COLORADO CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
cohemo.org

BLOODLINE

news from your local nonprofit for all bleeding disorders

Quarter One Newsletter

February 1, 2022

VISIT WEBSITE

A Note from Your Executive Director

Every day public health is improving and we continue to make a lot of progress toward getting back to pre-pandemic operations. During the final 6 months of last year, we are excited to have brought together cumulatively more than 500 individuals throughout a series of in-person community events. These gatherings maximized outdoor spaces and distance and were governed by health protocols – ensuring safety of all participants.

Looking ahead to the first half of this year, we're going to continue to use this formula. After considering many health variables, we will not be holding an Education Days annual meeting this spring overnight in hotel space. The length of time together inside over 2-3 days with many very young children presents many challenges ensuring safety and has evoked a lot of anxiety among community members. However, survey data tells us people feel comfortable in shorter, smaller gatherings, so be on the lookout for a variety of unique opportunities to connect, advocate and learn – through highly engaging experiences as detailed below. We are confident that by moving deliberately now, we can move forward together in health to again realize the joy of camps and other large interactive group experiences later this year.

Alongside,

Perry Jowsey, Executive Director

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

ADVOCACY AND YOU

The National Hemophilia Foundation (NHF) and the NHF Colorado Chapter has advocated for the needs and interests of people affected by hemophilia and related bleeding disorders for almost 60 years.

We invite you to join us in continuing these efforts the week of March 1-4 where we will undergo a series of advocacy related events in celebration of March as Bleeding Disorders Awareness Month.

STATE CAPITOL DAY - FRIDAY, MARCH 4

On Friday, March 4th members of the bleeding disorder community will gather to meet with their local legislators to share their stories and concerns. Join us for breakfast, including a brief training session, and show your support. Whether you are interested in sharing your story or sitting back to listen – your presence is crucial to the cause.

We will be advocating for the following:

- Support policies that increase affordability and access to care
- Prohibit non-medical switching, accumulator adjuster programs and step therapy

As we advocate for the rights of bleeding disorder patients, we hope that you are standing there next to us. We are planning for an in-person experience to advocate and share with our legislators.

ADVOCATE LOCALLY on MARCH 4

WASHINGTON DAYS - REGISTRATION CLOSES FRIDAY

NHF's Washington Days is an opportunity for people affected by inherited blood disorders to advocate for issues that are important to them. In 2021, Washington Days had more than 400 volunteer advocates from 45 states that met with legislators and staff to discuss federal funding for bleeding disorder programs and support policies that increase the affordability of coverage and access to care.

The 2022 key priorities are:

- Bleeding Disorders Awareness (*March is our month!*)
- Federal Funding for Bleeding Disorders Program
- HR 5801 (Accumulator Adjuster Legislation)

Ensure Lower Patient Copays Act (HELP Copays Act) HR 5801

The bipartisan HELP Copays Act requires health plans to count the value of copay assistance toward patient cost-sharing requirements. This would bring much-needed relief to financially vulnerable patients by ensuring that all payments—whether they come directly out of a patient's pocket or with the help of copay assistance—count towards their out-of-pocket costs.

“Health plans have changed the rules on how they count copay assistance programs and have found ways to limit protections for coverage of medicines. This legislation recognizes the bipartisan consensus that people with pre-existing conditions must be protected from insurance practices that target and discriminate against them,” said National Hemophilia Foundation Senior Director of Payer Relations Kollet Koulianos. “The HELP Copays Act is a bipartisan solution that will help already vulnerable patients afford medically necessary prescription drugs.”

Please note that Washington Days 2022 will be an entirely virtual experience. Washington Days programming will take place during the dates of March 1-2 with a highly suggested training taking place mid-February. Register ASAP to make sure your voice is heard!

ADVOCATE FEDERALLY on MARCH 1 & 2

SHARE YOUR STORY!

There are hundreds of scenarios that can have a negative impact on the Bleeding Disorder Community. We want to hear your story! If you're interested in sharing your story and advocating on behalf of the community, please click the link below to complete the short form.

ADVOCATE BY SHARING YOUR STORY!

CONNECTIONS, COFFEE, AND CONVERSATIONS
THURSDAY FEBRUARY 3, 12:00 - 1:00 PM
‘Twelve-year-old Tanner has a rare bleeding disorder and somethings 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.’

Connections, Coffee, and Conversations is for individuals looking to make connections throughout the bleeding disorders community. Designed to welcome and support newly diagnosed or young families through connectivity.We families from all walks of life to join us virtually for the first ever ***Connections, Coffee, and Conversations THIS THURSDAY, February 3rd.***

Registrants for the first Connections, Coffee, and Conversations will receive a copy of Super Seven and a discussion guide to help make those hard conversations easier. You will also receive a $10 Einsteins Gift Card to enjoy coffee with the conversations! *(1 per household, see event for further details)*

SIGN ME UP

PROGRAMS AND EVENTS

NOTE FOR IN PERSON EVENTS: *Consistent with NHF COVID Policy, all participants aged 12 and older must demonstrate proof of vaccination or a negative PCR test within 72 hours of the event. Contact chapter staff directly with questions.*

BLEEDERS AND BLADES - A WOMEN'S EVENT

WEDNESDAY, FEBRUARY 9TH, 6:00 - 8:30 PM

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. Kick off the new year with an exciting way to challenge yourself – AXE THROWING!

REGISTER TODAY!

SCHOLARSHIP Q&A

WEDNESDAY, FEBRUARY 16TH

Your education is an investment in your future. At the Colorado Chapter of National Hemophilia Foundation, we offer two separate scholarship opportunities and have a supportive team that will help guide you through the financial aid opportunities available. Join members of the Scholarship Committee on Wednesday February 16th for an opportunity to learn more about the program and how to best apply.

LEARN MORE

BACKPACKS + BLEEDERS
ICE SKATING AT EVERGREEN LAKE
SATURDAY, FEBRUARY 26TH, 1:00 - 3:00 PM

We will not skate around the point – we want YOU to join us at Evergreen Lake on Saturday, February 26th for some ice-skating fun and hot cocoa! Bring your family or a friend - you're invited to TRAILBLAZE with Backpacks + Bleeders over ice! Registration includes ice skate rentals, a private warming hut and ice rink for two hours!

LETS TRAILBLAZE

BOWLING AND BUDS - A MEN'S EVENT
MONDAY MARCH 7TH, 6:30 - 8:30 PM

Join us for the second ever MEN’S CONNECTION GROUP event on Monday, March 7th at 6:30 PM! This event is designed for men to connect and engage with other men in the bleeding disorder community. Whether you’re a seasoned bowler or believe in using the bumper rails – this event is for YOU! There is no time to SPARE, register today!

REGISTER TODAY

MAIN EVENT

FOR YOUNG ADULTS AGES 16-26
SUNDAY, FEBRUARY 27 FROM 2:00 - 7:00 PM

Growing up has it's own challenges, and it can get more complicated when a chronic condition is part of your daily life. For this reason, Sue Geraghty (with her expertise as a former nurse at the HTC in Colorado) created a presentation called Choices! Choices! Choices! that will provide you with information about your options ot help you make the best possible decisions that are just right for you!

A vital tool for creating a better quality of life is connection with others. We've arranged an all you-can-eat buffet, snacks, soda,arcade, bowling, and plenty of time and space for you to connect with others that can relate with you and the challenges you face. Friendship and support from peers in your community demonstrates that you are not alone. This is an in-person opportunity for young adults (ages 16-26) living with a bleeding disorder.

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.

Join us on Sunday, February 27th
from 2:00—7:00 pm @ Main Event
64 Centennial Boulevard
Highlands Ranch, CO 80129
Please RSVP by Monday, February 21st to
Victoria Vicory by phone or email:
720.505.6251; vvicory@infucarerx.com

Presented by:

octapharma
For the safe and optimal use of human proteins

InfuCare Rx

National Hemophilia Foundation Mourns the Loss of Longtime CEO, Val Bias

Dec. 31, 2021 – New York, NY – NHF is deeply saddened to announce that former NHF CEO and community member, Val Bias, passed away suddenly on Thursday, Dec. 30.
NHF will forever honor Val's legacy and all that he accomplished for the inheritable blood disorders community in the United States and internationally. Most remarkably, Val was a uniquely skilled community builder, building bridges, coalitions and cultivating champions for our community. Prior to his tenure as CEO of NHF, Val served as Chairman of The Board of Directors of NHF from Jan 1992 - Jan 1994. He also served in multiple capacities on the global stage working closely with the World Federation of Hemophilia, including advancing the International Twinning Program.

READ MORE HERE

NEWS ARTICLES

Most recent articles found on the Colorado Chapter and National Hemophilia Foundation page:

January28, 2022

New Medscape Activity Seeks to Prepare Clinicians for Gene Therapy

Medscape has launched a new enduring activity designed to enhance clinicians' awareness of gene therapy for hemophilia and increase their confidence when it comes to the eventual integration of these paradigm-shifting therapeutics into the clinical care of patients.

The program, which was developed through a partnership between Medscape and NHF, is intended for an international audience of hematologists/oncologists, pediatricians, hematology/oncology nurses, nurse practitioners, and physician assistants.

January 27, 2022

Co-pay Accumulator Policies Hurt Patients. There's a Simple Solution.

This piece is a joint effort by Amy Niles, executive vice president at the PAN Foundation, and Kollet Koulianos, vice president of payer relations at the National Hemophilia Foundation.
Each year on January 1, health plans reset for millions of Americans with serious and complex illnesses, restarting the slow and often expensive process of working toward their annual deductible and maximum out-of-pocket limit. But for people with co-pay accumulator policies built into their health insurance plans, there's a much steeper hill to climb.

December 14, 2021

Clinical Study and New Website to Focus on von Willebrand Disease and Pregnancy

The onset of childbirth and the postpartum period are times when women with von Willebrand disease (VWD) are at an increased risk for excessive bleeding, exposing them to further, and in some instances, serious complications. While there exist therapies with VWD-specific indications, it is not uncommon for these patients to still experience excessive bleeding while receiving treatment. These scenarios are challenging as there is sparce clinical data and a subsequent lack of clear guidance on the optimal management of bleeding in these particular settings.

NHF's Information Resource Center

HANDI

(P) 800.424.2634 (E) handi@hemophilia.org
Monday-Friday 9-5PM ET

NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

SAVE THE DATE FOR THESE UPCOMING EVENTS

FEBRUARY 3: Connections, Coffee, and Conversations Super 7 Book Launch, virtual event
FEBRUARY 9: Bleeders and Blades, a Women's Event, in person
FEBRUARY 16: Scholarship Program Q&A session, 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: Bleeders On The Slopes in Winter Park, in person event
APRIL 9: Beyond Bouder Cycling, in person event
APRIL 23 - 30: Education Empowerment Days Spring Series - mix of virtual and in person events

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.

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