

# the artery

*Serving Michigan's bleeding disorders community*

Spring 2018



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



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

## The Advocacy Issue


### Connecting Community Members to their Representatives


Shown here are Dakota and Hunter meeting with their representative, Congressman Bergman, during Washington Days.




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 Hemophilia Foundation of Michigan

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

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# We Are Community, We Are Family!

## Dear HFM family and friends,

My fairly recent experience of becoming a grandparent is truly one of the wonders in my life. I am so very grateful for this extraordinary gift.

When I first began my work with HFM in the early 1980s, I fell in love with our bleeding disorders community. We were like family: passionate, opinionated, quirky, loving, judgmental, forgiving - you know, the qualities and challenges we often experience within our families of origin.

Then the horror of HIV-AIDS devastated hundreds in our Michigan hemophilia family and thousands across the country. Countless hearts were broken as our beloved community members lost their lives with families shattered. Following 13 years of service with HFM, in 1995 I felt compelled to move on. We lost so many amazing people and my heart needed time to heal.

My family stayed connected to HFM, supported events, made contributions. We even volunteered with camp. Our daughter, Jenna, who as an infant slept in my office at the foundation, 'suddenly' became a college student who applied to work in arts and crafts at HFM's Camp Bold Eagle.

There have been many love connections that have taken place with adult counselors, nursing staff, med students, and others over the years – yet, I admit to being a bit surprised when Jenna shared that she was falling for a young man named Tim who happened to have hemophilia.

Jenna and Tim have now been married more than seven years and are the delighted parents of our darling Charlie and Margeaux.

I have been deeply committed to the value of advocacy throughout my career in the nonprofit sector. In my experience, often, for advocacy to be truly effective a significant level of vulnerability and sharing of our being must be shared – **our story is what makes a deep impact.** I felt a clear and absolute responsibility to our bleeding disorders community in the past – now with our son-in-law living with severe hemophilia and our sweet Margeaux a carrier of hemophilia my commitment to advocacy is unconditional.

Please consider sharing your personal stories about the issues you care about.

**We can make all the difference.**

Susan Fenters Lerch  
Executive Director - Great Lakes Region  
V-E Treatment Center Network Director

**CSL Behring** **Pfizer** Hemophilia  
Biotherapies for Life®

We are grateful for the partnership of Pfizer and CSL Behring and their support of HFM's and the Michigan community's advocacy efforts, throughout the year.

**A heartfelt thanks to our 2017 donors and members listed on pages 3 & 4.  
Please consider supporting HFM in 2018!**

PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER.

With gratitude

# HFM Members & Donors - 2017

## you're invited!

HFM invites you to join us in our work as a dues-paying member. Members help direct the work of HFM by having the opportunity to vote on important issues that affect the Michigan bleeding disorders community and by making an annual membership contribution. Lifetime members make a sustaining financial contribution to ensure HFM's ongoing work. We are very appreciative of our 2017 annual members and are especially grateful for our lifetime members. Many additional people have paid membership dues in 2018 and we look forward to continuing to grow. Thank you.

## members

### 2017 Annual Members

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Drs. Judith Andersen Berk  
& William Berk  
Susan and Dan Lerch  
Drs. Deanna Mitchell and  
Gary Rich  
Bill & Laura Sparrow

If you would like to become a member, please contact Gwyn Hulswit at [ghulswit@hfmich.org](mailto:ghulswit@hfmich.org) or 734.544.0015. All of your gifts – your time, your involvement and your financial contributions – are greatly appreciated.

Thank you to our individual financial donors. **This list represents contributions recorded from January 1, 2017 through December 31, 2017** outside of program or registration fees. HFM is grateful to our many supporters that make our community programs and services available.

We would like to acknowledge the following individuals and families who supported our efforts throughout the 2017 calendar year. **Please consider making a donation to HFM in 2018.**

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*With gratitude*

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Please accept our apologies for any errors or omissions. Please contact Gwyn Hulswit at [ghulswit@hfmich.org](mailto:ghulswit@hfmich.org) or at 734.544.0015 to correct our records.





Advocating on behalf of the Michigan bleeding disorders community are Ben Boelens, Elizabeth Boelens, Dakota Moon, Amy Moon, Hunter Klepadlo, Sarah Procario, Allison Albright, Troy Longman.

# Michigan Advocates in Washington

Elizabeth Boelens

Capitol Hill was awash in a sea of red ties as a group of over 500 volunteer advocates from all across the country made their way to Washington DC to attend this year's NHF Washington Days. Val Bias, NHF's CEO, stated that this year was the best attended in the history of the event. Everyone was wearing their red ties in honor of the Red Tie Challenge and Bleeding Disorders Awareness Month.

Ten of us from Michigan had the opportunity to meet with legislative aids from Michigan's two senate offices and several of our representatives' offices to advocate on behalf of the bleeding disorders community.

The meetings focused on how the Affordable Care Act has affected the bleeding disorders community. Our group asked that the patient protections introduced in the ACA continue to be maintained, including the removal of lifetime caps and the ban on discriminating against those with preexisting conditions. We also discussed the need to maintain funding levels for federal hemophilia programs, the inclusion of the Hemophilia Treatment Centers in the 340b program, and the 340b drug discount program that supports income for Hemophilia Treatment Centers.

Overall, our discussions with the legislators and their staff were very productive. Many wanted to hear the personal stories from our families about how having a bleeding disorder has impacted our way of life. Others were interested in hearing how they could help our community and support affordable and accessible health care for all.

Congressman Jack Bergman was interested in learning more about comprehensive care for bleeding disorders and will be visiting the Munson Medical Center in Traverse City in April.

But the advocacy doesn't stop there. **HFM's Lansing Days are coming up on May 22 and 23.**

## Sarah Procario Bleeding Disorders Advocate

All people hold the power to affect change on a personal, local, and global scale when they commit to get involved. I found my own voice in college when I joined a campaign to register students to vote and finally felt like I was making an impact. And now, as a firm believer that all humans deserve access to not only life-saving medication, but also life-enhancing medication, it is extremely important that I lend my time and energy to support improvements in health care.

As the Advocacy Manager at the Hemophilia Foundation of Michigan, I have the privilege to support those affected by bleeding disorders to find their voice and learn how to create positive change for the betterment of themselves and all affected by bleeding disorders.

Washington Days and Lansing Days provide the opportunity for individuals to take action by sharing their story and expressing their concerns with those making decisions. Together we work to represent the bleeding disorders community and protect our future.

I am here to support you—to find your voice, to share your story, to get involved, and to make a difference for yourself and all those in our community.





# Your dreams. Our dedication.

At Shire we are driven to help improve the lives of members of the bleeding disorders community. You inspire us. Each pioneering new product and program represents another step toward our ultimate goal: **a life full of dreams and free of bleeds.**

Michelle  
vWD  
Nevada



[bleedingdisorders.com](http://bleedingdisorders.com)



# ADVOCATE FOR YOUR HEALTHCARE

## hfm<sup>®</sup> Lansing Days '18

Advocating for Michigan's bleeding disorders community

**Questions?** Contact  
**Sarah Procario**  
sprocario@hfmich.org  
734.961.3516

Open to community members and loved ones directly impacted by bleeding disorders.

*Teens 13-17, welcome with permission from parent/guardian, without parent/guardian attendance required.*

On **May 22 & 23, 2018** help support the Michigan bleeding disorders community by sharing your story with your state representatives.

This **free event**, begins **Tuesday, May 22** with an evening of dinner and training at the Kellogg Hotel and Conference Center where HFM will prepare participants for their legislative meetings.

On **Wednesday, May 23**, HFM and community advocates will attend meetings with state representatives and senators to discuss issues impacting the bleeding disorders community.

To learn more, or to register, go to [www.hfmich.org/lansingdayreg](http://www.hfmich.org/lansingdayreg) by May 4, 2018



### Fred Shaltz

I think being a bleeding disorders advocate is learning to discuss our needs. We go to Lansing to explain what resources we need to help us take care of our disorders.



### Kathy Gerus

Every time I attend HFM's Lansing Days I learn something new. Being an active community member requires me to read, engage, ask questions, and stay tuned in to the important issues for people with bleeding disorders. When we have the opportunity to share our personal stories with our elected representatives, it is empowering for both sides. I also enjoy working as teams and meeting new community folks. It is always energizing for me because I feel that I am actively involved in helping all members of our community by educating our lawmakers. I am so very thankful that HFM organizes these events.



### Suzan Higgins

Advocacy stems from our past - lessons from the past guide our future.

Advocacy affects our present - by impacting our daily lives: both treatment and quality of life needs.

Advocacy secures our future - by improving access to those treatments and addressing insurance coverage needs.



### Ken Martin

We in the bleeding disorders community know everything there is to know about our condition, situation, wants, and needs. We need to educate the people that can use what we know in making everyone's future better and brighter.

**Who doesn't want to be part of the solution?**

### Kelly Otto

Bleeding disorders advocacy is important to me because I have two sons with mild Hemophilia A. It took 15 years for us to become involved in Lansing Days, but I'm glad we did! Not only are many of the legislators unfamiliar with hemophilia and Children's Special Health Care Services, but our advocacy also helps to put a face with the disease, and to see that these are fully functioning kids with no visible signs of having a life altering disease!

HFM has always been committed to advocacy. The recent addition of Sarah's staff position has allowed enhanced learning & connections. We invite everyone to add their voice to our efforts.

We're pleased other chapters around the country are emulating this model.



# Policy Update

*Sarah Procaro*

HFM works diligently behind the scenes to research and monitor policies and regulations that may impact the bleeding disorders community. The following updates explain issues that HFM has been monitoring. By staying informed and engaged, we can all become better advocates for the bleeding disorders community.

If you have questions about your medications or insurance, please talk to your Hemophilia Treatment Center. Everyone has a unique situation based on his or her diagnosis, insurance benefits, and provider, and your HTC will be best able to answer your personal questions.

## Michigan Opioid Legislation

On December 27, 2017, the Lieutenant Governor signed a package of legislation into law aimed at curbing the opioid epidemic. Several of the reforms have caused concern for members of the bleeding disorders community who rely on pain medications to relieve chronic pain from a lifetime of joint bleeds.

**The most relevant reforms are explained below.**

### **7 Day Limit on Opioid Prescriptions for Acute Pain:**

Beginning July 1, 2018, if a prescriber is treating a patient for acute pain, the prescriber shall not prescribe the patient more than a 7-day supply of an opioid within a 7-day period. “Acute pain” is defined as pain that is the normal, predicted physiological response to a noxious chemical or thermal or mechanical stimulus and is typically associated with invasive procedures, trauma, and disease and usually lasts for a limited amount of time.

The bill allows for some exemptions including chronic pain, cancer pain, or palliative care.

### **Mandatory Michigan Automated Prescription System:**

Effective June 1, 2018, all licensed prescribers in Michigan will be required to search the Michigan Automated Prescription System (MAPS) when prescribing controlled substances to any patient.

### **Bona Fide Prescriber-Patient Relationship:**

Beginning March 31, 2018, a licensed prescriber shall not prescribe a controlled substance listed in schedules two to five (drug lists can be found at [www.dea.gov/](http://www.dea.gov/)

**druginfo**) unless the prescriber is in a “bona fide prescriber-patient relationship.” Meaning, doctors must have reviewed the patient’s history and provide follow-up care.

We are in communication with Michigan Hemophilia Treatment Centers to better understand the impact this legislation will have on our patients’ access to medication. We will keep the community informed as we learn more. As always, we suggest contacting your Hemophilia Treatment Center regarding medication questions.

## Copay Choice Legislation

Patient advocacy groups across the country have been working to provide solutions for patients who struggle with high out-of-pocket costs for their prescription medications. Copay choice legislation is an attempt to alleviate the impact and uncertainty of high out-of-pocket costs on patients in the beginning of the year (before they have met their deductible). This legislation would require insurance plans to offer a copay only option, which would not require patients to reach a deductible before their insurance begins to pay a portion of the cost. A flat rate copay option, rather than coinsurance which charges a percentage of the prescription cost, would provide consistency for patients so they can plan for payments.



# Accumulator Adjustment Programs

The bleeding disorders community has been monitoring a recent change in how some pharmacy benefit managers are accepting pharmaceutical copay cards. Since January, a number of pharmacy benefit managers (PBMs) have delivered letters to hemophilia patients informing them of a change in their coverage.

Beginning January 2018, a few health plans, specifically high deductible plans offered by self-insured employer groups, have changed the way they calculate copays for patients using these cards. Up until this January, prescription coupons/copay cards have always counted towards a patient's deductible and out-of-pocket maximum. For companies implementing this change, only money paid by the patient will count towards out-of-pocket maximums. PBMs

argue that patients who have no "skin in the game" may choose more expensive drugs without considering cost (because the patient wouldn't be the one paying the price). By only allowing money paid by the patient to count towards their accumulator, they hope to incentivize patients to choose generic drugs and limit unnecessary spending.

Copay cards will still be accepted, however, once a patient uses the full value of their drug coupon/copay card—typically within the first 3 to 5 months of the year—they will still be responsible to cover their expenses (deductible & copays) until they reach their out-of-pocket maximum as defined by their health insurance plan. Because of this change, patients could soon be faced with significant additional financial burdens.

HFM is working closely with other stakeholders to advocate on a state and federal level to inform payers of the unintended consequences of these changes.

HFM works with the National Hemophilia Foundation and the Hemophilia Federation of America to monitor all policies that may affect the bleeding disorders community. We will continue to update and share pertinent information to all members of the bleeding disorders community on policy changes that might impact access to care.

If you have questions about policy changes, have experienced an issue with step therapy or an accumulator adjustment program, or if you are interested in joining advocacy efforts, please contact Sarah Procario at [sprocario@hfmich.org](mailto:sprocario@hfmich.org).

And join HFM on May 22 & 23 at Lansing Days 2018.



their insurer will cover their doctor prescribed medication. The bleeding disorders community maintains that step therapy should not be used when prescribing clotting factor. Biologics products are not therapeutically equivalent and should be prescribed by hemophilia-specialists who have a strong relationship with their patients.

## Step Therapy

Step therapy is utilized by insurance companies to control their costs. Before a plan will cover some (generally more expensive) drugs, they require you to try other (generally less expensive) drugs that also treat the condition. Sometimes referred to as "fail-first" policies, patients must fail on these cheaper or preferred medications, before

Unfortunately, insurers are beginning to incorporate step therapy protocols into their plans. HFM is working closely with the American Autoimmune Related Disease Association to share information and resources with patients and doctors. To learn more about this step therapy initiative, visit [www.letmidoctorsdecide.org](http://www.letmidoctorsdecide.org).

**Advocate for the bleeding disorders community**

## Join HFM's ACTION NETWORK

**Sign up for Advocacy Alerts**  
Sarah Procario at [sprocario@hfmich.org](mailto:sprocario@hfmich.org)

## G L O S S A R Y : *Courtesy of Hemophilia Federation of America*

**Accumulator** – a running total of money you've paid towards your out-of-pocket maximum for covered health care services (this includes your deductible and copays but NOT your premiums).

**Coinurance** – a patient's share of the cost of a health care service, calculated as a percentage (i.e. 20%).

**Copay (copayment)** – a fixed amount you pay for a covered health care service, usually when you get the

service. The amount can vary by the type of coverage.

**Controlled substances** – a drug or chemical whose manufacture, possession, or use is regulated by the government.

**Deductible** – the amount owed for health care services before an insurer begins to pay.

**Out-of-pocket maximum** – the maximum amount you will be required to pay for covered health care services in a year before the plan covers 100% of the costs.

**Pharmacy benefit manager** – contracts with health insurers to handle claims and administrative functions for prescription drugs. PBMs maintain a drug formulary by contracting with specific pharmacies and negotiating rebates with manufacturers.

LIVE IN THE  
BLEED-FREE MOMENT

...with FEIBA prophylaxis patients can have more bleed-free days as compared to on-demand treatment.

Every joint bleed has the potential to do permanent damage<sup>1,2</sup>

Median ABR with prophylaxis vs. on-demand<sup>\*3</sup>

72%

REDUCTION

in median ABR with prophylaxis treatment<sup>3</sup>

28.7 median ABR with on-demand treatment<sup>3,4</sup>

629 bleeding episodes occurred during on-demand treatment<sup>3,4</sup>

VS

7.9 median ABR with prophylaxis treatment<sup>3,4</sup>

196 bleeding episodes occurred during prophylaxis treatment<sup>3,4</sup>

## NO BLEEDS

occurred in 18% (3 out of 17) of patients on FEIBA prophylaxis in a clinical study<sup>†3</sup>

\*Based on the results from the FEIBA PROOF clinical study of 36 hemophilia A and B patients with inhibitors receiving FEIBA for prophylaxis or on-demand treatment for 12 months.<sup>4</sup>

†Of those patients who achieved zero bleeding events, two-thirds completed 12 months of the study.<sup>4</sup>

FEIBA is the ONLY FDA-approved treatment indicated for use in hemophilia A and B patients with inhibitors for routine prophylaxis.<sup>3</sup>

Actual FEIBA patient.

## Indications for FEIBA [Anti-Inhibitor Coagulant Complex]

FEIBA is an Anti-Inhibitor Coagulant Complex indicated for use in hemophilia A and B patients with inhibitors for:

- Control and prevention of bleeding episodes
- Use around the time of surgery
- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes.

FEIBA is not indicated for the treatment of bleeding episodes resulting from coagulation factor deficiencies in the absence of inhibitors to coagulation factor VIII or coagulation factor IX.

## Detailed Important Risk Information for FEIBA

## WARNING: EVENTS INVOLVING CLOTS THAT BLOCK BLOOD VESSELS

- Blood clots that block blood vessels and their effects have been reported during postmarketing surveillance following infusion of FEIBA, particularly following the administration of high doses and/or in patients with a risk of forming blood clots.
- If you experience any of these side effects, call your doctor right away.

You should not use FEIBA if:

- You had a previous severe allergic reaction to the product (reactions causing discomforts that are damaging and life threatening)
- You have signs of development of small blood vessel clots throughout the body
- You have sudden blood vessel clots or blocked blood vessels, (e.g., heart attack or stroke)

Events involving blood clots blocking blood vessels can occur with FEIBA, particularly after receiving high doses and/or in patients with risk factors for clotting.

Infusion of FEIBA should not exceed a dose of 100 units per kg body weight every 6 hours and daily doses of 200 units per kg of body weight. Maximum injection or infusion rate must not exceed 2 units per kg of body weight per minute.

**References:** 1. Pergantou H, Matsinos G, Papadopoulos A, Platokouki H, Aronis S. Comparative study of validity of clinical, X-ray and magnetic resonance imaging scores in evaluation and management of haemophilic arthropathy in children. *Haemophilia*. May 2006;12(3):241-247. 2. Gringeri A, Ewenstein B, Reininger A. The burden of bleeding in haemophilia: is one bleed too many? *Haemophilia*. Jul 2014;20(4):459-463. 3. FEIBA Prescribing Information. 4. Antunes SV, Tangada S, Stasyshyn O, et al. Randomized comparison of prophylaxis and on-demand regimens with FEIBA NF in the treatment of haemophilia A and B with inhibitors. *Haemophilia*. 2014;20(1):65-72.

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S25994 12/16

At first sign or symptom of a sudden blood vessel clot or blocked blood vessel (e.g., chest pain or pressure, shortness of breath, altered consciousness, vision, or speech, limb or abdomen swelling and/or pain), stop FEIBA administration promptly and seek emergency medical treatment.

Allergic-type hypersensitivity reactions, including severe, sometimes fatal allergic reactions that can involve the whole body, can occur following the infusion of FEIBA. Call your doctor or get emergency treatment right away if you get a rash, hives or welts, experience itching, tightness of the throat, vomiting, abdominal pain, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Because FEIBA is made from human plasma it may carry a risk of transmitting infectious agents, e.g., viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent.

The most frequent side effects observed during the prophylaxis trial were anemia, diarrhea, bleeding into a joint, signs of hepatitis B surface antibodies, nausea, and vomiting.

The serious side effects seen with FEIBA are allergic reactions and clotting events involving blockage of blood vessels, which include stroke, blockage of the main blood vessel to the lung, and deep vein blood clots.

Call your doctor right away about any side effects that bother you during or after you stop taking FEIBA.

Please see next page for Important Facts about FEIBA.

To see the Full Prescribing Information, including BOXED WARNING on blood clots, go to [www.FEIBA.com](http://www.FEIBA.com).

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



## **Important Facts about FEIBA (Anti-Inhibitor Coagulant Complex)**

### **What is FEIBA used for?**

FEIBA (Anti-Inhibitor Coagulant Complex) is used for people with Hemophilia A or B with Inhibitors to control and prevent bleeding episodes, before surgery, or routinely to prevent or reduce the number of bleeding episodes. It is NOT used to treat bleeding conditions without inhibitors to Factor VIII or Factor IX.

### **When should I not take FEIBA?**

You should not take FEIBA if you have had hypersensitivity or an allergic reaction to FEIBA or any of its components, including factors of the kinin generating system, if you have a condition called Disseminated Intravascular Coagulation, which is small blood clots in various organs throughout the body, or currently have blood clots or are having a heart attack. Make sure to talk to your healthcare provider about your medical history.

### **What Warnings should I know about FEIBA?**

**FEIBA can cause blood clots, including clots in the lungs, heart attack, or stroke, particularly after high doses of FEIBA or in people with a high risk of blood clots.** Patients that have a risk of developing blood clots should discuss the risks and benefits of FEIBA with their healthcare provider since FEIBA may cause blood clots. FEIBA can cause hypersensitivity or allergic reactions and infusions site reactions, and these reactions can be serious. Because FEIBA is made from human plasma, it may carry the risk of transmitting infectious agents, for example, viruses, including Creutzfeldt-Jakob disease (CJD) agent, and the variant CJD agent. Although steps have been taken to minimize the risk of virus transmission, there is still a potential risk of virus transmission.

### **What should I tell my healthcare provider?**

Make sure to discuss all health conditions and medications with your healthcare provider. If you are pregnant or are planning to become pregnant, or are a nursing mother, make sure to talk with your healthcare provider for advice on using FEIBA.

### **What are the side effects of FEIBA?**

The most frequent side effects of FEIBA are: low red blood cell count, diarrhea, joint pain, hepatitis B surface antibody positivity, nausea, and vomiting. The most serious side effects of FEIBA include: hypersensitivity reactions, including anaphylaxis, stroke, blood clots in the lungs, and blood clots in the veins. Always immediately talk with your healthcare provider if you think you are experiencing a side effect.

### **What other medications might interact with FEIBA?**

The use of other clotting agents with FEIBA is not recommended, for example, tranexamic acid and aminocaproic acid. Be sure to talk with your healthcare provider and pharmacist about all medications and supplements you are taking.

**You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088**

**The risk information provided here is not comprehensive. To learn more, talk about FEIBA with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at [http://www.feiba.com/us/forms/feiba\\_pi.pdf](http://www.feiba.com/us/forms/feiba_pi.pdf) or by calling 1-800-423-2090 and selecting option 5.**

# Meet Shelley, your CoRe Manager



Hello! I'm Shelley Gerson and I'm a CoRe Manager for Bioverativ. It is my job to connect you with others in the community, introduce our educational programs, and to support you on your journey. I am here so we can take action together! I also have severe hemophilia A.

.....

**Contact me!**

[shelley.gerson@bioverativ.com](mailto:shelley.gerson@bioverativ.com) | 781.663.1807

.....



 Connect with Us @BioverativCoRes





# Teen Retreat: Teens, Tweets, & Technology

*Sarah Procario*

Every year, HFM hosts a weekend retreat for teens to get together, learn more about the bleeding disorders community, and have fun.

This year, our teens learned about advocacy and their role in the bleeding disorders community. Throughout our community's history, advocacy has been extremely important to the improvement of care and coverage for affected individuals. As political discussions continue to focus on health care and health policy reform, patient advocacy in the bleeding disorders community remains as important as ever. And it's critical that teens understand how important their voices are in the conversation.

During the Teen Retreat, HFM staff helped empower our teens to take action to influence a cause by utilizing media and technology. The teens spent time with friends, filmed videos advocating for their personal cause, and learned how powerful their voice can be. The groups of teens filmed videos

advocating for gun reform, mental health care equality, and world hunger programs. After our activity, we discussed how to use social media in the same way when advocating for the bleeding disorders community.

If you are interested in the work our teen advocates are doing, **stop by HFM's Advocacy Action Booth at SpringFest on Saturday, April 21.** We have a dedicated and empowered group of teens that are readily becoming the next generation of leaders in our community.

*"I really learned what advocacy means to me, how to put it out there and why it was important."*

*~Ali Haidar*

Thanks to our sponsor, for helping to support this event.

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# Federal Advocacy Update

Deema Tarazi, JD Policy Analyst, Hemophilia Federation of America

Activity at the federal level is not as hectic as it was a year ago, when both the House and Senate were trying to repeal the Affordable Care Act (ACA). Today the bleeding disorders community is still facing a lot of challenges, but we find ourselves in a better position than we could have hoped for a year ago.

It is unlikely that Congress will try again this year to repeal the ACA. However, even though a legislative effort to repeal the ACA is unlikely, administrative action to further change the ACA via rulemaking is certain. The Hemophilia Federation of America (HFA) is actively keeping an eye on Executive Orders and is submitting comments in response to federal agency rulemakings that may impact the community's access to quality health care.

In addition to administrative actions to roll back the ACA, some members of Congress have started to introduce bills to make minor "fixes" to the ACA. On the House side, Representatives Ryan Collins (R) and Collin Peterson (D) introduced a bill to create a \$30 billion stability fund

over the next three years, as a reinsurance fund that is allocated to the States. Similarly, on the Senate side, Senators Susan Collins (R) and Bill Nelson (D) introduced a bill that would leverage 1332 waivers (which allow states to waive ACA requirements) that would provide \$5 billion in funding to support states in establishing risk pools and reinsurance programs in 2019 and 2020. A reinsurance fund may help subsidize the cost of providing health insurance to individuals with high premiums and out of pocket costs. It is currently unclear which, if any, of the ACA repair bills might move forward in 2018. Therefore, HFA will continue to keep a close eye on any legislation that affects the community's access to care and will continue to ask for your voice to be heard!

Furthermore, Medicaid has started to receive increased national attention. Medicaid is a joint state-federal program: the federal government provides much of the funding and establishes minimum standards, but states administer the program and can seek waivers from certain federal requirements. The

federal Centers for Medicare and Medicaid Services (CMS) has started to approve certain Medicaid waivers that the past Administration did not allow, including (most controversially) imposing work requirements on individuals who receive Medicaid.

Patient advocates have concerns about Medicaid work requirements. Most non-disabled adult Medicaid enrollees who can work already do so. Perhaps most concerning, at least five states are proposing to combine work requirements with lifetime caps on benefits or other extreme limits on the periods for which enrollees can remain eligible for Medicaid benefits. HFA is closely monitoring the states that have applied for Medicaid waivers—Michigan has not applied for this type of waiver.

HFA thanks the HFM community for their continuation of your grassroots advocacy. Challenges will continue in 2018, so please stay engaged, vigilant, and continue to have your voice be heard!

## Advocacy

{the act of supporting a cause}

For many, the word advocacy makes one think of HFM's annual legislative event, Lansing Days. While legislative days are wonderful ways to advocate, they only happen once a year and are just one type of advocacy. Advocacy, the act of supporting a cause or proposal, can be accomplished in a myriad of ways such as educating friends and peers, sharing education online, starting a petition, and simply standing up for your own health care needs at your doctor's appointment.

HFM community member, **Daphne**, showed us how to be a bleeding disorders advocate outside of Lansing Days. Daphne joined the **Red Tie Campaign** during Bleeding Disorders Awareness Month to support von Willebrand Disease Awareness. Daphne asked all of her friends on social media to GO RED on March 26. Many thanks to Daphne for her dedication to bleeding disorders advocacy.



**How can you bring attention to an issue of importance (like bleeding disorders awareness!) and if needed, support a path for change?**



# SWINGING for Smiles

Monday, June 4, 2018 | Washtenaw Golf Club, Ypsilanti | [hfmich.org/golf](http://hfmich.org/golf)

Online registration  
[www.hfmich.org/golf](http://www.hfmich.org/golf)

**Foursome, includes dinner \$750**  
**Individual, includes dinner \$200**  
**Dinner only (no golf) \$50**

For more information, contact  
**Carrie McCulloch** at  
[cmcculloch@hfmich.org](mailto:cmcculloch@hfmich.org)



benefiting  
HFM's Eagle Journeys  
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## Charity Golf Outing

Join HFM for an unforgettable evening of transformation.

# Butterfly

B E N E F I T

- Honoring **Dr. Deanna Mitchell**
- And, hear from community member **Ben Boelens**

Thursday, May 10, 2018 | 5:30-9pm | Grand Rapids Art Museum | [hfmich.org/benefit-tickets](http://hfmich.org/benefit-tickets)

### Music, Dinner, Auction & more!

Make a night of it with your friends and help send West Michigan children with bleeding disorders to summer camp.

**Purchase tickets or make a donation:**  
[www.hfmich.org/benefit-tickets](http://www.hfmich.org/benefit-tickets)

Limited Seating - starts at \$40

For more information,  
contact Carrie McCulloch  
HFM Special Events Manager  
West Michigan Office  
[cmcculloch@hfmich.org](mailto:cmcculloch@hfmich.org)  
734.544.0015 ext. 503



benefiting



Our walks are **UNITING!** Participate. Volunteer. Donate.

**Registration Opens April 20th!**

<https://www.uniteforbleedingdisorders.org/>

**August 26**

UNITE for Bleeding  
Disorders Walk  
(Walkin' on the Wild Side)  
Detroit Zoo, Royal Oak  
[cmcculloch@hfmich.org](mailto:cmcculloch@hfmich.org)

**October 20**

UNITE for Bleeding  
Disorders Walk  
(Walkin' on the West Side)  
Fifth Third Ballpark, Grand Rapids  
[cmcculloch@hfmich.org](mailto:cmcculloch@hfmich.org)

# Unite

for Bleeding Disorders



*The hemophilia treatments  
of today were once  
the dreams of yesterday.  
Proof that when*

# SCIENCE AND THE COMMUNITY

*come together, great things happen.*

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*Let's put science to work*





# The Perspective We Needed

Jay McCulloch

"I'll be the only thirteen-year old out there with a helmet on my head!" As Jonas' four siblings and I were sprinting out our van door to the sledding hill, my wife, Amber, heard this emotional response from Jonas, our adopted son from China, on his first sledding adventure since he had become a part of our family. Forty-five minutes later, after many tears and concerns of being embarrassed on the slope from having to wear a bike helmet and phone calls to our friend and nurse, Missy, from Children's Hospital of Michigan, Jonas finally emerged with a helmet to sled with his siblings down that snow-covered hill.

We officially adopted Jonas in November of 2016, our first child with hemophilia. It has been a brand new and exciting world for us, yet having a child with severe hemophilia A has also been an anxiety-filled journey with a tremendous learning curve for our whole family, especially Amber. Our lives now include infusions twice a week, expensive medication arriving on our porch, and increased awareness of everyday dangers that could cause an internal bleed. We have been able to face these new challenges thanks to the support of the hemophilia staff at Children's Hospital of Michigan and wonderful friends and advocates, like Shari Wilson Luckey,

Advocacy and Outreach Coordinator at the Hemophilia Foundation of Michigan. These "sledding moments" are now not seen as obstacles and trials but needed, refreshed perspectives on life.

Since Jonas has joined our family, we have learned how much we take for granted as we rise each day from our beds, with no concerns about needing factor and no thought about the added awareness of being safe to avoid cuts and bruises. Now, with our beloved Jonas, experiences, like sledding and amusement park visits and bike rides, mean that we must be aware of more than ourselves. When his ankle hurts from a past bleed or when infusions require multiple "pokes," we see Jonas' struggle with hemophilia. But we also see a young man with joy and determination who blesses us with his unyielding spirit. Sure he may have to wear a helmet (his mom has since bought him a "cool" snowboarding helmet), but he is enjoying the thrill of plunging down that hill. Today, we celebrated one of his first self-infusions where he found success on his first "poke". He is determined to live life to its fullest, and that has inspired us and improved the way we all live in the McCulloch family.

**For more information on hemophilia adoption opportunities, please contact HFM's Advocacy and Outreach Coordinator, Shari Luckey, at [sluckey@hfmich.org](mailto:sluckey@hfmich.org).**

To learn more about Delta Dental insurance, go to [www.hfmich.org/dentalinsurance](http://www.hfmich.org/dentalinsurance). If you have questions about the program or eligibility, contact Lisa Clothier, LMSW, Outreach and Community Education Manager at [lclothier@hfmich.org](mailto:lclothier@hfmich.org) or 734.961.3512.





## FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN

*For people with hemophilia, Factor treatment temporarily replaces what's missing.<sup>1</sup> With a long track record of proven results, Factor treatment works with your body's natural blood clotting process to form a proper clot.<sup>2,3</sup>*

*Brought to you by Shire, dedicated to pursuing advancements in hemophilia for more than 60 years.*

**Stay empowered by the possibilities.**

**References:** **1.** Peyvandi F, Garagiola I, Young G. The past and future of haemophilia: diagnosis, treatments, and its complications. *Lancet*. 2016;388:187-197. **2.** Wolberg AS. Plasma and cellular contributions to fibrin network formation, structure and stability. *Haemophilia*. 2010;16(suppl 3):7-12. **3.** King MW. Introduction to blood coagulation. <http://themedicalbiochemistrypage.org/blood-coagulation.php>. Last modified January 2, 2017. Accessed January 2, 2017.

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# Advocating for Children's Special Health Care Services

Sarah Procario

## What is it?

Children's Special Health Care Services (CSHCS) is a program within the Michigan Department of Health and Human Services, administered under Title V of the Federal Social Security Act. It was created to find, diagnose, and treat children and some adults in Michigan with chronic health care needs. CSHCS is committed to removing barriers to appropriate health care and may be able to help with paying specialty medical bills, covering insurance co-pays and deductibles for private insurance, helping families to keep private insurance, and addressing transportation needs for medical care. CSHCS covers people under the age of 21 with a qualifying medical condition. However, the age limitation is waived

for patients with certain blood clotting disorders (hemophilia and other bleeding disorders) and cystic fibrosis. Families of all incomes are eligible to join, including those with other health insurance including Medicaid—though there may be a yearly fee to join CSHCS based on family income and family size.

Visit [www.michigan.gov/cshcs](http://www.michigan.gov/cshcs) or call the CSHCS Family Phone Line at 800.359.3722 for more information.

## Why does HFM advocate for CSHCS every year at Lansing Days?

CSHCS's funding can change yearly. The program is funded through a combination of federal (Title XIX and Title V) funds, as well as state general funds. While Title V funds are capped,

state general funding levels may vary based on the state budgetary needs. Additionally, language providing adult coverage must be maintained in the annual appropriations bill each year to ensure access for our adult population. In 2005, the Granholm Administration proposed eliminating coverage for cystic fibrosis and hemophilia adults in the Title V population. The bleeding disorders community organized an effective campaign against the proposal and successfully saved the adult coverage.

CSHCS provides valuable assistance to our bleeding disorders community. We invite you to join us at Lansing Days to talk to representatives about the value of the program to ensure it is not faced with such a threat again.

## SpringFest 18

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# Got Work?

Ellen Kachalsky, LMSW; Suzanne Rogers, LMSW

"Got Work?" was a collaborative opportunity put together by the social workers at the Hemophilia Foundation of Michigan, and the Hemophilia Treatment Centers at Children's Hospital of Michigan, Karmanos Cancer Center, and Henry Ford Cancer Institute through support by the Hemophilia Federation of America.

This educational dinner program was held on November 28th in Detroit. The event was open to individuals of all ages with the goal of providing information about career-planning assistance available for patients with bleeding disorders.

Three local agencies made their services available to assist our patients: The Urban League of Detroit, Southwest Solutions, and IT in the D. Each offered a different perspective on how to conduct a job search. Participants learned about a range of jobs from trucking and manufacturing to high tech entry-level positions, such as working a help-desk. Many of these jobs include training and support as well as stipends.

Additional agencies, not represented by speakers, provided flyers detailing their worthwhile programs, from resume building to internet networking.

With enthusiasm and rekindled hope as initial measures of success, the evening proved most beneficial. Evaluations indicated patients were thrilled to learn about new resources, and felt validated and supported for their tenacity and willingness to seek work, against the odds. Building on the support of the program, next steps include tapping into self-motivation and interpersonal skills to develop a network and promote oneself in the job market. But for these determined patients, it's all in a day's work!

Future meetings on this topic, with other organizations are being considered.

## PAID CONSUMER OUTREACH

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Antihemophilic Factor  
(Recombinant), Single Chain



# Join Us in the Health Center at Camp Bold Eagle



HFM's camping programs create a special place where every child with a bleeding disorder can experience a sense of belonging. Camp Bold Eagle was established in 1969; we are proud of our distinction as the oldest hemophilia camp in the United States—in fact in the world!

Camp Bold Eagle offers a traditional summer camp environment with the addition of a robust Health Center. Staffed by doctors, nurses, social workers, and physical therapists from HTC's throughout the region, as well as volunteer members of the health care community, we work hard to ensure the health and safety of our campers.

We are happy to invite volunteer nurses from our community to join us this summer at camp. Please contact me if you are interested in volunteering or if you would like more information!

**Diana Mathis, RN BSN-BC**  
**Health Center Director**  
dlmathis@umich.edu  
734.544.0015

## PAID CONSUMER OUTREACH

A large advertisement for IXINITY. It features a close-up of a woman's face, with a semi-transparent image of a person riding a bicycle overlaid on the left side. The background is a light, textured blue. The IXINITY logo is in the top right, and the text 'Discover more about IXINITY' is in the bottom right. The Aptevo Therapeutics logo is in the bottom left.

**IXINITY<sup>®</sup>**  
coagulation factor IX  
(recombinant)

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*"We are so thankful for all that Dr. Gruppo has contributed to the bleeding disorders community; he will be missed greatly!" ~ Susan Fenters Lerch*

# Dr. Ralph Gruppo Retires

Lisa Littner, LISW-S



Dr. Ralph Gruppo, director of the Comprehensive Hemophilia and Thrombosis Center at Cincinnati Children's Hospital, retired at the end of 2017 and now serves as Professor Emeritus. Dr. Gruppo began his residency at Cincinnati Children's Hospital in 1968, working with Dr. Beatrice Lampkin, the Hematology/Oncology Medical Director at that time, to care for patients with blood disorders.

Cincinnati Children's was the first hemophilia treatment center established in Ohio and began as a pilot project to offer comprehensive care. Dr. Gruppo became the director of Cincinnati

Children's Hemophilia Treatment Center in 1974. Based on the success of the model at Cincinnati Children's under Dr. Gruppo's direction, a number of pediatric hemophilia centers in Ohio were subsequently designated.

Dr. Gruppo was the Associate Director of the Division of Hematology/Oncology from 1988 to 1991 and acting director from 1991 to 1994. In 2011, he received the Cincinnati Pediatric Society Founder's Award. He has had numerous publications and was the primary investigator for various studies related to blood disorders. Dr. Gruppo also made significant contributions in the area of thrombosis

and pioneered the treatment of congenital atypical hemolytic uremic syndrome with Eculizumab.

Dr. Gruppo plans to remain connected to the hemophilia community by serving on the advisory board with the Tri-State Bleeding Disorder Foundation's Dr. Joseph E. Palascak Endowed Chair in Bleeding and Clotting Disorders Campaign.

At his recent retirement celebration, Dr. Gruppo reflected on his years of practice. "I always tell the residents, Hematology/Oncology is unique. It has been a wonderful career."

## PAID CONSUMER OUTREACH

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

**17%** Factor IX (FIX) levels sustained after 7 days with a single 40 IU/kg dose in adults with  $\leq 2\%$  factor levels\*



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

\*In two phase 3 studies, factor levels were evaluated for 1 week after the first dose of Rebinyn® 40 IU/kg. The average levels after 7 days were 16.8% in 6 adults, 14.6% in 3 adolescents, 10.9% in 13 children ages 7 to 12 years, and 8.4% in 12 children up to age 6 years. Image of hemophilia B patient shown is for illustrative purposes only.

#### INDICATIONS AND USAGE

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

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

#### IMPORTANT SAFETY INFORMATION

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

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

##### Who should not use Rebinyn®?

Do not use Rebinyn® if you:

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

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

Tell your health care provider if you:

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

##### How should I use Rebinyn®?

- Rebinyn® is given as an infusion into the vein.

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

- Do not stop using Rebinyn® without consulting your healthcare provider.

##### What are the possible side effects of Rebinyn®?

- Common side effects include swelling, pain, rash or redness at the location of the infusion, and itching.
- Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction: hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.
- Tell your healthcare provider about any side effect that bothers you or that does not go away.

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

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

Rebinyn® is a prescription medication.

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

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(Recombinant), GlycoPEGylated



**rebiny<sup>®</sup>****Coagulation Factor IX  
(Recombinant), GlycoPEGylated****Brief Summary Information about:  
REBINYN<sup>®</sup> Coagulation Factor IX  
(Recombinant), GlycoPEGylated****Rx Only**

This information is not comprehensive.

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

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

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

**What is the most important information I need to know about REBINYN<sup>®</sup>?**

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

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

**What is REBINYN<sup>®</sup>?**

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

REBINYN<sup>®</sup> is used to treat and control bleeding in people with hemophilia B.

Your healthcare provider may give you REBINYN<sup>®</sup> when you have surgery.

REBINYN<sup>®</sup> is not used for routine prophylaxis or for immune tolerance therapy.

**Who should not use REBINYN<sup>®</sup>?**

You should not use REBINYN<sup>®</sup> if you

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

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

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

**What should I tell my healthcare provider before I use REBINYN<sup>®</sup>?**

You should tell your healthcare provider if you

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

**How should I use REBINYN<sup>®</sup>?**

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

REBINYN<sup>®</sup> is given as an infusion into the vein.

You may infuse REBINYN<sup>®</sup> at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your hemophilia treatment center or healthcare provider. Many people with hemophilia B learn to

infuse the medicine by themselves or with the help of a family member.

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

**Call your healthcare provider right away if your bleeding does not stop after taking REBINYN<sup>®</sup>.**

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

**Use in children**

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

**If you forget to use REBINYN<sup>®</sup>**

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

**If you stop using REBINYN<sup>®</sup>**

Do not stop using REBINYN<sup>®</sup> without consulting your healthcare provider.

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

**What if I take too much REBINYN<sup>®</sup>?**

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

**What are the possible side effects of REBINYN<sup>®</sup>?****Common Side Effects Include:**

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

**Other Possible Side Effects:**

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

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

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

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

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

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

**What are the REBINYN<sup>®</sup> dosage strengths?**

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

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

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

**How should I store REBINYN<sup>®</sup>?**

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

Store in original package in order to protect from light. Do not freeze REBINYN<sup>®</sup>.

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

If you choose to store REBINYN<sup>®</sup> at room temperature:

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

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

**After Reconstitution:**

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

The reconstituted REBINYN<sup>®</sup> should be used immediately.

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

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

**What else should I know about REBINYN<sup>®</sup> and hemophilia B?**

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

**More detailed information is available upon request.**

Available by prescription only.

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

Revised: 11/2017

REBINYN<sup>®</sup> 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

For information about REBINYN<sup>®</sup> contact:

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800 Scudders Mill Road

Plainsboro, NJ 08536, USA

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USA17BIO03951 12/2017



## 2018 EVENTS

### May 10

Butterfly Benefit  
Grand Rapids Art Museum (GRAM)  
cmcculloch@hfmich.org

### May 22-23

Lansing Days  
Kellogg Center, East Lansing  
sprocaro@hfmich.org

### June 4

Swinging for Smiles  
Charity Golf Outing  
Washtenaw Golf Club, Ypsilanti  
cmcculloch@hfmich.org

### June 8

Community Night  
Craig's Cruisers, Grand Rapids  
cmcculloch@hfmich.org

### August 26

UNITE for Bleeding Disorders Walk  
(Walkin' on the Wild Side)  
Detroit Zoo, Royal Oak  
cmcculloch@hfmich.org

### September TBA

Women's Retreat  
Location TBA  
pthomas@hfmich.org

### September 28-29

Upper Peninsula  
Education Weekend  
Marquette  
lclothier@hfmich.org

### October 19-21

Bleeder and a Buddy  
Location TBA  
twicks@hfmich.org

### October 20

UNITE for Bleeding Disorders Walk  
(Walkin' on the West Side)  
Fifth Third Ballpark, Grand Rapids  
cmcculloch@hfmich.org

### October 26

Community Night  
Incredible Mo's, Traverse City  
cmcculloch@hfmich.org

### November 2

Community Night  
Spare Time, Lansing  
cmcculloch@hfmich.org

## FIRST EVER!

### November 10-11

HFM's 2018 National Conference  
Being Visible: Women and Hemophilia  
Amway Grand Hotel  
Grand Rapids  
pthomas@hfmich.org

### December TBA

End of the Year Community Gathering  
(Holiday Party), Troy  
cmcculloch@hfmich.org



734. 544.0015

[www.hfmich.org](http://www.hfmich.org)

1921 West Michigan Ave.  
Ypsilanti, Michigan 48197

## Camp Registration Closes May 25, 2018!

Questions about camp? Please contact  
Tim Wicks or Anthony Stevens @ 734.544.0015



### Eagle Journeys Camping PROGRAMS

#### June 2-8

Eagle Quest  
(Ages 18+)

#### June 17-23

Eagle Outpost  
(Ages 14-15)

#### July 1-7

CBE Teen Camp  
(Ages 13-17)

#### July 9-28

CIT Program

#### July 11-14

Camp Staff Training

#### July 15-19

CBE Session One  
(Ages 6-9)

#### July 21-27

CBE Session Two  
(Ages 10-12)

#### August 1-9

Eagle Expedition  
(Ages 16+)

#### September 14-16

Camp Old Beagle  
(Ages 18+)

#### December 15

Camp Holiday Party  
twicks@hfmich.org

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 Hemophilia Foundation of Michigan