

CELEBRATING 35 YEARS

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org

VIRTUAL FAMILY EDUCATION WEEKEND

Program Guide

November 13-14th, 2020

SWOOGO

Your Home for Family Education Weekend!

https://nhf.swoogo.com/NEFEW2020

You'll find:

- Virtual Sponsor Booths
- Links for All Sessions
- Link for Bombardier Watch Party
- Downloadable Program

EVERYTHING YOU NEED FOR FAMILY EDUCATION WEEKEND

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Dear NENHF Bleeding Disorders Community,

NOVEMBER 2020

We are so excited that you are joining us for our first ever Virtual Family Education Weekend. We know this isn't how we wanted this program to happen this year but we know the importance of community, being together and experiencing life together. We know that FEW won't have the same feel this year but we've worked hard to make this a meaningful and fun weekend for your entire family.

We know that Family Education Weekend is a place to learn, to grow, to have fun and to connect as a community. We want to have fun learning and experiencing something new. We really hope you have a good time at our virtual FEW during our live sessions and all the fun stuff you get to do offline with your family.

Your 'FEW in a Box' was designed to get you as close to the Family Education Weekend experience as we can get! You'll find all your sponsor goodies, a fun craft, a tablet courtesy of the Hemophilia Alliance Foundation, Nebraska NHF stickers and a movie watching kit for Bombardier Blood. We hope you like the boxes, even though we know it's no substitute for being together. We don't know when we will be able to gather again safely, so thank you for still joining us for these virtual events while we wait for the pandemic to subside enough to start holding in person events again. Our calendar in 2021 will look different than it has the past few years but we will be utilizing virtual, small in person, and hybrid events while we hope to once again to full in person events by year end. We miss you all so very much and I hope you know that we are here for you regardless. I hope you are able to connect with your community this weekend, learn something new, enjoy your goodies and still feel apart of this amazing bleeding disorders family. Our sponsors have worked with us to ensure this virtual event will go on, that your programs are supported and that we can offer assistance to those in need.

We know this is an incredibly difficult time for our entire community. We hate that we can't be together in person, but we hope education weekend will provide a space for you to feel connected, have fun and build relationships while we are socially distant. We hope all the info you need is here, but if you have questions or need assistance don't hesitate to call, text or email me. I'm here for you.



Can't wait to see you!

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SCHEDULE OF EVENTS

https://nhf.swoogo.com/NEFEW2020

Friday, November 13th

5:30- 5:45 PM- Welcome and Sponsor Introductions
5:45- 6:30 PM- Diamond Sponsor Presentations
6:30 -7:30 PM- Talking About What Isn't Talked About- NHF
7:30- 8:00 PM- *Virtual Exhibit Time*
8:00- 8:30 PM- Chapter Update

Saturday, November 14th

2:00- 3:00 PM - Gene Therapy Breakout- NHF
2:00- 3:00 PM Taking Care of You Breakout- Octapharma
3:00-3:30 PM- *Virtual Exhibit Time*
3:30-4:30 PM- Evaluating your Insurance Options Breakout- Sanofi Genzyme
3:30-4:30 PM- Self Infusion Step-by- Step- Takeda
4:30-5:00 PM- *Virtual Exhibit Time*
5:00-5:45 PM HTC Update with Doctor Harper
5:45-6:30 PM *Dinner Break*
6:30- 7:30 PM- Coping with Persistent Pain - Pfizer
6:30- 7:30 PM- Von Wille-What? Diagnosed with a bleeding disorder as an adult
7:30- 8:00 PM- *Virtual Exhibit Time*
8:00 PM- **Bombardier Blood Watch Party**

GooseChase Scavenger Hunt Game-
Monday, Nov 9-Saturday, Nov 14

SESSION DESCRIPTIONS

TALKING ABOUT WHAT ISN'T TALKED ABOUT- NHF

Mental health conversations have always had a stigma attached to them. Join us as we talk about what isn't talked about, the importance of mental health and chronic conditions.

GENE THERAPY- NHF

Recently there has been an explosion of innovation in the treatment of Hemophilia. It is becoming more important than ever to stay informed on all the advancements – what they are and how they work in the body. Understanding all the options, the potential as well as the limitations, risks and unknowns of each type of therapy will enable community members to have robust conversations with their providers and to ultimately make the best decision on treatment. This presentation is designed to provide a basic overview making these complex concepts more understandable

TAKING CARE OF YOU- OCTAPHARMA

When your loved one has a bleeding disorder, their healthcare needs often come first. 'Taking Care of You' provides support to help caregivers rebalance their lives and focus on their needs.

EVALUATING YOUR INSURANCE OPTIONS- SANOFI GENZYME

Discuss different insurance plans and important terminology to help you evaluate your options.

SELF INFUSION- STEP BY STEP- TAKEDA

Home and Self Infusion can truly help to empower patients. Learn about the benefits of self-infusion and what you should consider beforehand. This take provides a step-by-step guide for getting started.

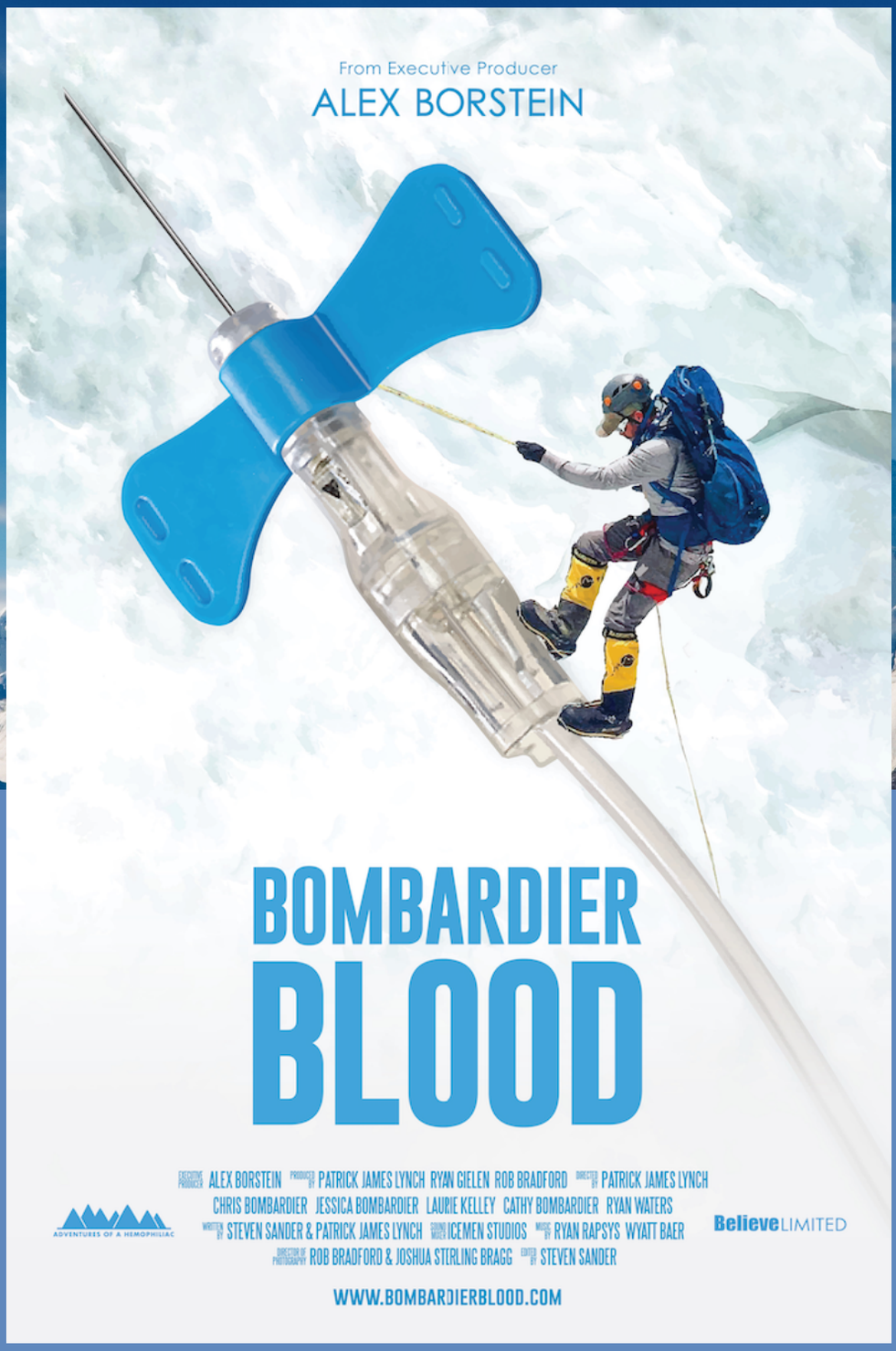
COPING WITH PERSISTENT PAIN- PFIZER

An overview of coping with persistent pain in the general population as well as how it may affect those with hemophilia. Emphasis is places on the impact of persistent pain, individual assessment of pain, and ways to communicate with your healthcare team.

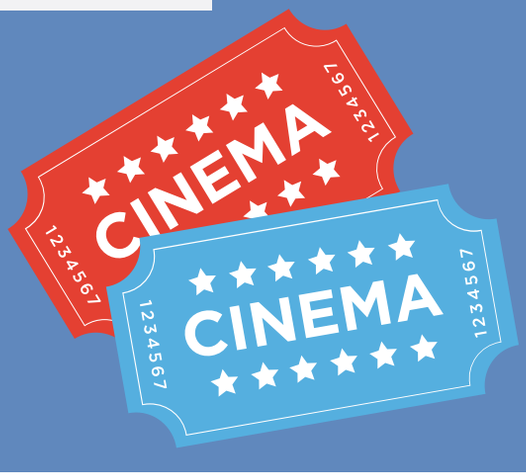
VON WILLE- WHAT? DIAGNOSED WITH A BLEEDING DISORDER AS AN ADULT- CSL BEHRING

From an early age, Kristin experienced mysterious bruising and was teased for being clumsy. And yet, she could never recall exactly how she got the purple and red splotches. When she started menstruating, her periods were long and heavy. Kristin thought it was normal since her mother and sister experienced the same thing. It was not until her son was diagnosed with hemophilia A and von Willebrands disease that the true cause of her bleeding disorder was revealed. Today Kristin shares her story to help educate others about living with Hemophilia and VWD.





November 14th
8:00 PM
Virtual Watch Party!



WHAT'S IN YOUR BOX?

- Program Guide
  - Includes Goosechase and Zoom Instructions
- NENHF Stickers (how cute!)
- Fall Craft
  - Paint and Brushes
  - Foam Kit
  - Wooden Truck Kit
- Movie Screening Goodies
- Industry Branded Items
- Industry Goodies and Give Aways
- Samsung Tablet (For those requested it!)



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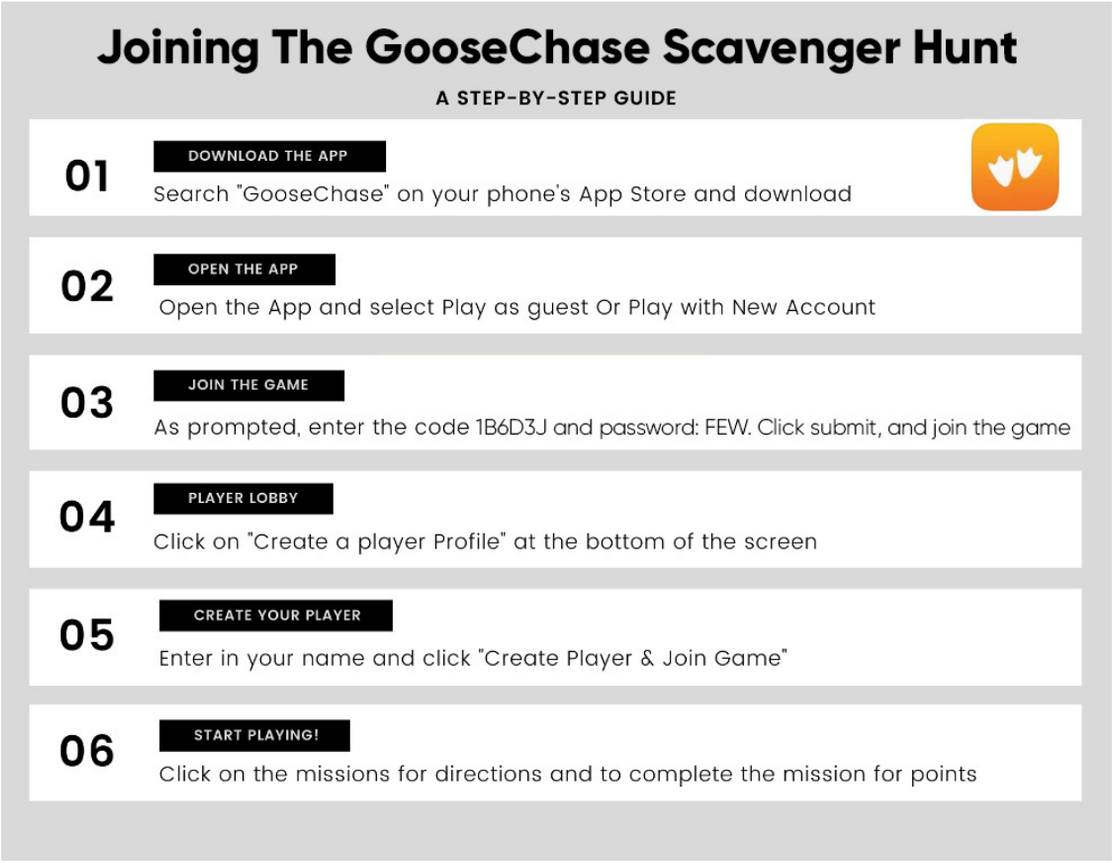


GOOSECHASE MOBILE APP INSTRUCTIONS

Goosechase is a virtual platform used by educators to offer hands-on learning. During the global pandemic, many organizations in the Bleeding Disorders community are using the app to engage community members while we cannot be together for in-person programming. We chose Goosechase as one of our primary tools for Family Education Weekend because of its accessibility on mobile devices and easy-to-use interface. We hope you enjoy it too!

Activities in Goosechase are referred to as "missions". When you enter NENHF's Family Education Weekend Game, you will see a series of missions to complete. We've designed programming that can be done largely away from a screen and on your own time. Use the instructions in each mission to participate safely and successfully. To receive points, you'll either respond to a question or submit a photo or video based on the activity.

Each HOUSEHOLD that earns 75% of the available points by the time the game ends will receive a $50 Amazon Gift Card! How many points can you earn?



Virtual FEW Game will open on Goosechase beginning Monday, November 9th, 8 AM and close Sunday, November 15th, 7 PM



LIVE PROGRAMMING IN ZOOM

Zoom has become synonymous with 2020! We opted to use Zoom's Meeting platform because of its accessibility and safety features. Registered Virtual Family Camp attendees will receive links to each live session by email prior to each event.

Please review the following points to help you make the most of our live programming.

Zoom Tips and Reminders:

• **Recording:** Virtual Family Education Weekend live Zoom sessions will be recorded for safety and to use for promotion and planning future virtual events. If you do not want to be included in the recording, please turn your camera off. Attendees are not permitted to record the session yourself either through Zoom or a third party device.

• **Audio & Participation**: Attendees will be on mute during most live virtual events. Participation is still encouraged! While we can't always hear you, we can see you and your movements (if you are on camera), which will be particularly useful for the campfire.

• **Camera:** You can turn on/off your camera on your own (lower left of screen). If you'd like to add a virtual background, do this by clicking the arrow button next to the camera and selecting an image.

• **Adjusting The View:** You can use gallery view or speaker view to change how you see others (upper right of screen).

• **Interaction**: Use non-verbal feedback/emojis to let us know what you think! Zoom has the option to add a thumbs-up and hand clap to your screen (lower right of screen).

• **Waiting Room**: We've enabled a "Waiting Room" on Zoom as a security feature. All attendees will be admitted to the room by the host. If you leave the meeting and return, you'll need to be re-admitted by the host.

• **Dialing-In**: You do not have to have a computer or smartphone to log on; users have the option to dial-in on the phone.

• **Tech Issues Are Not Uncommon**: If you have any issues, try leaving the meeting and coming back. If the video is an issue, you can always listen on the phone.

• **Zoom's Website Has Several Quick Guides & Videos**: If you'd like to learn more, we suggest reviewing their materials to familiarize yourself with the platform.



GUIDELINES & EXPECTATIONS FOR FAMILY ED WEEKEND

General Guidelines for Zoom and Goosechase:

• Only permitted NENHF employees, board members and registered community will be admitted to the Virtual Family Education Weekend Scavenger Hunt in Goosechase and Zoom sessions.
• Anyone who contributes to an unsafe, uncomfortable, or inappropriate experience will be prohibited from further participation at our discretion.
• All programming is approved and monitored by the Executive Director throughout the entirety of the weekend.
• A survey will be sent after FEW ends on November 14th. NENHF is constantly evolving and we need your feedback to make your virtual experience the best it can be.
• Email or call us anytime. Our goal is to serve you, please let us know if you have questions.



Maureen Grace, NENHF Executive Director: mgrace@hemophilia.org | 402.499.8025



Misti Mitchell, Development Manager: mmitchell@hemophilia.org | 402.889.0792

Guidelines for Zoom:

These guidelines were developed based on the best practices for child abuse prevention and have been adapted to protect campers in a virtual setting. NENHF will follow these during live programming.

• Live sessions are recorded for safety and quality assurance.
• All Zoom sessions are privacy protected. Only registered community members can access Zoom session links; DO NOT share them with others.
• All Zoom sessions are facilitated by two NENHF employees or volunteers.
• All employees leading sessions have undergone virtual program training, and have recent and clear criminal background checks.
• Zoom chat box will be set to public so attendees will not be able to chat privately.
• Screen sharing will be restricted to the Chapter staff and speakers only.
• All NENHF employees and board members will adhere to virtual programming safety protocol and staff policies.



FAQ

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Q- I'M STARTING TO GET BURNT OUT ON VIRTUAL PROGRAMS AND BEING ON A SCREEN. WILL EVERYTHING TAKE PLACE ONLINE?

Each of our sessions will be online. However, many of the activities in the Scavenger Hunt don't require you to be in front of a computer. We have limited sessions for our FEW and started them later on Saturday to hopefully limit time you'll be on a computer or tablet.

Q- DO I HAVE TO PARTICIAPTE IN EVERY COMPONENT OF FEW?

No, this is up to you. We hope you will participate in all of the live events but it's not enforced or required. We welcome the level you are able to be a part of FEW. We hope to see you at all the live sessions if possible. Our sponsors and speakers have transitioned to a virtual format with us and we want to have as many attendees logged in as possible.

Q- WHAT DEVICES CAN I ACCESS FAMILY EDUCATION WEEKEND FROM?

You can access family education weekend from any type of device with internet access such as a laptop, smartphone or tablet. We are using Zoom which works on all devices. Goosehunt works best on the app.

Q- DO I HAVE TO BE 'SEEN' ON VIDEO?

No. You have the option to join with video but you can turn that off at anytime. You can also call in on your phone for audio only listening. We would LOVE to see your faces, but it's at your comfort level how much you are on video.

Q- HOW WILL WE CONNECT WITH OTHER FAMILIES DURING FEW?

Interactions with your community and sponsors will be available each day of FEW. You'll be able to see each other during our Live Zoom sessions. In Goosechase, you'll share videos and photos of activities and these will show up on the leader board.

Q- WHAT PRECAUTIONS WERE TAKEN IN SHIPPING BOXES IN LIGHT OF COVID 19

All items in your boxes were ordered in advance and were able to sit for a few days. Maureen packed all your boxes and took every precaution to ensure safety.

Q- HOW WILL NENHF PROTECT ONLINE SECURITY FOR FEW?

Only registered members for FEW will be given access to our Zoom links. We will have a waiting room in place to we can ensure the people we admit are supposed to be there. We will also moderate the sessions for safety throughout. Every participant is a member of the Nebraska Bleeding Disorder Community.

SPONSORS

DIAMOND SPONSORS

Takeda

BAYER

octapharma

PLATINUM SPONSORS

CSL Behring
Biotherapies for Life™

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