the artery

Serving Michigan's bleeding disorders community

Winter 2021/2022

EAGLE JOURNEYS
CAMPING PROGRAMS

HFM's Eagle Journeys exists to educate and empower kids with bleeding disorders to live a life of freedom and independence

hfm©

HFM exists to enhance the quality of life for all affected by bleeding disorders

ALSO INSIDE THIS ISSUE

Community Night: Decorate a Backpack!

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How to Utilize Self-Advocacy to Support Your Mental Health

page 11

EDITOR
Sarah Procario


Susan Fenters Lerch

We are here for you.

> "Courage says, “I will not let the fact that I cannot do everything keep me from doing what I can."
> ~Glennon Doyle

Dear HFM friends and family,

My appreciation to each of you as we move toward the final days of 2021. It has continued to be a trying time for so many with break-through and other COVID infections, continued hospitalizations, and loss.

Our HFM board and staff are continuing our best efforts to determine how to offer programming and services in safe and productive ways. As a social service health agency, with additional significant responsibilities related to our federal region of treatment centers, **we believe community and patient safety is a top priority**. We hope to be in a position to offer in-person programs in the new year, yet we will continue to monitor public health and medical community perspectives with final decisions forthcoming.

We have mailed and emailed our latest **community assessment** to each household in our confidential lists to invite you to share your perspectives regarding HFM’s program services via education, advocacy, learning opportunities, and support activities. We ask that you share your perspectives, feedback, and input—your involvement is important, and we are grateful.

Did you know that in addition to Michigan-specific programming, HFM supports various educational efforts to benefit people across the United States as well as those closer to home?

Please read a bit about our recent **HFM National Conference for Women and Teens with Hemophilia and Rare Factor Deficiencies**. The first of its kind, we completed our 4th year of this amazing conference (2nd virtual year!) in October and are already looking ahead to 2022. Our HFM staff team is thankful for the participation of so many remarkable women and support from medical leaders, various care providers, and community leaders who volunteer their expertise. Our expanded women’s conference sponsors make this important educational weekend possible.

HFM’s Eagle Journeys camp programs are available to kids, young adults, and camp staff who come together from Michigan, Ohio, Indiana, other states—countries—to provide education and skill development for those living with bleeding disorders. I hope you are proud to be an integral part of HFM as we continue to lead the way with innovative and valuable education and community support. Fingers crossed we will be able to offer our camp programs in person in the summer of 2022!

As we look toward a new year it is my hope we will **find joy in being together in spirit and that 2022 will provide peace and wonder**.

Love,

Susan Fenters Lerch
HFM Executive Director
Federal Great Lakes Region –
V-E HTC Network Director

Please see our **2022 events policy** on page 20 to learn how we’ll be making decisions about in-person events.

HFM reaffirms what has always been in our hearts and what we aspire to convey through our actions: that each individual has inherent value and is worthy of acceptance and equality. We accept all with this respect and care regardless of their race, sexual orientation, gender identity, religion, disability, or socioeconomic status.

PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER.

Celebrating Thanks. Celebrating Giving. **Celebrating the HFM Community.**

It may seem a bit out of step to talk about celebrating this past year. We recognize that for many, the challenges of COVID-19 have brought tremendous loss, anxiety, and overload. Like you, the staff at the Hemophilia Foundation of Michigan (HFM) had to continue to make changes mid-stream as we tried to predict, but then had to reimagine, what coming together would look like this year. As we take a moment though to reflect, even while acknowledging the difficulty of change and disappointment, there are many moments that stand out as worth celebrating this past year. And we are so glad that you were with us for these moments because you have made this community one to celebrate.

You, and hundreds of other members of the Michigan bleeding disorders community, joined us this past year for virtual programs. We were so pleased that so many of you participated in our first fully virtual SpringFest weekend, and that our second year of camp online was such a success. With your help and involvement, we created expanded opportunities to provide education and support with a new VWD Symposium, ongoing dinner talk evenings, women's programming, advocacy webinars, and so much more. We continued to provide medical ID tags and offer dental assistance. Some of our virtual programs actually had an increase in attendance over earlier in-person events!

Let's face it, this past year has been difficult. It has been disruptive to our lives and our traditions, and it has forced us to think differently about how we can support and connect with one another. But you stood by us and supported one another. You helped shape what meaningful connection and engagement could look like. At a time when the Michigan community needed you most, you were there. Thank you.

We are so fortunate to have this community of ours, and **we hope that you know exactly how appreciated you are**. We hope that you will consider making an end of the year donation to continue the work HFM has been able to accomplish, thanks to you. Your support will help continue to provide robust and engaging education and services as we all look forward to 2022. We know we cannot do this work without you.

Thank you. We celebrate you!

Please consider a year-end donation: www.hfmich.org/donate

Your support provides hope and connections when our community needs it most!

The CARES Act in 2021 expanded charitable deductions for those who do not itemize. You can claim $300 "above the line" deduction as an adjustment in determining your adjusted gross income in 2021; $600 for those married who are filing jointly.

hfm SpringFest 2022

Sat., April 23 and Sun., April 24, 2022*
Amway Grand Hotel, Grand Rapids & Virtually

Check www.hfmich.org in late February for more information.

*All in-person events are tentative. Please be advised that HFM will be making final decisions on whether events will be hosted in-person or virtually closer to each event date. Please see our 2022 events policy on page 20 to learn how we'll be making these decisions.

GRAND RAPIDS

PAID CONSUMER OUTREACH

Michelle Leona Cecil, M.P.A.

Patient advocate

About Michelle

Michelle is a Novo Nordisk Hemophilia Community Liaison who lives with a bleeding disorder. She is passionate about supporting people in the community and helping them take full advantage of the trusted products of Novo Nordisk.

Connect with Michelle

VQMC@novonordisk.com
(614) 674-0147

Hemophilia Community Liaison

Great Lakes (MI and WI)

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

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novo nordisk®

2021 National Conference for Women and Teens with Hemophilia and Rare Factor Deficiencies

October 8 & 9, 2021 ~ Presented virtually

See pages 6, 7, 8 & 9 for more information

Links to two of our sessions are located on page 8.

As HFM moved into our fourth year (second year virtual) of the National Conference for Women with Hemophilia, we were excited to find new ways to provide education along with a sense of unity for attendees from across the country and the world. With the help of our dedicated conference planning committee, we not only created another exceptionally engaging educational experience fresh with new topics and opportunities for women, we also expanded the conference to include women with rare factor deficiencies. We were thrilled this year to provide Spanish translation for all main stage sessions and select breakout sessions and a new teen and young adult program with special breakouts throughout the conference.

Several days prior to the conference, attendees began receiving their conference-enhancement packages building a sense of anticipation and togetherness. We were pleased to be able to provide a feeling of in-person comfort through these boxes filled with special treats, supplemental materials for sessions, and valuable information to support attendees' conference experience.

The conference kicked off with a virtual whitewater rafting theme exploring personal areas to cultivate, while identifying personal challenges to ‘let go.’ Our GutMonkey staff guides, Haelynne and Margaret, were excellent facilitators of this process.

National organization representatives joined us to update attendees about current and future efforts to prioritize and improve women’s initiatives in bleeding disorders nationally and internationally. We learned that earlier this year, the National Hemophilia Foundation’s Medical and Scientific Advisory Committee (MASAC) announced the appointment of Rose Bender as the first female patient representative. This accomplishment was a direct result of the letter writing campaign spearheaded by attendees at the 2019 conference with Dr. Meera Chitlur’s pledge to hand deliver them to the committee.

Full conference presentation topics were planned to address persistent issues, new technology, uterine concerns, and prophylaxis research relevant to our attendee population. Dr. Jill Johnsen, Dr. Alan Mast and Jim Munn, RN provided information regarding iron deficient anemia, a concern for all menstruating women but even more prevalent in women with bleeding disorders. Causes, signs and symptoms, and treatment options were supplied. The biggest takeaway from this presentation was the importance of starting teens on a multivitamin with iron when they begin menstruating. New and exciting information was presented about utilizing ultrasound technology to identify and manage joint bleeds by Dr. Joanna Davis and Stacie Akins, PT. Some HTCs are currently using this technology to improve assessment and outcome of joint health. Dr. Jill Johnsen and Dr. Judy Simms-Cendan educated attendees about health challenges for pregnancy, delivery, and uterine bleeding. Finally, Dr. Robert Sidonio outlined current research on prophylaxis with women with bleeding disorders. There is a real need for women within the bleeding disorders community to participate in research to further our understanding of prophylaxis in women.

A wide range of breakout topics were engaging and well attended with many requests for tapes of concurrent sessions. Topics included aging women, emotional well-being, World Federation of Hemophilia’s (WFH) Women’s Committee, relationship with treaters, pain management, and uterine problems.

This year’s conference ended with a song written especially for our mission with the help and input of attendees throughout Saturday. Singer/songwriter Ruby Jane Smith performed the song at the close of the conference and the chat feature erupted with enthusiasm for our new theme song. Ruby Jane was able to capture the emotion of the conference and the effort and struggle this community has had. If a picture is worth a thousand words, a song can validate a world of emotions. To see the video, go to **www.hfmich.org/rubyjane**.

THANK YOU TO OUR SPONSORS

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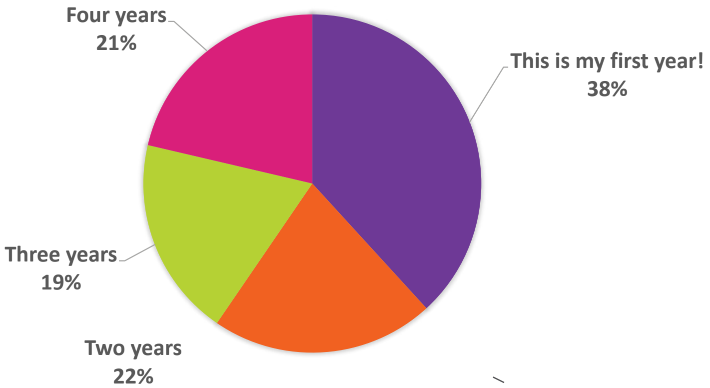
2021 Women's Conference continued from page 5

> "I absolutely would recommend this conference for women. It's a place where you can openly discuss your bleeding issues without any judgment. A place where you realize you're not alone in your journey." ~ *Conference attendee, 2021*

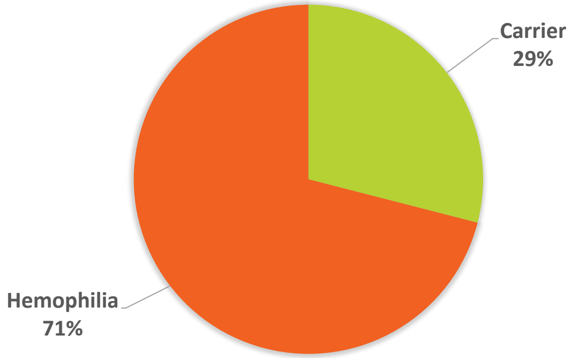
Attendees Shared...

Poll data gathered during the Hemophilia Foundation of Michigan's National Conference for Women and Teens with Hemophilia and Rare Factor Deficiencies, 2021

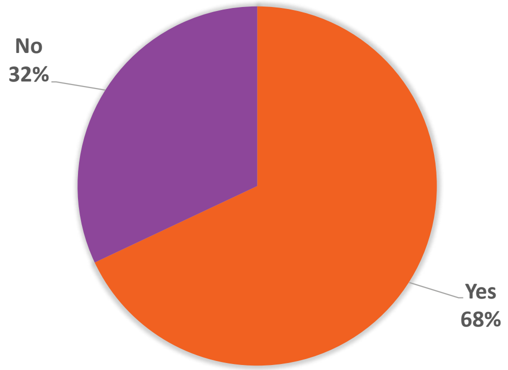
1 How many years have you attended HFM's National Women's Conference?



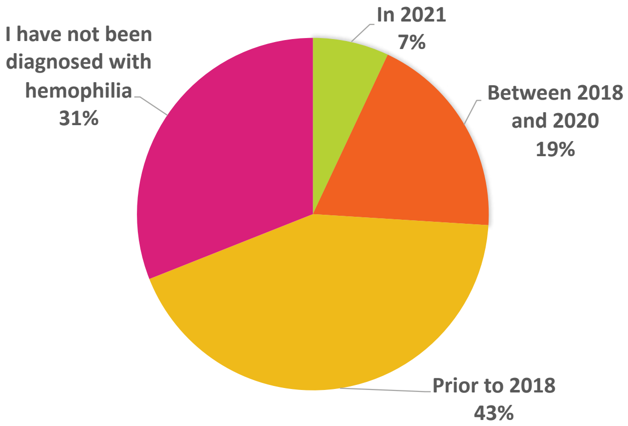
2 Do you consider yourself a carrier or do you consider yourself having hemophilia?



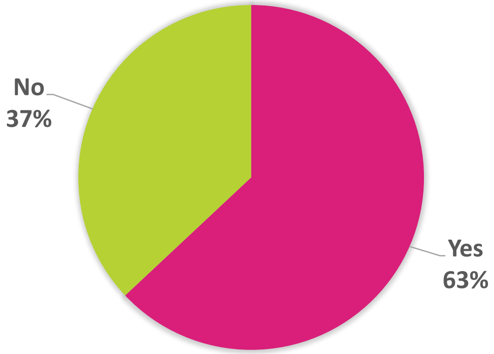
3 Have you been diagnosed with hemophilia by a healthcare provider?



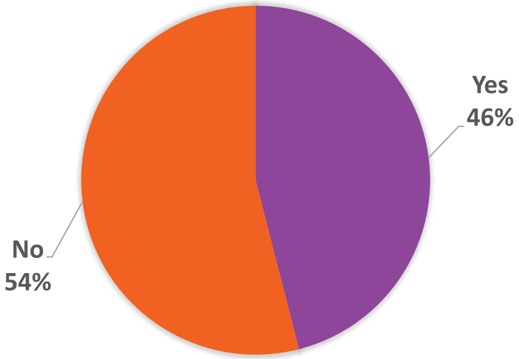
4 If you have been diagnosed with hemophilia, when were you diagnosed?



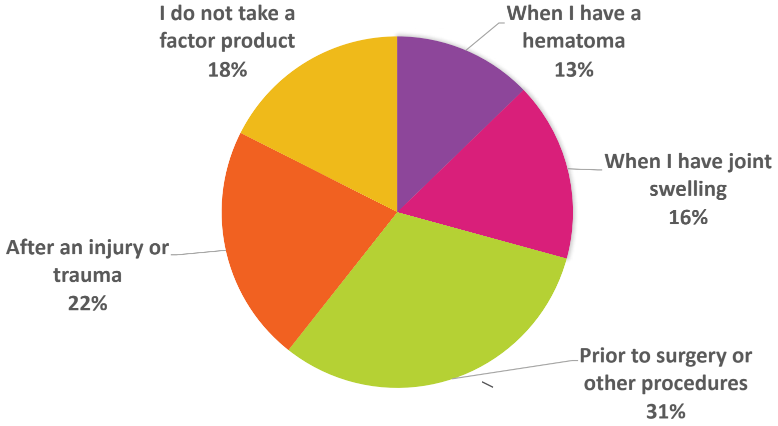
5 Do you ever treat with a factor product?



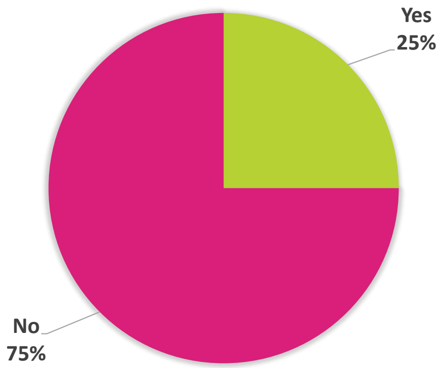
6 Do you have factor for yourself?



7 When do you take a factor product?



8 Has your healthcare provider ever talked to you about prophy treatment for yourself?



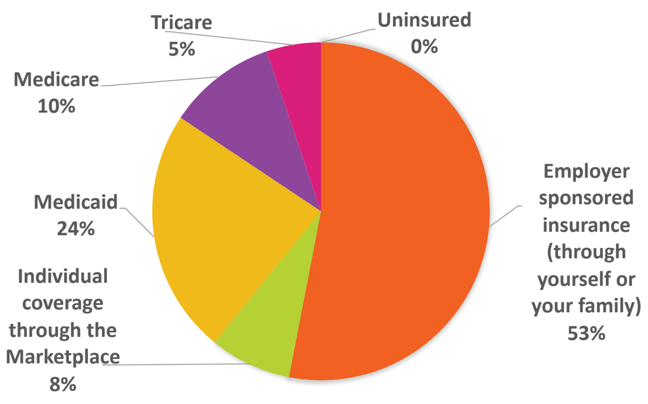
Final 2021 registration: 280+ individuals representing our speakers, staff, community leaders, medical care providers, and most importantly 184 women living with hemophilia or rare factor disorders from 38 states!

Arizona
Arkansas
California
Colorado
Connecticut
Florida
Georgia
Idaho
Illinois
Indiana
Iowa
Kansas
Kentucky
Louisiana
Maine
Maryland
Massachusetts
Michigan
Mississippi
Missouri
Nebraska
Nevada
New Hampshire
New Jersey
New Mexico
New York
North Carolina
Ohio
Oklahoma
Oregon
Pennsylvania
South Carolina
Tennessee
Texas
Utah
Virginia
Washington
Wisconsin

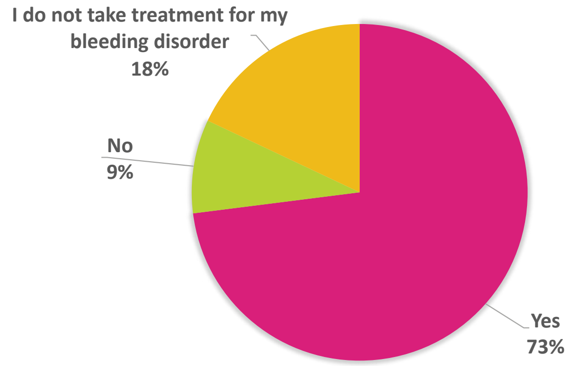
Because of the virtual nature of this year's conference, we were able to also accommodate women from: Bangladesh, Guatemala, Puerto Rico, Australia, and New Zealand.

2021 Women's Conference continued from page 7

9 What type of insurance do you have?



10 Does your insurance provide affordable access to your physician prescribed treatment?



11 What is your biggest take away from day one of the National Women's Conference?

Inspiring education

Doctors who care!

Fabulous!

affirmation

Advocacy

Empower

sisterhood

factor

progress

inspired

strength

Borderless

Community

Misogyny

rewarding

Self-Love

Clarity

speak up

Understanding

Support

unity Love

Amazing

Caring

empowerment

All the love

More research needed

> "This conference is the best conference I have ever attended. I love that we can connect with each other. Meeting other women that are living with hemophilia is amazing. Knowing that I'm not alone. Being at this conference makes me feel validated in my diagnosis. Even though we are all from different walks of life, there is such a bond that ties us together."
>
> ~ Conference attendee, 2021

Two conference sessions for you to view!

Iron Deficient Anemia

www.hfmich.org/wc-anemia

Many women and girls with bleeding disorders suffer from undiagnosed iron deficient anemia. This session will discuss the symptoms, medical consequences, and provide suggestions for treatment of iron deficient anemia.

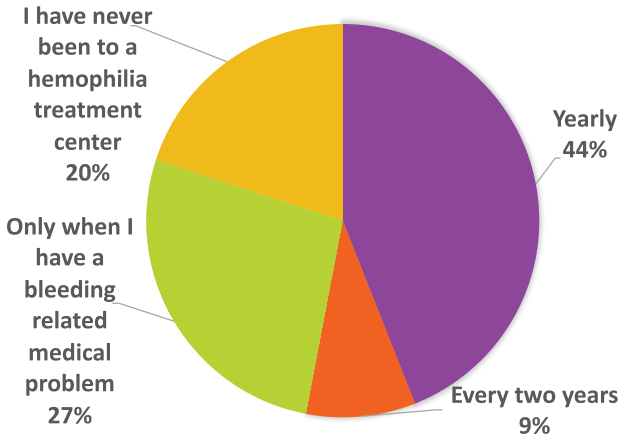
Emergent Women and Girl's Health Challenges

www.hfmich.org/wc-healthchallenges

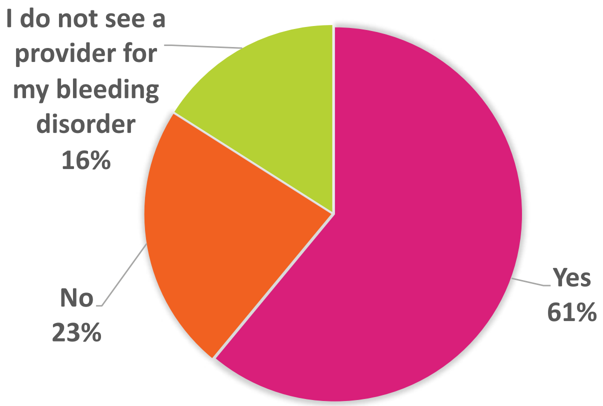
Two important health issues are covered in this session. Planning for pregnancy and delivery is a critical aspect of self-care when you have a bleeding disorder, and this topic will be covered with specifics about communication with medical staff and having plans documented. We will also discuss the other possible causes of reproductive health bleeds that are not related to a woman's bleeding disorder.

> **“This effort is monumental and your conference is a huge part of attaining health equity for women. Thank you.”**
>
> ~ Conference attendee, 2021

12 Do you visit a hemophilia treatment center for your own health care?



13 After you leave your appointment at your health care provider: Do you feel heard?



Men’s Support Group

Karen Boyd, LMSW, Center for Bleeding and Clotting at MSU;
David Rushlow, LMSW, Bleeding Disorders at Munson Medical Center

As the COVID pandemic began and isolation started to impact many within the community, HFM staff approached us about the opportunity to provide a specialized support group for men with bleeding disorders. Karen and I have facilitated support groups together for many years and were excited to provide a new forum for social support within the community.

Together, we created the Men’s Support Group to provide a safe, confidential setting to share common concerns, discuss any issues, and to give and receive support amongst group members. The support group takes place via Zoom the first Tuesday evening of every month and is open to all men 18 years of age or older who reside in Michigan.

The sessions have no assigned topic to allow men to share what is most relevant to their current lives.

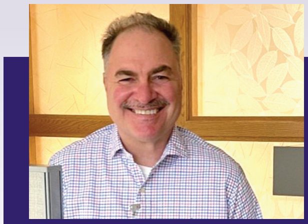
Two members have shared their thoughts on the group:

“I find the Men’s Support Group very helpful because it allows me to connect with people who have similar experiences and concerns. We discuss the way our disorder affects us in everyday life. For example, we talk about how we deal with joint pain and the difficulties it creates. We have discussed the way hemophilia affects our relationships. I have learned quite a bit about the way other people are coping with the disorder. It has also been very valuable to discuss the latest treatments and innovations that will be available soon. Our group hosts Karen Boyd and Dave Rushlow have done an excellent job fostering a safe and supportive environment. Thanks to their guidance and dedication, every group member is able to express themselves, be heard and understood.”

“The monthly men’s online support group has been useful as an opportunity to share personal and medical concerns, offer support to fellow hemophiliacs, and to obtain input from qualified and capable social workers. I would encourage men in our community to join the group to try it out! What do you have to lose?”

We are privileged to facilitate the men’s group and it is a special honor for the men to allow us into their hearts. Please consider joining us!

Contact Lisa Clothier, lclothier@hfmich.org to sign up.



Congratulations Dave Rushlow, LMSW, Social Worker, Traverse City Hemophilia Treatment Center, for receiving the prestigious **National Hemophilia Foundation Social Worker of the Year** award! Dave's work has positively impacted so many patients and families in the bleeding disorders community. HFM thanks him for his generous support of many HFM programs including the monthly Men’s Support Group.

Community Night: Decorate a Backpack

Who is adorable, creative, and ready to learn? Any one of the children that attended our Decorate-A-Backpack Community Night! We wanted our kids to be ready to go back to school with something that would display their personality and create an opportunity for HFM kids to gather together. Voila! Backpacks for all with everything they would need to make it their own: puffy paint, beads, markers, and some magnetic buttons to decorate.

Our kids gathered via Zoom and listened to a presentation from Lynn Vanderwal, MSW from Helen DeVos Children's Hospital about going back to school anxiety and how we can make it a smooth transition. Thank you, Lynn! Everyone gets a little nervous at the start of school yet having some prepared coping tools can help calm those worries!

From there, kids began painting, drawing, and in some cases, creating a goopy (yet beautiful!) mess. The pride was evident as they each held up their backpacks for the group to admire! We hope that the start of the school year was just as wonderful as their designs and that their special backpacks led to many chances to talk with their classmates and make friends. Great job!

Thank you to everyone that attended and our sponsors for helping us to host such a supportive and fun night!

Thank you to our sponsors

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PAID CONSUMER OUTREACH

PAID CONSUMER OUTREACH

How to Utilize Self-Advocacy to Support Your Mental Health

Positive mental health allows people to realize their full potential, cope with the stresses of life, work productively, and make meaningful connections with their communities, friends, and loved ones. Unfortunately, the COVID pandemic has had a substantial impact on the mental health of individuals across the country. People are experiencing increases in anxiety, depression, substance abuse, and suicide. Adults reporting symptoms of anxiety disorder and/or depressive disorder increased by 30% from June 2019 to January 2021. Mental health conditions are disproportionately affecting specific populations, especially young adults, Hispanic persons, black persons, essential workers, unpaid caregivers for adults, and those receiving treatment for preexisting psychiatric conditions.

Robert Loudin, MSW, LCSW from the Indiana Hemophilia and Thrombosis Center (IHTC), joined HFM to discuss this significant impact of the COVID pandemic and how to cultivate self-advocacy skills to support your own mental health.

Self-advocacy is the ability to understand and communicate your needs to other individuals. Historically, people in the bleeding disorders community are often experienced/familiar with advocating for their physical health; this may look like informing your school about your disorder, speaking up if you have a bleed, and talking to your doctor about treatment options.

It is just as important to invest in our mental health as it is our physical health. Self-advocacy for your mental health may look like reaching out to a friend, taking a sick day, scheduling an appointment with your physician, and/or looking for a mental health care provider. When we are feeling unwell, it can be harder to advocate for ourselves and therefore it is even more important to have tools prepared.

Follow Bob's tips below to be a more effective self-advocate:

- Believe in yourself
- Know your rights
- Know the facts
- Have a plan
- Gather support: some examples include your family, friends, HTC staff, HR department, and school counselors
- Assert yourself clearly, calmly, and politely
- Be firm, persistent, and patient with the process
- Know your limits
- Practice, practice, practice

Mental Health Care Emergency

If you are experiencing a mental health care emergency, call the **National Alliance on Mental Health Crisis Line at 800-950-NAMI** or the **National Suicide Prevention Lifeline at 800-273-8255**.

Thank you to everyone who joined us for our Self Advocacy webinar with **Robert Loudin, MSW, LCSW** from the Indiana Hemophilia and Thrombosis Center (IHTC). And a special thank you to our sponsors Takeda, CSL Behring, Genentech, Pfizer and Sanofi Genzyme for supporting this important topic.

The Artery and the content of The Artery are for educational purposes and not intended to be medical advice. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition.

Thank you to our sponsors

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SAVE THE DATES!

Legislative Advocacy Event

hfm

Lansing Days

Tuesday, March 22 & Wednesday, March 23, 2022*

Go to **www.hfmich.org/events** for more info.
*See our 2022 events policy on page 20 to learn how we'll be making decisions about in-person events.

Community Needs Assessment

www.hfmich.org/comm-survey

Open to all members of Michigan's bleeding disorders community.

Help us understand the needs of the Michigan bleeding disorders community so we can enhance our programming and services. Your input is important and valued!

You may choose between responding online at **www.hfmich.org/comm-survey** or via the paper version with a prepaid envelope arriving to each household sometime at the end of October and beginning of November.

If you complete the survey and return it to HFM, with contact information included by December 31, 2021, you will be entered into a drawing for the following:

1st drawn - 1 gift card to Frankenmuth $250
2nd drawn - 1 gift card to Amazon: $150
3rd drawn - 1 gift card to Amazon: $100
4th drawn - 1 gift card to Amazon: $50

The drawing will take place in mid-January 2022 and recipients will be notified immediately following the drawing.

PAID CONSUMER OUTREACH

In hemophilia B
TAKE CONTROL TO A HIGH LEVEL WITH REBINYN®

17% Factor IX (FIX) levels sustained after 7 days with a single 40 IU/kg dose in adults with ≤2% factor levels[a]

Clayton, 34 years old, is a pilot who hikes and camps in his spare time. Clayton lives with hemophilia B.

[a] In two phase 3 studies, factor levels were evaluated for 1 week after the first dose of Rebinyn® 40 IU/kg. The average levels after 7 days were 16.8% in 6 adults, 14.6% in 3 adolescents, 10.9% in 13 children ages 7 to 12 years, and 8.4% in 12 children up to age 6 years.

Image of hemophilia B patient shown is for illustrative purposes only.

INDICATIONS AND USAGE

What is Rebinyn® Coagulation Factor IX (Recombinant), GlycoPEGylated?

Rebinyn® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Rebinyn® is used to treat and control bleeding in people with hemophilia B. Your healthcare provider may give you Rebinyn® when you have surgery. Rebinyn® is not used for routine prophylaxis or for immune tolerance therapy.

IMPORTANT SAFETY INFORMATION

What is the most important information I need to know about Rebinyn®?

- **Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center.** Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing Rebinyn®.

Who should not use Rebinyn®?

Do not use Rebinyn® if you:

- are allergic to Factor IX or any of the other ingredients of Rebinyn®.
- are allergic to hamster proteins.

What should I tell my health care provider before using Rebinyn®?

Tell your health care provider if you:

- have or have had any medical conditions.
- take any medicines, including non-prescription medicines and dietary supplements.
- are nursing, pregnant, or plan to become pregnant.
- have been told you have inhibitors to Factor IX.

How should I use Rebinyn®?

- Rebinyn® is given as an infusion into the vein.
- **Call your healthcare provider right away if your bleeding does not stop after taking Rebinyn®.**
- Do not stop using Rebinyn® without consulting your healthcare provider.

What are the possible side effects of Rebinyn®?

- **Common side effects include** swelling, pain, rash or redness at the location of the infusion, and itching.
- **Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.
- **Tell your healthcare provider about any side effect that bothers you or that does not go away.**
- Animals given repeat doses of Rebinyn® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

Please see Brief Summary of Prescribing Information on the following page.

Rebinyn® is a prescription medication.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Learn more at **rebinyn.com**

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Printed in the U.S.A. US19REB00015 June 2019

rebinyn®
Coagulation Factor IX (Recombinant), GlycoPEGylated

rebinyn®

Coagulation Factor IX (Recombinant), GlycoPEGylated

Brief Summary Information about:
REBINYN® Coagulation Factor IX (Recombinant), GlycoPEGylated

Rx Only

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/REBINYN.pdf to obtain FDA-approved product labeling
- Call 1-844-REB-INYN

Read the Patient Product Information and the Instructions For Use that come with REBINYN® before you start taking this medicine and each time you get a refill. There may be new information.

This Patient Product Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about REBINYN® after reading this information, ask your healthcare provider.

What is the most important information I need to know about REBINYN®?

Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing REBINYN® so that your treatment will work best for you.

What is REBINYN®?

REBINYN® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Hemophilia B is an inherited bleeding disorder in all age groups that prevents blood from clotting normally.

REBINYN® is used to treat and control bleeding in people with hemophilia B.

Your healthcare provider may give you REBINYN® when you have surgery.

REBINYN® is not used for routine prophylaxis or for immune tolerance therapy.

Who should not use REBINYN®?

You should not use REBINYN® if you

- are allergic to Factor IX or any of the other ingredients of REBINYN®
- if you are allergic to hamster proteins

If you are not sure, talk to your healthcare provider before using this medicine.

Tell your healthcare provider if you are pregnant or nursing because REBINYN® might not be right for you.

What should I tell my healthcare provider before I use REBINYN®?

You should tell your healthcare provider if you

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing.
- Are pregnant or planning to become pregnant.
- Have been told that you have inhibitors to Factor IX.

How should I use REBINYN®?

Treatment with REBINYN® should be started by a healthcare provider who is experienced in the care of patients with hemophilia B.

REBINYN® is given as an infusion into the vein.

You may infuse REBINYN® at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your hemophilia treatment center or healthcare provider. Many people with hemophilia B learn to infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much REBINYN® to use based on your weight, the severity of your hemophilia B, and where you are bleeding. Your dose will be calculated in international units, IU.

Call your healthcare provider right away if your bleeding does not stop after taking REBINYN®.

If your bleeding is not adequately controlled, it could be due to the development of Factor IX inhibitors. This should be checked by your healthcare provider. You might need a higher dose of REBINYN® or even a different product to control bleeding. Do not increase the total dose of REBINYN® to control your bleeding without consulting your healthcare provider.

Use in children

REBINYN® can be used in children. Your healthcare provider will decide the dose of REBINYN® you will receive.

If you forget to use REBINYN®

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and continue as advised by your healthcare provider.

If you stop using REBINYN®

Do not stop using REBINYN® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

What if I take too much REBINYN®?

Always take REBINYN® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you infuse more REBINYN® than recommended, tell your healthcare provider as soon as possible.

What are the possible side effects of REBINYN®?

Common Side Effects Include:

- swelling, pain, rash or redness at the location of infusion
- itching

Other Possible Side Effects:

You could have an allergic reaction to coagulation Factor IX products. **Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.

Your body can also make antibodies called "inhibitors" against REBINYN®, which may stop REBINYN® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

You may be at an increased risk of forming blood clots in your body, especially if you have risk factors for developing blood clots. Call your healthcare provider if you have chest pain, difficulty breathing, leg tenderness or swelling.

Animals given repeat doses of REBINYN® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

These are not all of the possible side effects from REBINYN®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

Tell your healthcare provider about any side effect that bothers you or that does not go away.

What are the REBINYN® dosage strengths?

REBINYN® comes in three different dosage strengths. The actual number of international units (IU) of Factor IX in the vial will be imprinted on the label and on the box. The three different strengths are as follows:

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Yellow	2000 IU per vial

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

How should I store REBINYN®?

Prior to Reconstitution (mixing the dry powder in the vial with the diluent):

Store in original package in order to protect from light. Do not freeze REBINYN®.

REBINYN® vials can be stored in the refrigerator (36-46°F [2°C-8°C]) for up to 24 months until the expiration date, or at room temperature (up to 86°F [30°C]) for a single period not more than 6 months.

If you choose to store REBINYN® at room temperature:

- Note the date that the product is removed from refrigeration on the box.
- The total time of storage at room temperature should not be more than 6 months. Do not return the product to the refrigerator.
- Do not use after 6 months from this date or the expiration date listed on the vial, whichever is earlier.

Do not use this medicine after the expiration date which is on the outer carton and the vial. The expiration date refers to the last day of that month.

After Reconstitution:

The reconstituted (the final product once the powder is mixed with the diluent) REBINYN® should appear clear without visible particles.

The reconstituted REBINYN® should be used immediately.

If you cannot use the reconstituted REBINYN® immediately, it should be used within 4 hours when stored at or below 86ºF (30°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

What else should I know about REBINYN® and hemophilia B?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use REBINYN® for a condition for which it is not prescribed. Do not share REBINYN® with other people, even if they have the same symptoms that you have.

More detailed information is available upon request.

Available by prescription only.

For more information about REBINYN®, please call Novo Nordisk at 1-844-REB-INYN.

Revised: 11/2017

For Patent Information, refer to: http://novonordisk-us.com/patients/products/product-patents.html

Manufactured by:
Novo Nordisk A/S
Novo Allé, DK-2880 Bagsværd, Denmark

For information about REBINYN® contact:
Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA

USA17BIO03951 12/2017

novo nordisk®

Brushing Up on Dental Health

As part of HFM's ongoing commitment to dental health we are excited to share the addition of several dental health education videos to the HFM YouTube channel.

Special thanks to the hemophilia treatment center staff that participated in making this educational information available:

Christy Clark, RDH, Helen DeVos Children's Coagulation Disorders Program

Jill Foley, RDH, RN, BSN and **Heather Messenger, MSDH**, Michigan State Center for Bleeding & Clotting Disorders

Jennifer Kerns, BS, RDH, Northern Regional Bleeding Disorders Center

Karen Ridley, RDH, MSDH, University of Michigan Center for Bleeding & Clotting Disorders

View all HFM dental videos at **www.hfmich.org/healthyteeth**.

hfm **Dental Health** tips

Why You Keep Getting Cavities– Cavity Prevention

presented in collaboration with

Jennifer Kerns, BS, RDH
Northern Regional Bleeding Disorders Center

Hemophilia Foundation of Michigan (HFM) | www.hfmich.org

For additional ways to support your dental health please visit our website at: **www.hfmich.org/dental-health**
If you have any questions regarding your dental health, please contact your hematologist's staff to discuss your needs.

Protecting Your Dental Health

Did you know that your dental health offers clues about your overall health — or that problems in your mouth can affect the rest of your body? Protect yourself by learning more about the connection between your dental health and overall health.

Visit our website for more information about ways to protect your dental health at: **www.hfmich.org/dental-health/.**

Need Dental Insurance?

If you are uninsured or underinsured with your dental coverage, we may be able to help. We understand that our community faces challenges obtaining dental care to meet unique and individual needs. HFM has partnered with Cascade Hemophilia Consortium to offer free dental insurance to those who need it.

*To maintain your coverage you must visit the dentist two times during the calendar year for regular teeth cleanings.

In order to be eligible for this program you must:

- Have a bleeding disorder
- Be a Michigan resident
- Have no dental insurance or only Children's Special Health Care Services
- However, if you have Medicare, Medicaid, or an employer based private insurance plan you may be eligible for limited-time coverage based on special circumstances – these exceptions are limited and determined on a case by case basis. Please call us for more information.

Questions? Contact **Lisa Clothier**, LMSW, ACSW, Outreach and Community Education Manager, at **lclothier@hfmich.org** or 734.961.3512.

You can find the application here: www.hfmich.org/dental-health/

DELTA DENTAL®

CASCADE
HEMOPHILIA CONSORTIUM
SINCE 1994

hfm®

staff

Front row left to right: Anne Dimitry, Colleen Joiner, Jordan Burkey, Sue Carlini, Stephanie Sibrel, Stephanie Raymond, Devin Bromley, Mary McClure

Back row, left to right: Paul Kasdorf, Joanna Pangilinan, Gail Donehue, Kirk Haddas, Chelsea Seal, Debbie Whelan, Mike Altese

Not pictured: Rebecca Blumenfeld, Ted Beimel, Roxana Dumitrache, Kristina Halcomb, Dean Hindenlang, Melissa Laustroer, Amy Luczak, Megan Urie

Center of Care: Cascade Hemophilia Consortium

How long has Cascade operated or when did it open?

As one of the original hemophilia organizations designated as a covered entity under the 340B program, Cascade has been providing services and resources to the bleeding disorder community for over 25 years. In response to the financial challenges of treating bleeding disorders, The Hemophilia Foundation of Michigan, other community members, and our federal partners worked together to create Cascade. In September of 1994 we were incorporated as a 501(c)3, non-profit organization and welcomed our first patient.

How do you and HFM collaborate?

In addition to HFM's role as a chapter since 1956, HFM began serving as the federal Regional Core Center for the Great Lakes Region hemophilia treatment center network in the mid 1980's. This network includes Cascade as a covered entity/HTC together with 18 hospital-based or stand-alone treatment centers in Michigan, Ohio, and Indiana. Cascade and HFM work together to determine financial support for the HTCs in our region via 340B program funds, as well as regional support to HFM given administrative and fiduciary responsibilities required by our federal partners.

In addition, Cascade provides funding support to NHF recognized chapters in Ohio, Michigan, and Indiana following annual funding requests for educational programming and activities. Cascade is served by a volunteer board of directors which include individuals appointed by both Cascade and HFM.

Where are you located?

We are located in downtown Ann Arbor, Michigan. We are bursting at the seams in our current location and have recently signed a lease for a new, larger facility on the northside of Ann Arbor. We're moving from a 3,800 square ft. building into a total of 13,000 SQ FT! We hope to be in our new location by year's end and look forward to welcoming everyone for a visit.

What is your service area and who do you serve?

Our service area is restricted to our federal region of Michigan, Indiana, and Ohio. We can provide services to all patients, adults and children, in our region who are also patients of our HTC partners. Cascade manages our own pharmacy program as well as many HTC pharmacy programs.

Do you have any specialty clinics, outreach clinics, or programs that you would like to highlight?

We are very fortunate to be able to support many specialty clinics and outreach programs within our region. We collaborate with and financially support our HTC partners and their valuable educational programs and outreach clinics We are also very proud of the support we provide for Delta Dental Programs via chapters, giving our community access to affordable dental care.

Do you have any new staff members?

Even though the past year has been a challenge, dealing with the COVID pandemic, we have continued to grow and have acquired additional staff. In 2019 we were working with a staff of 14. We have recently increased our team to 22! Our team consists of 5 pharmacists, 3 pharmacy technicians, 2 social workers, 1 registered nurse, a billing team, finance team, and management team. Our most recent addition is a director of public policy, advocacy, and community impact.

What do you see as your biggest strength?

Short answer–our team. Longer answer–everyone we work with, coworkers, local, regional and national colleagues, as well as our patients. We are incredibly fortunate to be located in the Great Lakes Region and to work with all the folks we do. They are dedicated and work tirelessly to improve the care and the lives of the families we serve.

What inspires your staff?

Definitely our families and patients. We all agree that it's truly inspiring and heartwarming to help our patients and HTC partners overcome obstacles in accessing care and resources. The long-time relationships that we've built over the years is extremely gratifying.

Are you Sparty fans or Wolverine fans?

Some at Cascade have definite loyalties. We do have our friendly rivalries. We even have some OSU fans!

Stay tuned for Cascade's new address.
Email: info@cascadehc.org
Phone: 734.996.3300

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NUWIQ®

Antihemophilic Factor
(Recombinant)

www.NUWIQUSA.com

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Factor VIII Complex
(Human)

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Resources for patients & caregivers, support for those navigating care, reliable educational materials, and uplifting community connection.

Factor My Way Assistance

Free trial, co-pay assistance, and real-world insurance know-how for eligible patients.

Factor My Way Connection

Meet experts and join our online support community to help you access resources and build relationships.

Factor My Way Events

Join scheduled live and on-demand digital information programs and events.

Factor My Way Learning

Learn-as-you-go, practical information about bleeding disorders, treatment, and lifestyle management.

Join Today! factormyway.com

For personalized assistance, contact your local Octapharma Representative:

Bri Vieke

Phone | 551.502.7007

E-mail | briana.vieke@octapharma.com

"I have a passion for making a difference. As a Patient Experience Manager at Octapharma, I get to do that every day! I am dedicated to providing education and support for people living with bleeding disorders and their families. I'm proud to work for a company that shares the same mission and commitment to making a difference in the bleeding disorders community."

Date of preparation: 8/2021. NUW-0415-CAD

octapharma

Enhanced Subsidies Could Lower Your **Marketplace Insurance Costs** for 2022

The American Rescue Plan Act (ARPA) of 2021 increases and expands eligibility for Affordable Care Act (ACA) premium subsidies for people enrolled in Marketplace health plans.

This means you may be eligible for more help paying for your 2022 Marketplace coverage. **Average savings under the ARPA subsidies could be $70 per month** for current individual market purchasers.

Individuals and families earning:

- between 100-150% of the federal poverty level (FPL) are eligible for silver health insurance plans with $0 premiums and a significantly lower deductible[1]
- between 150-400% of FPL will get an increase in premium subsidies that they currently receive
- above 400% of FPL (previously ineligible for subsidies due to income) are now eligible for help with their premiums

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1. For information regarding the federal poverty levels, please visit: www.healthcare.gov/glossary/federal-poverty-level-fpl/

Open enrollment for the 2022 Marketplace health plans is open from November 1, 2021 through January 15, 2022 at www.healthcare.gov.

DON'T
automatically
renew!

1. Don't Auto-Renew!

Look at all available Marketplace options. With enhanced subsidies you may find a better deal than your current health plan.

2. Review the Details!

3. Review the plan options to answer the following questions:

- Will it cover your factor product or other necessary treatments?
- What is the deductible? What is the co-insurance or copayment?
  ✓ A plan with a high deductible may not be the best option any longer, as more health plans utilize co-pay accumulator or maximizer programs.
- Does the plan have an accumulator? Will copay assistance count toward your out-of-pocket maximum?
  ✓ This may not be easy to identify when reviewing plans. Ask questions before you make a final decision!

Communicate with Your HTC or Pharmacy Provider!

Share any updates or changes to your health plan with your HTC or pharmacy provider to ensure there will not be a disruption to your current treatment plan.

Questions?

If you have questions about open enrollment, potential subsidies available in 2022, or accumulator or maximizer programs, contact your hemophilia treatment center, Cascade Hemophilia Consortium, or HFM staff. Together, we work to ensure patients have access to the care and information you and your family need to make the most informed decision in your health care.

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734-996-3300

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hfm@hfmich,org
734-544-0015

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A **ONCE-WEEKLY** TREATMENT OPTION FOR HEMOPHILIA B.

HOW DOES THIS FACTOR IN?

To find out about a prescription option, talk to your doctor or visit **OnceWeeklyForHemophiliaB.com**

PP-HEM-USA-1424-01

February 2021

Thank you to these walkers for participating in our walk, and for sharing their photos!
Jacey's Crazies;
Ibrahim & Serene Ahmad;
Lakshmi Narayanaswamy &
Mylan Selveraj

Unite for Bleeding Disorders Walk

Go to **www.hfmich.org/walkvideos** to view messages from community members!

This year's **Unite for Bleeding Disorders Walk** provided more nail biters than anticipated! Would we hit our walk goal? Who will win the GooseChase showdown? Who will win top team? The answers to these questions really came down to the last couple of days, and we must say that when our community members compete, they really compete!

The walk was a virtual event which is always fun as it allows for a bit of creativity with our walk program. Virtual meant that there was no weather to contend with, and no rush to make it to a particular destination by a certain time. Walkers could pour a cup of coffee, kick back, and gather the kids to start off the event.

The best part of our virtual walk is that it allowed us the opportunity to pause and focus on HFM's mission in a meaningful way. This year, we interviewed Office Manager, **Ashley Fritsch**, who told us why the lesser-known medical ID tag program is one of HFM's most important initiatives and can help save lives. By learning more about this program, walkers had a better understanding of the resources and services HFM makes available to the community.

A virtual walk also means that we entertain ourselves in different ways. This year, **Tim Wicks and Carrie McCulloch** were the hosts along with some guest camp counselors from Camp Bold Eagle. Walkers replicated camp stretches thanks to **Angellica "Gelli" Kelley** and had craft time thanks to **Haylee Horn**. Even our local sponsors got in on the stretching action.

We also entertained ourselves leading up to the actual walk event this year by introducing a **GooseChase scavenger hunt**. Walkers were issued 1-2 challenges each day that were mission-driven or fundraising-focused… often with a silly twist. The grand prize that they were trying to win was a membership to their local zoo! Walkers found themselves cramming their bodies into as many t-shirts as possible, doing chalk art, and sharing their stories.

The GooseChase competition was so intense in the last couple of days that a clear winner was not emerging. After quite an effort, **Arianna Lozano** took the grand prize. We did not have the heart to let our second and third-place participants go empty-handed after their valiant efforts, so we were delighted to provide zoo day passes to **Adrienne Jankens & Family and Amy Moon & Family**. Have fun and thank you for the laughs!

Our top team proved to be another down to the wire competition. The **Jankens family** did such an incredible job of fundraising throughout the walk season and are deserving of much gratitude and praise! Little did we know that **Team Tanner** had a surprise from their consistent year-round fundraising efforts and pulled ahead at the last minute to win the top award! Congratulations to them and thank you to both of our teams for showing us all how it is done!

And finally, there was the question of whether we would surpass our $25,000 goal. Yes, indeed! At the end of the day, our walkers showed up for the bleeding disorders community by raising **$29,124**!!! We could not be more grateful to this year's walkers, teams, and donors. **You were there for this community, and together we are going to do some amazing things! Thank you.**

SPECIAL THANKS TO OUR SPONSORS.

National Presenting Sponsors
- Takeda
- The Hemophilia Alliance

National Community Partners
- BioMarin
- Sanofi Genzyme
- Pfizer

National Partners
- AscellaHealth
- Bayer
- Grifols
- Optum

Unite National Virtual Partners
- Spark Therapeutics
- uniQure
- BPL Bio Products Laboratory

HFM Local Walk Sponsors
- CSL Behring
- Genentech
- novo nordisk

HFM does not endorse any specific product or company.

2022 Events

www.hfmich.org/events

All in-person events are tentative. Please see our explanation (below, right) of how we'll be making decisions for in-person events.

HFM's Ruby Connection Virtual
January 25; Feb 22; March 22; April 26; May 24; June 28; Sept 27; Oct 25; Nov 22; Dec 13

March 11-13
Teen Retreat

March 22-23
Lansing Days

April 23-24
SpringFest

May
Women's Retreat

June TBA Virtual
VWD Education Day & Symposium

June 3 and 4
Community Night Craig's Cruisers
Grand Rapids

June 11-17
Eagle Quest

June 24 Virtual
Community Night Toledo Zoo

June 26-July 2
Teen Camp

July 4-23
Camp Bold Eagle CIT Program

July 10-14
Camp Bold Eagle Session 1

July 16-22
Camp Bold Eagle Session 2

August 2-10
Eagle Expedition

August 7-13
Eagle Outpost

August 19 Virtual
Community Night "Let's Talk Lunch"

September 9-11
Camp Old Beagle

October 7-9
National Conference for Women and Teens with Hemophilia and Rare Factor Deficiencies

November 11
Community Night Incredible Mo's
Traverse City

Fall 2022
Unite Walks

November 4-6
Bleeder and a Buddy

December 17
Camp Holiday Party

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734. 544.0015
www.hfmich.org
1921 West Michigan Ave.
Ypsilanti, Michigan 48197

HFM's 2022 Event Policy

Please be advised that HFM will be making final decisions on whether events will be hosted in-person or virtually closer to each event date. Decisions will be guided by the data and health statistics available at the time as well as guidance provided by the CDC, bleeding disorders community medical professionals, and the state of Michigan. While we hope to see you all in-person, the health and safety of our community is our highest priority.

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