the artery

Spring 2016 • Serving Michigan's bleeding disorders community

hfm©

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

www.hfmich.org
734.544.0015

INSIDE

...and more!

SpringFest 2016 Fun For All!

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

We Are Community

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Dear friends,

It seems Michigan's spring is finally upon us with the expectation of glorious summer days right around the corner!

Our **2016 SpringFest** hosted a record number of participants in mid-April with more than 700 community members in attendance. We invited attendees to share their thoughts via a large banner and colorful markers – and of course the comments are quite special:

SpringFest means to me…

- ...education, friendship, family, fun – and amazing memories…
- ...connecting with others like us…
- ...we love SpringFest – it was very awesome this year…
- ...fun with family and friends...
- ...making memories – building a strong foundation for our future…
- ...unity of bleeding disorder members enjoying fellowship…
- ...love…
- ...my lifeline in VWD…
- ...new way to learn about advancements in medications…
- ...friendship…

Among our 700 attendees, more than **200 individuals attended HFM's SpringFest for the first time this year** - and nearly **100 parents participated with sessions for new families!** We are grateful SpringFest is available to offer new and continued connections and support, together with opportunities for a variety of important educational sessions. SpringFest is a huge undertaking and the cost is quite significant, well beyond registration fees requested. We appreciate our sponsors' outstanding support which makes this annual conference possible.

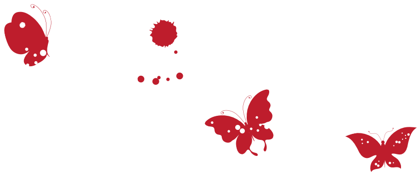
This year, HFM's team offered participants a new opportunity to give a contribution toward financial assistance for another community member to attend SpringFest. I would like to express heartfelt appreciation to the people who donated in addition to their registration fee to support this effort. Thank you!

2017's SpringFest will take place in a new location. We want to do our best to prevent the need for a waiting list while providing roomier space for educational sessions and meals. Frankenmuth has offered a wonderful venue for many years and we know it can be difficult to consider change. Please know we promise to share 2017 dates and location as soon as possible – we look forward to seeing you there!!

One of my favorite quotes from the 2016 SpringFest banner: **"It is epic."**

Wishing you and yours all the best,

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



PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER.

hfm's SpringFest 2016

SPECIAL THANKS TO OUR SPONSORS

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HFA
Hemophilia Federation of America

SpringFest Display

Accredo Specialty Pharmacy
Alnylam Pharmaceuticals
BioRx, a Diplomat company
Cottrill's Specialty Pharmacy
CVS Specialty Pharmacy
Dimension Therapeutics
Grifols
Homecare for the Cure, a Matrix Health Group Company
Novo Nordisk
Octapharma
Option Care
Pfizer Hemophilia

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

Photos: ©2016 wildcardfilms.com

Friday, April 15 - Sunday, April 17

Bavarian Inn Lodge, 1 Covered Bridge Lane, Frankenmuth, Michigan

SpringFest 2016 was an amazing opportunity for more than 700 consumers and family members to come together to learn and make connections. This annual educational conference is one of the highlights of the year and we are thrilled that so many people from the community attended.

While SpringFest is a unique opportunity for people across the state to reunite, the main focus of SpringFest is the many educational sessions. This year we had eighteen educational sessions for participants to choose from, many of them new topics. We also had a new keynote speaker on Saturday morning, Pat "Big Dog" Torrey. Pat is a great motivational speaker, is very knowledgeable about adventure education, and has worked with many bleeding disorder camps around the country. Pat talked about being prepared for not only the physical world, but also the intangible things we experience. He offered a chance to practice skills that will help us to weather whatever may face us with perspective and resilience.

This year's sessions utilized topic tracks that helped organize content. The three tracks were: Relationships and Communication, Newly Diagnosed Individuals and Families, and Lifestyle and Wellness for Young Adults. In the Relationships and Communication track, Sarah Watson, LPC, facilitated one of the sessions called "Let's Be Frank About Sex!" Topics covered were defining and enhancing intimacy with your partner. The Newly Diagnosed Individuals and Families track held two back-to-back roundtable sessions, with five different topics covered at each session. Those included, "Life with a school aged child with Hemophilia," "Everything you need to know about an ER visit," and "Advocating for your child in the school setting." Topic speakers included many of our community HTC nurses and social workers, as well as community members. The Lifestyle and Wellness track offered topics such as healthy eating and PiYO (a mix of Pilates and yoga).

Also new this year were industry medical presentations titled "Understanding Product Development and Research." These sessions were open to industry sponsors, and eight companies chose to participate. A few companies discussed their innovative approaches to treating bleeding disorders that do not rely on factor replacement, but instead are investigating gene therapy and other methods of treatment. The purpose of these sessions was to provide research information to consumers in a non-marketing atmosphere and to allow for questions with medical personnel.

While adults participated in breakout sessions, children and teens had their own fun. Children traveled to a local school where they created art projects, played outside in the beautiful weather, and made slime during the Mad Science Workshop. Our teens participated in team building, icebreakers, and games and discussion with Pat Torrey from Gut Monkey.

Continued on page 4

hfm's SpringFest 2016

Continued from page 3

Another first for HFM SpringFest were two sessions designed for our Spanish-speaking community members. We are thrilled that new families joined us this year and were able to attend sessions in their primary language. We plan to continue to diversify SpringFest programming in the future, so that we continue to be more inclusive of various cultures and perspectives.

While SpringFest 2016 incorporated many new and exciting elements, the heart and connection of this beloved annual event remained unchanged. Participants were asked to share what SpringFest means to them and this is what our community shared:

"Learning new things, meeting new people."

"Learning lots to help our family."

"A new way to learn about medications and to spend time with family and friends."

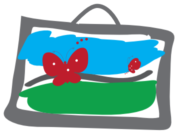
"…supporting our community and providing a space to hear their stories."

We couldn't agree more and we look forward to seeing you all in 2017.

hfm's

Butterfly Benefit

An evening of transformation



Special thanks to our Butterfly Benefit sponsors

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Thursday, May 19 ~ 5:30pm reception | **6pm** program
Grand Rapids Art Museum 101 Monroe Center St NW, Grand Rapids

Join HFM for an enchanting evening at the **Grand Rapids Art Museum**. Hear stories of **inspiration and hope** surrounded by magnificent works of art. Beautiful music, a strolling dinner, silent auction, and much more await you. Your participation will positively impact children and families in West Michigan affected by bleeding disorders. **Make a night of it with your friends!**

Featuring the music of Chris Wiser who has been performing professionally as a vocalist/guitarist and composing original music for more than 20 years, primarily in West Michigan. He was a member of several musical groups in the Grand Rapids area including "Soul Syndicate" and "Two Headed Sam." He has opened for "Bad Company," "Blue Oyster Cult," and "The Storm." Chris is known for his versatility in performing songs from a broad spectrum of music. We are so grateful to Chris for donating his time and talent to perform at HFM's Butterfly Benefit.

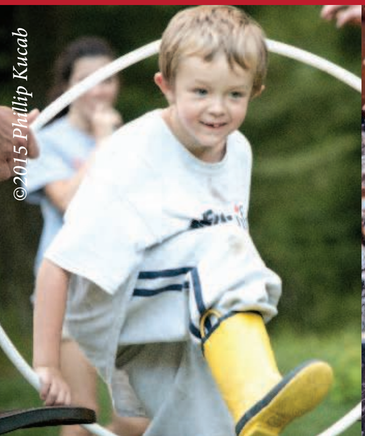
Two Artists Donating to our Silent Auction

- We're so excited that painter, photographer, and writer, **Chelsea Michal Garter**, will be joining us at the Butterfly Benefit! Chelsea is generously creating and donating an original framed painting to be unveiled at the Benefit.
- **Tia Riva**, artist and designer, is donating two original mixed media watercolors.

Purchase your tickets today!
www.hfmich.org/butterflybenefittickets

Thanks to your participation and gifts, HFM's campers will receive an experience that will last a lifetime, providing skills needed to manage their bleeding disorders, in order to live a life of freedom and independence without limitations.

> **"HFM camps have given my children lifelong friends and a sense that anything is possible."**
>
> *~Claire Zellner, mother of HFM campers*



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PAID CONSUMER OUTREACH

ELOCTATE®
[Antihemophilic Factor (Recombinant), Fc Fusion Protein]

THE FIRST FACTOR VIII WITH A PROLONGED HALF-LIFE

Learn how a prolonged half-life may affect your infusion schedule

Meet your CoRe Manager Shelley Gerson
E: shelley.gerson@biogen.com T: 248-703-3434

Indications

ELOCTATE, [Antihemophilic Factor (Recombinant), Fc Fusion Protein], is a recombinant DNA derived, antihemophilic factor indicated in adults and children with Hemophilia A (congenital Factor VIII deficiency) for: on-demand treatment and control of bleeding episodes, perioperative management of bleeding, and routine prophylaxis to reduce the frequency of bleeding episodes. ELOCTATE is not indicated for the treatment of von Willebrand disease.

Important Safety Information

Do not use ELOCTATE if you have had an allergic reaction to it in the past.

Tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, supplements, or herbal medicines, have any allergies, are breastfeeding, are pregnant or planning to become pregnant, or have been told you have inhibitors (antibodies) to Factor VIII.

Allergic reactions may occur with ELOCTATE. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called, "inhibitors," against ELOCTATE, which may stop ELOCTATE from working properly.

The most frequently occurring side effects of ELOCTATE are headache, rash, joint pain, muscle pain and general discomfort. These are not all the possible side effects of ELOCTATE. Talk to your healthcare provider right away about any side effect that bothers you or that does not go away, and if bleeding is not controlled after using ELOCTATE.

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 Brief Summary of full Prescribing Information on the next page.

This information is not intended to replace discussions with your healthcare provider.

Biogen

FDA-Approved Patient Labeling
Patient Information
ELOCTATE® /el' ok' tate /
[Antihemophilic Factor (Recombinant), Fc Fusion Protein]

Please read this Patient Information carefully before using ELOCTATE and each time you get a refill, as there may be new information. This Patient Information does not take the place of talking with your healthcare provider about your medical condition or your treatment.

What is ELOCTATE?

ELOCTATE is an injectable medicine that is used to help control and prevent bleeding in people with Hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ELOCTATE when you have surgery.

Who should not use ELOCTATE?

You should not use ELOCTATE if you had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ELOCTATE?

Talk to your healthcare provider about:

- Any medical problems that you have or had.
- All prescription and non-prescription medicines that you take, including over-the-counter medicines, supplements or herbal medicines.
- Pregnancy or if you are planning to become pregnant. It is not known if ELOCTATE may harm your unborn baby.
- Breastfeeding. It is not known if ELOCTATE passes into the milk and if it can harm your baby.

How should I use ELOCTATE?

You get ELOCTATE as an infusion into your vein. Your healthcare provider will instruct you on how to do infusions on your own, and may watch you give yourself the first dose of ELOCTATE.

Contact your healthcare provider right away if bleeding is not controlled after using ELOCTATE.

What are the possible side effects of ELOCTATE?

You can have an allergic reaction to ELOCTATE. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash or hives.

Your body can also make antibodies called, "inhibitors," against ELOCTATE. This can stop ELOCTATE from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

Common side effects of ELOCTATE are headache, rash, joint pain, muscle pain and general discomfort.

These are not the only possible side effects of ELOCTATE. Tell your healthcare provider about any side effect that bothers you or does not go away.

How should I store ELOCTATE?

- Keep ELOCTATE in its original package.
- Protect it from light.
- Do not freeze.
- Store refrigerated (2°C to 8°C or 36°F to 46°F) or at room temperature [not to exceed 30°C (86°F)], for up to six months.
- When storing at room temperature:
- Note on the carton the date on which the product is removed from refrigeration.
- Use the product before the end of this 6 month period or discard it.
- Do not return the product to the refrigerator.

Do not use ELOCTATE after the expiration date printed on the vial or, if you removed it from the refrigerator, after the date that was noted on the carton, whichever is earlier.

After reconstitution (mixing with the diluent):

- Do not use ELOCTATE if the reconstituted solution is not clear to slightly opalescent and colorless.
- Use reconstituted product as soon as possible.
- You may store reconstituted solution at room temperature, not to exceed 30°C (86°F), for up to three hours. Protect the reconstituted product from direct sunlight. Discard any product not used within three hours.

What else should I know about ELOCTATE?

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

44279-02

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“Stuff the Tent” benefiting **Camp Bold Eagle**

HFM asked SpringFest attendees to consider supporting our campers by donating an item or two that many campers forget, or simply don’t have to bring with them. The goal was to make sure that our camp staff has as many needed items on hand so that campers are never delayed in having the time of their lives.

The tent was set up just prior to registration and immediately we could see that SpringFest attendees were thinking of our kids. **Dawn Bowles** placed a stack of washcloths in the tent. **Jennifer and Jason Wakefield** made a special trip to buy the flag football tags, and **Novo Nordisk** provided 150 beach towels and water bottles. The tent was stuffed with fans, bathing suits, toiletries, and lanyards. Our children will not have to worry about having these items, and we have you, our wonderful HFM community to thank for it. **Thank you, Thank you, Thank you!!!**

With your help, SpringFest transformed a meek little tent, into a **MIGHTY symbol of support!** Because of the generosity of our community, campers will receive the items that they need to have a fun and carefree summer camp experience.

Eagle Journeys
HFM Camping Adventures
hfm


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Honoring our diversity!
¡Honorar nuestra diversidad¡

The first Session in Spanish at SpringFest 2016!
HFM celebrated our very first (and very successful) session IN SPANISH at SpringFest. The session was entitled “Steps to Managing Your Health Care Independently,” organized and presented by Baxalta. The presentation included important discussions about how to equip children with the tools they need to manage their own bleeding disorders. Families, pharmaceutical representatives and HFM staff members attended the session. It was an engaging time of connection and collaboration, and done completely in Spanish! We look forward to having many future sessions entirely in Spanish.

La PRIMERA Sesión en Español en SpringFest 2016!
HFM se celebró la primera (y muy exitosa) sesión EN ESPAÑOL en SpringFest. La sesión se tituló “Pasos para manejar los cuidados de tu salud de forma independiente,” y fue organizado y presentado por Baxalta. La presentación incluyó discusiones importantes sobre cómo equipar a los niños con las herramientas que necesitan para administrar sus propios trastornos hemorrágicos. Las familias, los representantes farmacéuticos y los miembros del personal HFM asistieron a la sesión. Fue un tiempo de conexión y la colaboración muy maravilloso, y fue hecho completamente en español! Esperamos tener muchas más sesiones futuras totalmente en español.

“[SpringFest] fue una hermosa experiencia. Espero que tengamos más eventos como eso. Fue de gran bendición.”

“[SpringFest] was a beautiful experience. I hope we have more events like this. It was a big blessing.”


©2015 Becky Porter


©2015 Phillip Kucab


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WALK | Volunteer | Sponsor | Donate

$20 registration fee includes a family-friendly walk, t-shirt, delicious food, entertainment, fun activities, and the opportunity to come together as a strong community supporting those with bleeding disorders. Recognition and top fundraising awards will be presented at both events!

REGISTER TODAY for one or both walks! **www.hemophilia.org/walk**

National Hemophilia Foundation and Hemophilia Foundation of Michigan Present
HEMOPHILIA walk '16
Every step makes a difference
National Presenting Sponsor
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hfm's Walkin' on the wild side

Southeast Michigan

Sunday, August 28, 2016
Detroit Zoo
7:30am Check-in opens
8:30am Walk begins-one mile

Contact Carrie McCulloch
Special Events Manager
cmcculloch@hfmich.org
734.544.0015 ext. 503
walk.hemophilia.org/Detroit

hfm's Walkin' on the west side

West Michigan

Saturday, October 8, 2016
Fifth Third Ballpark
9am Check-in opens
10am Walk begins-5k

Contact Janelle L. Gunn
Special Events Manager-West Michigan
jgunn@hfmich.org
616.301.0020
walk.hemophilia.org/GrandRapids

Stephanie and two of her children have bleeding disorders. Her youngest son Harrison, shown here, attends Camp Bold Eagle. Harrison is also a wonderful spokesperson for HFM.

Why I walk...

"HFM is family to us, and supports us. They have given my children the confidence and freedom to be kids while providing education and feelings of security for me. Camp has been such a blessing for them, and the time is irreplaceable. The reasons for why I walk are truly endless."

~ Stephanie Brown

REGISTER TODAY www.hemophilia.org/walk

HFM **SpringFest** Award Winners

Many community members left SpringFest 2016 with awards! Recognition included HFM Academic Scholarships, Photographer and Volunteer of the Year, Social Media Supporters, and more! HFM awarded several lucky community members with gifts cards for updating contact information and filling out evaluations, and our grand prizes, trips to NHF & HFA annual conferences, were awarded for session attendance.

AWARDS PRESENTED THROUGHOUT THE WEEKEND!

A **Phil Kucab** was recognized as HFM's Photographer of the Year.

B **Shenay Mills** won a trip to NHF's Annual Conference in Orlando.

C **Stephanie Rogers** won a trip to HFA's Annual Conference in Rhode Island.

D **Kelly Alber-Drake** was recognized as HFM's Volunteer of the Year.

HFM Academic Scholarships were presented to:
E **Zackary Swisher**
F **Allison Albright's** mom accepted on her behalf.

Scholarship Anniversary & Leadership Recognition was presented to:
G **Lynn Allen**

Recognition for "Enthusiastic Support" on social media was presented to:
H **Dawn Bowles**
I **Jennifer Wakefield**
Stephanie Brown (not shown)

SpringFest Instagram Contest winners:
J **Hali Schumacher**
K the **Hollers Family**

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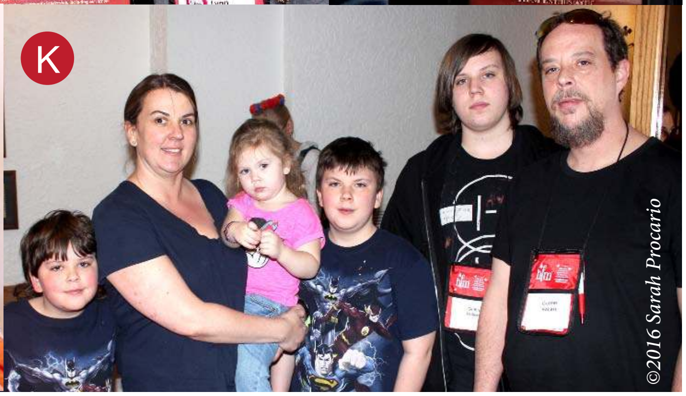

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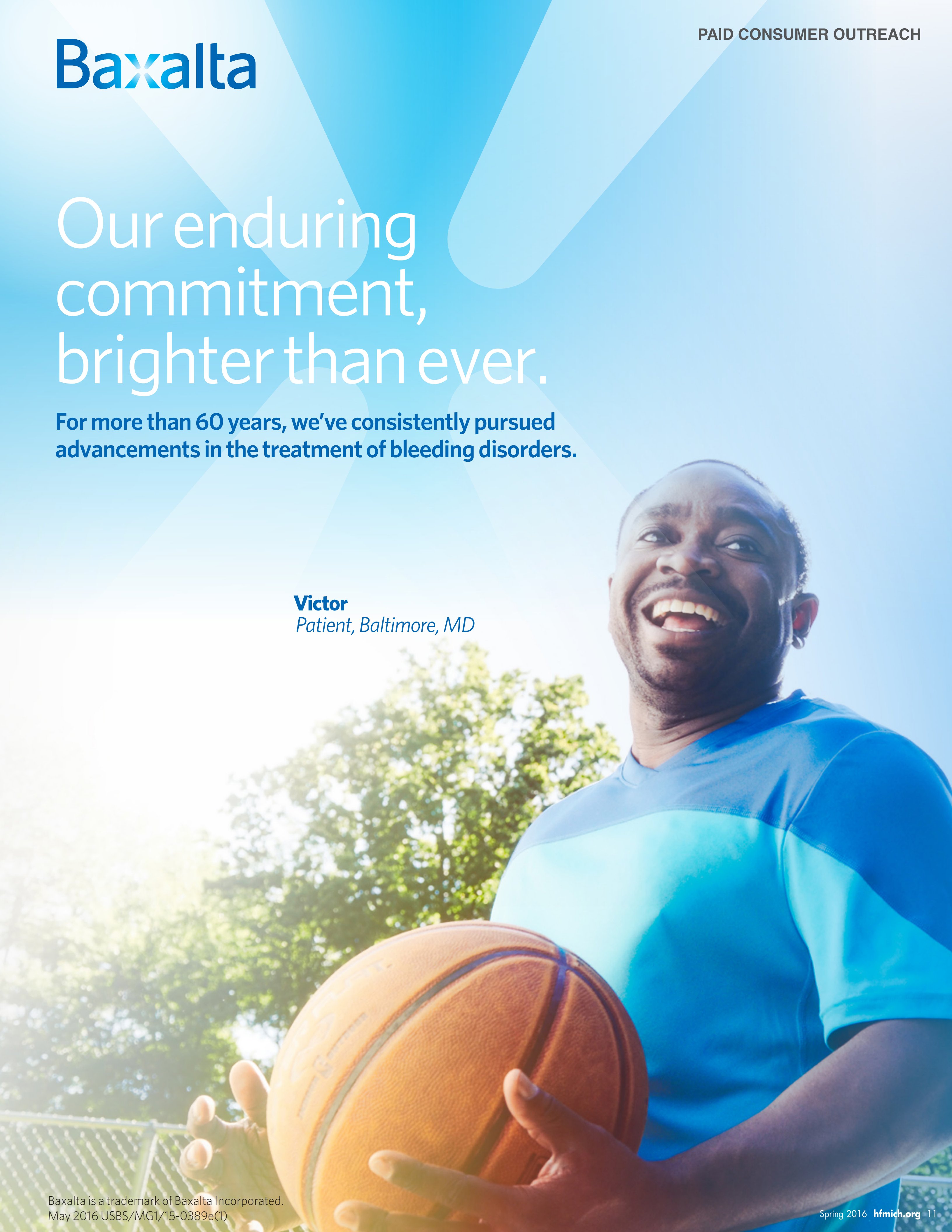

Symposium 2016
Together We Are Resilient

Lisa Clothier, LLMSW, HFM Outreach and Community Education Manager

I have always wondered if it was true that it is light all summer in Alaska. When I attended the HFA Conference in Las Vegas, Nevada this past March I was able to ask an HFA board member who had traveled from Alaska! It turns out that it is only light all summer in some parts of the state. This is but one of the many things I learned at the conference.

I met folks from all over the United States, all with at least one thing in common – their passion for supporting the bleeding disorders community. I met moms and dads, kids, siblings, grandmas and grandpas, health care professionals, and other community supporters while I was there.

The thing that resonates with me the most from my time with these individuals is the resiliency of this community. I even attended a session on “Raising Resilient Kids” presented by Mark J. Borowski, M.S. Like many of you raising children, this is extremely important to me. The session emphasized that while we may not meet every mark on raising a resilient child, we can strive to provide children with “unconditional love, absolute security, and a deep connection to at least one adult.” Resiliency is truly all around us in the bleeding disorders community.

The conference fostered a great casual atmosphere of community where people could get to know each other inside and outside of the sessions. I look forward to going back next year to Rhode Island. See you there!

www.hemophiliafed.org/programs/meetings-events/educational-symposium/

Thanks to **Munson HTC** for ROCKING the **RED TIE CHALLENGE!**

NATIONAL LEVEL

NHF Washington Days 2016
Learning to be an Advocate

Sarah Procario, HFM Special Projects Coordinator - Advocacy/Communications

This February I was invited to accompany HFM's executive director, Sue Lerch, to NHF's annual advocacy event in Washington, D.C. "Washington Days" gives members of the bleeding disorders community a chance to meet with representatives in Congress, share their personal experiences, and learn about advocacy at the national level.

NHF organizes extensive training on the issues affecting our community, how to utilize social media for advocacy, and how to talk to your legislator. As a Washington Days newcomer, I tried to absorb everything. But even with my experience in political advocacy and a degree in political science, I couldn't help but feel intimidated by the meetings ahead.

As we sat down with representatives and congressional staffers the next day, I let my fellow advocates take the lead. I sat in awe of their ability to explain their disorders so clearly and with such passion. After our first meeting, I felt my nerves transform into excitement as I realized that the legislators actually wanted to hear from us. In the following meetings I found myself contributing more of my personal connection to our community. I ended the day with an overwhelming sense of empowerment.

This experience solidified my belief that one voice can affect change. Every advocate who spoke up for the needs of our community helped further the interests of *all* affected by bleeding disorders. NHF finished the event by training us to continue our advocacy at the state level. I look forward to speaking up for the bleeding disorders community in Lansing this May and I hope to see some of you by my side.

STATE LEVEL

Lansing Day 2016,
State Advocacy Day

HFM's state advocacy day, Lansing Day, is quickly approaching. Participants will be in store for a few changes to this year's event and we couldn't be more excited.

HFM has invited all participants to join us for an evening of dinner and training at the Radisson Hotel the night before Lansing Day. Katie Verb, Advocacy and Government Relations Manager at the Hemophilia Federation of America (HFA), and Bill Robie, Government Relations Specialist at the National Hemophilia Foundation (NHF), will train participants on how to talk to their legislators. During this training our advocates will practice telling their stories and talking about how health policy affects our community. Katie and Bill will show us that everyone in our community can be an advocate. The teens will have a separate training with Sarah Shinkman, also with HFA.

On Wednesday, May 18, community participants will meet with over 40 legislators, informing them about the critical needs of people with bleeding disorders. Participants will share their stories and discuss the critical role of Children's Special Health Care in maintaining their access to affordable care. We will encourage the legislators to continue to support this important program.

Advocating for the needs and special interests of individuals with bleeding disorders is a critical aspect of serving our community. HFM looks forward to growing our group of advocates throughout the year to continue the important work!

JOIN US FOR A FUN DAY OF GOLF!

And, help HFM send more kids affected by bleeding disorders to camp this summer!

SWINGING FOR SMILES

CHARITY GOLF OUTING
BENEFITING HFM CAMPS

MONDAY, JUNE 6

THE POLO FIELDS
WASHTENAW
2955 PACKARD ROAD, YPSILANTI, MI

REGISTER: www.hfmich.org/golfregister

SPECIAL THANKS TO OUR EVENT SPONSORS

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PAID CONSUMER OUTREACH

Track it!

Kathleen Anderson, LPN, BS, Clinical Coordinator, Michigan State University

You've probably heard this many times from your hematologist and nurses:

- You need to keep logs of your factor usage and bleeds!
- There are many benefits to keeping accurate records of factor you use and bleeds you treat.
- Here are the why's, what's and how's of factor logging.

WHY?

- **Optimal Treatment**—keeping a factor infusion and bleeding episode log will help in recognizing patterns of bleeds and infusions. Do you frequently bleed on Saturdays while doing prophylaxis on Monday and Thursday? Adjusting prophy days to Wednesday and Saturday could help you prevent those break through bleeds, but it is hard to recognize patterns if you do not keep a log.
- **Insurance**—some insurance companies are requiring you keep a treatment log to ensure you are using factor as ordered, as a condition for continued reimbursement. This may become more common in the future.
- **Disability Benefits**—If you need to apply for financial help from the Social Security Administration or your employer, having a clear record of your bleeding episodes will make it much easier.
- **Factor Recalls**—this may be rare, but if you have a complete infusion log you will be able to check specific lot numbers you used in the past against those recalled.

WHAT?

Record this information each time you have a bleed and/or infuse.

For Prophylaxis Infusions:
- Date and time of infusion
- Name of factor, expiration date & lot #
- Number of units infused
- Reason for infusion (scheduled or pre-activity)

For Bleeding Episodes:
- All of the above
- Date and time of the bleed
- Location & severity of the bleed
- Cause of the bleed, or whether spontaneous
- Other treatment: pain medication, ice, compression wrap, etc.

HOW?

- **Handwritten Factor Log Sheets** or **Factor Calendar Logs:** These can be obtained from your Hemophilia Treatment Center (HTC) and should be given to your HTC on a regular basis.
- **ATHN Advoy Website** (or iPhone app): Once you have registered through your HTC, you can download the app or login on the website to record data. HTC staff can then login and see your data in real time.
- **Smartphone Apps:**
  - ➢ **Beat Bleeds:** You can log infusions and bleeds, track your Annual Bleed Rate and email your logs directly to HTC nurses.
  - ➢ **MicroHealth:** HIPAA compliant platform that syncs across devices. Allows you to connect to HTC nurses through the app and to receive personalized reminders.
  - ➢ **Other apps to check out:** HemaGo,HemMobile, FactorTrack, HemoTool, HemoTrax, MyFactor.

Photos: ©2016 Sarah Procario

Some of our community members took the ***RED TIE CHALLENGE*** *at HFM's Bowling for Bleeders Community Fun night this past March in Novi, MI.*

Bowling for Bleeders Community Fun Night

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Bayer HealthCare

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Cottrills Specialty Pharmacy
Novo Nordisk

HFM's Bowling for Bleeders: Community Fun Nights had their first event this March in Novi, MI. Families and individuals from around the area, even as far as two hours away, traveled to Novi Bowl to spend an evening with their bleeding disorders community. The room was filled with warm greetings and an appetite for friendly competition. After a filling dinner of pizza and cake, participants hit the lanes for two games of bowling!

The night was such a success, we are happy to announce that we will be hosting Community Fun Nights at three more locations throughout the state. **Follow us on Facebook** or **check our events on hfmich.org** for updates.

Upcoming Bowling Nights:

- **June 24th Traverse City**
- **August 5th Grand Rapids**
- **November 18th Lansing**

We are thankful for our wonderful sponsors! Without their support we could not have offered such a great event for our community. Sponsorships are unique to each Community Fun Night and are available for each of the upcoming events.

Ask a Social Worker

Samantha Carlson, LMSW, OSW-C, ACHP-SW
Director of Social Services Medical Social Work, Dietician and Volunteer Services West Michigan Cancer Center

Q: What is a Durable Power of Attorney (DPOA) and do I need one?

A: Yes; it is a very important part of your health care especially with a chronic health condition that could be life threatening.

A DPOA is a document that outlines your health care wishes and designates an advocate you select to speak on your behalf if you are unable to talk during a medical emergency. The DPOA paperwork is a guideline for your caregiver to talk on your behalf about what you want or don't want for your health care.

It does not take away your rights to make decisions, and it is not active until an emergency that prevents you from making decisions. Two physicians must activate the DPOA, or a physician and a psychologist, to certify you are unable to make health care decisions (either mentally or physically).

If you do not have a DPOA, your wishes may not be honored. Additionally, your spouse or parent may not be an automatic default decision maker. In some cases where family disagrees, probate court may appoint an advocate to make decisions for you.

In the state of Michigan, you can fill out the form free of charge through many organizations. Social workers are trained to educate patients on their rights and how to complete the form. Many forms outline common situations that may occur, and give options for care. In the state of Michigan you do not need a lawyer and it does not need to be notarized.

It is important to bring the form with you when you travel and to have a copy posted in your home for emergency responders. It should be updated regularly. The advocate you designate, as well as your healthcare team, should have a copy of your DPOA.

For more information and education, talk to your social worker. For non-profit community education, visit: Making Choices Michigan: **http://makingchoicesmichigan.org/** Michigan State Medical Society: **www.msms.org/Resources/ForPractices/DurablePowerofAttorney(DPA)Forms.aspx**


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> "[I am looking forward to] being whole-heartedly invested in this community. This community has been my foundation, my life blood."
>
> *~ Torey Allen*

We're thrilled that Torey Allen, HFM community member, is now HFM's Educational Services Manager/Associate Camp Director.

Get to know Torey Allen

How did you become involved with the Hemophilia Foundation of Michigan? How old were you?
My dad, Lynn Allen, used to be board president. He has severe hemophilia. When I was a child, I used to think he was the president of Michigan. He also worked as a staff member in the initial years of Camp Bold Eagle. I am a carrier. Since I am so connected to this community, it is a very large part of my identity.

How many years have you worked at camp? What is you favorite part about working at CBE?
I went to camp several years as a camper, but really got involved in 2003 when I was 16, as a CIT. That year several other well known community members were CITs as well: Brad Medrano, Cory Tipsword, Nick Gamber, Harvey Liverman, and Travis Tussing was my CIT Director! I worked at camp every year from 2003-2016, except for one year.

What were you doing before you accepted the position at HFM?
Teaching for seven years, K & 1st grade. I was most recently a dual language teacher, teaching half the day in English and half the day in Spanish.

What are you looking forward to most about working with HFM again?
Being whole-heartedly invested in this community. This community has been my foundation, my life blood.

What do you hope to accomplish in your new role?
Reach out to underserved communities. I also want to have a heavy emphasis on education at camp, to support and train camp staff.

From Counselor to HFM Staffer

Did you ever imagine/aspire to work at HFM?
It has always been a dream of mine to hold a high level of leadership at camp.

Why do you go to camp and what makes you come back to camp (almost) every year?
The culture of camp, the feeling of belonging and connection you sense the moment you step foot on camp. Camp creates a culture of lifelong family.

Spanish Speaker

When/how did you learn how to speak Spanish?
I studied it all through college and lived in Mexico twice.

How do you plan to use your Spanish language skills?
I plan to incorporate our Spanish-speaking families more than they have been in the past. I also want to develop more educational programming in Spanish in order to serve the community to the best of our ability.

What is your favorite phrase/saying in Spanish?
I'm not sure about a favorite phrase, but I have a favorite word. I like to use *"esquincles"* as an endearing term for a little kid. It's just fun to say!

Teen Retreat: Focusing on Wellness

Over the February 19th weekend, HFM provided the opportunity for teens to get away at our annual Winter Teen Retreat at Howell Nature Center. Activities throughout the weekend focused on a theme of wellness. The teens created Wellness Wheels, a tool that is split into 6 dimensions: emotional, physical, intellectual, occupational, social/family, and spiritual. The group learned how to use their wheels to gauge their level of satisfaction in each wellness category and practiced determining ways to improve their satisfaction.

Just a short hike from the cabin, the teens also took part in the zip line. The Nature Center staff provided equipment and safety instructions for the teens. Though some individuals were more eager than others, the retreat attendees walked away with 100% participation!

The two-night stay at Howell Nature Center gave these teens a chance to strengthen connections with old friends, establish new relationships with other teens in the bleeding disorders community, and work on whole body wellness.

Photos: ©2016 Lisa Clothier

CASCADE HEMOPHILIA CONSORTIUM

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

www.hfmich.org
734.544.0015

DELTA DENTAL®

Got Dental?

Do you have a bleeding disorder? Are you a Michigan resident? Do you need dental insurance? We may be able to help!

In partnership with Cascade Hemophilia Consortium, HFM is administering a Delta Dental program for members of the bleeding disorder community. Check out the list below to see if you might qualify.

- You must have a bleeding disorder or be a symptomatic carrier
- Be a Michigan resident
- Have no dental insurance or only Children's Special Health Care Services

If you have Medicaid, you may be eligible for time-limited coverage based on special circumstances – these exceptions are limited and determined on a case by case basis. Please call us for more information.

Eligibility Disqualifications

- You have current Medicaid dental coverage ***you are not eligible*** (unless there is a special circumstance – these exceptions are limited and determined on a case by case basis).
- You have access to dental coverage through your employer or your spouse's employer, even if you choose not to participate in that coverage, ***you are not eligible*** for coverage under this program.

The program premium cost levels are $0, $50, $100, or $150 per year based on your income.

To Apply

For a child or adult application, go to **www.HFMich.org/deltadental**. Please submit your application to HFM, 1921 W. Michigan Ave., Ypsilanti, MI 48197. If you have questions about the program or eligibility contact Lisa Clothier, Outreach and Community Education Manager at **lclothier@hfmich.org** or **734.961.3512**.

Adoption Opportunities

In China, there are many children with bleeding disorders looking for families to adopt them. After children age out of the foster system at age 14, they will likely not have access to live-saving treatments. However, in the United States these children would have access to the best healthcare available; hemophilia is a manageable condition and individuals with bleeding disorders can live a full life outside of the hospital.

Our Advocacy and Outreach Coordinator, Shari Luckey, works to match these children with families in the U.S. interested in adopting a child with hemophilia. Shari and her husband, Dave, adopted their son, Luke, from China on January 25, 2010. Luke has hemophilia and was therefore considered unadoptable in China. He was small and frail and suffered from many bleeds in his right knee. Now, six years later, Luke is an inextricable part of the Luckey family and receives the care and love he needs. **Shari's personal experience adopting a child from China has fueled her passion to find more children "Forever Families."** ***She shares that it "has been a bigger blessing than I could have ever imagined."***

Help us find **Forever Families** for these beautiful boys with hemophilia

Angelo, 1 year old

Hemophilia A & high muscle tone in upper right limb

This little guy is a love bug. He delights in cuddling and babbling with his caregivers. He enjoys listening to music, especially while being rocked, and is fascinated by toys with bright colors and sounds. Most of all, he appears to love being loved. He has normal mental development.

Hudson, 5 years old

Hemophilia A & heart defect

Hudson loves to play with toys, help his caregiver cook, watch cartoons, sing songs, and read picture books. He longs to go to school and asks for a school bag. When Hudson has a bleed and is hospitalized for treatment, the hospital staff reports that he is always polite and cooperative.

Bryan, 8 years old

Hemophilia

Bryan's caregivers describe Bryan as extroverted, sociable, smart, and able. His Chinese name means "loving heart with a soul as clear as a creek." He loves animals, plants, toys, and games. He wants a family to call his own and access to the world's best medical care so he can live an active, pain-free life.

Miles, 8 years old

Hemophilia

Though Miles has painful bleeds, he is a happy boy. He is very outgoing, and loves to help the caregivers take care of the younger children. He can be a little naughty–he loves to climb and jump, both restricted activities–when his caregivers are not looking! With treatment, he would be safe doing the physical activities he longs to do.

WE CAN HELP!

For many families, finances may be a prohibitive factor when determining their ability to adopt. HFM's Advocacy and Outreach Coordinator, Shari Luckey, is available to assist families access information on adoption grants and fundraising options. If you have any questions or would like more information, please contact Shari Luckey at **sluckey@hfmich.org**.

Shoe Drive Fundraiser

to Support Alaina Furr's Adoption Fund

May 9–August 6, 2016

Please help Alaina Furr raise funds to adopt a child with hemophilia.

How you can help:

- Donate any gently worn, clean, used, or new shoes (athletic shoes, dress shoes, sandals, boots, sneakers, sports cleats, etc.) in men's, women's, or kid's sizes. NOTE: Please connect pairs by tying laces or rubber band (do not tape)
- Ask friends and family to donate shoes
- Spread the word through social media

We cannot accept: Slippers; Single/unpaired shoes; Damaged shoes (broken heel, holes, worn out, falling off sole, etc.)

Goal: 7500 pairs of shoes! Alaina earns $0.40 for each lb of shoes donated. All shoes are donated to support micro enterprises in 25 countries around the world.

Repurpose and recycle: keep shoes out of landfills by giving them a new life!

No shoes to donate? Consider making a donation at: https://www.youcaring.com/alaina-furr-460507#.VteFB_clu2c.facebook

DROP-OFF LOCATIONS

HFM is pleased to be a shoe drive drop-off location!
1921 W. Michigan Ave.
Ypsilanti, MI 48197
734.544.0015*
*Please call ahead to arrange a drop-off time.
(Open Mon.–Fri., 9am–5pm. Please do not leave shoes outside building.)

Veronica's Market
1235 E. Beecher St., Adrian, MI 49221
Open daily 9am-9pm
Contact: Rhonda Medina
517.442.4831

Questions?
Shari Luckey
734.223.8051

Alaina Furr
616.914.4616
alaina.shoe.drive@gmail.com

PAID CONSUMER OUTREACH

Pfizer Hemophilia

Save up to $12,000 in 2016!

Eligible patients can save up to $12,000 annually on co-pay, deductible, and coinsurance costs with the Pfizer Factor Savings Card.

Beginning in 2016 (follow these steps):

1. Get your prescription for a Pfizer factor product from your doctor.
2. Visit **PfizerFactorSavingsCard.com** and fill out a brief registration form.†
3. Save and print your card right from your computer. The card is now activated.
4. Keep your card and use it for every purchase until the maximum benefit has been reached or the card has expired, whichever comes first.

Save up to $12,000 Pfizer Hemophilia Factor Savings Card This co-pay card is not health insurance.

Get your card online now…

Scan the QR code or visit **PfizerFactorSavingsCard.com** to download your card today.*

This card will be accepted only at participating pharmacies. This card is not health insurance. No membership fees. You will receive a total benefit of $12,000 per calendar year, or the amount of your co-pay over one year, less a patient financial responsibility of $10 per month, whichever is less.

If you have any questions about the use of the Pfizer Factor Savings Card, please call 1-888-240-9040 or send questions to: Pfizer Factor Savings Program, 6501 Weston Parkway, Suite 370, Cary, NC 27513. The Pfizer Factor Savings Card cannot be combined with other offers and is limited to one per person.

*Terms and conditions apply; visit PfizerFactorSavingsCard.com for complete terms and conditions. For commercially insured only. Medicare/Medicaid beneficiaries are not eligible.

†You can also request a card from your doctor, or by calling 1-855-PFZ-HEMO.

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Upcoming Events

May 19, 2016
Butterfly Benefit
Grand Rapids Art Museum
Grand Rapids, MI
jgunn@hfmich.org

June 3 & 4, 2016
Days for Girls Sewing Project
HFM Office
Ypsilanti, MI
pthomas@hfmich.org

June 6, 2016
Swinging for Smiles
Charity Golf Outing
Polo Fields Golf Course
Ypsilanti, MI
cmcculloch@hfmich.org

2016 Eagle Quest - NEW!
6/10-6/16, 2016 (18+)

2016 Eagle Outpost
July 31-Aug. 6, 2016 (14-15)
July 29-30 I Staff Training

2016 Camp Bold Eagle
Session 1: 7/10-7/14 (6-10)
Session 2: 7/16-7/23 (11-13)
Session 3: **NEW!** 6/26-7/2 (14-17)

2016 Eagle Expedition
August 9-17, 2016 (16+)

2016 CIT Program
July 4-24, 2016 (16-17)

August 28, 2016
Walkin' on the Wild Side
Detroit Zoo, Royal Oak, MI
cmcculloch@hfmich.org

October 8, 2016
Walkin' on the West Side
Fifth Third Ballpark
Grand Rapids, MI
jgunn@hfmich.org

December 2016
End of the Year
Community Celebration
Troy High School
Troy, MI
cmcculloch@hfmich.org

www.hfmich.org
734.544.0015
Hemophilia Foundation of Michigan
1921 West Michigan Avenue
Ypsilanti, MI 48197

Register your child for camp today!

Eagle Journeys
HFM Camping Adventures
hfm

2016 Camp Bold Eagle

June 26-July 2 I **NEW! CBE Session Three** (Ages 14-17)
July 10-14 I **CBE Session One** (Ages 6-10)
July 16-23 I **CBE Session Two** (Ages 11-13)

2016 Eagle Quest - NEW!

June 10 – June 16, 2016 (Ages 18+)

2016 Eagle Outpost

July 31 – August 6, 2016 (Ages 14-15)

2016 Eagle Expedition

August 9 – 17, 2016 (Ages 16+)

2016 Counselor-In-Training Program

CIT Program Dates: July 4-24, 2016 (Ages 16-17)

A few spots left! We still have space available in each of our sessions and we'd love for your child to join us! **YOUR COST for your eligible child to attend HFM camp is $25! Go to: www.hfmich.org/campingprograms**

LAST DAY TO REGISTER is Friday, May 27th!

QUESTIONS ABOUT CAMP? PLEASE CONTACT TIM WICKS OR TOREY ALLEN @ 734.544.0015

- 2013 & 2014 Nike Girl Effect Champion
- Top-rated nonprofit on Great Nonprofits
- Gold Level Guide Star
- Global Giving Superstar Level

HFA Blood Sisterhood
hfm

You're invited to join us for HFM's Days for Girls Sewing Project!

Fri., June 3, 6-9pm and Sat., June 4, 10am-4pm, at the HFM office.

HFM is partnering with HFA/Blood Sisterhood to further the mission of Days for Girls by making menstrual hygiene kits for distribution to girls in countries where they do not have access to feminine hygiene products. To learn more about this, please go to www.daysforgirls.org.

Everyone is invited to participate! No sewing experience necessary!

For more information, please email Patrice Thomas at **pthomas@hfmich.org**.

100,000+ KITS PROVIDED

95% OF FUNDS TO PROGRAMS

220+ CHAPTERS & TEAMS WORLDWIDE

75+ COUNTRIES REACHED

Days for Girls empowers women and girls around the globe through providing sustainable feminine hygiene solutions and health education. In areas where women have been taught that menstruation is a curse and a reminder that they are somehow less, DfG is helping them to remember that their bodies are their own, and that they are worthy of health, opportunity, and dignity.

DAYS FOR GIRLS INTERNATIONAL

Every girl. Everywhere. Period.

www.DaysforGirls.org • info@daysforgirls.org