hfm©

THE ARTERY

SPRING/SUMMER 2022

THIS ISSUE

HFMICH.ORG • SERVING THE BLEEDING DISORDERS COMMUNITY

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MUCH HAS CHANGED IN OUR LIVES AND THOUGH IT HAS BEEN CHALLENGING, IT ACTUALLY SEEMS THAT SOME CHANGES HAVE CREATED OPPORTUNITIES TO CLEARLY CONSIDER HOW WE BEST MOVE FORWARD WITH EDUCATION AND SERVICES.

WE ARE HERE FOR YOU

Dear HFM friends and family,

We anticipate the days, weeks, and months ahead will bring incremental change and transition as we navigate moving forward with the challenges, issues, and opportunities that affect our lives in Michigan, across our region, country, and world.

Please know that the health and safety of our community remains HFM's top priority. We have reinitiated in-person programs and events with specific protocols. We will continue many virtual educational and community activities since we've discovered many appreciate this kind of engagement and find it easily accessible. We are also exploring the feasibility of hybrid programming that is viable and effective.

I understand there are numerous transitions we will want to consider in determining how to best meet the programming interests and needs of our bleeding disorders community. Much has changed in our lives and though it has been challenging, it actually seems that some changes have created opportunities to clearly consider how we best move forward with education and services.

As this newsletter demonstrates, we have kept *The Artery* and its traditions, while transitioning some of its style and approach. In this issue you'll 'meet' new staff and bid farewell to two others. We've spotlighted HFM's 2021 community needs assessment; HFM's staff team, community members, medical professionals, and board of directors are taking the assessment's information to heart as we build HFM's future. Be assured we will continue to request your input and engagement.

As we look toward amazing possibilities with continued development and improved treatment for all affected by bleeding disorders, many transitions continue in our community. We have lost and gained friends and loved ones, welcomed new medical providers, newborns and adults have been diagnosed with bleeding disorders – and together we press on in support and care for one another.

With gratitude and love,

Susan Fenters Lerch
HFM Executive Director
Regional Director, Great Lakes Federal HTC Network

IN THIS ISSUE

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PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER

WITH SINCERE GRATITUDE

THANK YOU TO OUR INDIVIDUAL FINANCIAL DONORS. THIS LIST REPRESENTS CONTRIBUTIONS RECORDED FROM JANUARY 1, 2021 THROUGH DECEMBER 31, 2021 OUTSIDE OF PROGRAM OR REGISTRATION FEES. HFM IS GRATEFUL TO OUR MANY SUPPORTERS WHO MAKE OUR COMMUNITY PROGRAMS AND SERVICES AVAILABLE. WE WOULD LIKE TO ACKNOWLEDGE THE FOLLOWING INDIVIDUALS AND FAMILIES WHO SUPPORTED OUR EFFORTS THROUGHOUT THE 2021 CALENDAR YEAR. PLEASE CONSIDER MAKING A DONATION TO HFM IN 2022. YOUR SUPPORT TRULY MAKES A DIFFERENCE.

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UP TO $100

Not listed are the many individual supporters who donated less than $100 or those foundations and companies who also support the work of HFM. Thank you for your generosity; every gift makes a difference.

THE HEMOPHILIA COMMUNITY LOST A NATIONAL LEADER WITH THE SUDDEN PASSING OF VAL BIAS, NHF'S FORMER CEO, ON DECEMBER 30, 2021. VAL WAS A LIFE-LONG ADVOCATE LIVING WITH HEMOPHILIA AND HIV. HE CARED DEEPLY ABOUT AFFECTING CHANGE AND SERVED THE COMMUNITY WITH COURAGE AND PASSION. VAL INITIATED NHF'S WASHINGTON DAYS ADVOCACY EFFORTS AND WAS INTEGRALLY INVOLVED WITH EFFORTS THAT RESULTED IN THE FEDERAL RICKY RAY RELIEF ACT. HE LEFT BEHIND HIS BELOVED WIFE, ROBIN, AND SON, LANGSTON.

Please accept our apologies for any errors or omissions.
Please contact Carrie McCulloch at ***cmcculloch@hfmich.org*** *or at* ***734-544-0015*** *to correct our records.*

COMMUNITY MEMBER FEATURE

JENNIFER TEPER

HOW DID YOU FIRST HEAR ABOUT HFM'S PROGRAMS AND EVENTS?

My hematologist first told me about HFM probably 18 years ago. She said I could get a medical alert bracelet and that HFM was the closest and best organization to support my bleeding disorder, which is not hemophilia, but a platelet issue.
I did order the bracelet but didn't do anything else.

WHEN OTHERS WERE FEELING LESS ENGAGED DURING THE PANDEMIC, YOU DECIDED TO GET INVOLVED. WHAT INTERESTED YOU IN HFM'S ONLINE OFFERINGS?

I was aware of HFM programming, but I was always apprehensive about attending in person events that were far away from my home since I don't have hemophilia and didn't know anyone. The online programming afforded me the opportunity to participate in the comfort of my home and start to see what HFM was all about. HFM had a wide range of online programs, ranging from education about treatment and research to emotional support and mental wellness. During the pandemic, I know I needed and welcomed all of those kinds of programs, so I started logging on.

WHAT WAS YOUR FIRST EVENT WITH HFM?

It was a dinner talk. I found the dinner talk topics to be informative and enjoyable and good way to start, being that they were only an hour long.

YOU HAVE SINCE JOINED HFM AT MANY OF OUR EVENTS AND PROGRAMS. WHAT HAS KEPT YOU SO INVOLVED IN THE COMMUNITY?

Once I started attending the dinner talks, I became more aware of other programming, and registered and attended the Women's Retreat, which I found to be enriching and entertaining. The attendees were a very supportive and welcoming group of women.

Then things really took off for me. I continued attending the Dinner Talks, then the Ruby Connection women only events and SpringFest. With my event participation I was getting informed on HFM's advocacy efforts, and the copay accumulator adjuster issue really hit home. I have participated in NHF Washington Days twice and was excited to attend HFM Lansing Days, as my first in-person event with the foundation.

HOW WAS YOUR FIRST IN-PERSON EXPERIENCE AT HFM'S LANSING DAYS?

In a word, FABULOUS! Although I had "met" several HFM staff members digitally via Zoom, I was blown away by the friendliness of the HFM community members and how welcoming they, along with the HFM staff and sponsors were.

The advocacy initiatives are so important. Participating in the advocacy efforts is a purposeful initiative to help not only HFM community members, but all patients with rare and chronic conditions who rely on high-cost medications.

HFM not only gave me programs to look forward to and participate in during the pandemic, but the advocacy initiatives gave me opportunities to participate in something meaningful and purposeful to help the community as a whole. 💧

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78

COMMUNITY ADVOCATES ATTENDED HFM'S ADVOCACY WEBINAR SERIES

10

STATE LEGISLATORS' OFFICES VISITED ON COPAY ACCUMULATOR REFORM

182

COMMUNITY MEMBERS ATTENDED 21 GATHERINGS FOR SOCIAL SUPPORT AND CONNECTION VIA THE MEN'S GROUP AND RUBY CONNECTION

206

COMMUNITY MEMBERS PARTICIPATED IN 11 DINNER TALK PROGRAMS HELD BY HFM AND OUR INDUSTRY PARTNERS

IN 2021, HFM WAS ABLE TO SERVE THE COMMUNITY IN SO MANY WAYS THROUGH OUTREACH, EDUCATION, SUPPORT, AND CELEBRATION. AND IT IS BECAUSE OF YOU, OUR DONORS AND COMMUNITY MEMBERS, THAT WE WERE ABLE TO PROVIDE THE FOLLOWING VIRTUAL EVENTS AND PROGRAMS. THANK YOU! 💧

180

ADULTS AND KIDS PARTICIPATED IN OUR FUN AND INFORMATIVE COMMUNITY NIGHTS

300

COMMUNITY MEMBERS ATTENDED SPRINGFEST – ONE OF THE LARGEST BLEEDING DISORDERS GATHERINGS IN THE COUNTRY

147

INDIVIDUALS ENROLLED IN THE DENTAL INSURANCE PROGRAM

280

COMMUNITY MEMBERS ATTENDED OUR WOMEN'S CONFERENCE

110

PEOPLE ATTENDED OUR FIRST VIRTUAL VON WILLEBRAND SYMPOSIUM

84

WOMEN ATTENDED OUR WOMEN'S RETREAT

25

COMMUNITY MEMBERS ATTENDED EACH DAY OF OUR UP RETREAT

247

COMMUNITY MEMBERS WERE PROVIDED FINANCIAL ASSISTANCE TO MEET EMERGENCY NEEDS INCLUDING HOUSING, UTILITIES, FOOD, TRANSPORTATION, AND MORE

2021 YEAR BY THE NUMBERS

856

COMMUNITY MEMBERS RECEIVED MEDICAL TAGS

71

KIDS WITH 18 CAMP STAFF PARTICIPATED IN AN IMMERSIVE CAMP BOLD EAGLE AT HOME EXPERIENCE

ORAL FACIAL PIERCINGS CAN HAVE DETRIMENTAL EFFECTS ON YOUR TEETH

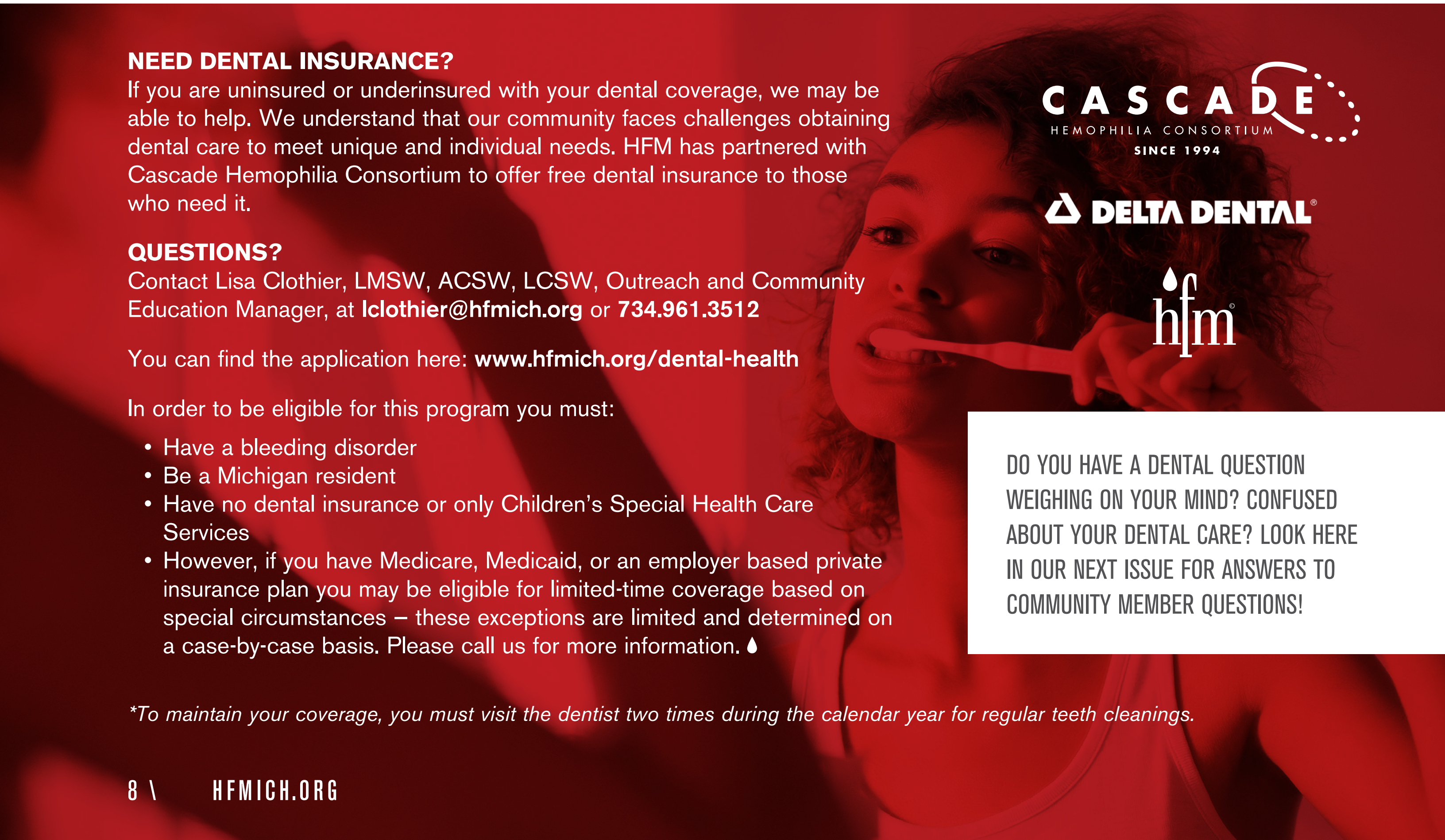
JENNIFER KERNS, BS, RDH

Barbells, rings, or posts, whether in your tongue, lip, or cheek, can all cause trauma to the teeth. Tiny fractures called craze lines begin microscopically when the tooth comes into contact with the jewelry. These craze lines get worse over time until eventually, when two of them meet, a piece of tooth breaks off. After lightly plinking the jewelry against the teeth while you sleep, eat, and speak, biting forces add to the destruction and make the perfect scenario for chipping away portions of your teeth. Unfortunately, the damage is permanent and cannot be undone. Jewelry made of Bioplast acrylic or coated in silicone are less traumatic but can still cause damage. See your dental professional to check for any small fractures that might be forming before it's too late.

Jennifer Kerns, BS, RDH is a practicing clinician, continuing education provider, and grant writer. She is the dental hygienist for the Thomas Judd Care Center as well as the Northern Regional Bleeding Disorder Center at Munson Healthcare, and she often consults for various national and community projects. Jennifer is also the dental outreach coordinator for Northwest Michigan Health Services in Traverse City, where she oversees dental students as an adjunct clinical faculty member for the University of Michigan, providing free dental care to veterans.

Contact Jennifer
231-721-5337
jkerns@nmhsi.org

WELCOME TO TOOTH TIME!



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.

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

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

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.

DO YOU HAVE A DENTAL QUESTION WEIGHING ON YOUR MIND? CONFUSED ABOUT YOUR DENTAL CARE? LOOK HERE IN OUR NEXT ISSUE FOR ANSWERS TO COMMUNITY MEMBER QUESTIONS!

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

DENTAL PROCEDURE OUTCOMES IN PERSONS WITH HEMOPHILIA IN THE ERA OF PROPHYLAXIS

WRITTEN IN COLLABORATION WITH HEATHER MESSENGER, MSDH AND ROSHNI KULKARNI, MD, MICHIGAN STATE UNIVERSITY CENTER FOR BLEEDING AND CLOTTING DISORDERS

Oral healthcare is an important part of overall care for people with hemophilia. In fact, dental extraction (DE) is one of the most common procedures in people with hemophilia A or hemophilia B. Unfortunately, there is no standard way to treat people with hemophilia undergoing dental extraction and little is known about the impact of the type of hemophilia and hemostatic therapies on bleeding outcomes following DE.

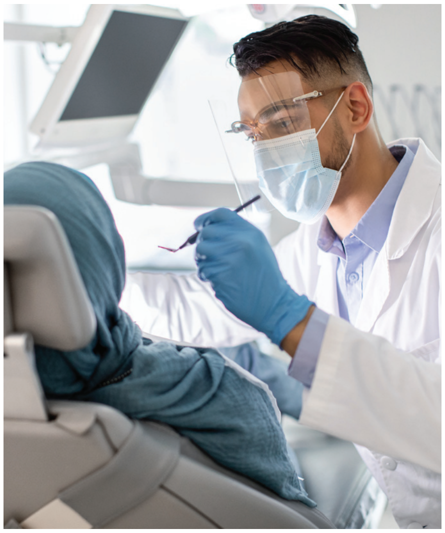
The Michigan State University Center for Bleeding and Clotting Disorders (MSU CBCD) was interested in gaining a better understanding of the relationships between people with hemophilia and dental procedure outcomes to aid in the prevention of complications and management of dental patients with severe hemophilia.

Heather Messenger, dental hygienist with the MSU CBCD comprehensive care team, was awarded the American Thrombosis and Hemostasis Network (ATHN) Care Grant to conduct the largest study of dental extraction outcomes in people with hemophilia using a national database termed the ATHN dataset.

Heather was able to look for patterns in prophylactic factor use and its impact on bleeding outcomes following dental extraction in 19,048 people with hemophilia who visited one of the 134 ATHN affiliated sites between 2013 and 2019. 1157 people had 1301 episodes of dental extraction. Most (74.9%) were affected by hemophilia A and 94.4% were male. The researchers hypothesized that patients treating prophylactically would experience less bleeding than those treating on demand. However, the findings didn't show a significant difference between prophylaxis and on-demand treatment in bleeding outcomes.

The study, however, did find that the use of ANY treatment for bleeding, such as Amicar, factor therapies, etc., was associated with less bleeding.

The best way to support your overall dental health is to partner with your hemophilia treatment center comprehensive care team and other health care professionals to develop a treatment plan when having any dental procedure. Good dental care can lead to better health outcomes and quality of life. Participation in the ATHN dataset at your HTC supports research that ultimately improves patient care. 🩸



WE ASKED. YOU ANSWERED.

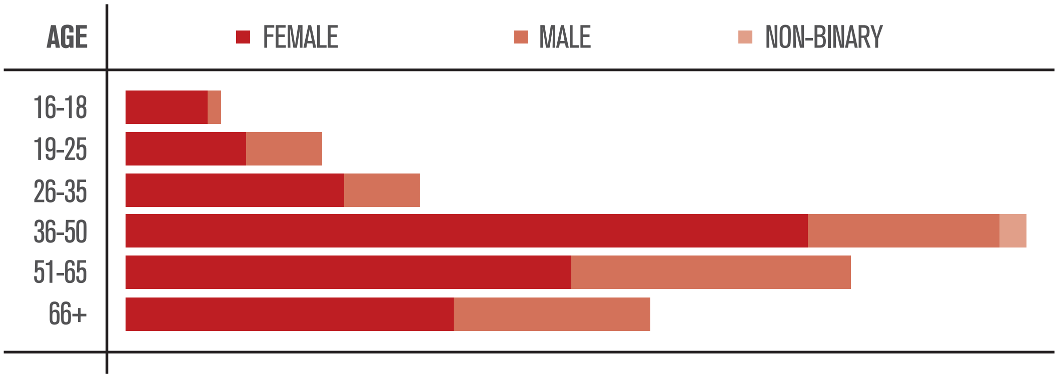
2021 HFM COMMUNITY NEEDS ASSESSMENT

In October 2021, HFM shared a community needs assessment with the Michigan bleeding disorders community to receive feedback on current HFM programs and services and to gain an understanding of the evolving needs of the community.

Paper copies of the survey were mailed to each household on our mailing list and the survey was made available electronically via hfmich.org. We received 116 electronic responses and 142 mailed in surveys for a total of 258 responses.

Thank you to those of you who shared your voices with us! Your responses will help HFM plan future programs and services that best meet the needs of the community.

DEMOGRAPHICS OF COMMUNITY MEMBERS WHO RESPONDED TO THE SURVEY



VIRTUAL PROGRAMMING

Community members were asked about a variety of online events hosted by HFM between the fall of 2020 and the fall of 2021 including SpringFest, the Women's Retreat, Community Nights, Dinner Talks, and more.

While we know that many in the community are eager to come together in person again, virtual programming has offered several unique advantages including expanded access to programming for individuals where location or transportation can be a barrier to participation.

SURVEY RESPONDENTS FROM 28 COUNTIES ACROSS THE STATE WERE ABLE TO PARTICIPATE IN HFM ONLINE PROGRAMMING!

ALLEGAN
BAY
CLINTON
GENESEE
GRAND TRAVERSE
HOUGHTON
INGHAM
IONIA
KALAMAZOO
KENT
LENAWEE
LIVINGSTON
MACOMB
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MECOSTA
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MONTCALM
MUSKEGON
NEWAYGO
OAKLAND
OCEANA
OTSEGO
OTTAWA
ROSCOMMON
SHIAWASSEE
WASHTENAW
WAYNE

COMMON TOPICS COMMUNITY MEMBERS EXPRESSED AN INTEREST IN LEARNING ABOUT:

AGING
VWD
RARE BLEEDING DISORDERS
GENE THERAPY
MENTAL HEALTH
INSURANCE BENEFITS
INTRODUCTION FOR NEWLY DIAGNOSED

COMMUNICATIONS

HFM's work to provide programs, services, and support to Michigan residents with bleeding disorders relies on the ability to effectively communicate with you. Two of HFM's largest means of sharing information with the community are the Artery newsletter and HFM's website, hfmich.org.

94% of respondents feel the Artery contains valuable information.

Of those of you who have visited the HFM website, **95%** found information that answered your questions about HFM services and programs.

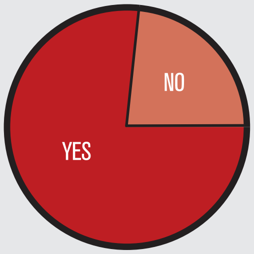
We were pleased that **97%** feel that they and their family have access to educational information about bleeding disorders including treatment, diagnosis, and care through HFM programming and communications.

> "I WHOLEHEARTEDLY THANK HFM FOR ALL THEIR ACTIVITIES IN GENERAL, AND ESPECIALLY DURING COVID RESTRICTIONS. LOOKING FORWARD TO MORE EXCITING IN-PERSON EVENTS!"

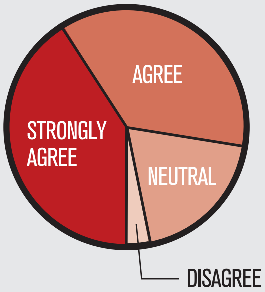
ADVOCACY

One of HFM's priorities is to advocate for the needs of the bleeding disorders community and to inform and empower community members to be their own best advocate.

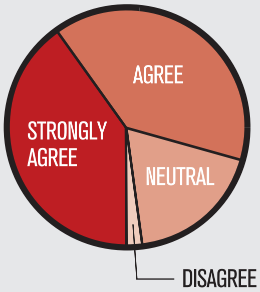
DO YOU KNOW THAT HFM ADVOCATES FOR THE INTERESTS OF THE BLEEDING DISORDERS COMMUNITY TO STATE OFFICIALS, REGULATORY AGENCIES, MANUFACTURERS, AND PAYERS?



I FEEL REPRESENTED BY HFM ADVOCACY EFFORTS TO STATE LEGISLATORS AND LOCAL DECISION-MAKERS.



BASED ON THE INFORMATION AND SKILLS I'VE LEARNED FROM HFM'S EDUCATIONAL PROGRAMMING, I CAN ADEQUATELY ADVOCATE FOR MYSELF AND/OR MY FAMILY MEMBERS WITH OUR MEDICAL TEAM SO WE RECEIVE QUALITY CARE.



COMMUNITY NIGHT:

THANKSGIVING LEFTOVERS

Our November Community Night could be described as warm, cozy, fun, and delicious! It was truly a night of good cheer and learning as the group enjoyed a Thanksgiving leftover recipe demonstration from Chef Mike Hargett following an educational program focused on updated guidelines and the "My Plate" Healthy Eating Plan. We learned the value of layering flavors, the difference between stock and broth, and shared more than enough soup puns as we watched Chef Mike create his "Creamy Dreamy Turkey and Wild Rice Bisque." Yes, it was soup-erb! There was a lot of discussion about our favorite Thanksgiving recipes and Novo Nordisk rep, Michelle Cecil, was nice enough to share her Grandma's Caramel Pie recipe after many requests from the group. This event really was the perfect way to conclude our 2021 Community Nights. It was relaxed, educational, fun, and full of good chatter. Most importantly it was full of connection. Thank you to the more than 180 community members who joined our Community Nights in 2021! We hope that you will join us again in 2022 both virtually and in-person! 🩸

THANK YOU TO OUR SPONSOR

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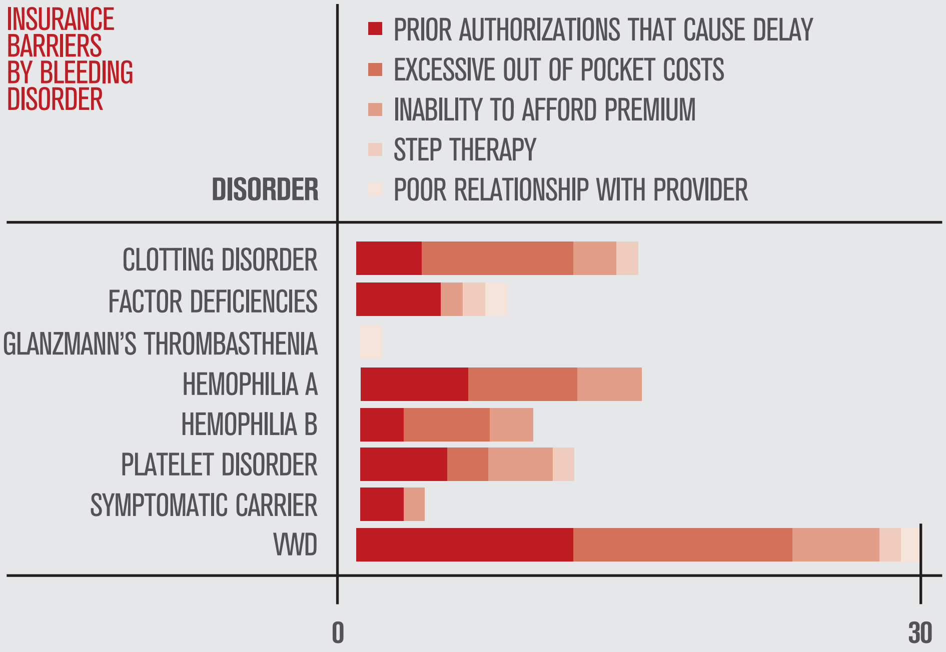
The majority of community respondents feel comfortable advocating for themselves, yet **64%** of our respondents have not participated in any HFM advocacy action requests, such as emailing representatives or signing a petition. If just a few more community members responded to action requests, our community's impact would be even greater.

Community respondents shared the challenges getting in the way of accessing quality healthcare. Your responses help direct HFM's advocacy efforts.



2021 YEAR END GATHERING

The 2021 Year End Gathering celebrated the kids of HFM's community and all things animals – the perfect combination! We started by meeting our sponsors' pets which ranged from a flock of parakeets to cats, dogs, and a fish. Then it was time to learn about Santa's favorite animal sidekicks: reindeer. (Did you know that reindeer and caribou are really the same thing?) From there, the kids had fun designing their own reindeer to add to Santa's fleet. These reindeer had superpowers, outfits, and unique personalities.

Santa Antonio joined us once again this year and met with each family alongside Gelli the Elf! While the families each took a turn with Santa, we hosted some special guests: staff and animals from the Toledo Zoo. We met a tortoise, a chinchilla, a bearded dragon, and even a skunk named Stinkerbell! The Zoo staff answered all of our questions and really took the time to make our time together special.

We ended our gathering by sharing our own pets. Many furry pals graced the camera! Camp Director Tim Wicks even shared his adorable dog Winnie with the group. Unbeknownst to the kids, Winnie would play an important role in the surprise gift that would be heading their way.

Each child who attended the gathering received a package in the mail that included their very own stuffed Winnie complete with a custom dog tag, birth certificate, and letter that included Winnie facts and a promise to see all of the campers at Camp Bold Eagle this summer! Winnie also came bearing Scooby Snack cookies and Hot Cocoa. What a good dog!

Thank you to all of the families that joined us and to our sponsors for partnering with us to provide such a fun morning!

THANK YOU TO OUR SPONSORS

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DEDICATION AND PERSONAL SUPPORT

RARE DISEASE
PATIENT AFFAIRS

Introducing your Pfizer Patient Affairs Liaison, a professional dedicated to serving the rare disease community by connecting patients, caregivers, and patient advocacy organizations with Pfizer Rare Disease tools and resources. A Patient Affairs Liaison's work is guided by the principles of **compassion**, **commitment**, and **connection**.

Chris Liddell

Southern OH, MI, KY, IN

I'm here to:

- **Provide compassion by understanding** the needs of patients, caregivers, and patient advocacy organizations and serving as a point of contact for questions they may have
- **Maintain commitment by educating patients and caregivers** about Pfizer Rare Disease patient support resources
- **Facilitate connection by providing educational programs** that bring patients, caregivers, and patient advocacy organizations together to share experiences and support advocacy for their communities

> *"I've worked in rare disease for 15 years, and I have experience collaborating with and advocating for different members of this community."*

To get in touch with Chris:

☎ 248-660-7384

✉ chris.liddell@pfizer.com

Pfizer Rare Disease

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For additional information please contact:
Lauren Hecht MA, LLP
Senior Manager Coagulation Products
248-310-0202
Lauren.Hecht@CSLBehring.com

PAID CONSUMER OUTREACH

GET TO KNOW YOUR INSURANCE

(SO THAT IT WORKS THE BEST FOR YOU!)

Last December, HFM was joined by the Cascade Hemophilia Consortium for the advocacy webinar Get to Know Your Insurance (So That It Works the Best for You!). A special thank you to our speakers Colleen Joiner, LMSW, Stephanie Sibrel RN, and Debbie Whelan, LMSW for volunteering their time to make sure members of the bleeding disorders community understand and feel comfortable working with their insurance plans.

It's not too late to get to know your insurance plan!

View Cascade's full insurance newsletter here:
www.hfmich.org/chc_insuranceguide

Missed the webinar? Watch the recording here:
www.hfmich.org/advocacydec16

HFM is grateful to our advocacy webinar sponsors for supporting these valuable programming opportunities. ♦

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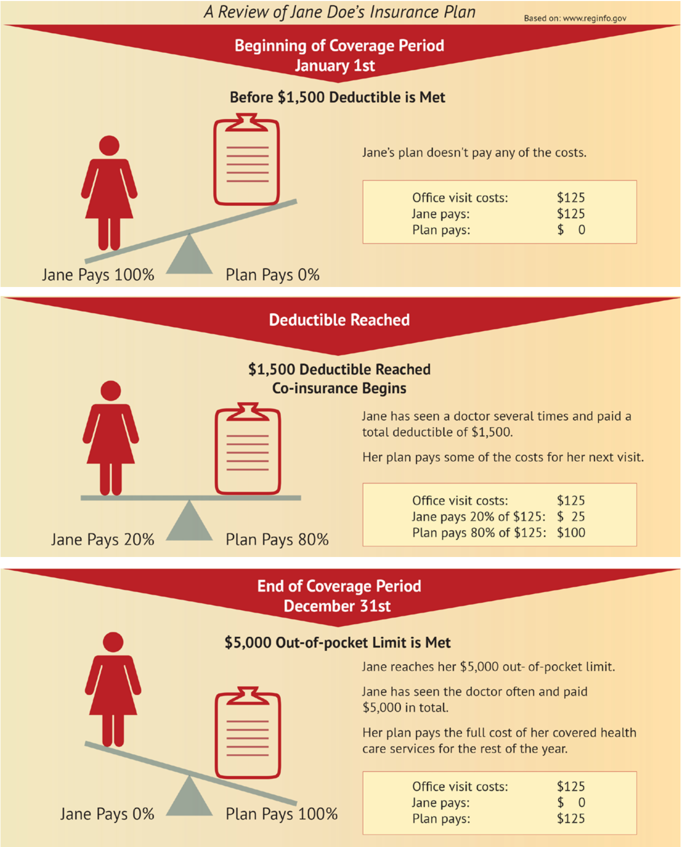
HOW YOU AND YOUR INSURER SHARE COSTS:



A Review of Jane Doe's Insurance Plan

Based on: www.reginfo.gov

Beginning of Coverage Period
January 1st

Before $1,500 Deductible is Met

Jane's plan doesn't pay any of the costs.

Office visit costs:	$125
Jane pays:	$125
Plan pays:	$ 0

Deductible Reached

$1,500 Deductible Reached
Co-insurance Begins

Jane has seen a doctor several times and paid a total deductible of $1,500.

Her plan pays some of the costs for her next visit.

Office visit costs:	$125
Jane pays 20% of $125:	$ 25
Plan pays 80% of $125:	$100

End of Coverage Period
December 31st

$5,000 Out-of-pocket Limit is Met

Jane reaches her $5,000 out- of-pocket limit.

Jane has seen the doctor often and paid $5,000 in total.

Her plan pays the full cost of her covered health care services for the rest of the year.

Office visit costs:	$125
Jane pays:	$ 0
Plan pays:	$125

INSURANCE CHECKLIST

UNDERSTAND YOUR INSURANCE

- ☑ Does your insurance require a primary care physician (PCP) and referrals to specialists? If so, have you seen your PCP?
- ☑ Does your insurance cover your factor product and/or medication? Is your factor covered by the medical or pharmacy benefit?
- ☑ Many insurances cover preventative health services such as annual physicals, flu shots, and women's health, free of charge. Does yours?

WHAT ARE YOUR OUT-OF-POCKET COSTS? DO YOU NEED HELP PAYING THEM?

- ☑ Review your deductible, co-insurance, and co-pay costs. Can you afford them?
- ☑ Do you have an out-of-pocket maximum? Do the deductibles, co-insurance, and co-pays count toward your maximum out-of-pocket costs?
- ☑ Have you explored state programs such as BCMH (Ohio) or Children's Special Health Care Services (Michigan) to help with extra bleeding disorder expenses?
- ☑ Have you explored the Manufacturer's Co-pay Assistance Programs to help cover factor costs? (No income guideline required.)
- ☑ If you have Medicare, have you explored assistance with costs? Ask your HTC social worker or Cascade care manager if you quality.

KNOW YOUR NETWORK! (PROVIDERS APPROVED BY YOUR INSURANCE COMPANY)

- ☑ Are all of your providers in your insurance network? (Primary Care, HTC, Specialty Pharmacy, Home-Care)
- ☑ Are you able to go outside of the network? If so, at what cost?

MULTIPLE INSURANCE PLANS? COORDINATE YOUR BENEFITS. IT'S THE LAW!

- ☑ Call all of your insurance plans and tell them about all other plans, as they will eventually find out about each other and deny your claims. Nobody wants a big bill coming back at you!
- ☑ Tell all of your health care providers about all of your insurance plans! There are rules about which plan is primary. Not following those rules could mean that you will be responsible for payment.
- ☑ Understand that Children's Special Health Care, BCMH or Medicaid are always the payer of last resort, when you have two or more plans.

IS YOUR INSURANCE CHANGING? CALL YOUR HOMECARE COMPANY OR PHARMACY IF YOU HAVE INSURANCE CHANGES.

CASCADE
HEMOPHILIA CONSORTIUM
SINCE 1994

MAKING TIME FOR YOUR MENTAL HEALTH

STEVE EDWARDS, LMSW
MICHIGAN STATE UNIVERSITY CENTER FOR BLEEDING AND CLOTTING DISORDERS

As the pandemic continues to impact our daily lives, our natural and learned resilience continues to be tested. We find ourselves increasingly frustrated and down. As these feelings get worse, there are some days where it may feel easier to do nothing. And when we do nothing, we feel worse! Fortunately, there are proven strategies that can help all of us who are struggling.

Behavioral activation is one of these approaches. Adapted from cognitive behavioral therapy, behavioral activation involves scheduling activities to improve one's mood. When we're feeling down, we often have the thought of, "If I felt better, I could do more activities." Behavioral activation takes a different approach and says, "I'll feel better when I do more activities." In the beginning, this can involve evaluating your day and making a small change initially. Is there a time of day when you are mindlessly watching TV? Schedule this time to call a friend, go for a walk, or redecorate a room. Writing out your schedule will help you identify some areas to make small but rewarding changes. These small changes will yield big payoffs!

While the pandemic is restrictive, it can be an opportunity to think outside of the box. Do you like going to the movies, but don't want to go to the theater? Schedule a movie watch party with your friends over Zoom. Is there a skill that you have always wanted to learn, like cooking or drawing? Consider online videos and lessons. You can find several free resources on YouTube and other video sites, or you can find several reasonably priced subscription services. And if you need additional materials, you can have almost anything safely delivered to your home. Get creative!

If you need additional mental health resources, please reach out to your hemophilia treatment center social worker. If you are experiencing a crisis, please dial 911 or go to your nearest emergency room.

NUWIQ®

Antihemophilic Factor
(Recombinant)

www.NUWIQUSA.com

wilate®

von Willebrand
Factor/Coagulation
Factor VIII Complex
(Human)

www.wilateusa.com

factor my way™

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."

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

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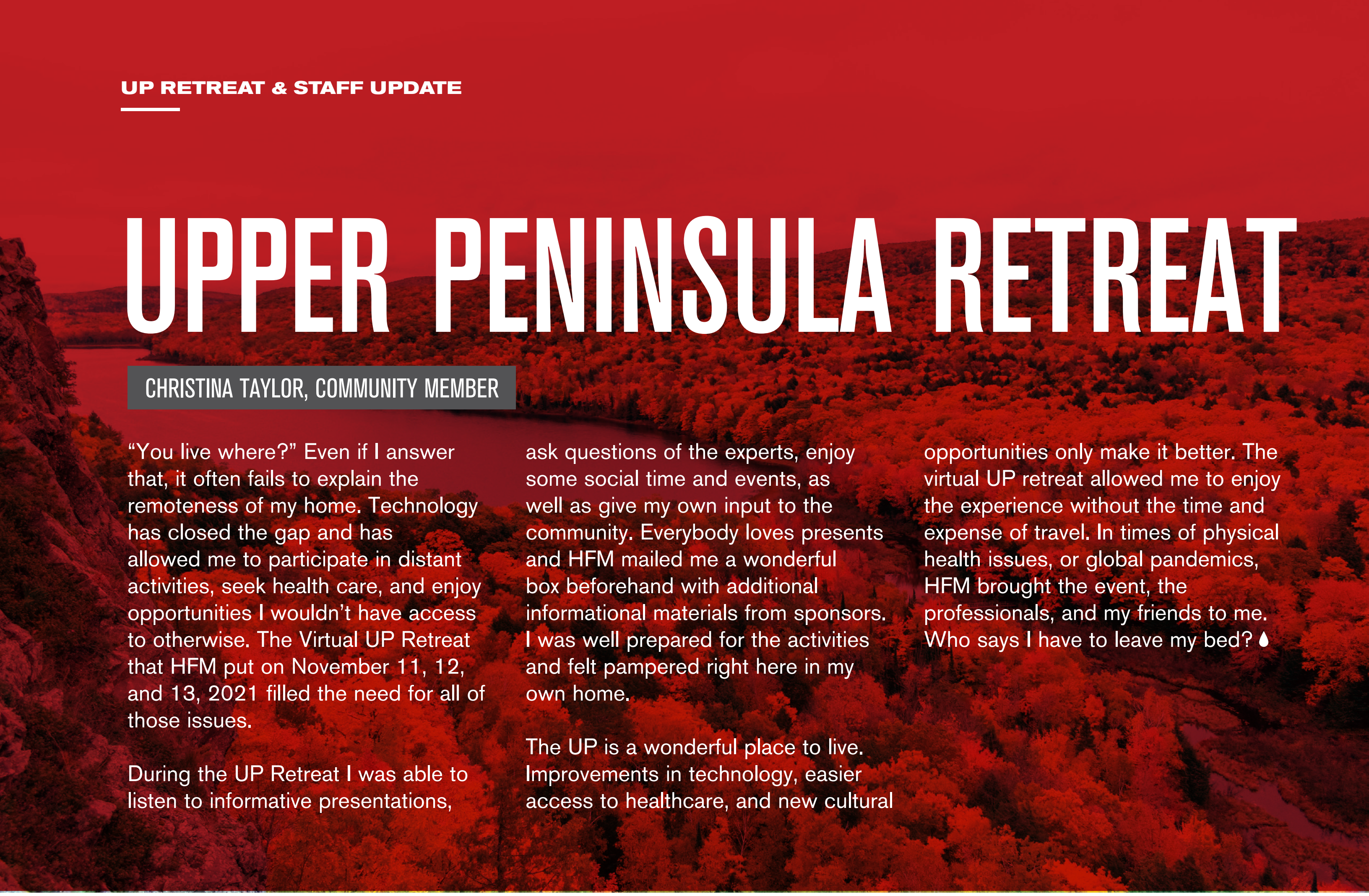
octapharma



UPPER PENINSULA RETREAT

CHRISTINA TAYLOR, COMMUNITY MEMBER

"You live where?" Even if I answer that, it often fails to explain the remoteness of my home. Technology has closed the gap and has allowed me to participate in distant activities, seek health care, and enjoy opportunities I wouldn't have access to otherwise. The Virtual UP Retreat that HFM put on November 11, 12, and 13, 2021 filled the need for all of those issues.

During the UP Retreat I was able to listen to informative presentations, ask questions of the experts, enjoy some social time and events, as well as give my own input to the community. Everybody loves presents and HFM mailed me a wonderful box beforehand with additional informational materials from sponsors. I was well prepared for the activities and felt pampered right here in my own home.

The UP is a wonderful place to live. Improvements in technology, easier access to healthcare, and new cultural opportunities only make it better. The virtual UP retreat allowed me to enjoy the experience without the time and expense of travel. In times of physical health issues, or global pandemics, HFM brought the event, the professionals, and my friends to me. Who says I have to leave my bed?

TOGETHER WE CAN:

EDUCATION AND CONNECTION AT THE UPPER PENINSULA VIRTUAL RETREAT

JILL FOLEY RDH, RN, BSN

It was an honor to be a part of the 2021 Adult Patient & Family Upper Peninsula Virtual Retreat. This retreat is a wonderful collaboration between HFM and the MSU Center for Bleeding and Clotting Disorders to provide education and open communication with our Upper Peninsula patients. Working with the HFM staff was wonderful and I learned a great deal in planning and presenting this retreat.

Our outreach clinics are a unique way that MSU Center for Bleeding and Clotting Disorders staff can travel to serve our rural areas providing patient specialty care, education, and support to rural providers. With the help from HFM, the Upper Peninsula Retreat is an additional way for us to reach out to that community and discuss issues and concerns that are present when living with a bleeding disorder. Due to the pandemic, we met virtually over three days, providing educational information and inviting questions and good conversation.

Our MSU team believes that increased knowledge about our health and wellbeing creates an atmosphere of trust and compliance, resulting in optimum healthcare outcomes and quality of life. And with the help from HFM, this retreat provided an opportunity for healthcare providers to join with patients in the UP community to discuss the struggles, challenges, and successes of living with a bleeding disorder. I would like to thank HFM, the health care presenters, and the patients for the time and effort spent making this retreat a success. Together we can continue to achieve healthcare goals while building trust as we serve those living with a bleeding disorder. GO HFM and GO GREEN!

HAPPY CAMPER SPONSOR:

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UP RETREAT SPONSORS:

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STAFF UPDATES

MEGHAN MAIR CROSSLIN

Prior to joining HFM this year as the marketing and communications director, Meghan built her career managing communications, special events, fundraising initiatives, and digital asset creation with nonprofit organizations. More recently, she expanded her career to include corporate clients as well as nonprofit organizations. Meghan contracted with HFM on various projects over the past five years, and we are delighted she has now joined our staff.

Meghan has an appreciation for well-designed spaces and unique eye wear selections. A perfect day includes delicious local food, soulful vinyl, and time spent with her husband, Dave, and daughter, Leela – and of course, thinking of meaningful, creative communication opportunities to support Michigan's bleeding disorders community!

ALYSSA SILLETTI

Alyssa's passion for building community and supporting others led her to pursue her MSW from the University of Michigan. She has since worked in a multitude of nonprofits serving individuals from diverse backgrounds. Alyssa has worked in higher education, early childhood care, suicide prevention for Native youth, and most recently in a mentorship program for youth who've experienced foster care. She is passionate about advocacy and creating inclusive spaces that allow individuals to show up as their most authentic self. Alyssa enjoys investing in her personal wellness by being in the kitchen, reading, doing yoga, and organizing. She is excited for the opportunity to join the HFM community as the new program services manager!

FAREWELL TO BELOVED HFM COLLEAGUES

ROBIN WHITFIELD

In 2014 HFM's branded materials transformed thanks to Robin Whitfield's tremendous graphic design talent, writing, and communication skills. Robin beautified our print and online materials, always with the bleeding disorders community close to her heart and top of mind. We have such gratitude for her commitment to HFM's community these last seven years – including her generous support as a HFM Lifetime Member. We wish Robin absolute joy as she embarks on a journey to explore all that life has to offer!

ASHLEY FRITSCH

Since 2016, Ashley Fritsch worked tirelessly to assure HFM community members were well cared for. From medical ID tags and dental coverage, to being the friendly and familiar voice that answered HFM's phones, Ashley served as the detail-oriented and creative voice behind many HFM initiatives. We know many community members love her as much as we do. Ashley's work ethic extended beyond her fulltime position to recently achieving a master's degree. She is now utilizing her skills in the for-profit world, though she has promised to volunteer with us from time-to-time! We know the bleeding disorders community joins us in thanking Ashley for her dedication and is cheering her on in this new adventure.

WE WISH BOTH ROBIN AND ASHLEY THE VERY BEST!!

Many thanks to Laura Olson who has adjusted her role with HFM and has taken over many of Ashley's responsibilities. You will always have a friendly person to speak with when you reach out to HFM!

Congratulations to Carrie McCulloch for her promotion to HFM Development Director! In her new role, Carrie will focus on enhancing HFM's donor and community partnerships. We are grateful she is on our team.

Connected to you.

EAGLE JOURNEYS
CAMPING PROGRAMS

REGISTER FOR HFM'S CAMPING PROGRAMS

HFM IS LOOKING FORWARD TO HOSTING EAGLE JOURNEYS CAMPING PROGRAMS IN-PERSON IN 2022! TO PARTICIPATE IN AN HFM CAMP, ALL ATTENDEES MUST PROVIDE PROOF OF FULL COVID VACCINATION. LEARN MORE AT WWW.HFMICH.ORG/COVIDPOLICY

REGISTER FOR CAMP BY MAY 27, 2022 AT WWW.HFMICH.ORG/CAMP

NEW THIS YEAR EAGLES NEST FAMILY CAMP

JULY 24-27, 2022

Eagles Nest Family Camp is intended to introduce young children with bleeding disorders and their families to the Camp Bold Eagle experience. Eagles Nest is open to the immediate families of children with bleeding disorders ages 5-9 who have not previously attended Camp Bold Eagle.

EAGLE QUEST (OPEN TO ADULTS)

JUNE 11-17, 2022

CAMP BOLD EAGLE

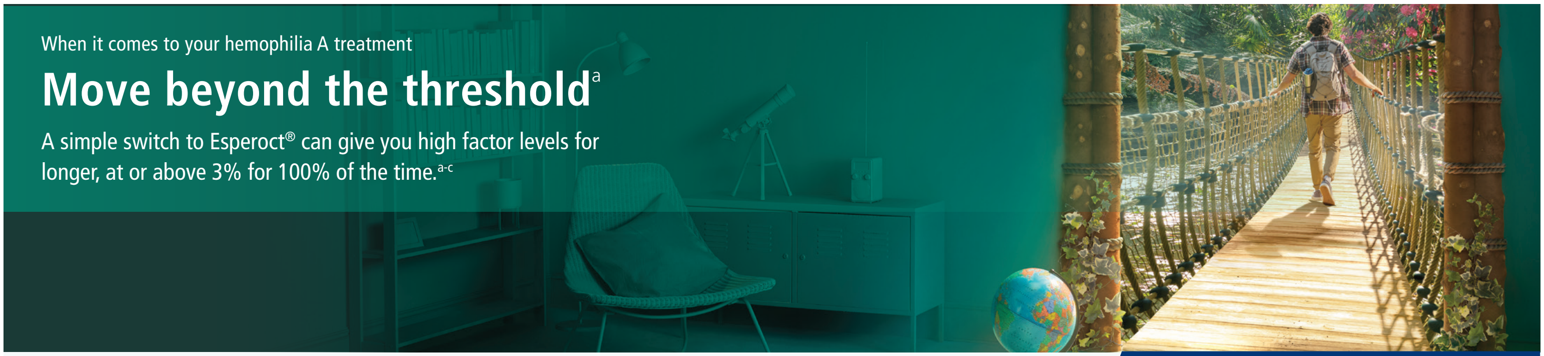
- SESSION 1 (AGES 6-9): JULY 10-15, 2022
- SESSION 2 (AGES 10-12): JULY 17-23, 2022
- TEEN CAMP (AGES 13-17): JUNE 26-JULY 2, 2022

EAGLE OUTPOST (AGES 14-17)

JULY 24-30, 2022

OLD BEAGLE (OPEN TO ADULTS AND THEIR FAMILIES)

SEPTEMBER 9-11, 2022



When it comes to your hemophilia A treatment

Move beyond the threshold[a]

A simple switch to Esperoct® can give you high factor levels for longer, at or above 3% for 100% of the time.[a-c]

[a] Trough level goal is 1% for prophylaxis.
[b] Compared with standard half-life products.
[c] Data shown are from a study where 175 previously treated adolescents and adults received routine prophylaxis with Esperoct® 50 IU/kg every 4 days. Pre-dose factor activity (trough) levels were evaluated at follow-up visits. Mean trough levels for adolescents (12-<18 years) were 2.7 IU/dL.

Discover more at **Esperoct.com.**

What is Esperoct®?

Esperoct® [antihemophilic factor (recombinant), glycopegylated-exei] is an injectable medicine to treat and prevent or reduce the number of bleeding episodes in people with hemophilia A. Your healthcare provider may give you Esperoct® when you have surgery

- Esperoct® is not used to treat von Willebrand Disease

IMPORTANT SAFETY INFORMATION

Who should not use Esperoct®?

- You should not use Esperoct® if you are allergic to factor VIII or any of the other ingredients of Esperoct® or if you are allergic to hamster proteins

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

- Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center
- Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as: hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face

What should I tell my healthcare provider before using Esperoct®?

- Before taking Esperoct®, 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, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII
- Your body can make antibodies called "inhibitors" against Esperoct®, which may stop Esperoct® from working properly. Call your healthcare provider right away if your bleeding does not stop after taking Esperoct®

What are the possible side effects of Esperoct®?

- Common side effects of Esperoct® include rash or itching, and swelling, pain, rash or redness at the location of infusion

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

novo nordisk®

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esperoct®
antihemophilic factor (recombinant), glycopegylated-exei

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esperoct®

antihemophilic factor (recombinant), glycopegylated-exei

Brief Summary information about ESPEROCT® [antihemophilic Factor (recombinant), glycopegylated-exei]

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/esperoct.pdf to obtain FDA-approved product labeling
- Call 1-800-727-6500

Patient Information

ESPEROCT®
[antihemophilic factor (recombinant), glycopegylated-exei]

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

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

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

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 ESPEROCT® so that your treatment will work best for you.

What is ESPEROCT®?

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

ESPEROCT® is used to treat and prevent or reduce the number of bleeding episodes in people with hemophilia A.

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

Who should not use ESPEROCT®?

You should not use ESPEROCT® if you

- are allergic to Factor VIII or any of the other ingredients of ESPEROCT®
- 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 ESPEROCT® might not be right for you.

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

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 VIII.

How should I use ESPEROCT®?

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

ESPEROCT® is given as an infusion into the vein.

You may infuse ESPEROCT® 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 A learn to infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much ESPEROCT® to use based on your weight, the severity of your hemophilia A, 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 ESPEROCT®.

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

Use in children

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

If you forget to use ESPEROCT®

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 ESPEROCT®

Do not stop using ESPEROCT® 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 ESPEROCT®?

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

What are the possible side effects of ESPEROCT®?

Common Side Effects Include:

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

Other Possible Side Effects:

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

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

These are not all of the possible side effects from ESPEROCT®. 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 ESPEROCT® dosage strengths?

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

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Gray	1500 IU per vial
Yellow	2000 IU per vial
Black	3000 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 ESPEROCT®?

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

Protect from light. Do not freeze ESPEROCT®.

ESPEROCT® can be stored in refrigeration at 36°F to 46°F (2°C to 8°C) for up to 30 months from the date of manufacture until the expiration date stated on the label.

ESPEROCT® may be stored at room temperature (not to exceed 86°F/30°C), for up to 12 months within the 30-month time period. Record the date when the product was removed from the refrigerator. The total time of storage at room temperature should not exceed 12 months. Do not return the product to the refrigerator.

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) ESPEROCT® should appear clear and colorless without visible particles.

The reconstituted ESPEROCT® should be used immediately.

If you cannot use the reconstituted ESPEROCT® immediately, it must be used within 4 hours when stored at or below 86°F (30°C) or within 24 hours when stored in a refrigerator at 36°F to 46°F (2°C to 8°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 ESPEROCT® and hemophilia A?

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

Revised: 02/2019

ESPEROCT® is a trademark of Novo Nordisk A/S.

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

More detailed information is available upon request. Available by prescription only.

For information about ESPEROCT® contact:
Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA
1-800-727-6500

US19ESP00010 August 2019

novo nordisk®

HFM HONORS THE DEDICATION OF THE HTC STAFF

During National Social Work Month in March, HFM and the bleeding disorders community recognized and expressed our appreciation for HTC social workers. Their tireless efforts to support the bleeding disorders community are making a difference in health outcomes and quality of life for patients and families. You are appreciated!

In May HFM honors all the HTC nurses and nurse practitioners during National Nurses Month. The bleeding disorders community flourishes because of the dedication, extra hours, and hard work of nurses and nurse practitioners working with the community. Thank you for all you do, seen and unseen. You are appreciated.

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JOIN US AS WE GROW OUR MEMBERSHIP!

WE ARE SO PLEASED THAT OUR HFM MEMBERSHIP INCLUDES BOTH LIFETIME MEMBERS AND ANNUAL MEMBERS WHOSE GIFTS HELP SUPPORT HFM'S WORK EVERY DAY. EACH OF THESE INDIVIDUALS HAS MADE A SPECIAL COMMITMENT TO THE MICHIGAN BLEEDING DISORDERS COMMUNITY. WE ARE VERY APPRECIATIVE OF OUR NEW AND RETURNING 2021 ANNUAL MEMBERS AND WE ARE ESPECIALLY GRATEFUL FOR OUR LIFETIME MEMBERS. YOUR SUPPORT, INSIGHT, AND ENGAGEMENT TRULY MAKE A DIFFERENCE. THANK YOU.

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LIFETIME MEMBERS

Dr. Judith Andersen & Dr. William Berk
Kathleen Donohoe
Susan Fenters Lerch & Dan Lerch
Shelley & Gary Gerson
Dean M. Hindenlang
Gwyn Hulswit & Jay Sennett
Dr. Deanna Mitchell & Dr. Gary Rich
Laura & Bill Sparrow
Jeanne White-Ginder
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Larry West II
Jenna & Tim Wicks

ARE YOU INTERESTED IN BECOMING A HFM MEMBER AND LEARNING HOW YOU CAN MAKE A GREATER IMPACT ON THE COMMUNITY AND HELP DIRECT THE WORK OF HFM? CONTACT CARRIE MCCULLOCH, HFM'S DEVELOPMENT DIRECTOR, AT **CMCCULLOCH@HFMICH.ORG** TO LEARN HOW YOUR GIFT OF MEMBERSHIP CAN MAKE A DIFFERENCE.

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

UPCOMING 2022 EVENTS

May 21-22
Women's Retreat
Hilton Garden Inn, Plymouth
Virtual and in-person

May 24
Ruby Connection
Cooking Demo
Virtual

Starts in June
HFM Eagle Journeys Camp Programs
In-person

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

June 11
VWD Symposium
Virtual

June 24
Community Night
Toledo Zoo
Virtual

June 29
Ruby Connection
Virtual

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

FOR MORE INFORMATION AND OTHER UPCOMING HFM EVENTS, PLEASE VISIT **HFMICH.ORG/EVENTS**.

Photo by Steven Miller

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