

COLORADO CHAPTER NATIONAL HEMOPHILIA FOUNDATION



JANUARY 2022 PROGRAMS UPDATE

[VIEW WEBSITE](#)

2022 COVID-19 COMMUNITY SURVEY KEEPING THE COMMUNITY SAFELY CONNECTED



In this time of uncertainty it is more important than ever to stay UNITED. NHF Colorado is committed to providing updated resources and tools for the community. At this time we feel confident in moving forward with a mix of in person, virtual, and hybrid events. Though please note that all scheduled events are subject to change with little notice due to the ever-changing COVID situation in Colorado.

In order to continue to plan and meet the communities needs we ask for 2-3 minutes of your time to complete this quick survey. We want to hear your feedback so we can continue to serve you to the best of our abilities during this time. Please fill the survey below and let us know your thoughts (your answers will be anonymous).

[TAKE COVID-19 COMMUNITY SURVEY](#)

BACKPACKS + BLEEDERS INDOOR ROCK CLIMBING

Sunday, January 16, 2022

1:00 - 3:00

Ubergripping, 8610 E 21st Ave, Denver, CO 80238

Trailblaze with Backpacks + Bleeders through this indoor climbing experience! Try a new skill or strengthen your current techniques at Ubergripping Sunday, January 16th! Learn from the experts proper footwork techniques and have the opportunity to gain your belay certification. This activity is for community members ages 6+, and all climbers under the age of 18 will require an adult (18+) to accompany them.

NOTE: Consistent with NHF COVID Policy, all participants age 12 and older must demonstrate proof of vaccination or a negative PCR test within 72 hours of the event. Contact us directly with questions.



LET'S TRAILBLAZE

THE PROMISE OF GENE THERAPY A VIRTUAL EVENT

Wednesday, January 19th

2:00 - 3:00 PM via ZOOM



The National Hemophilia Foundation (NHF) and the National Organization of Rare Disorders (NORD) are partnering with the Chronic Care Collaborative (CCC) on this event! Please pre-register at the link below!

We are honored to announce our featured presenter will be Dr. Michael Wang, who specializes in pediatric hematology and oncology, and the University of Colorado Anschutz Medical Center and Children's Hospital Colorado. The program will also include panelists from NHF, NORD, and CCC to discuss what gene therapy means for patients living with rare conditions and how our policy work can support patients getting the right treatment recommended by their doctors at the right time.

[RSVP TODAY!](#)

GAME ON TEEN LEADERSHIP EVENT

Saturday, January 22, 11:00 AM - 3:00 PM

Family Sport Center at South Suburban Parks and Rec. 6901 S Peoria St, Englewood, CO 80112

We invite all teens ages 13-17 impacted by a bleeding disorder to join us for a day of adventure and leveling up! Join us as we excel through the various levels of life AND the activities to offer!

What is adulting with a bleeding disorder? Join your bleeding disorder friends to find out! Together we will learn how to level up and take control of the game. The program is designed to help young adults move forward with tips on personal accountability, staying healthy, maintaining insurance coverage, and planning for college or a career. All the grown-up stuff they need to know as they move towards adulthood. And all without parents standing over their shoulder.

From rock wall climbing or laser tag to learning how to navigate life – there is a new level for everyone to experience!

NOTE: Consistent with NHF COVID Policy, all participants age 12 and older must demonstrate proof of vaccination or a negative PCR test within 72 hours of the event. Contact us directly with questions.

[REGISTER TODAY!](#)



CONNECTIONS, COFFEE, AND CONVERSATIONS SUPER SEVEN BOOK LAUNCH

Thursday, February 3, 2022

12:00 pm-1:00 pm

VIRTUAL VIA ZOOM

Join us for the kick-off event of the Connections Program! Taking place virtually over the lunch hour, we invite families from all walks of life to join us for this engaging and inspiring hour. Book Co-Author, Nikole Skappe will join us for a short reading of 'Super Seven' – A Story for Rares.

'Twelve-year-old Tanner has a rare bleeding disorder and sometimes feels like no one understands what he's going through. Does this sound like you? Super Seven: A Story for Rares, is a book about a kid with a rare bleeding disorder for children with rare bleeding disorders. Join the discussion on how this book can help generate conversations about some of the themes of the book, including sports, disclosing your bleeding disorder, and school issues.

All attendees will receive a \$10 Einstein's Gift Card, a copy of Super Seven, and a discussion guide (one of each per household).

[REGISTER TODAY!](#)



BLEEDERS AND BLADES A WOMEN'S EVENT

Wednesday, February 9, 6:00 PM - 8:30 PM

Primal Axe House 3545 S Platte River Dr. Unit M-1 Sheridan, CO 80110

Kick-off the new year with an exciting way to challenge yourself – AXE THROWING! Are you looking for some fun and connectivity with other women in the bleeding disorder community? Then look no further! We invite you to join us for BLEEDERS AND BLADES on Wednesday, February 9th at 6:00 PM! Join the other women in your community for an opportunity to strengthen or learn a new skill. We will learn proper throwing techniques and games from experts at Primal Axe house.

Registration includes dinner and 2 hours of throw time. This is an in-person event that you do not want to miss!

NOTE: Consistent with NHF COVID Policy, all participants age 12 and older must demonstrate proof of vaccination or a negative PCR test within 72 hours of the event. Contact us directly with questions.

SAVE MY SPOT!

NATIONAL RESOURCE CENTER - HANDI

NHF's information resource center **HANDI** is ready to assist you! Now in its 30th year, HANDI continues to be a trusted source of information and referrals for those affected by inheritable bleeding disorders and the general public.

Information specialists are adept at providing the latest resources on a wide variety of bleeding disorder-related topics, including but not limited to:

Hemophilia

Von Willebrand disease

Women and girls with bleeding disorders

Rare factor deficiencies

School issues

Aging issues

Financial assistance

Gene therapy

HANDI has access to education and information resources in print, digital, and video formats, and provides referrals to healthcare providers and HTCs, local chapters, and to other support organizations based in the United States and abroad. There are several easy ways to reach HANDI:

Call: **800.424.2634** (extension 2), 9am-5pm Eastern, Monday to Friday,

Email: handi@hemophilia.org

Submit an information request via [HANDI's online portal](#).

COVID-19 EVENT GUIDELINES

Starting **October 1, 2021**, NHF and national chapter face to face meetings and events (indoors and outdoors) will require that all attendees, including NHF staff and sponsors aged 12 and older, show proof of being fully vaccinated or a negative COVID-19 test within 72 hours of attending the event. Additionally, for indoor events, all attendees must wear masks regardless of vaccination status. NHF strongly recommends that all attendees wear masks at outdoor events as well, but hosts should follow the strictest guidelines – either CDC, local, regional or state guidelines.

SAVE THE DATE FOR THESE UPCOMING EVENTS

JANUARY 16: Backpacks + Bleeders Indoor Rock Climbing at Ubergripping

- JANUARY 19:** The Promise of Gene Therapy, a Virtual Event
- JANUARY 22:** Teen Leadership, GAME ON, an in-person event
- FEBRUARY 3:** Connections, Coffee, and Conversations Super 7 Book Launch, a virtual event
- FEBRUARY 9:** Bleeders and Blades, a Women's Event, an in person
- FEBRUARY 16:** Scholarship Program Q&A session, a virtual event
- FEBRUARY 26:** Backpacks + Bleeders on Ice at Evergreen Lake, an in person event
- MARCH 4:** State Advocacy Day, an in person event
- MARCH 7:** Bowling and Buds, a Men's Event, an in-person event
- MARCH 26:** Backpacks + Bleeders, Bleeders On The Slopes at Winter Park, an in person event

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.

Dedication and Personal Support



Your Pfizer Patient Affairs Liaison is a professional dedicated to serving you and the hemophilia community by connecting patients and caregivers with Pfizer Hemophilia tools and resources. These Pfizer colleagues are committed to continuing Pfizer's more-than-20-year history of listening to the hemophilia community and working to meet its needs.



Patty Eastin

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"Having worked at Pfizer for 17 years, I am passionate about supporting and educating the amazing rare disease community."

My work is guided by:

- Compassion**—Listening to your needs and addressing questions and concerns that you may have
- Commitment**—Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more
- Connection**—Connecting you with hemophilia advocacy groups and programs like Leading Edge, the National Hemophilia Foundation, The Coalition for Hemophilia B, and others

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 HemMobile is not intended for curing, treating, seeking treatment for, managing, or diagnosing a specific disease, disorder, or any specific health condition. Pfizer will not have access to any personal information you enter into HemMobile.

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