



# BLOODLINE

**news from your local nonprofit for all bleeding disorders**  
**Quarter One Newsletter**  
**March 4th, 2021**

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## A Note from Your Executive Director

One year ago 17 advocates from our Chapter joined others from more than 40 states in the Bleeding Disorders community for NHF's Washington Days. The impact was significant – maintaining crucial appropriations for valuable programs like the 340B, as well as urging for support for HR 133 to improve access to skilled nursing facilities for Medicare beneficiaries – which ultimately passed!

This year more advocates from our Chapter, including several first-time participants, engaged with legislators virtually in the Washington Days effort. While things looked a little different, the importance has never been greater as members of our community have reported thousands of dollars in expenses due to accumulator adjusters in their insurance policies. *WE HAVE THE POWER TO END THIS DEVASTATING LOOPHOLE.*

We are working as a Chapter on plans to implement live events for the summer and fall in a safe and responsible manner, so please stay tuned for updates. In the meantime, our programs have an advocacy focus for the next 3 months. Join us virtually to make your voice heard! And use the tools we are providing to contact your congressional representative and urge them to sign the McEachin-Davis letter – a bipartisan call to action that prohibits insurance industry from applying accumulator adjusters.

Alongside,

**Perry Jowsey, Executive Director**

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## MARCH IS BLEEDING DISORDERS AWARENESS MONTH

March is a wonderful month for many reasons – the grass is getting greener, the days are lasting a little longer. Though to top it all – it is Bleeding Disorders Awareness Month! Ever since March 2016, this month advocates from around the world raises their voices just a little louder to help create awareness about their stories and their lives. What had originally started as the Red Tie Campaign has now grown into a month-long celebration of the bleeding disorder community. Bleeding Disorder Awareness Month has become a time where members, friends, and supporters of the community are invited to join us in raising critical awareness and funds to improve the lives of those diagnosed with a bleeding disorder.

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### HOW CAN YOU GET INVOLVED?



If you are on social media, you can update your Facebook or Twitter profile picture with a supporting ribbon. Use the hashtags #BDAM and #BleedingDisordersAwarenessMonth when posting to help our cause go viral.

You can also help raise critical funds for your local Coloradoans by starting a fundraiser! Creating a fundraiser can be as easy 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.





City of Denver proclamation declaring March as Bleeding Disorders Awareness Month



City of Aurora Proclamation declaring March 2020 as Bleeding Disorders Awareness Month

## PARTICIPATE IN DATA COLLECTION AND RESEARCH

### COMMUNITY VOICE RESEARCH

This community-powered registry will help researchers understand what it really means to live with a bleeding disorder and how current treatments, therapies, and policies affect the community. CVR will collect information from the people directly affected: people with bleeding disorders, their parents, siblings, partners, and caregivers.

People who participate in this will share information through surveys. This will allow researchers to better understand how bleeding disorders affect individuals and their family members across their lifespan. It will also help participants understand their individual situation and how a bleeding disorder affects their life.

Your participation will help researchers understand what it means to live with a bleeding disorder from the community member's perspective with the ultimate goal to improve quality of life and identify research questions important to the community.

Enroll Today!

**NHF**  
Community  
Voices in  
Research

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## ADVOCATE!

Advocating for yourself and loved ones can take various forms. It can start from educating your school staff to sharing important information at the grocery store all the way to speaking with your local and federal legislators.

### WASHINGTON DAYS 2021

Over the past week advocates from your local community have been preparing to advocate on behalf of the bleeding disorders community. Advocating for proper funding to federal programs like the CDC, NIH, and HRSA. Even more critical is advocacy for policy change to ensure copay assistance programs will be accepted and that companies will not have the ability to implement an accumulator adjuster.

### CALL TO ACTION ADVOCACY

We are excited to introduce a new way for our local community to use their voices to advocate for themselves and for our cause. This new tool will provide community members with the ability to connect with and advocate to their local legislators with the click of a button.

This tool will allow you to reach out to your legislator using a template that will already be populated with a call-to-action message as well as your legislator's information. All you will need to do is write your name and hit send!

If you would like, you will have the ability to edit and personalize the message in your email, but it will not be required to make a difference!

We will use this new tool for the first time to let the local Colorado Legislators know that we will be hosting NHF Colorado's virtual **State Advocacy Days Thursday, April 22th at 6:00 PM.**

**First we need YOU to take the first step and enroll in the new advocacy program!**

Sign Up to Join Advocacy Efforts

## CROSS STATE ADVOCACY GAME

During the week of March 22nd you are invited to join your local community to compete against chapters across the nation! Keep an eye out for a separate email on how YOU can get involved!

## EDUCATION SERIES



### **PARADISE PAINT A WOMEN'S EVENT MARCH 11TH AT 6:00PM**

For those women in the community who want to try something unique and creatively pass the time, we bring you the Paradise Paint event! Join our interactive free session and create your own version of "Paradise". Community member Molly McCabe will guide you through lively creativity and laughs! No experience is needed to have a good time. Let's be honest we could all use some much-needed art therapy. So sit back, relax and enjoy some painting fun from the comfort of your own home.

**RSVP by end of day Friday, March 5th**

[RSVP Today!](#)

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### **FUTURE LEADERSHIP ADVOCACY SUMMIT A TEEN EVENT FOR AGES 13+ MARCH 18TH AT 6:00PM**

Join us for a Virtual Advocacy Summit with an educational presentation, engaging conversation and everything you need to know to start being the best advocate for yourself and your community. This summit is open to ages 13-19 in the bleeding disorder community.

Join teens from across 4 different states for this fun, hands on event!

#### **Presentations and Engagement Include:**

Empowered: Tools for Self Advocacy with Pfizer

A Personal Advocacy Story with Nathan Schafer, VP of Public Policy for NHF Advocacy Support Box including t-shirt, red tie and more.

**Register by March 10th, 2021 to receive event box.**

**In partnership with:**



Get Involved Today!

## BACKPACKS + BLEEDERS

As the days get longer, the adventures will be too! We are excited for the glimmers of hope that we could be trailblazing together in person soon. Over the winter, individuals from across the state participated in the Winter Photo Scavenger Hunt. By exploring our backyards, we discover the beauties hidden between the branches.

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



**Community Cycle Event: May 22nd**



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



**Fly Fishing Clinic: Virtual Component TBA, on the water September 25th**

## BOARD OF DIRECTORS

**EXECUTIVE COMMITTEE**

Board Chair - Jalpa Sheth  
Vice Chair - Mitch Fish  
Secretary - Salome Aguilar  
Treasurer - Briana Reinking

**MEMBERS AT LARGE**

Joseph Mah  
Kim Nicks  
Angie Blue (ex-officio)



**Our Contact Information**

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