the artery

Serving Michigan's bleeding disorders community

Spring/Summer 2021

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

HFM board member, community member Ronia Cole shows her art from HFM's Michigan Women's Retreat, May 15, 2021

Michigan Women Connect!

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INSIDE THIS ISSUE

We are here for you.

Susan Fenters Lerch

To view HFM's Board President, Jim Mohnach's SpringFest video please go to: **www.hfmich.org/membership21**

Dear HFM friends & family,

Summer is upon us! Always a favorite season for Michiganders as we spend more time outdoors, consider day trips, weekends, and vacations to our many gorgeous parks, freshwater lakes, and beaches.

This year, summer is brighter as the number of people who have received COVID-19 vaccinations continues to grow. This trend creates more comfort to safely spend time with friends and loved ones.

I'm proud to share that our HFM staff have all received the COVID-19 vaccine and are continuing to practice safe protocols. If you have delayed receiving the COVID-19 vaccine - have questions or concerns regarding vaccines in relation to your bleeding disorder or other issues – it is crucial that you speak with your HTC physician and/ or primary healthcare provider.

HFM's virtual programming, including Camp Bold Eagle and HFM's Unite Walk, will continue through 2021 as we work together to assess when we may consider returning safely to in person events. In several instances, we've discovered virtual activities have allowed individuals to participate who previously could not attend in person for any number of reasons. What a wonderful and surprising consequence of this difficult time in our lives! Of course, many also look forward to real hugs and time in one another's physical presence.

During SpringFest, HFM's Board President, Jim Mohnach shared a valuable update on the state of our community. If you missed Jim's thoughts, I recommend that you watch the video, **www.hfmich.org/membership21**. I join Jim in extraordinary pride of our community, staff, Board, and HTCs. We have come together to offer fun and impactful virtual education and programming for you and various groups within our community. I hope you've participated with an HFM activity, if not, please consider joining us over the next few months.

It is a priority to us that you and yours are managing well in the midst of this ongoing health crisis. If you need support please call HFM, **734-544-0015**. We invite you to visit our website at **www.hfmich.org** for mental health, dental health, and emergency financial assistance resources and information.

I know each of us is doing our best to carry on while handling so many challenges. Please know we are here to encourage and cherish all those who make up our bleeding disorders family.

Love,

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

With sincere gratitude

Thank you to our individual financial donors. This list represents contributions recorded from January 1, 2020 through December 31, 2020 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 2020 calendar year. Please consider making a donation to HFM in 2021. **Your support truly makes a difference.**

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Not listed are the many individual supporters who donated less than $100. Thank you for your generosity; every gift makes a difference.

Please accept our apologies for any errors or omissions. Please contact **Gwyn Hulswit at ghulswit@hfmich.org** or at 734.544.0015 to correct our records.

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 2020 annual members and of our 2019 annual members whose membership was extended an additional year, and we are especially grateful for our lifetime members. Your support, insight, and engagement truly makes a difference. Thank you.

Lifetime Members

Dr. Judith Andersen & Dr. William Berk
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Susan Fenters Lerch & Dan Lerch
Shelley & Gary Gerson
Gwyn Hulswit & Jay Sennett
Dr. Deanna Mitchell & Dr. Gary Rich
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Colleen Yorick

Supporting the COVID-19 Vaccine Program

Learn more about the COVID-19 vaccine on page 5.

Kathi administering Dave's COVID-19 vaccine.

Special Thanks to Kathi Sheldon & Dave Rushlow

HTC nurse Kathi Sheldon and social worker Dave Rushlow have been supporting the Munson Health Center vaccine program.

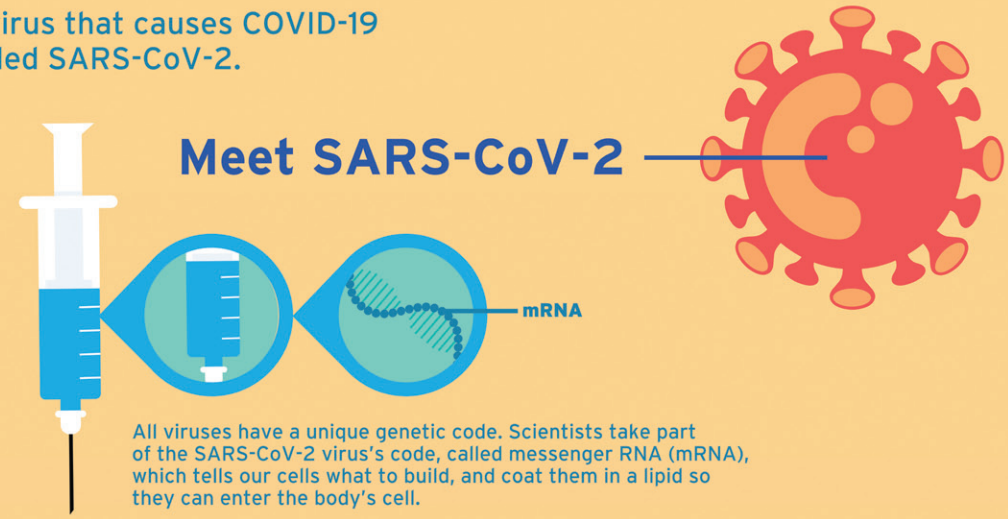
Our HFM staff team members are proud recipients of the COVID-19 vaccine and remain committed to practicing safe protocols including masking and social distancing as required by the CDC and other public health recommendations to protect vulnerable individuals.

Susan Fenters Lerch with grandaughter Margeaux.

How mRNA vaccines work

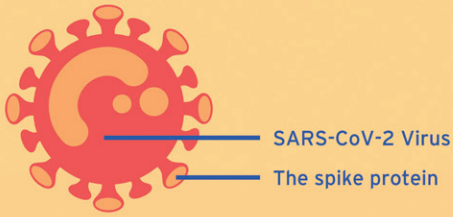
Every virus is different.

The virus that causes COVID-19 is called SARS-CoV-2.



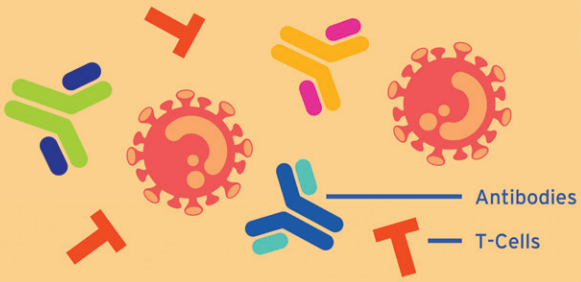
All viruses have a unique genetic code. Scientists take part of the SARS-CoV-2 virus's code, called messenger RNA (mRNA), which tells our cells what to build, and coat them in a lipid so they can enter the body's cell.

This is injected into the patient.



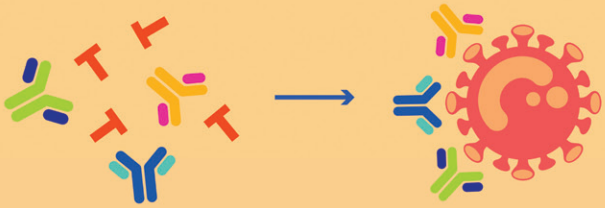
CREATE

The mRNA tells the cells to make a specific part of the SARS-CoV-2 virus: the spike protein.



LEARN

The immune system then produces antibodies and activates T-cells to destroy the spike proteins.



PROTECT

If you are exposed to the virus in the future, your immune system will quickly recognize the spike protein and has the antibodies and T-cells ready to begin destroying the virus.

The Benefit of Getting Vaccinated

The virus that causes COVID-19 replicates quickly. Without the vaccine, your body has to identify the virus, learn how to fight it and carry out an immune response. In the meantime, the virus can replicate to a level beyond what your immune system can handle – which means you feel sick. With the vaccine, your body can more quickly identify the virus and skip straight to starting its immune response.

mRNA technology isn't new.

mRNA vaccines are a product of decades of study on RNA therapies and treatment by medical scientists. mRNA therapies are being used to develop personalized cancer treatments, as well as vaccines for infectious diseases such as Zika virus. Researchers are also exploring whether mRNA treatments can be used as protein-replacement therapies for rare conditions such as the blood-clotting disorder haemophilia.

MDHHS Michigan Department of Health & Human Services

COVID-19 Vaccine Information

Everyone 12 years of age and older is now eligible to get a COVID-19 vaccine. Find a vaccination location and schedule an appointment with the **CDC COVID Vaccine Finder: www.vaccines.gov/search/**

Check the website of your local health department or hospital to find out their process. You can also find registration forms at: **www.michigan.gov/coronavirus/0,9753,7-406-98178_103214_104822---,00.html#block-3_121336)**

Or, check additional vaccination sites, such as local pharmacies like Meijer, Rite Aid, Walgreens, CVS, Kroger, Walmart (Mid/Central & Northern MI) or Snyder Drugs (U.P. residents).

Individuals who don't have access to the internet or who need assistance navigating the vaccine scheduling process can call the **COVID-19 Hotline** at **888-535-6136 (press 1)** Monday through Friday from 8am to 5pm,Saturday and Sunday 8am to 1pm.

For more information on the COVID-19 vaccine in Michigan, visit **www.michigan.gov/covidvaccine**

If you have questions about bleeding disorders and the COVID-19 vaccine, please check with your HTC or primary care team.

SpringFest 2021

VIRTUAL around the world

Presented virtually April 15, 16, 17
GooseChase April 12-17

SpringFest 2021: Around the World was a landmark event for us all. Continuing in the safest manner of education and connection for our community, HFM hosted a virtual SpringFest on April 15-17, 2021 via the online platform, Socio. Community members, healthcare professionals, industry supporters, and more joined HFM staff for our largest, virtual annual education conference.

HFM planned "a trip around the world" as the theme for this year's SpringFest event. Those who signed up by the box deadline started their SpringFest trip with wonderful conference boxes filled with activities for SpringFest, information from our sponsors, and a specially designed SpringFest plane.

We were thrilled to have friends of HFM, Anne Henningfeld and Michael J. Garner, join us as MCs and bring along their friends from Cirque Du Soleil who live around the world. World Hemophilia Day also took place during our event and we were able to acknowledge that world-wide event by connecting with the World Federation of Hemophilia and learning about their efforts to improve the lives of people with bleeding disorders through their mission of treatment for all.

Throughout the weekend, we were also joined by a selection of expert speakers, including many healthcare staff from our Michigan HTCs, who shared information on the latest treatment options, aging with a bleeding disorder, policy to ensure access to skilled nursing facilities, advocating for yourself and your loved ones, the impact of COVID-19, and care available at HTCs.

Yet we all know, SpringFest wouldn't be the same without the opportunities to connect with others in the community. In addition to the time we had together during the sessions and in our chats, we had an amazingly fun time learning and exploring through GooseChase. Thank you to all those who participated in HFM's GooseChase scavenger hunt during the week of SpringFest. Reading your submissions, viewing your photos, and observing the fierce competition warmed our hearts and made us feel closer than we have been in over a year.

SpringFest 2021 was yet another great opportunity to come together for support and connection!

Thoughts from community members...

"Thank you all for a very fun, enlightening conference! I appreciate all you do for the bleeding community."

"We had the best time this year. From the moment our box came in the mail until the final session."

"The Goose Chase was AWESOME! Thank you for the week!! It was huge, getting a break from Covid was the best!!"

"Even though we weren't together, there was a sense of togetherness. First time attending, and would attend again, great job!"

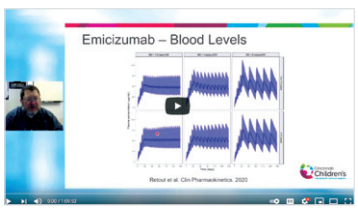
"We loved everything that was done for our community and we are so appreciative of all the hard work that goes into the event!!"

SpringFest 2021 Session Videos

The links to the sessions below are available by direct hyperlink and by going to our youtube channel, **www.hfmich.org/youtube**.

SpringFest 2021: Opening Night Extravaganza
www.hfmich.org/sf21opening

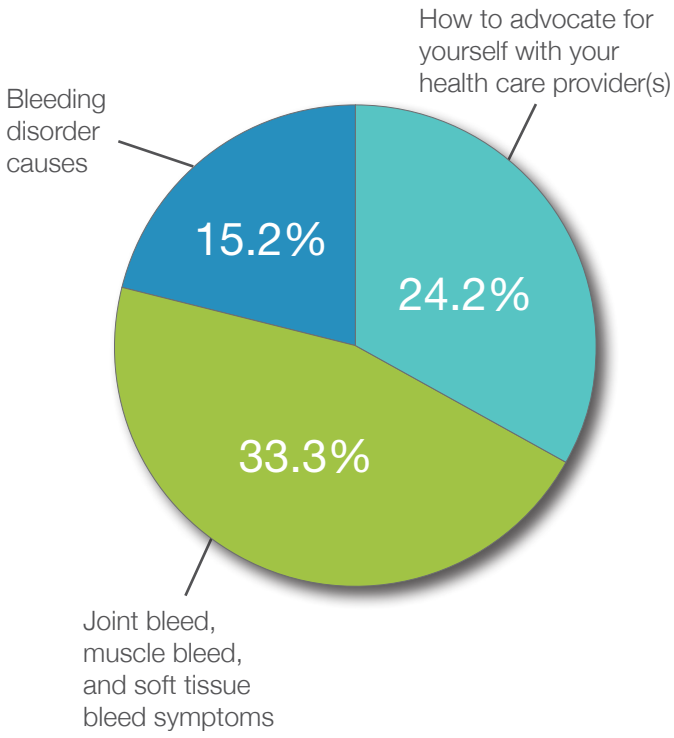
SpringFest 2021: Care Available Via HTCs: What They Do, How They're Funded
www.hfmich.org/sf21htcs



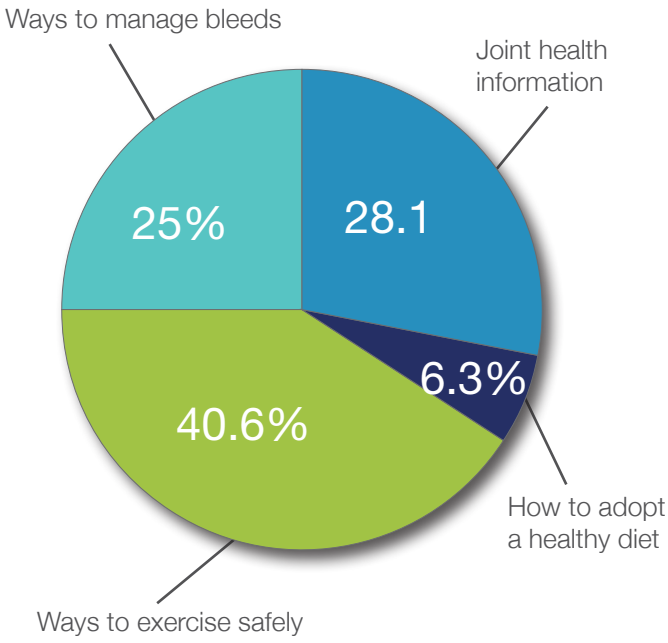
SpringFest 2021: New Kids on the Block: Overview of New Treatments
www.hfmich.org/sf21nkotb

SpringFest participants shared...

What would you most like to learn about your bleeding disorder?



Which bleeding disorders-related resources would best help inform you?



hfm SpringFest 2021 VIRTUAL around the world

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GO SEEK. GO EXPLORE. GO AHEAD.

PEOPLE LIKE YOU. STORIES LIKE YOURS.
Explore more at HEMLIBRAjourney.com

Discover your sense of go. Discover HEMLIBRA.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.

These serious side effects include:

- **Thrombotic microangiopathy (TMA),** a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events),** which may form in blood vessels in your arm, leg, lung, or head

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.

HEMLIBRA®
emicizumab-kxwh
injection for subcutaneous use | 150 mg/mL

Medication Guide
HEMLIBRA® (hem-lee-bruh) (emicizumab-kxwh) injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

See "**What are the possible side effects of HEMLIBRA?**" for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See "**What is the most important information I should know about HEMLIBRA?**"

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 10/2018

HEMLIBRA®
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

Genentech
A Member of the Roche Group

Dental Quick Tips

To view Karen Ridley's **Basics for Healthy Teeth** video, go to **www.hfmich.org/healthyteeth**

Karen Ridley, RDH, MS, University of Michigan Hemophilia and Clotting Disorders Program

Invest in a Dental Home

Having a consistent dental provider and receiving regularly scheduled preventive or restorative dental care saves money and provides a resource for good oral health.

Stop Sweet Sips

Soda, juice, and sweetened coffee/tea provide a ready resource of sugar for the bacteria in the mouth. Water is the ideal beverage for both oral and general health.

Baby, Baby, Baby

From the moment teeth begin to erupt in the baby's mouth, they require daily care. Establishing a pattern of good oral hygiene early will help provide a healthy dentition for life.

Developing Healthy Snacking Habits

Nibbling your way through long COVID days? Be selective. Choose non sticky, low sugar snacks. Popcorn, pretzels, nuts, and of course fruits and veggies are good choices.

Dentures Need Professional Care

Plan a yearly visit with the dentist. Have your denture professionally cleaned. The dentist will check the fit and examine the tissue in the mouth.

Where's Your Retainer?

The retainer is an important part of successful orthodontic treatment. It should be in the mouth except when eating or swimming, not in a pocket or on the sink.

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

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Katherine Scott, MD, Program Director, Pediatrics; Jennifer Luitje, RN, Hemophilia Nursing Coordinator; Muhammad Usman, MD, Hemophilia Program Director; Nancy Inverso, RN, Hemophilia Program Manager;

Center of Care

Bronson Hemophilia Treatment Center

Molly Murdock, Bronson Health

Where is your HTC located?

The Bronson Hemophilia Treatment Center is located inside the Bronson Cancer Center on the campus of Bronson Methodist Hospital in downtown Kalamazoo, Michigan. The recently opened 85,000 sq. ft. facility provides hematology, oncology, and infusion services for adult patients. We also care for pediatric patients at Bronson Children's Hospital, conveniently located across the street.

What is your catchment area?

We serve patients across nine counties in the southwest Michigan area of the state.

Do you serve pediatric or adult patients or are you a lifespan center?

We care for patients at every step of their journey – from childhood through adulthood. Adults, ages 18+ receive care at Bronson Cancer Center, while children are seen at Bronson Children's Hospital, the area's only children's hospital.

How long has your HTC operated or when did it open?

Our program began at Bronson Methodist Hospital in the late 1970s. Over time, it grew to include separate offices – adults being seen at West Michigan Cancer Center and children being seen at Bronson Children's Hospital. This year, our adult practice relocated from West Michigan Cancer Center to the new Bronson Cancer Center.

Do you have any new staff members?

Yes! Since the opening of the new Bronson Cancer Center, we have hired three new team members. **Randi Klop** is a clinical dietitian who helps ensure our patients eat properly for their unique health needs. **Lisa Batsell** and **Matthew DeJong** are social workers who help connect our patients with necessary community resources and information.

What do you see as your biggest strength as a center?

We provide care across the lifespan. We form lasting connections with our patients and their families, providing empowerment, hope, and positivity. Also, as a part of the area's leading healthcare system, we have access to state-of-the-art medicine and technology, skilled clinical staff, education and support services, and more. Plus, all our patients have their hemophilia care coordinated within the Bronson Healthcare system along with the other medical services they receive there. This enhances communication between providers and patients and allows all visits to be documented in one central electronic health record to ensure the best possible care for each patient.

What inspires your staff?

It is a privilege to provide care for our patients. Helping them and their families overcome obstacles and barriers to be able to lead life to the fullest makes coming to work every day a joy.

Are you Sparty or Wolverine fans?

We cheer for the Western Michigan University Broncos!

Contact:

Bronson Hemophilia Treatment Center
805 John St.
Kalamazoo, MI 49001

P: 269-286-7180

SAVE THE DATES!

HFM's 2021 National Conference for Women & Teens with Hemophilia

Fri., October 8 & Sat., October 9

Women and teens who are eligible to join our **special two-day virtual program** will learn from national experts and health care providers, and have numerous opportunities to connect with other attendees who each bring their own unique wisdom and experience of living with hemophilia.

- Accepted attendees will receive our conference-enhancement package if they are accepted by September 14
- **Questions?** Contact Patrice Thomas at pthomas@hfmich.org, 734.544.0015

Application is required.
Opens July 13 & closes September 14

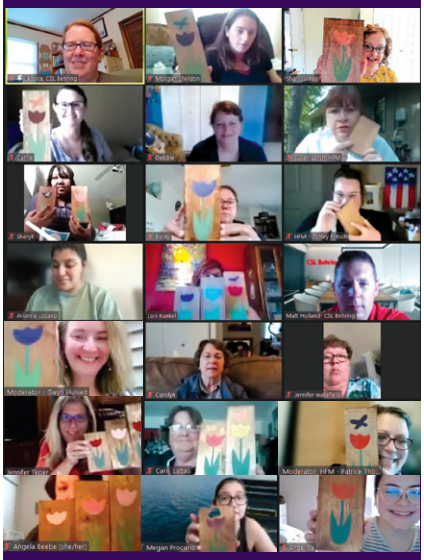
HFM's 2021 Women's Retreat

Shari Luckey

May 15th was a beautiful spring day in Michigan and a new beginning for our annual Women's Retreat. Thirty-eight women from the bleeding disorders community around Michigan joined together via Zoom for a day of connection and renewal. The six-hour day was packed with education, discussion, and fun. I couldn't believe how quickly our time went by.

Our theme of renewal this year was enhanced by sessions like Mindfulness, A Moment in Time; Gratitude Nation; and Laughing Through Stress. We got the opportunity to practice calming techniques, acknowledge the good things in our life, and have some much-needed laughter. We had an amazing presentation about Adult Women's Preventative Health Care from physicians Anne Greist, hematologist and co-medical director at the Indiana Hemophilia and Thrombosis Center, Inc. and Amy Hepper, MD, clinical assistant professor of Internal Medicine and Pediatrics at Michigan Medicine; MD at Canton Health Center. This presentation was the beginning of a much-needed discussion that we hope to continue. Collaboration between hematologists and primary care physicians, OB/Gyns, etc. will improve care for women with bleeding disorders.

We are so grateful for our speakers, sponsors, HFM staff, and most importantly to the women that made this such an amazing day! We look forward to planning next year's retreat and while we hope we will be able to safely return to an in-person event, know that we'll include ways for women to participate virtually!



Creative Time

Sign Language for Kids Community Night

Some lucky kids from our community learned sign language (ASL) via zoom from our friend **Mary Ferrell**, from Nashville, TN. Thanks Mary!

Also, thanks to **Lisa Batsell, LMSW**, Bronson Hemophilia Treatment Center social worker for her talk on inclusivity and embracing difference. Thanks Lisa!

THANKS TO OUR SPONSORS:

Breath Work for Kids: A relaxation technique

Lisa Clothier, LMSW, ACSW

Especially now, most all of us are looking for ways to relax and recenter our minds and bodies. Kids are no different. Try this simple tip below. Be sure to practice this with your kiddos when they are calm. That way they will have mastered it when they need to use it to relax.

Smelling Flowers Relaxation Breathing Technique

Tell your little one to imagine they are smelling a flower, breathing in deeply through the nose and out through the mouth. Smelling flowers is one of the easiest breathing exercises to master, and a good starting point for your child.

Source: www.moshisleep.com/blog/deep-breathing-exercises-for-kids/

Mental Health Support

Anyone can experience a mental health crisis and during the pandemic there may be additional stressors for those already struggling.

The National Suicide Prevention Lifeline (1-800-273-8255) is a national network of local crisis centers that provides free and confidential emotional support to people in suicidal crisis or emotional distress 24 hours a day, 7 days a week.

*This content is for educational purposes and is not intended to constitute medical advice.

Advocacy in Action: Michigan House Passes Copay Accumulator Reform

MICHIGAN ALL COPAYS COUNT COALITION

Sarah Procario

For the past year, HFM and the MI All Copays Count (MACC) coalition have been working to enact copay accumulator reform in Michigan to ensure all copays count.

Earlier this year, the Michigan House introduced a 15-bill package described as "patient centered" reforms to healthcare that includes a bill that reforms copay accumulator adjustment programs–HB 4353. This package is similar to the 2020 health care reform package championed by previous House Health Policy Chair Hank Vaupel.

During the month of March, HFM and the MACC coalition worked with the Health Policy Chairwoman, Bronna Kahle, the lead sponsor on HB 4353, to educate the Health Policy Committee and garner support for reform.

MACC coalition representatives, including HFM's Advocacy Director, **Sarah Procario**, and Camp Director, **Tim Wicks**, testified in support of the bill during Health Policy Committee hearings on Thursday, March 4 and Wednesday, March 10.

On March 11, the Health Policy Committee voted to move HB 4353 out of committee without a single no vote.

As the bill headed to a full vote in the MI House of Representatives, HFM asked community members to reach out to their representatives asking them to VOTE YES. Thank you to all of you who contacted your reps; you truly made a difference.

With overwhelming bipartisan support, the MI House passed HB 4353 to ensure all copays count. **View MACC's press release here.** https://hfmich.org/patient-advocates-thank-state-house-members-for-bipartisan-vote-approving-bill-to-ensure-all-copays-count/

The bill is currently up for review in the Michigan Senate Health Policy and Human Services Committee. We will contact the community when there is an opportunity for action!

Follow along with HFM's advocacy work in our new monthly Policy and Advocacy e-newsletter. To receive emails from HFM, please email Laura Olson, **lolson@hfmich.org.**

Sharing Our Stories: Celebrating Bleeding Disorders Awareness Month

Sarah Procario

On March 16, members of the Michigan bleeding disorders community joined HFM staff to celebrate Bleeding Disorders Awareness Month (BDAM) through an interactive story telling event.

During BDAM, we are often invited to share our bleeding disorder stories to create awareness, understanding, or change. HFM's social work intern, Angela Beebe, guided us through a life map activity to support us in identifying significant moments in our lives, with an emphasis on events related to our bleeding disorders.

We then discussed how to utilize our life maps to help us share our stories in the most impactful and powerful ways, whether we are sharing with friends or advocating for the needs of ourselves and the entire bleeding disorders community.

Thank you to all participants who joined us and shared pieces of their own stories with us.

Thanks to our advocacy sponsors

Takeda CSL Behring

HFM does not endorse any specific product or company.

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For Additional Safety Information, please visit ADVATE.com or ADYNOVATE.com and discuss with your HCP.

ADVATE [Antihemophilic Factor (Recombinant)]

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated]

my PK FiT

Congratulations to HFM's 2021 Academic Scholarship Recipients

We are happy to announce HFM's 2021 Academic Scholarship recipients, Audriyana Jaber and Kandhan Nadarajah. Thank you to our scholarship committee members: Laura Olson, James Semiski, and Lynn R. Allen.

Audriyana Jaber

By winning this scholarship I have demonstrated to myself that hard work and dedication pay off. I am so thankful for the scholarship committee for giving me the opportunity to continue my education. I am majoring in physiology on the pre-med track and minoring in Arabic and integrated studies in leadership in the Lyman Briggs College at Michigan State University. I enjoy painting, baking, and playing board games with my brothers.

Kandhan Nadarajah

The HFM scholarship is a signal to me that the hemophilia community will back me wherever I go. The community has already given me so much and with this scholarship it will help me through the next stage in my life. I am so thankful for the scholarship and I will use it to gain the best education I can in the next 4 years. I will be majoring in mechanical engineering at the Georgia Tech Institute of Technology. In my free time I love to work on my cars, create entrepreneurial ideas, and play tennis.

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hfm ruby connection

women's group

Join HFM's NEW women's group, HFM's Ruby Connection. Alternating between noon-1pm and 7-8pm the fourth Tuesday of the month, adult women in the bleeding disorders community are invited to come together for an online social experience that includes an educational speaker or activity and connection with other women in the community. Previous topics have included budgeting, cooking, and zoom tips.

The group is open to women affected with a bleeding disorder or involved in the bleeding disorders community. There is no obligation to attend every month, come when you can.

Bee Encounter

with Kathy Gerus-Darbison and Bill Darbison
Tuesday, June 22 ~ 12-1pm

Kathy Gerus-Darbison, a life long member of the bleeding disorders community, and her husband, Bill Darbison, volunteer their time and talents at Eagle Journeys camp programs and other events. Together they enjoy caring for their bees and sharing their knowledge and the sweet rewards.

Registration is required.
www.hfmich.org/rubyjune22

HFM's July Ruby Connection

Tuesday, July 27, 7-8pm
The Owls Hidden in our Culture
www.hfmich.org/rubyjuly27

For people with hemophilia A or B with inhibitors, it's time to

Spread your wings

Controlling bleeds, whenever they happen

- Proven to treat bleeds for people with hemophilia A or B with inhibitors

Safety supported by clinical experience[a]

- Low rate (0.2%) of blood clots reported in clinical trials

Speed when it's needed

- Fast to mix, fast to infuse, and fast to control bleeds[b]

NovoSeven® RT—committed to your experience

- More than 30 years of research and long-term clinical experience[c]

[a]For people with hemophilia A or B with inhibitors.
[b]Administer as a slow bolus injection over 2-5 minutes, depending on the dose administered.
[c]Compassionate use, also known as expanded access, began enrolling in 1988; FDA approval received in 1999.

Chase, 5 years old, *has hemophilia A with inhibitors, and loves anything that has to do with cars, planes, or playing golf.*

Visit **NovoSevenRT.com** today to learn more.

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Peel-off labels for convenient infusion tracking

What is NovoSeven® RT?

NovoSeven® RT (coagulation Factor VIIa, recombinant) is an injectable medicine used for:

- Treatment of bleeding and prevention of bleeding for surgeries and procedures in adults and children with hemophilia A or B with inhibitors, congenital Factor VII (FVII) deficiency, and Glanzmann's thrombasthenia with a decreased or absent response to platelet transfusions
- Treatment of bleeding and prevention of bleeding for surgeries and procedures in adults with acquired hemophilia

Important Safety Information

What is the most important information I should know about NovoSeven® RT?

NovoSeven® RT may cause serious side effects, including:

- **Serious blood clots** that form in veins and arteries with the use of NovoSeven® RT have been reported
- Your healthcare provider should discuss the risks and explain the signs and symptoms of blood clots to you. Some signs of a blood clot may include pain, swelling, warmth, redness, or a lump in your legs or arms, chest pain, shortness of breath, or sudden severe headache and/or loss of consciousness or function
- Your healthcare provider should monitor you for blood clots during treatment with NovoSeven® RT
- You should not use NovoSeven® RT if you have ever had allergic (hypersensitivity) reactions, including severe, whole body reactions (anaphylaxis) to NovoSeven® RT, any of its ingredients, or mice, hamsters, or cows. Signs of allergic reaction include shortness of breath, rash, itching (pruritus), redness of the skin (erythema), or fainting/dizziness

What should I tell my healthcare provider before using NovoSeven® RT?

- Tell your healthcare provider if you have any of the following, as these may increase your risk of blood clots:
  - congenital hemophilia and are also receiving treatment with aPCCs (activated prothrombin complex concentrates)
  - are an older patient particularly with acquired hemophilia and receiving other agents to stop bleeding
  - history of heart or blood vessel diseases
- Tell your healthcare provider and pharmacist about all the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies

What are the possible side effects of NovoSeven® RT?

- The most common and serious side effects are blood clots
- Tell your healthcare provider about any side effects that bother you or do not go away, and seek medical help right away if you have signs of a blood clot or allergic reaction

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

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

NovoSeven® RT
Coagulation Factor VIIa (Recombinant)

NOVOSEVEN® RT
Coagulation Factor VIIa (Recombinant)

Rx only

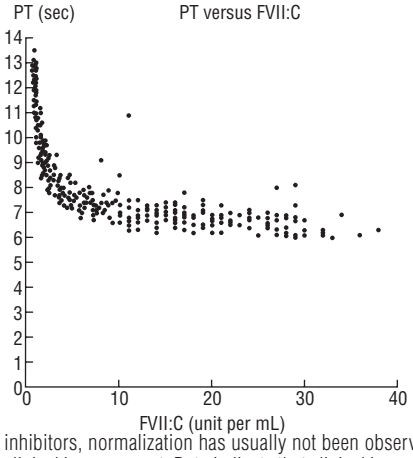
BRIEF SUMMARY. Please consult package insert for full prescribing information.

WARNING: THROMBOSIS: Serious arterial and venous thrombotic events following administration of NOVOSEVEN® RT have been reported. *[See Warnings and Precautions]* Discuss the risks and explain the signs and symptoms of thrombotic and thromboembolic events to patients who will receive NOVOSEVEN® RT. *[See Warnings and Precautions]* Monitor patients for signs or symptoms of activation of the coagulation system and for thrombosis. *[See Warnings and Precautions]*

INDICATIONS AND USAGE: NOVOSEVEN® RT, Coagulation Factor VIIa (Recombinant), is indicated for: Treatment of bleeding episodes and peri-operative management in adults and children with hemophilia A or B with inhibitors, congenital Factor VII (FVII) deficiency, and Glanzmann's thrombasthenia with refractoriness to platelet transfusions, with or without antibodies to platelets; Treatment of bleeding episodes and peri-operative management in adults with acquired hemophilia.

CONTRAINDICATIONS: None known.

WARNINGS AND PRECAUTIONS: Thrombosis: Serious arterial and venous thrombotic events have been reported in clinical trials and postmarketing surveillance. Patients with congenital hemophilia receiving concomitant treatment with aPCCs (activated prothrombin complex concentrates), older patients particularly with acquired hemophilia and receiving other hemostatic agents, or patients with a history of cardiac, vascular disease or predisposed to thrombotic events may have an increased risk of developing thrombotic events *[See Adverse Reactions and Drug Interactions]*. Monitor patients who receive NOVOSEVEN® RT for development of signs or symptoms of activation of the coagulation system or thrombosis. When there is laboratory confirmation of intravascular coagulation or presence of clinical thrombosis, reduce the dose of NOVOSEVEN® RT or stop the treatment, depending on the patient's condition. **Hypersensitivity Reactions:** Hypersensitivity reactions, including anaphylaxis, can occur with NOVOSEVEN® RT. Patients with a known hypersensitivity to mouse, hamster, or bovine proteins may be at a higher risk of hypersensitivity reactions. Discontinue infusion and administer appropriate treatment when hypersensitivity reactions occur. **Antibody Formation in Factor VII Deficient Patients:** Factor VII deficient patients should be monitored for prothrombin time (PT) and factor VII coagulant activity before and after administration of NOVOSEVEN® RT. If the factor VIIa activity fails to reach the expected level, or prothrombin time is not corrected, or bleeding is not controlled after treatment with the recommended doses, antibody formation may be suspected and analysis for antibodies should be performed. **Laboratory Tests:** Laboratory coagulation parameters (PT/INR, aPTT, FVII:C) have shown no direct correlation to achieving hemostasis. Assays of prothrombin time (PT/INR), activated partial thromboplastin time (aPTT), and plasma FVII clotting activity (FVII:C), may give different results with different reagents. Treatment with NOVOSEVEN® has been shown to produce the following characteristics: PT: As shown below, in patients with hemophilia A/B with inhibitors, the PT shortened to about a 7-second plateau at a FVII:C level of approximately 5 units per mL. For FVII:C levels > 5 units per mL, there is no further change in PT. The clinical relevance of prothrombin time shortening following NOVOSEVEN® RT administration is unknown.



INR: NOVOSEVEN® has demonstrated the ability to normalize INR. However, INR values have not been shown to directly predict bleeding outcomes, nor has it been possible to demonstrate the impact of NOVOSEVEN® on bleeding times/volume in models of clinically-induced bleeding in healthy volunteers who had received Warfarin, when laboratory parameters (PT/INR, aPTT, thromboelastogram) have normalized. aPTT: While administration of NOVOSEVEN® shortens the prolonged aPTT in hemophilia A/B patients with inhibitors, normalization has usually not been observed in doses shown to induce clinical improvement. Data indicate that clinical improvement was associated with a shortening of aPTT of 15 to 20 seconds. FVIIa:C: FVIIa:C levels were measured two hours after NOVOSEVEN® administration of 35 micrograms per kg body weight and 90 micrograms per kg body weight following two days of dosing at two hour intervals. Average steady state levels were 11 and 28 units per mL for the two dose levels, respectively.

ADVERSE REACTIONS: The most common and serious adverse reactions in clinical trials are thrombotic events. Thrombotic adverse reactions following the administration of NOVOSEVEN® in clinical trials occurred in 4% of patients with acquired hemophilia and 0.2% of bleeding episodes in patients with congenital hemophilia. **Clinical Trials Experience:** Because clinical studies are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug product cannot be directly compared to rates in clinical trials of another drug, and may not reflect rates observed in practice. Adverse reactions outlined below have been reported from clinical trials and data collected in registries. Hemophilia A or B Patients with Inhibitors: In two studies for hemophilia A or B patients with inhibitors treated for bleeding episodes (N=298), adverse reactions were reported in ≥2% of the patients that were treated with NOVOSEVEN® for 1,939 bleeding episodes (see Table 3 below).

Table 3: Adverse Reactions Reported in ≥2% of the 298 Patients with Hemophilia A or B with Inhibitors

Body System Reactions	**# of adverse reactions** (n=1,939 treatments)	**# of patients** (n=298 patients)
Body as a whole		
Fever	16	13
Platelets, Bleeding, and Clotting		
Fibrinogen plasma decreased	10	5
Cardiovascular		
Hypertension	9	6

Serious adverse reactions included thrombosis, pain, thrombophlebitis deep, pulmonary embolism, decreased therapeutic response, cerebrovascular disorder, angina pectoris, DIC, anaphylactic shock and abnormal hepatic function. The serious adverse reactions of DIC and therapeutic response decreased had a fatal outcome. In two clinical trials evaluating safety and efficacy of NOVOSEVEN® administration in the perioperative setting in hemophilia A or B patients with inhibitors (N=51), the following serious adverse reactions were reported: acute post-operative hemarthrosis (n=1), internal jugular thrombosis adverse reaction (n=1), decreased therapeutic response (n=4). *Immunogenicity:* There have been no confirmed reports of inhibitory antibodies against NOVOSEVEN® or FVII in patients with congenital hemophilia A or B with alloantibodies. The incidence of antibody formation is dependent on the sensitivity and specificity of the assay. Additionally, the observed incidence of antibody (including neutralizing antibody) positivity in an assay may be influenced by several factors including assay methodology, sample handling, timing of sample collection, concomitant medications, and underlying disease. For these reasons, comparison of the incidence of antibodies to NOVOSEVEN® RT with the incidence of antibodies to other products may be misleading. Congenital Factor VII Deficiency: Data collected from the compassionate/emergency use programs, the published literature, a pharmacokinetics study, and the Hemophilia and Thrombosis Research Society (HTRS) registry showed that 75 patients with Factor VII deficiency had received NOVOSEVEN®: 70 patients for 124 bleeding episodes, surgeries, or prophylaxis; 5 patients in the pharmacokinetics trial. The following adverse reactions were reported: intracranial hypertension (n=1), IgG antibody against rFVIIa and FVII (n=1), localized phlebitis (n=1). *Immunogenicity:* In 75 patients with factor FVII deficiency treated with NOVOSEVEN® RT, one patient developed IgG antibody against rFVIIa and FVII. Patients with factor VII deficiency treated with NOVOSEVEN® RT should be monitored for factor VII antibodies. The incidence of antibody formation is dependent on the sensitivity and specificity of the assay. Additionally, the observed incidence of antibody (including neutralizing antibody) positivity in an assay may be influenced by several factors including assay methodology, sample handling, timing of sample collection, concomitant medications, and underlying disease. For these reasons, comparison of the incidence of antibodies to NOVOSEVEN® RT with the incidence of antibodies to other products may be misleading. Acquired Hemophilia: Data collected from four compassionate use programs, the HTRS registry, and the published literature showed that 139 patients with acquired hemophilia received NOVOSEVEN® for 204 bleeding episodes, surgeries and traumatic injuries. Of these 139 patients, 6 patients experienced 8 serious adverse reactions. Serious adverse reactions included shock (n=1), cerebrovascular accident (n=1) and thromboembolic events (n=6) which included cerebral artery occlusion, cerebral ischemia, angina pectoris, myocardial infarction, pulmonary embolism and deep vein thrombosis. Three of the serious adverse reactions had a fatal outcome. Glanzmann's Thrombasthenia: Data collected from the Glanzmann's Thrombasthenia Registry (GTR) and the HTRS registry showed that 140 patients with Glanzmann's thrombasthenia received NOVOSEVEN® RT for 518 bleeding episodes, surgeries or traumatic injuries. The following adverse reactions were reported: deep vein thrombosis (n=1), headache (n=2), fever (n=2), nausea (n=1), and dyspnea (n=1). **Post marketing Experience:** Adverse reactions reported during post marketing period were similar in nature to those observed during clinical trials and include reports of thromboembolic adverse events.

DRUG INTERACTIONS: Avoid simultaneous use of activated prothrombin complex concentrates. Do not mix NOVOSEVEN® RT with infusion solutions. Thrombosis may occur if NOVOSEVEN® RT is administered concomitantly with Coagulation Factor XIII. *[See Warnings and Precautions]*

USE IN SPECIFIC POPULATIONS: Pregnancy: Risk Summary: There are no adequate and well-controlled studies using NOVOSEVEN® RT in pregnant women to determine whether there is a drug-associated risk. Treatment of rats and rabbits with NOVOSEVEN® in reproduction studies has been associated with mortality at doses up to 6 mg per kg body weight and 5 mg per kg body weight respectively. At 6 mg per kg body weight in rats, the abortion rate was 0 out of 25 litters; in rabbits at 5 mg per kg body weight, the abortion rate was 2 out of 25 litters. Twenty-three out of 25 female rats given 6 mg per kg body weight of NOVOSEVEN® gave birth successfully, however, two of the 23 litters died during the early period of lactation. No evidence of teratogenicity was observed after dosing with NOVOSEVEN®. In the U.S. general population, the estimated background risk of major birth defect and miscarriage in clinically recognized pregnancies is 2-4% and 15-20%, respectively. **Lactation:** Risk Summary: There is no information regarding the presence of NOVOSEVEN® RT in human milk, the effect on the breastfed infant, and the effects on milk production. The developmental and health benefits of breastfeeding should be considered along with the mother's clinical need for NOVOSEVEN® RT and any potential adverse effects on the breastfed infant from NOVOSEVEN® RT or from the underlying maternal condition. **Pediatric Use:** Clinical trials enrolling pediatric patients were conducted with dosing determined according to body weight and not according to age. Hemophilia A or B with Inhibitors: During the investigational phase of product development NOVOSEVEN® was used in 16 children aged 0 to <2 years for 151 bleeding episodes, 27 children aged 2 to <6 years for 140 bleeding episodes, 43 children aged 6 to <12 for 375 bleeding episodes and 30 children aged 12 to 16 years for 446 bleeding episodes. In a double-blind, randomized comparison trial of two dose levels of NOVOSEVEN® in the treatment of joint, muscle and mucocutaneous hemorrhages in hemophilia A and B patients with and without inhibitors 20 children aged 0 to <12 and 8 children aged 12 to 16 were treated with NOVOSEVEN® in doses of 35 or 70 micrograms per kg dose. Treatment was assessed as effective (definite relief of pain/tenderness as reported by the patient and/or a measurable decrease of the size of the hemorrhage and/or arrest of bleeding within 8 hours [rated as excellent = 51%], within 8-14 hours [rated as effective = 18%] or after 14 hours [rated as partially effective = 25%]) in 94% of the patients. NOVOSEVEN® was used in two trials in surgery. In a dose comparison 22 children aged 0 to 16 years were treated with NOVOSEVEN®. Effective intraoperative hemostasis (defined as bleeding that had stopped completely or had decreased substantially [rated as effective = 86%] or bleeding that was reduced but continued [rated as partially effective = 9%]) was achieved in 21/22 (95%) patients. Effective hemostasis was achieved in 10/10 (100%) patients in the 90 mcg/kg dose group and 10/12 (83%) in the 35 mcg/kg dose group at 48 hours; effective hemostasis was achieved in 10/10 (100%) in the 90 mcg/kg dose group and 9/12 (75%) in the 35 mcg/kg dose group at 5 days. In the surgery trial comparing bolus (BI) and continuous infusion (CI) 6 children aged 10 to 15 years participated, 3 in each group. Both regimens were 100% effective (defined as bleeding has stopped completely, or decreased substantially) intra-operatively, through the first 24 hours and at day 5. At the end of the study period (Postoperative day 10 or discontinuation of therapy) hemostasis in two patients in the BI group was rated effective and hemostasis in one patient was rated as ineffective (defined as bleeding is the same or has worsened). Hemostasis in all three patients in the CI group was rated as effective. Adverse drug reactions in pediatric patients were similar to those previously reported in clinical trials with NOVOSEVEN®, including one thrombotic event in a 4 year old with internal jugular vein thrombosis after port-a-cath placement which resolved. Congenital Factor VII deficiency: In published literature, compassionate use trials and registries on use of NOVOSEVEN® in congenital Factor VII deficiency, NOVOSEVEN® was used in 24 children aged 0 to <12 years and 7 children aged 12 to 16 years for 38 bleeding episodes, 16 surgeries and 8 prophylaxis regimens. Treatment was effective in 95% of bleeding episodes (5% not rated) and 100% of surgeries. No thrombotic events were reported. A seven-month old exposed to NOVOSEVEN® and various plasma products developed antibodies against FVII and rFVIIa [*see Adverse Reactions and Overdosage*]. Glanzmann's Thrombasthenia: In the Glanzmann's Thrombasthenia Registry, NOVOSEVEN® was used in 43 children aged 0 to 12 years for 157 bleeding episodes and in 15 children aged 0 to 12 years for 19 surgical procedures. NOVOSEVEN® was also used in 8 children aged >12 to 16 years for 17 bleeding episodes and in 3 children aged >12 to 16 years for 3 surgical procedures. Efficacy of regimens including NOVOSEVEN® was evaluated by independent adjudicators as 93.6% and 100% for bleeding episodes in children aged 0 to 12 years and >12 to 16 years, respectively. Efficacy in surgical procedures was evaluated as 100% for all surgical procedures in children aged 0 to 16 years. No adverse reactions were reported in Glanzmann's thrombasthenia children. **Geriatric Use:** Clinical studies of NOVOSEVEN® RT in congenital factor deficiencies and Glanzmann's thrombasthenia did not include sufficient numbers of subjects aged 65 and over to determine whether they respond differently from younger subjects.

OVERDOSAGE: Dose limiting toxicities of NOVOSEVEN® RT have not been investigated in clinical trials. The following are examples of accidental overdose. One newborn female with congenital factor VII deficiency was administered an overdose of NOVOSEVEN® (single dose: 800 micrograms per kg body weight). Following additional administration of NOVOSEVEN® and various plasma products, antibodies against rFVIIa were detected, but no thrombotic complications were reported. One Factor VII deficient male (83 years of age, 111.1 kg) received two doses of 324 micrograms per kg body weight (10-20 times the recommended dose) and experienced a thrombotic event (occipital stroke). One hemophilia B patient (16 years of age, 68 kg) received a single dose of 352 micrograms per kg body weight and one hemophilia A patient (2 years of age, 14.6 kg) received doses ranging from 246 micrograms per kg body weight to 986 micrograms per kg body weight on five consecutive days. There were no reported complications in either case.

More detailed information is available upon request.

For information contact:
Novo Nordisk Inc.
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SPECIAL THANKS TO OUR 2020 END OF YEAR COMMUNITY GATHERING SPONSORS

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2020 End of Year Community Gathering

Once again, HFM is grateful to our own Santa Antonio and his elf Gelli for bringing an afternoon of cheer to the children in our community. While our celebration was virtual this year, there was no shortage of opportunities for everyone to connect and have fun together. Carrie played Mad Libs with the group and Tim created a scavenger hunt that had kids dashing off to retrieve fun and funny items. Each family had the opportunity to chat with Santa Antonio to make sure that their most heartfelt wishes were heard. Each family also received a winter break fun kit that included treats and HFM inspired items to share including a special puzzle featuring Camp Bold Eagle and a Camp Bold Eagle card game! We hope that this time together brought everyone a bit of joy!

Thank you to everyone that attended!

Memories of Santa Antonio and his elves in 2019

In 2020 HFM was able to serve the community in so many ways through outreach, education, and celebration. And it is because of YOU, our donors and community members, that we were able to provide the following events and programs. Thank you!

- HFM quickly brought programming and connection to the online space with our first virtual event on April 4, 2020 with our SpringFest Watch Party
- **118** people participated in camp
- **95** community advocates attended HFM's advocacy webinar series
- **200** community members participated in Community Nights
- **66** families, **98** kids attended the End of Year Community Gathering
- **659** community members received Medical Tags
- **133** individuals were enrolled in the Dental Program
- **123** women participated in HFM's two-day National Conference for Women & Teens with Hemophilia and represented **35** states, **6** countries
- **35** women attended HFM's Women's Retreat
- HFM met with **8** state representatives and **2** policy staff on copay accumulator reform
- HFM hosted **15** Dinner Talk programs with our industry partners, bringing education, activities, and connection

2020

Events through October:

Go to hfmich.org/events for additional information

June 12, 9:30am-3pm
Von Willebrands Disease Symposium

June 18, 6pm
Community Night! Summer Mocktails

June 22, 12-1pm
HFM Ruby Connection: Bee Encounter

July 5-30
Camp Bold Eagle

July 6, 6:30pm
Men's Support Group

July 16, 6pm
Community Night! Toledo Zoo

July 27, 7-8pm
HFM Ruby Connection: Hidden Owls

August 3, 6:30pm
Men's Support Group

August 12, 6pm
Advocacy Webinar: Topic TBD

August 20, 6pm
Community Night! Decorate a Backpack

August 24, 12-1pm
HFM Ruby Connection TBD

September TBD
Old Beagle

September 7, 6:30pm
Men's Support Group

September 18
Unite Michigan Virtual Walk

September 28, 7-8pm
HFM Ruby Connection: Topic TBD

October 5, 6:30pm
Men's Support Group

October 8-9
HFM's National Conference for Women and Teens with Hemophilia

Fall 2021
Patient & Family Upper Peninsula Retreat

October 26, 12-1pm
HFM Ruby Connection: Topic TBD

October TBD
Bleeder & a Buddy

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1921 West Michigan Ave.
Ypsilanti, Michigan 48197

is United for Bleeding Disorders (Hooray!)

Virtual Michigan Unite Walk

Online Program:
September 18, 10am

We are truly embodying the theme of "Unite" this year, as we combine our walks into **ONE** virtual Michigan walk!

To learn how we reached the decision to go virtual and why we are inviting you to fundraise to support the work HFM does for the bleeding disorders community, please go to our Walk event page:
www.hfmich.org/unitewalk21

To register, please go to:
www.hfmich.org/unitewalkregister