the artery

Serving Michigan's bleeding disorders community

Eagle Journeys
HFM Camping Adventures

hfm

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

www.hfmich.org
734.544.0015

Spring/Summer '17

SpringFest 2017 Waves of Change!

SpringFest 2017 keynote speaker, Mike Callaghan, M.D., of Children's Hospital of Michigan, Detroit, shared his insights on the topic of New Horizons for Care in Bleeding Disorders. Dr. Callaghan was also the recipient of HFM's inaugural Dr. Penner Award. Read Dr. Callaghan's interview with HFM's Sarah Procario about Advancements in the Treatment of Bleeding Disorders. pg. 9

HFM's SpringFest 2017! pg. 6,7

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

We Are Community

Left to right: HFM's Advocacy/ Communications Manager, Sarah Procario; HFM's Executive Director, Susan Fenters Lerch and Congresswoman Debbie Dingell during SpringFest 2017

Dear friends,

HFM's spring and summer months bring large community undertakings–we are grateful to our outstanding and committed staff and volunteers. **More than 650 community members participated with SpringFest 2017**. Educational sessions received excellent reviews as did this year's outstanding kids' programming. Yep, the food and meal service was a problem and we have addressed that directly with the Eagle Crest Marriott's General Manager and senior staff. We are appreciative of the many positive aspects of this annual, growing, education-focused weekend and appreciate our terrific presenters and participants!

HFM is deeply committed to community education and advocacy in Michigan particularly, though we also recognize the importance and value of regional, national, and global involvement. Our year-round commitment to advocacy programming includes an active committee, education and training efforts, and sharing of information regarding how to make our voices heard. Congresswoman Debbie Dingell presented during SpringFest to encourage our community's continued bi-partisan efforts to share personal stories and the importance of both national and state programs that provide support to the bleeding disorders community. Our 2017 Lansing Days program included 100 community members' involvement with expanded training and legislator visits. We maxed out hotel space this year with more involvement than ever! We must keep this momentum going so legislators understand our community's needs and challenges.

Meanwhile, I just returned from a two week trip to Sri Lanka, a small country just south of India. Travel to Sri Lanka from Detroit includes more than two days of flights! The World Hemophilia Federation supported this "twinning" assessment visit to determine if HFM and the Hemophilia Association of Sri Lanka (HASL) are a good fit to provide strategic planning and program development support. This twinning project has been in process for a couple of years thanks to the commitment of HFM Board member Jeeva Nadarajah who is native to Sri Lanka. I had the privilege to speak during HASL's World Hemophilia celebration with local medical professionals and more than 300 community members from across their country. This visit emphasized to me the good fortune we have in our country in a myriad of ways - including access to individualized care. I look forward to determining how we can share ideas and programming with our fellow bleeding disorders community members in Sri Lanka.

It is my heartfelt belief that giving of oneself represents how we individually and collectively improve the world – and we have the opportunity to do this in so many ways! Please consider becoming more involved with HFM by giving of your time, talent, and treasure. We are grateful for your commitment. Oh yes, HFM's Eagle Journey's summer camp programs are now in full swing - wow - it's summer, enjoy!!

Fondly,

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

PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER.

2016 Financial Snapshot

HFM Chapter/HFM Federal Regional Core Center for HTC Network (Michigan, Ohio, Indiana)

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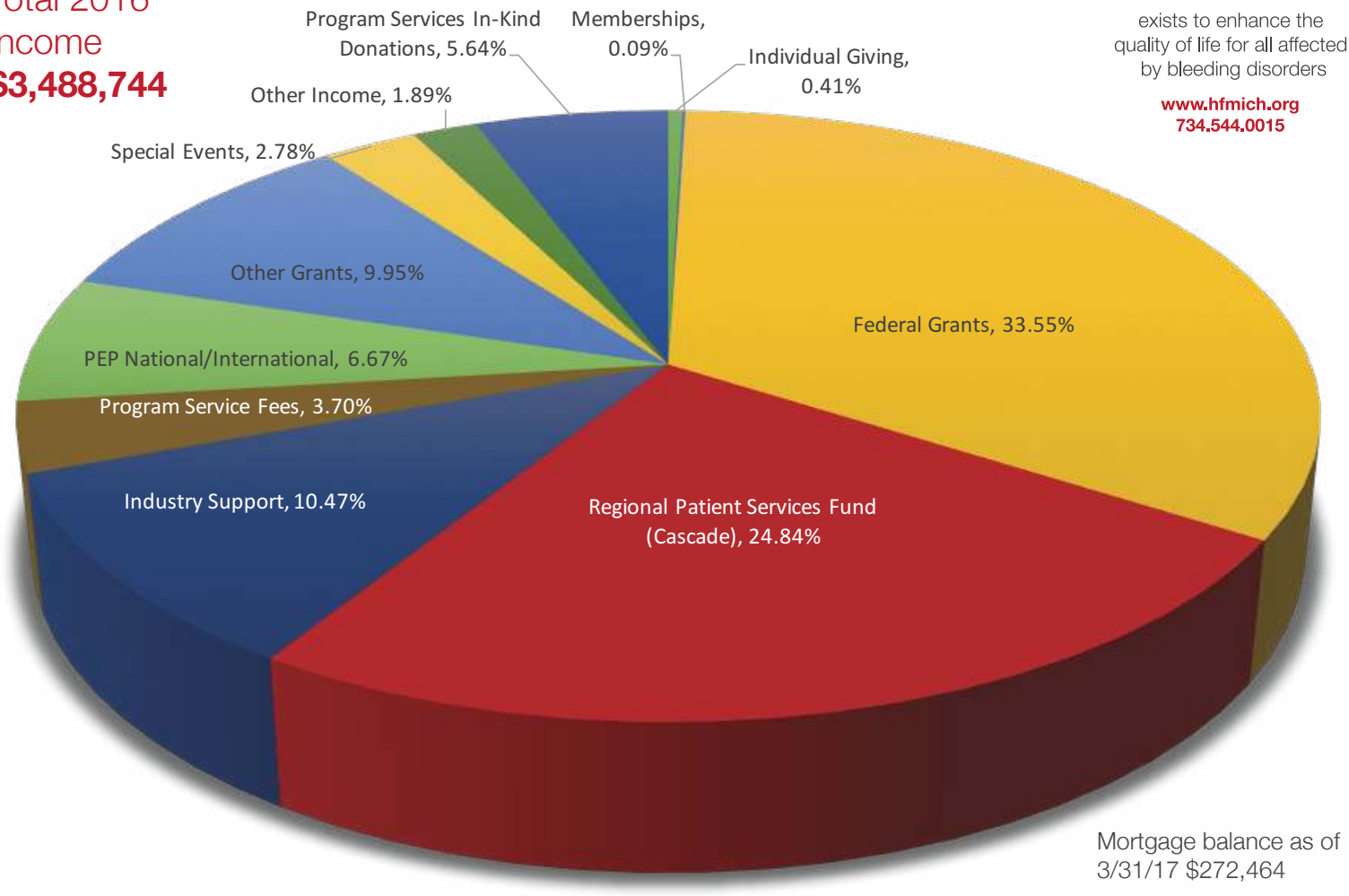
Total 2016 Income
$3,488,744



Mortgage balance as of 3/31/17 $272,464

Total 2016 Expenses
$3,483,379

Program Services (includes Camp & Communications)
$1,999,877
57.41%

Payment to HTCs
$957,154
27.48%

Operations & Development Services
$526,348
15.11%

Program Services Highlights ~ $1,999,877 ~ 57.41% (includes Camp & Communications)

- Financial assistance including academic scholarships
- Michigan and Ohio HTC nurse/social work meetings
- **Eagle Journeys:**
  - Eagle Quest
  - Eagle Outpost
  - Camp Bold Eagle – three one week sessions
  - Eagle Expedition
  - Old Beagle camp alumni retreat
- **Retreats**: women, HIV positive individuals & families, two teen retreats (Bleeder & a Buddy, and Teen Retreat)
- Detroit Youth Mentoring Program
- Outreach to Arabic and Spanish speaking community
- SpringFest (educational programs, childcare, meals, etc.)
- Lansing Days
- Advocacy coalition – year-round advocacy work
- Parents Empowering Parents (PEP)
- World AIDS Day Detroit (WADD)
- International Twinning Program with Sri Lanka
- International/National adoption program for children with bleeding disorders
- Days for Girls
- Social Media (Facebook, Instagram, Email marketing)
- The Artery (newsletter)
- HFM Web site

PAID CONSUMER OUTREACH

ADYNOVATE
[Antihemophilic Factor (Recombinant), PEGylated]

For patients with Hemophilia A, the FDA has now approved ADYNOVATE® for
+ Use in children under 12
+ Use in surgery

PROVEN PROPHYLAXIS + SIMPLE,* TWICE-WEEKLY DOSING SCHEDULE =

moments YOUR WAY

*ADYNOVATE allows you to infuse on the same 2 days every week.

The pediatric study (N=73) evaluated the efficacy, PK, and safety of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months.[1,2]

+Sixty-six patients (32 patients aged <6 years and 34 patients aged 6 to <12 years) received 40-60 IU/kg of ADYNOVATE prophylactically, twice weekly[2]

+Children experienced a median overall ABR of 2.0 (IQR: 3.9) and a median ABR of zero for both joint (IQR: 1.9) and spontaneous (IQR: 1.9) bleeds[1,3]

+38% (n=25) of children experienced zero total bleeds; 73% (n=48) experienced zero joint bleeds; and 67% (n=44) experienced zero spontaneous bleeds[1]

Talk to your doctor and visit ADYNOVATE.com

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated] Important Information

Indications

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

You should not use ADYNOVATE if you:
- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

You should tell your healthcare provider if you:
- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

You can have an allergic reaction to ADYNOVATE.
Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.
Please see following page for ADYNOVATE Important Facts.

For full Prescribing Information, visit www.ADYNOVATE.com.

References: 1. ADYNOVATE Prescribing Information. Westlake Village, CA: Baxalta US Inc. **2.** Mullins ES, Stasyshyn O, Alvarez-Román MT, et al. Extended half-life pegylated, full-length recombinant factor VIII for prophylaxis in children with severe haemophilia A. *Haemophilia*. 2016 Nov 27. doi: 10.1111/hae.13119 [Epub ahead of print]. **3.** Data on file; Shire US Inc.

S17617 01/17

Shire

ADYNOVATE
[Antihemophilic Factor (Recombinant), PEGylated]

Patient Important facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

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

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

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

What is ADYNOVATE?

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE 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 healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADYNOVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADYNOVATE to use based on your individual weight, level of physical activity, the severity of your hemophilia A, and where you are bleeding.

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

You may have to have blood tests done after getting ADYNOVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

How should I use ADYNOVATE? (cont'd)

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

What should I tell my healthcare provider before I use ADYNOVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

What are the possible side effects of ADYNOVATE?

You can have an allergic reaction to ADYNOVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADYNOVATE and Hemophilia A?

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at www.shirecontent.com/PI/PDFs/ADYNOVATE_USA_ENG.pdf or 855-4-ADYNOVATE.

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

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Westlake Village, CA 91362 USA
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Issued 12/2016

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Shire

A New SpringFest

Ashley Fritsch

It seemed like a wave was crashing around me: hemophilia, von Willebrand, factor, recombinant. It was my first week as the HFM Office Manager. "What is SpringFest?" I asked. I was told it was an educational event consisting of more than 600 community members and sponsors. So many aspects of the event were new to me, but this year, it was new for my colleagues and our community members as well; SpringFest needed to be moved to a new location due to our growing number of attendees!

Every month and every week throughout the year, we planned for SpringFest, organized materials, secured speakers, and soon enough, April came around. By now, I had retained some general information on bleeding disorders and heard personal stories from community members; yet, I was still unsure what the SpringFest experience would be like for me.

As soon as registration began, my nervousness and stress vanished. All of those who share in this cause came together, comforted one another, and marveled at their surroundings and the opportunities before them. All the work beforehand spread out into meaningful expressions and gratitude for this event. I did not need to learn about bleeding disorders from a brochure or some book; I needed to learn it from those who experience it every single day.

At my first SpringFest, I learned the day-to-day realities that come with living with a bleeding disorder. I engaged in conversations, attended sessions that highlighted valuable knowledge and understanding of the bleeding disorder community, and enjoyed many familiar faces–and began to feel a part of this community.

SpringFest

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SpringFest Display

Accredo Specialty Pharmacy
Alnylam Pharmaceuticals
Cottrill's Specialty Pharmacy
CVS Specialty
Diplomat Specialty Infusion Group
Grifols
Matrix Health Group
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SpringFest 2017, Waves of Change

Gwyn Hulswit

HFM's (The Hemophilia Foundation of Michigan's) SpringFest is an annual opportunity to provide education to Michigan consumers, family members, and caregivers over a three-day weekend conference. With an attendance of almost 700 affected individuals and family members, including many new families, SpringFest is one of the largest events in the country for those with bleeding disorders.

As an educational conference, HFM offered an array of educational opportunities throughout the weekend: twenty program sessions, including two roundtable sessions - twenty-four topics in the roundtable discussions; six medical presentations focused on research and innovative approaches to treating bleeding disorders; and five affinity group discussions. Program session topics ranged from Caring for the Carrier to Influencing Health Care Policy to Aquatic Fitness and many more.

In addition to education, SpringFest also served as an opportunity for furthering community connections. The bleeding disorders community in Michigan looks forward to SpringFest every year as a time to come together and reunite with old friends and to meet new people. Children and teens had their own fun with an Animal Magic show as well as a trip to the local waterpark for the younger kids and laser tag for the teens.

HFM is proud to have such engaged participants and loves bringing the community together in a family-friendly atmosphere every year. Thank you all for joining us!

Your experience is important to us!

For the first time in more than 15 years, HFM's SpringFest took place in a new location. We are so pleased that the Marriott Eagle Crest was able to provide the space we needed for programs, educational sessions, and resource displays. Unfortunately there were some issues over the weekend in regard to the food. We want to assure you that we are working with the Marriott to understand how these problems occurred and how they will be addressed if we return to the Marriott next year. SpringFest is for you and for your family and we want to make sure that the experience meets your expectations in every way.

Awards presented at SpringFest

A Inaugural Award honoring the memory of Dr. Jeanne Lusher who dedicated her life to individuals and families affected by hemophilia and other bleeding disorders through international research efforts and direct patient care
Presented to Dr. Roshni Kulkarni

B Dr. Penner inaugural Award honoring the memory of Dr. John Penner who understood the significance of collaboration across HFM community members and the medical and caregiving community in Michigan and across the country.
Presented to Dr. Michael Callaghan

C Outgoing Board **President Rob Hopper** and **Vice President Allan Kucab**

D **Mary May** won a gift basket for registering the most walkers.

E **Nate Cornell;** F **Angelica Kelly**
HFM Academic Scholarship winners

G **Sherry Hubble** H **Aarti Raheja**
Recognition for their many years of service to HFM's Eagle Journeys camping programs

I **Angelica Kelly**
SpringFest Instagram Contest winner

Not shown: Barb Hughes won a trip to NHF's Annual Conference in Chicago, Illinois.

Amanda Shuherk won a trip to HFA's Annual Conference in Cleveland, Ohio.

Meet **Shelley**, your CoRe Manager

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

Contact me!

[Shelley.Gerson@bioverativ.com] | [248.703.3434]

Bioverativ

Connect with Us

Waves of Change: Advancements in the Treatment of Bleeding Disorders

HFM Advocacy|Communications Manager, Sarah Procario, interviewed Dr. Mike Callaghan, pediatric hematologist from Detroit Children's Hospital to learn more about the on-going advancements in the treatment of bleeding disorders.

Can you give us a brief overview of the recent progress in advancing bleeding disorders' treatment?
This is the most exciting time I've ever seen to be in the field of bleeding disorders. Particularly in hemophilia, but also in von Willebrand disease and in other rare disorders.

The most exciting, big clinical trials are looking at gene therapy and novel clotting factor agents.

A lot is also being done on a smaller scale initiated by hemophilia treatment centers. There is an incredible amount of work going on.

What are the research areas currently receiving the most attention from the community?
Gene therapy is definitely one of them. For 30/40 years now, we've been talking about gene therapy. But some of the initial work and clinical trials didn't go anywhere and ran into some problems. And that slowed the field down, which made a lot of people concerned this wouldn't pan out. But since 2011, we have seen breakthroughs.

I'm aware of five Hemophilia B gene therapy studies going on–each with different approaches.

Spark Therapeutics, partnering with Pfizer, presented their Hemophilia B gene therapy study results in December 2016. They are getting great levels of factor IX, 15-35%.

Gene therapy in Hemophilia A is different–factor VIII is a lot harder for a cell to make. There are at least 3 studies I know of going forward with gene therapy for factor VIII. In the very recent past, BioMarin released data with patients with 200% factor VIII after receiving gene therapy.

Gene therapy is a headliner in the future of hemophilia.

There is also a lot of excitement about non-clotting factor approaches.

For example:
- Small interfering RNA, which helps people form clots more easily.
- ACE 910 is in trials, an antibody that mimics factor VIII.
- Tissue factor path-way inhibitor: TFPI

Excitement about these is that they have a different route of delivery and subcutaneous dosing is less frequent.

> "Gene therapy is a headliner in the future of hemophilia."
>
> ~ Dr. Mike Callaghan

What clinical studies are currently happening at Children's Hospital?
There are 25 studies going on at Children's right now… We have four doctors that are very interested in treating individuals with bleeding disorders. As well as the nine hemophilia treatment centers in Michigan, we all work very collaboratively. For the ACE910 study, we've had patients referred from four other HTCs.

You've mentioned the ACE910–an antibody that mimics Factor VIII in individuals with Hemophilia A–can you share information on the ACE910 trial you are working on at Children's?
ACE910 was initially made by a group in Japan at Nara Medical Institute. They have been working on this for more than a decade. Results from this study were published in May of this year in the New England Journal of Medicine.

We've been a part of a phase 3 trial at Children's Hospital with patients with inhibitors; it is very near completion. One thing really exciting about that drug is that it works on people with inhibitors. I can't say a lot until they release data, but we are excited about it.

What is happening in regard to Antithrombin3?
Several hemophilia treatment centers are thinking of working on a phase 3 study of antithrombin3. In order to make a blood clot, you need more thrombin than antithrombin3. So they are trying to lower antithrombin levels by using RNA, called small-interfering RNA (SIRNA), molecules that stop the production of antithrombin3.

Alnylam has been at the forefront with the drug fitusiran–which targets antithrombin3 in the liver through a once a month subcutaneous injection. It is working in a small group of patients.

Which study are you most excited about?
I think they are all really exciting. A lot of it comes down to the details. We do the studies because we don't know how they'll come out. When the results come out, any one of these could be a major breakthrough and really change the way we treat hemophilia. All of these have the potential to be great, but with any new drug you need some caution.

How would you define a cure for hemophilia? And, do you believe it is in sight?
There are a small number of people who have been cured; they've had liver transplants or an organ transplant where the transplanted organ makes factor at normal levels.

A lot of the studies right now seem less aimed at a cure, and more focused on converting patients with severe diseases to more moderate diseases. So, taking factor levels from 1% to 30%.

A cure would have to be something that maintains moderate or mild factor levels for the rest of your life and responds to bleeding problems the same way an individual without a bleeding disorder would. I don't think we are there yet, but we are relatively close.

PAID CONSUMER OUTREACH

IXINITY®
coagulation factor IX (recombinant)
Factoring in your world™

Just B Yourself

"Switching to IXINITY was the best decision I ever made with my doctor. Sometimes, I don't feel like someone with hemophilia.

—James has hemophilia B and uses IXINITY

See why James switched to IXINITY at JustBIXperiences.com

This information is based on James' experience. Different patients may have different results. Talk to your doctor about whether IXINITY® may be right for you.

INDICATIONS AND IMPORTANT SAFETY INFORMATION

What is IXINITY®?

IXINITY [coagulation factor IX (recombinant)] is a medicine used to replace clotting factor (factor IX) that is missing in adults and children at least 12 years of age with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Hemophilia B is an inherited bleeding disorder that prevents clotting. Your healthcare provider may give you IXINITY to control and prevent bleeding episodes or when you have surgery.

IXINITY is not indicated for induction of immune tolerance in patients with hemophilia B.

IMPORTANT SAFETY INFORMATION for IXINITY®

- You should not use IXINITY if you are allergic to hamsters or any ingredients in IXINITY.
- You should tell your healthcare provider if you have or have had medical problems, take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies, have any allergies, including allergies to hamsters, are nursing, are pregnant or planning to become pregnant, or have been told that you have inhibitors to factor IX.
- You can experience an allergic reaction to IXINITY. Contact your healthcare provider or get emergency treatment right away if you develop a rash or hives, itching, tightness of the throat, chest pain, or tightness, difficulty breathing, lightheadedness, dizziness, nausea, or fainting.
- Your body may form inhibitors to IXINITY. An inhibitor is part of the body's defense system. If you develop inhibitors, it may prevent IXINITY from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for development of inhibitors to IXINITY.
- If you have risk factors for developing blood clots, the use of IXINITY may increase the risk of abnormal blood clots.
- Call your healthcare provider right away about any side effects that bother you or do not go away, or if your bleeding does not stop after taking IXINITY.
- The most common side effect that was reported with IXINITY during clinical trials was headache.
- These are not all the side effects possible with IXINITY. You can ask your healthcare provider for information that is written for healthcare professionals.

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

Please see accompanying brief summary of Prescribing Information on next page.

Aptevo™ Therapeutics

Aptevo BioTherapeutics LLC, Berwyn, PA 19312

IXINITY®
coagulation factor IX
(recombinant)
Factoring in your world™

IXINITY® [coagulation factor IX (recombinant)]

Brief Summary for the Patient

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.IXINITY.com.

Please read this Patient Information carefully before using IXINITY. This brief summary does not take the place of talking with your healthcare provider, and it does not include all of the important information about IXINITY.

What is IXINITY?

IXINITY is a medicine used to replace clotting factor (factor IX) that is missing in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Hemophilia B is an inherited bleeding disorder that prevents clotting. Your healthcare provider may give you IXINITY when you have surgery.

IXINITY is not indicated for induction of immune tolerance in patients with hemophilia B.

Who should not use IXINITY?

You should not use IXINITY if you:

- Are allergic to hamsters
- Are allergic to any ingredients in IXINITY

Tell your healthcare provider if you are pregnant or breastfeeding because IXINITY may not be right for you.

What should I tell my healthcare provider before using IXINITY?

You should tell your healthcare provider if you:

- Have or have had any medical problems
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies
- Have any allergies, including allergies to hamsters
- Are breastfeeding. It is not known if IXINITY passes into your milk and if it can harm your baby
- Are pregnant or planning to become pregnant. It is not known if IXINITY may harm your baby
- Have been told that you have inhibitors to factor IX (because IXINITY may not work for you)

How should I infuse IXINITY?

IXINITY is given directly into the bloodstream. IXINITY should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia B learn to infuse their IXINITY by themselves or with the help of a family member.

See the step-by-step instructions for infusing in the complete patient labeling.

Your healthcare provider will tell you how much IXINITY to use based on your weight, the severity of your hemophilia B, and where you are bleeding. You may have to have blood tests done after getting IXINITY to be sure that your blood level of factor IX is high enough to stop the bleeding. Call your healthcare provider right away if your bleeding does not stop after taking IXINITY.

What are the possible side effects of IXINITY?

Allergic reactions may occur with IXINITY. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms:

- Rash
- Hives
- Itching
- Tightness of the throat
- Chest pain or tightness
- Difficulty breathing
- Lightheadedness
- Dizziness
- Nausea
- Fainting

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

The most common side effect of IXINITY in clinical trials was headache.

These are not all of the possible side effects of IXINITY. You can ask your healthcare provider for information that is written for healthcare professionals.

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

How should I store IXINITY?

250 IU strength only; store at 2 to 8°C (36 to 46°F). Do not freeze.

500, 1000, 1500, 2000 and 3000 IU strengths; store at 2 to 25°C (36 to 77°F). Do not freeze.

Do not use IXINITY after the expiration date printed on the label. Throw away any unused IXINITY and diluents after it reaches this date.

Reconstituted product (after mixing dry product with Sterile Water for Injection) must be used within 3 hours and cannot be stored or refrigerated. Discard any IXINITY left in the vial at the end of your infusion.

After reconstitution of the lyophilized powder, all dosage strengths should yield a clear, colorless solution without visible particles. Discard if visible particulate matter or discoloration is observed.

What else should I know about IXINITY?

Your body may form inhibitors to factor IX. An inhibitor is part of the body's immune system. If you form inhibitors, it may stop IXINITY from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests to check for the development of inhibitors to factor IX. Consult your doctor promptly if bleeding is not controlled with IXINITY as expected.

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

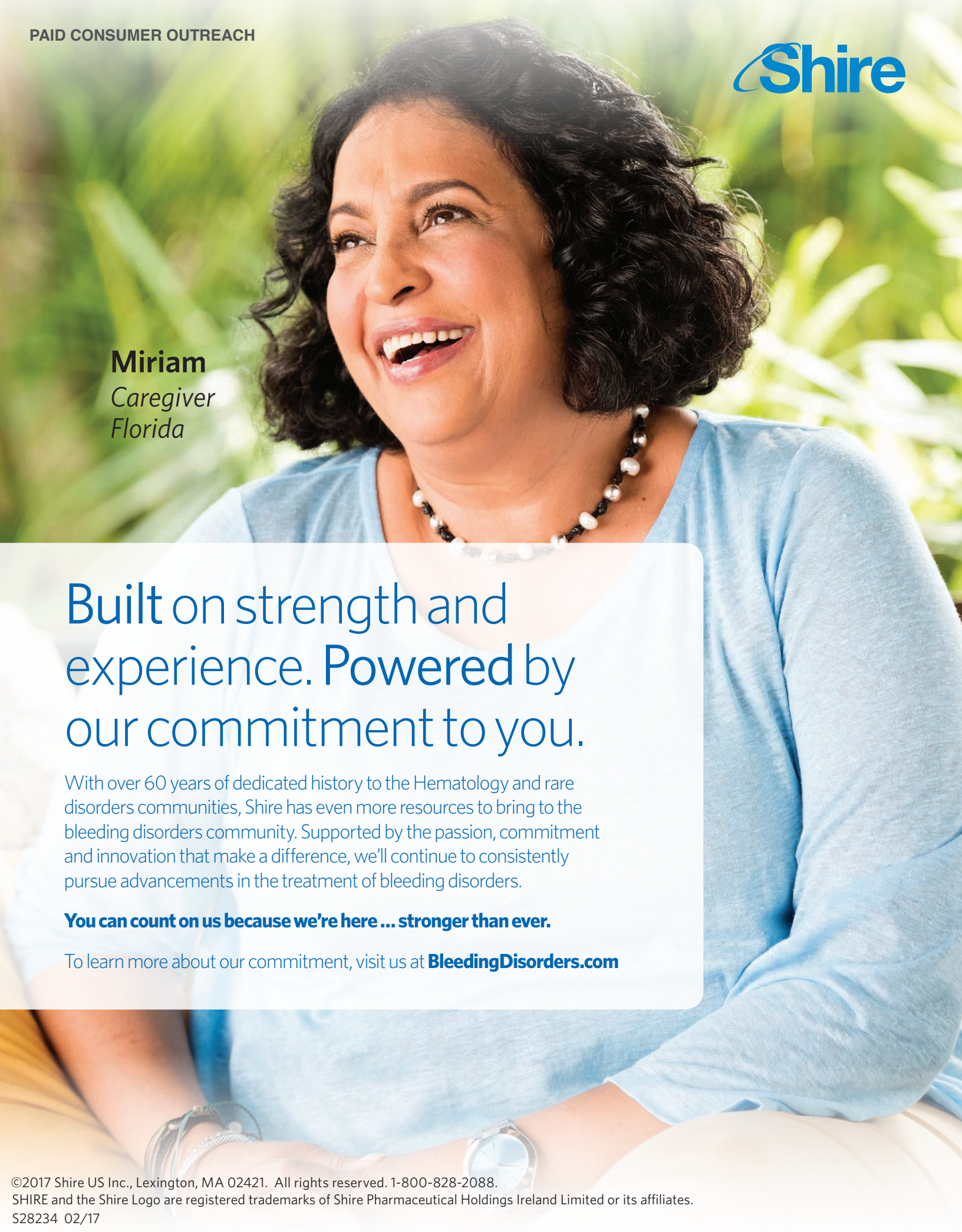
Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

Aptevo™ Therapeutics

Manufactured by:
Aptevo BioTherapeutics LLC
Berwyn PA, 19312
U.S. License No. 2054

Part No: 1000973_1
CM-FIX-0078

Shire



Built on strength and experience. Powered by our commitment to you.

With over 60 years of dedicated history to the Hematology and rare disorders communities, Shire has even more resources to bring to the bleeding disorders community. Supported by the passion, commitment and innovation that make a difference, we'll continue to consistently pursue advancements in the treatment of bleeding disorders.

You can count on us because we're here ... stronger than ever.

To learn more about our commitment, visit us at **BleedingDisorders.com**

PEP – Parents Empowering Parents

Patrice Thomas, MSW, MS

Parents Empowering Parents (PEP) is an educational support program for parents of children with bleeding disorders. Danna Merritt, LMSW, initiated and developed the program in the late 1990s, and serves as PEP Executive Director. PEP has grown with support from Bayer Healthcare. During the weekend-long workshops, parents learn strategies to thrive amidst the challenges of raising a child with a bleeding disorder.

Parents, social workers, and HTC staff lead PEP trainings, covering topics such as the basics of bleeding disorders, child development, identifying a worldview, and the role of self-esteem and communication in parenting. Parents/guardians often stay connected as support systems long after the weekend training is completed. If you are interested in attending a PEP program, please contact Lisa Clothier, LMSW at lclothier@hfmich.org.

To learn more about Delta Dental insurance, go to **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 or 734.961.3512.

CASCADE HEMOPHILIA CONSORTIUM

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DELTA DENTAL®

Pfizer Hemophilia

DEDICATION AND PERSONAL SUPPORT

The Patient Affairs Liaison role was created based on community feedback about the importance of helping to connect patients and caregivers with Pfizer Hemophilia tools and resources.

PATIENT AFFAIRS LIAISONS

Working for you—From the home of Motown to the Bluegrass State

Name: Chris Liddell

Home state: Michigan

Fun fact: If I'm watching TV, it's most likely sports-related. Go Tigers!

Ideal vacation spot: Anywhere quiet, unplugged from all electronics

What past experiences can you bring to this job? I've worked in hemophilia for over 10 years, so I've collaborated with and advocated for different members of this community.

To get in touch with Chris, call
Pfizer Hemophilia Connect 1.844.989.HEMO(4366)

What we do:

- Provide helpful information about Pfizer Hemophilia programs and services
- Serve as a resource to hemophilia treatment centers to help patients obtain access to Pfizer medicines
- Serve as a primary point-of-contact for local advocacy groups
- Participate in local and national events and programs
- Upon request, meet with patients and caregivers to answer questions related to Pfizer Hemophilia resources

"IT'S IMPORTANT TO CONNECT ON ALL LEVELS: HTCs, PATIENTS, FAMILIES, THE WHOLE COMMUNITY."

—Chris Liddell

PP-HEM-USA-0647-05 Printed in USA/November 2016

Pfizer

Community members gathered inside the State Capitol Building for HFM's annual advocacy program, Lansing Days.

Advocating for the Bleeding Disorders Community

Sarah Procario

On May 23 and May 24, 2017, 100 community members gathered in Lansing for HFM's annual Lansing Days–our largest group to date! Participants received an evening of dinner and training on Tuesday, May 23, with special guest speaker, Jack Schmitt, Chief of Staff to Democratic Floor Leader Sam Singh. At training, participants learned how to effectively advocate to their legislators through presentations by HFM's Advocacy and Communications Manager, Sarah Procario, and NHF's Government Relations Specialist, Bill Robie, and were provided time to practice telling their personal story.

On Wednesday, May 24, HFM participants attended meetings with more than 50 state legislators. In the meetings, community members educated lawmakers on the basics of bleeding disorders and explained the importance of Children's Special Health Care Services and the Medicaid expansion (expanded Medicaid coverage for low income adults) to the lives of those with bleeding disorders.

Participants also explained the importance of maintaining patient protections, such as the ban on annual and lifetime limits on benefits and the cap on out-of-pocket costs, through a robust definition of essential health benefits.

10 Essential Health Benefits defined in the Affordable Care Act: prescription drugs, maternity care, ambulatory care, emergency services, hospitalization, mental health and substance abuse, laboratory services, preventative services and chronic disease management, pediatric services, and rehabilitative and habilitative services.

Special thank you to our sponsors, guests, and speakers!

SPECIAL THANKS TO OUR SPONSORS

Genentech
A Member of the Roche Group

Shire

CSL Behring

Pfizer Hemophilia

HFM (Hemophilia Foundation of Michigan) does not endorse any specific product or company.

How else is HFM advocating for the bleeding disorders community?

Washington Days

On March 9, 2017, community members from across the country joined the National Hemophilia Foundation for their annual legislative advocacy event, Washington Days. HFM staff and community members met with five representatives from Michigan to discuss the current health care proposals.

Advocacy Committee

In November 2016, HFM initiated our very first Advocacy Committee, with representatives from the community, government relations specialists, and NHF and HFA staff members. The committee meets monthly and is committed to making sure community members are aware of emerging issues and how we can effectively make an impact.

Coffee Hours

HFM promotes weekly coffee hours for constituents from the bleeding disorders community to meet with their representative or senator at coffee shops in their district. Interested in meeting with your state legislators? Contact Sarah Procario at sprocario@hfmich.org.

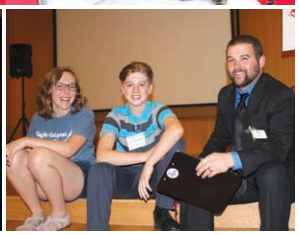
Policy Updates & Getting Involved

Interested in health policy that impacts the bleeding disorders community? Follow HFM on Facebook at **www.hfmich.org/facebook** and check out our advocacy page online at **www.hfmich.org/advocacy** to read more about the American Health Care Act, patient protections, and essential health benefits.

hfm Butterfly Benefit

Janelle Gunn

Thanks to the generosity of more than 130 guests, including medical professionals from Helen DeVos Children's Hospital and our dedicated event sponsors, HFM's second Butterfly Benefit in Grand Rapids was a night to remember. Supporters raised more than $38,000 to send 32 kids to one of HFM's Eagle Journeys camp programs this summer! Compelling personal experiences of life with a bleeding disorder were shared by campers Tommy Stopczynski (14) and Rachael Miller (16) and guests heard the inspirational power of the Legend of the Bold Eagle. We thank our supporters for making this FUNdraising event so enjoyable for everyone in attendance and for providing life-changing opportunities for our youth with bleeding disorders.



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SPECIAL THANKS TO OUR BUTTERFLY BENEFIT SPONSORS

SOARING EAGLE

Bioverativ

BENEFIT PARTNER

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HFM (Hemophilia Foundation of Michigan) does not endorse any specific product or company.

hfm Walk'n' on the wild side

Southeast Michigan
Sunday, August 27, 2017
Detroit Zoo
8:30am Walk begins-one mile

Contact Carrie McCulloch
cmcculloch@hfmich.org
734.544.0015 ext. 503

hfm Walk'n' on the west side

West Michigan
Saturday, October 7, 2017
Fifth Third Ballpark
10am Walk begins-5k

Contact Janelle Gunn
jgunn@hfmich.org
616.301.0020

www.hemophilia.org/walk

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HFM's Community Nights: Bowling for Bleeders

MARCH 31st, SUPER BOWL, CANTON

Bowling, pizza, and the chance to connect were on the menu for our latest Bowling for Bleeders event in Canton. Together we filled the lanes with smiles, welcomed new members to the community, and proved once again that what seems like a simple night out can be a meaningful chance to build friendships. Thank you to the more than 40 community members who joined us. We can't wait to do it again!

SPECIAL THANKS TO OUR SPONSORS

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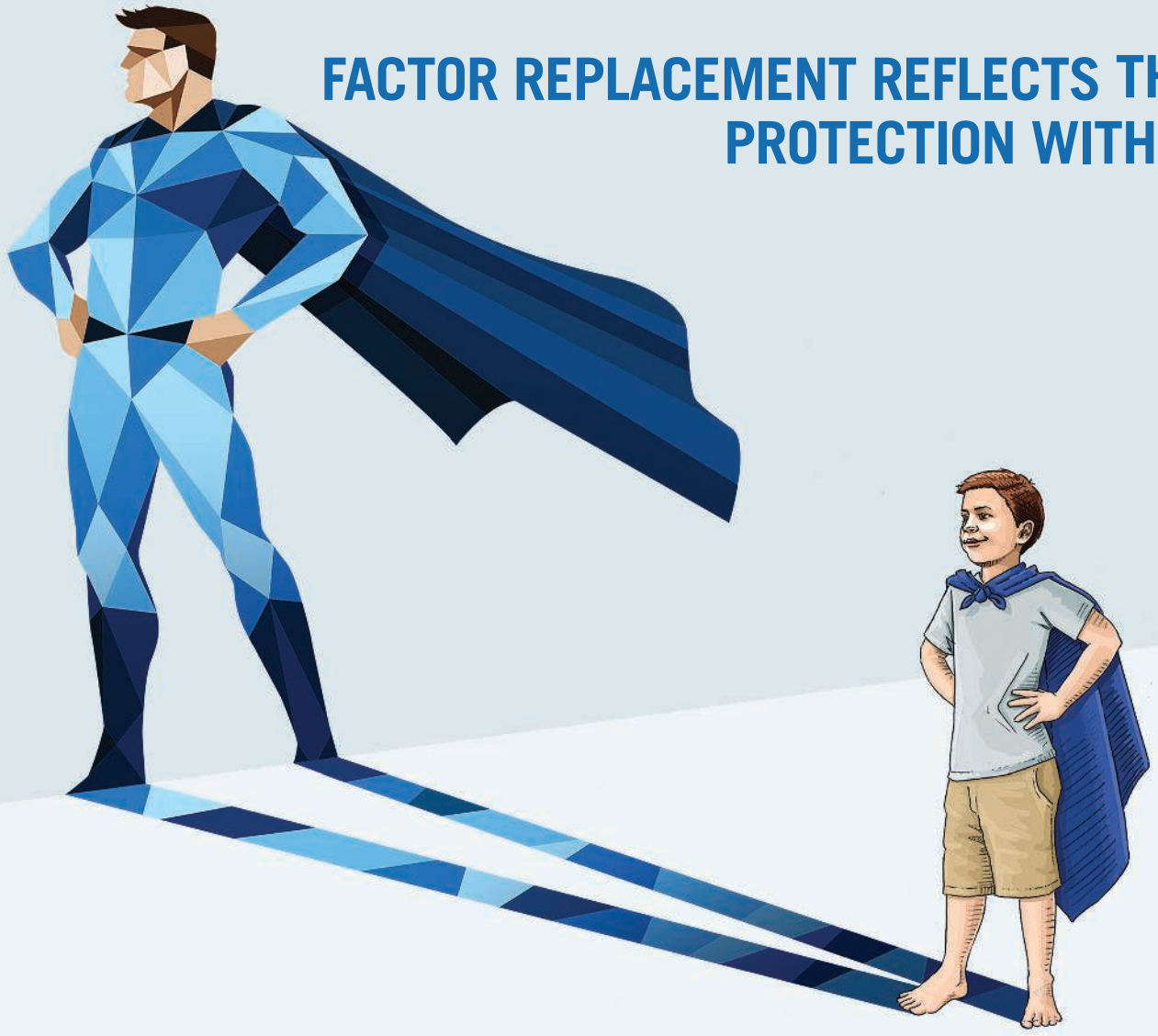
Accredo Specialty Pharmacy | Novo Nordisk

HFM (Hemophilia Foundation of Michigan) does not endorse any specific product or company.

FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN



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

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.

Shire



Left: *Participant and manager,Torey Allen at a go-kart mentoring outing.* ***Middle:*** *Participants and mentors at laser tag outing.* ***Right:*** *Mentoring participant and Children's Hospital of Michigan's Annie Phillips, LMSW.*

Mentoring Mondays

Torey Allen

HFM has been providing tutoring and mentoring to a small group of school-aged children with bleeding disorders who reside in Detroit. This has been the first year of our program via a grant from the Colburn–Keenan Foundation, and through a partnership with Detroit Children's Hospital.

HFM's Mentoring program is designed to support the youth socially, academically, and physically. During the academic school year, kids have been meeting weekly with adult mentors who are also living with bleeding disorders. Every Monday, the youth are picked up from their homes and taken to the Sickle Cell Disease Association office, where the mentoring program is housed.

Participants eat dinner, exercise through yoga or Tai Chi lessons, and then work with a mentor to complete homework or academic studies.

Once every couple of months, the kids are invited to attend special weekend outings in order to foster positive mentoring relationships and to have deeper conversations unrelated to academics. These outings have included Zap Zone laser tag and the Detroit Zoo Lights exhibition.

Already we have seen positive outcomes from HFM's Mentoring program. The kids involved in the program have made progress in their school work, but more than academics, the kids have developed deep relationships with one another and with their mentors. Meeting once a week has allowed the children the chance to delve into lasting conversations about living with bleeding disorders, managing schoolwork, and developing friendships. These kids are not just receiving weekly academic support, but have shown growth in their willingness to open up to both the mentors and to each other.

The goal of the HFM's Mentoring program is to support children leading to improvement in academic grades, expanded social and emotional support systems, enhanced participation, an increase in self-esteem, and increased knowledge of their bleeding disorder and appropriate self-care. We hope to be able to continue and even expand HFM's Mentoring program next school year!

Current Adoption Opportunities

Adrian is a sweet, shy 2 year old, who loves to smile and laugh. He has severe hemophilia A and previously had surgery for an intracranial hemorrhage. As of his last update, he can sit on his own and stand with support.

Ray is an active four year-old boy with hemophilia. He enjoys being read to, listening to music, and playing with cars and balls–his favorite activity is playing outside. Ray is talkative and responds well when others are talking to him.

Miles, left, was featured in our Spring 2016 and Fall 2016 editions of the Artery. **He currently has a family working toward bringing him home.**

Noah, right, has been matched! A family has submitted a letter of intent to adopt him and is working on bringing him home.

HFM's Advocacy & Outreach Coordinator, Shari Luckey, invests her heart and time into advocating for wonderful children to help their forever families find them! In June, Shari organized a fun luncheon for three families with adopted children, including her own. Thank you Shari!

For more information on hemophilia adoption opportunities, please contact HFM's Advocacy and Outreach Coordinator, Shari Luckey, at sluckey@hfmich.org.



Left: *HFM's Executive Director, Susan Lerch, and Educational Services Manager, Torey Allen, in Colombo, Sri Lanka. (Susan's husband, Dan, traveled at his own expense to provide support, photography and videography to document the visit.) Special thanks to HFM board member Jeeva Nadarajah's brother Ram, who graciously provided support to our team. Also, thanks to their driver (far left), Sameer.* ***Middle:*** *Susan Lerch with hemophilia healthcare professionals at the Lady Ridgeway Children's Hospital in Colombo, Sri Lanka.* ***Right:*** *Pinsiri Godamunna, president of the Hemophilia Association of Sri Lanka.*

HFM in Sri Lanka!

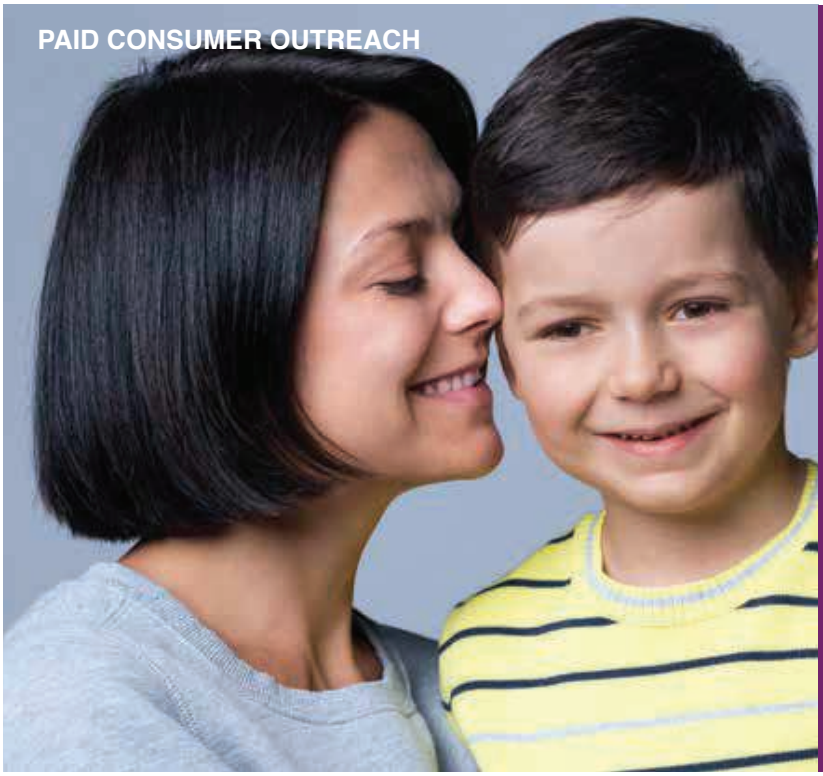
Torey Allen

HFM initiated the process of Twinning with the country of Sri Lanka, under the guidance and funding of the World Federation of Hemophilia. The purpose of the Twinning program is to partner with the Hemophilia Association of Sri Lanka (HASL), and to share knowledge in areas such as education, outreach, and program development.

Susan Lerch, HFM's Executive Director, and Torey Allen, Educational Services Manager, traveled to Sri Lanka at the end of May 2017, where they met with the president and board of directors of HASL, hematologists, patients, nurses, youth directors, and more! Dan Lerch, Susan's husband, also joined the team (at his own expense) in order to serve as the videographer. HFM's board member, Jeeva Nadarajah, played a significant role in planning and orchestrating the assessment visit, even organizing visits with her own family members and other community members.

HFM was represented when Susan Lerch spoke to more than 320 Sri Lankan community members at their World Hemophilia Day celebration. HFM was honored to receive recognition from the Sri Lankan community. We look ahead to a positive partnership with Sri Lanka, hoping to increase our service to people with bleeding disorders around the world.

PAID CONSUMER OUTREACH



Meet Bioverativ: putting patients first

A new company dedicated to the hemophilia community and building upon Biogen's legacy of science and innovation

Bioverativ has a singular purpose: striving for progress when and where people need it most

The pioneering hemophilia treatments provided by Biogen are now available to you through Bioverativ with a continued focus on quality, safety, manufacturing, and product accessibility.

Many of those who worked to advance treatments at Biogen are continuing their scientific pursuits at Bioverativ. Our dedicated team of Community Relations (CoRe) Managers will continue with Bioverativ to create lasting relationships with the hemophilia community using their decades of experience and understanding. Together, we are deeply committed to developing meaningful therapies for people with hemophilia and their caregivers.

We challenge the status quo at every step. Bioverativ is passionate about making a substantial impact in the lives of people with hemophilia and other rare blood disorders.

–The Bioverativ Community Relations (CoRe) Managers

Visit Bioverativ.com for more about us and our mission

Bioverativ



Left: *The winning trivia team poses for a photo at the Maumee Bay State Park Lodge.* ***Middle:*** *Female participants grouped outside of the "girl cabin."* ***Right:*** *Teens spending some of their down time playing card games in the cabin.*

Teen Retreat

Sarah Procario

The first weekend in March, HFM hosted our annual spring teen retreat at Maumee Bay State Park in collaboration with the Northern Ohio Hemophilia Foundation and the Northwest Ohio Hemophilia Foundation. Teens and adults were shocked at the accommodations–the cabins were equipped with linens, a full kitchen, cable TV, and even a hot tub! This location provided quite a special get-away for our group.

Our weekend included icebreakers, group games, free time, swimming, and bleeding disorders trivia. The questions were quite challenging this year, even for the adult participants; if you don't know what hematuria means or what a synovectomy is–just ask one of the teen participants.

We ended the weekend with a trip to Toledo for a Walleye hockey game at the Huntington Center, enjoying good company, entertainment, and lots and lots of ice cream. Because nothing says fun like ice cream. Am I right?

For many, the highlight of the weekend was simply the opportunity to spend time with friends whether that was at the pool, walking around the Huntington Center, or playing games in the cabin. We truly appreciate every opportunity to connect with our bleeding disorders community and look forward to seeing many more youth and young adults at our upcoming camping programs!

HFM's Educational Services Manager, Torey Allen, and HFM community members pose in front of an automobile on display at the Cobo Center.

Blood Brotherhood's Innovative Auto Show

Torey Allen

"Innovative!" "Extraordinary!" "Revolutionary!"
These were some of the terms that described the HFA-sponsored Blood Brotherhood event on Saturday, January 21, 2017. A group of twenty people of all ages met at Atwater Brewery in downtown Detroit for a lunch of hot dog sliders, waffle fries, and salad. While we ate, we listened to Dr. Mike Callaghan, pediatric hematologist from Detroit Children's Hospital, as he described the latest and greatest innovations in the treatment for bleeding disorders. Dr. Callaghan explained studies that are currently taking place around the world with long-acting factor replacement therapies, as well as gene therapy. Blood Brotherhood participants interacted with questions about the new treatments and provided anecdotal evidence from their own lives.

After the presentation from Dr. Callaghan, the group traveled to Cobo Center to attend the North American International Auto Show, where we witnessed the latest and greatest in the world of automobiles. The Blood Brotherhood participants marveled at the new cars, pointing out their favorites.

It was an afternoon of connection, learning, and marvel. We are thankful to HFA for their continued sponsorship of this program.

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LEARN IF **RIXUBIS®** MAY BE RIGHT FOR YOU

Visit RIXUBIS.com to find your local Shire sales representative

Indications for RIXUBIS [Coagulation Factor IX (Recombinant)]

RIXUBIS is an injectable medicine used to replace clotting factor IX that is missing in adults and children with hemophilia B (also called congenital factor IX deficiency or Christmas disease).

RIXUBIS is used to control and prevent bleeding in people with hemophilia B. Your healthcare provider may give you RIXUBIS when you have surgery. RIXUBIS can reduce the number of bleeding episodes when used regularly (prophylaxis).

Detailed Important Risk Information

You should not use RIXUBIS if you are allergic to hamsters or any ingredients in RIXUBIS.

You should tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies, have any allergies, including allergies to hamsters, are nursing, are pregnant or planning to become pregnant, or have been told that you have inhibitors to factor IX.

Allergic reactions have been reported with RIXUBIS. Call your healthcare provider or get emergency treatment right away if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea, or fainting.

Your body may form inhibitors to factor IX. An inhibitor is part of the body's defense system. If you form inhibitors, it may stop RIXUBIS from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for development of inhibitors to factor IX.

If you have risk factors for developing blood clots, the use of factor IX products may increase the risk of abnormal blood clots.

Common side effects that have been reported with RIXUBIS include: unusual taste in the mouth, limb pain, and atypical blood test results.

Call your healthcare provider right away about any side effects that bother you or if your bleeding does not stop after taking RIXUBIS.

Please see following page for RIXUBIS Important Facts.

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

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RIXUBIS
[COAGULATION FACTOR IX (RECOMBINANT)]
MOVING FORWARD

RIXUBIS
[COAGULATION FACTOR IX (RECOMBINANT)]

Important facts about

RIXUBIS [Coagulation Factor IX (Recombinant)]

This leaflet summarizes important information about RIXUBIS. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about RIXUBIS. If you have any questions after reading this, ask your healthcare provider.

What is RIXUBIS?

RIXUBIS is a medicine used to replace clotting factor (Factor IX) that is missing in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Hemophilia B is an inherited bleeding disorder that prevents blood from clotting normally. RIXUBIS is used to prevent and control bleeding in people with hemophilia B. Your healthcare provider may give you RIXUBIS when you have surgery. RIXUBIS can reduce the number of bleeding episodes when used regularly (prophylaxis).

Who should not use RIXUBIS?

You should not use RIXUBIS if you

- are allergic to hamsters
- are allergic to any ingredients in RIXUBIS.

Tell your healthcare provider if you are pregnant or breastfeeding because RIXUBIS may not be right for you.

What should I tell my healthcare provider before using RIXUBIS?

You should tell your healthcare provider if you

- have or have had any medical problems
- take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies
- have any allergies, including allergies to hamsters
- are breastfeeding. It is not known if RIXUBIS passes into your milk and if it can harm your baby
- are pregnant or planning to become pregnant. It is not known if RIXUBIS may harm your unborn baby
- have been told that you have inhibitors to factor IX (because RIXUBIS may not work for you).

How should I infuse RIXUBIS?

RIXUBIS is given directly into the bloodstream. RIXUBIS should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia B learn to infuse their RIXUBIS by themselves or with the help of a family member.

Your healthcare provider will tell you how much RIXUBIS to use based on your weight, the severity of your hemophilia B, and where you are bleeding. You may have to have blood tests done after getting RIXUBIS to be sure that your blood level of factor IX is high enough to clot your blood. Call your healthcare provider right away if your bleeding does not stop after taking RIXUBIS.

What are the possible side effects of RIXUBIS?

Allergic reactions may occur with RIXUBIS. Call your healthcare provider or get emergency treatment right away if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting. Some common side effects of RIXUBIS were unusual taste in the mouth and limb pain. Tell your healthcare provider about any side effects that bother you or do not go away. These are not all the side effects possible with RIXUBIS. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about RIXUBIS?

Your body may form inhibitors to factor IX. An inhibitor is part of the body's defense system. If you form inhibitors, it may stop RIXUBIS from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor IX.

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

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

The risk information provided here is not comprehensive. To learn more, talk about RIXUBIS with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at http://www.shirecontent.com/PI/PDFs/RIXUBIS_USA_ENG.pdf or by calling 1-800-FDA-1088.

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Programs

September 29-October 1
Women's Retreat
Weber Retreat & Conference Center, Adrian
pthomas@hfmich.org

October 27-29
Bleeder and a Buddy
Location TBA
twicks@hfmich.org

Camp

July 3, 4
2017 CIT Program

July 5-8
2017 Staff Training

2017 Camp Bold Eagle

July 9-13
CBE Session One (Ages 6-9)

July 15-21
CBE Session Two (Ages 10-12)

July 23-29
CBE Session Three (Ages 13-17)

August 1-9
2017 Eagle Expedition (Ages 16+)

Events

August 27
Walkin' on the Wild Side
Detroit Zoo, Royal Oak
Register or donate:
www.hemophilia.org/walk
cmcculloch@hfmich.org

September 15
Bowling for Bleeders
Incredible Mo's, Traverse City
cmcculloch@hfmich.org

September 22
Bowling for Bleeders
AMF Eastbrook Lanes, Grand Rapids
jgunn@hfmich.org

October 7
Walkin' on the West Side
Fifth Third Ballpark, Grand Rapids
Register or donate:
www.hemophilia.org/walk
jgunn@hfmich.org

Go to www.hfmich.org for more event info!

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

Camp Bold Eagle Important Information

Contact Numbers

734.544.0015: During business hours *(Monday through Friday, 9am to 5pm)*, ask to have a message relayed to camp.
734.961.3507: When HFM is closed, call this number and leave a message.

IN CASE OF EMERGENCY ONLY: Pioneer Trails **231.894.4768**

HFM Facebook Page

We will be posting several times throughout each camp session and will try to include a photo of every child. **www.hfmich.org/facebook**

Mail at Camp!

When a camper receives **THREE pieces of mail** (either email or USPS mail) on the same day, the camper will have the opportunity to tell a joke or a funny story to the rest of camp during dinner. Sending your child three separate pieces of mail to arrive at camp on the same day will ensure that he/she has the chance to participate in the fun!

Snail mail address

Camper's Name
c/o Pioneer Trails
1421 E Fruitvale Road
Holton, MI 49425

Email address

Email: campboldeagle@gmail.com
Subject line: Camper's first and last name