domino train to demonstrate the clotting cascade and show what happens when missing one of the clotting factors
- CELEBRATE! Take a photo of you and your family celebrating BDAM
- Unite! Send a screenshot of you registering for the Unite for Bleeding Disorders Walk

- Get Ready! Take a picture or video of how you prep your infusion or other therapy medication
- Social Media! Tweet/tag local official with BDA
- Dance! Post a video dancing to a clip of a song that mentions one of the following words: red, bleeding, blood, advocate
- BDAM Photo Prompt (found on NHF CO website)
- Teach Me! Post a video or photo showing how you would tie your red tie/bow tie/bandana/etc.
- Events! Share a photo of your favorite Chapter Event
- Illuminate it Red! Photo of Building 500 from March 7-14 (located on Anschutz Medical Campus)
- Camp Memories! Take a picture showing your favorite camp memory

**CONTEST RULES AND GUIDELINES**

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Scholarship Committee Member Stephanie Philips created her Run Red Team because she believes in the strength of the bleeding disorders community and investing in our young members bright future. Stephanie and her team completed a 3.8 mile hike while raising awareness for bleeding disorders. Way to go Stephanie!

## RUN RED AND RAISE FUNDS FOR SCHOLARSHIPS

**THERE IS STILL TIME TO RUN, WALK, STROLL OR BIKE** in celebration of Bleeding Disorders Awareness Month! Grab your friends and family and participate in this step challenge at your own pace, any place you'd like, any time you'd like during the month of March. This fully virtual event is happening March 1st - 31st and is a fun opportunity to challenge and stay connected those in your community while raising awareness and funds for the Scholarship Program. We challenge you to take the challenge and RUN RED!

Run Red is a run or walk-at-your-leisure kind of event. There is still time to track your activity time on the **Charity Miles App** to participate in the fun. From the ease of your own treadmill to your local trail, **Run Red** takes place anywhere you'd like, whenever you'd like! Funds raised will help support the Scholarship Program. Save the date to join us for the [Unite for Bleeding Disorders Walk](#) at Sloan's Lake on August 13th!

**All funds raised will help support the Scholarship Program provided by the Colorado Chapter of the National Hemophilia Foundation (NHF CO).**

RUN RED

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## BACKPACKS + BLEEDERS

BEYOND BOULDER CYCLING SATURDAY APRIL 9, 12:30 - 3:30 PM

Grab your bike or use one of ours, this 3-hour tour retraces the journey of Boulder's first gold seekers while cruising the paved paths along the beautiful Boulder Creek. Join Backpacks + Bleeders for this spring stroll and hike. Continuing exploring the sites of Boulder we can leave our bikes behind for a short, but fairly steep, hike up to Boulder's very own "red rocks" where kids (8+) and adults alike can climb around or simply take in the sweeping view of downtown Boulder, University of Colorado, the iconic Flatirons, and beyond. Not interested in hiking? No problem! Guides will be available to extend the bike ride to meet your needs.

NOTE: Consistent with NHF COVID Policy, all participants age 5 and older must demonstrate proof of vaccination or a negative PCR test within 72 hours of the event. Contact us directly with questions.

**REGISTRATION CLOSES ON APRIL 4th so act fast!**



LET'S TRAILBLAZE

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## Quality of Life

### HEALTH + WELLNESS

Learn about improving your health by developing good eating habits, moving your body, and managing stress. Finding balance in these three areas can positively impact your quality of life.

**MARCH 30 @ 6PM MST**

*Join us for a mix of fun and education at:*



**TOPGOLF**

10601 E Easter Ave, Centennial, CO 80112

EMAIL [QOL@PARAGONHEALTHCARE.COM](mailto:QOL@PARAGONHEALTHCARE.COM)  
FOR REGISTRATION/DETAILS!

[PARAGONHEALTHCARE.COM/QOL](http://PARAGONHEALTHCARE.COM/QOL)



## QUALITY OF LIFE

### TOP GOLF in CENTENNIAL

**WEDNESDAY, MARCH 30 at 6:00 PM**

Join Octapharma, Paragon Healthcare, and Medexus Pharma for a mix of fun and education at Top Golf in Centennial! Learn about improving your health by developing good eating habits, moving your body, and managing stress. Finding balance in these three areas can positively impact your quality of life!

**NOTICE:** This is an independent event organized by industry representatives and not run by NHF Colorado. In order to continue to best serve the community the chapter is partnering to provide information and resources that may impact you. Chapter representatives will be in attendance.

PLEASE RSVP VIA EMAIL [QOL@PARAGONHEALTHCARE.COM](mailto:QOL@PARAGONHEALTHCARE.COM)

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## SCHOLARSHIP APPLICATIONS ARE NOW OPEN!

"OPPORTUNITY. I remember thinking this word as I saw that I had been selected for an NHF scholarship. It was a joy that was felt deep in my core, under the stomach and ribs, just down the road from my soul. It brought me a chance to reflect.

I remembered: the times I felt like an outsider, having to use crutches or a wheelchair. The times that I felt wildly behind my peers, and the subsequent overcompensation. The times that I had been holed up resting a bleed and was isolated and weary. All of these times felt as if I had to toil for the opportunities that my peers took for granted.

The notice of this scholarship took these experiences and made me feel hopeful. Education is a tool to empower one's self, and I saw it as an opportunity to grow not only intellectually but in relation to how I can use my experiences, positive or otherwise, to empower those around me." - 2021 Scholarship Recipient, Joseph Reese

Your education is an investment in your future and the Colorado Chapter of National Hemophilia Foundation are proud to offer two separate scholarship opportunities. Applications are now open for the 2022 Scholarship Program and will close on May 1st.

[SUBMIT YOUR SCHOLARSHIP APPLICATION](#)

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## COVID-19 EVENT GUIDELINES

**Updated 3/1/2022: NHF and national chapter face-to-face meetings and events (indoors and outdoors) will require that all attendees, including NHF staff and sponsors age 5 and older, show proof of being fully vaccinated or a negative COVID-19 PCR test within 72 hours of attending the event. NHF strongly recommends that all attendees wear masks, regardless of vaccination status. NHF National Chapters, including Colorado, must follow local, state, or CDC masking guidelines, whichever is MORE strict. This means masking guidelines are subject to change per event, based on the event location and event structure. NHFCO will communicate any known guidelines in advance of events.**

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**SAVE THE DATE FOR THESE UPCOMING EVENTS**

**MARCH 26:** Backpacks + Bleeders, Bleeders On The Slopes at Winter Park, an in person event

**APRIL 9:** Backpacks + Bleeders, Beyond Boulder Cycling event

**APRIL 24-29:** Ed Empowerment Days, Spring Series

**APRIL 24:** Teen Track Outdoors Event

**MAY 12:** Women's Hybrid 'Get Cookin!' Event

**MAY 21-22:** Family Camp

**JUNE 25:** Backpacks + Bleeders, Fly Fishing Clinic

**JULY 15-17:** Teen Leadership Weekend with BOEC

**JULY 17-21:** Mile High Summer Camp

**AUGUST 13:** Unite for Bleeding Disorders Walk

*Please note that all scheduled events are subject to change with little notice due to the ever-changing COVID situation in Colorado. Changes may include, but are not limited to, different vaccination or testing requirements, canceling in-person events in favor of virtual events, and limiting attendance to in-person events.*



# H-Fit

with Dolvett Quince

Regular exercise is important. But moods vary. No two days are exactly the same. So we asked celebrity trainer Dolvett Quince to create a series of exercise videos called H-Fit. Each video features a different **hemophilia-friendly workout**. And each workout is built around a different mood. How are you feeling today? H-Fit has got you covered.

**Always talk to your health care provider before starting any new exercise routine.**



**Sign up with Novo Nordisk and register at [H-Fit.com](https://www.h-fit.com) to get **free access** to the H-Fit video library.**

Scan for [H-Fit.com](https://www.h-fit.com)

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