the artery

Winter 2015 • Serving Michigan's bleeding disorders community

hfm®
HEMOPHILIA FOUNDATION OF MICHIGAN
www.hfmich.org

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HFM's kids loved meeting "Santa-Antonio" at HFM's Annual Holiday Party

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From HFM's Holiday party, left to right:

Sue Lerch, HFM Executive Director
"Mrs. Claus"

Antonio Jenkins, HFM Board Member
"Santa-Antonio"

Carrie McCulloch, HFM Special Events Manager
"Tinsel"

Kayla McMaster, Office Coordinator
"Garland"

Dear HFM friends,

We are committed to offering programs that serve individuals, families and loved ones throughout their lives. Here in Michigan we have a special interest in fostering healthy relationships and opportunities for all of our community members.

HFM's annual holiday party, nationally-recognized summer residential camps, fund-raising events, weekend retreats, this year's first-ever regional von Willebrand Disease conference, our HIRED workshops, financial assistance, SpringFest (and more!) all contribute to the overall health of our community members in sometimes unexpected yet quite significant ways.

If you participated with our 2015 holiday party at Troy High School it looked like many holiday gatherings: children decorating gingerbread houses, guests eating pizza and cookies while playing games, and of course, kids sharing heartfelt wishes with Santa. **Our very own Santa-Antonio encouraged each child to select a special gift to take home** that very day, **thanks to our generous supporters**.

Yet, when you looked closely at our HFM holiday party – you could see something more happening…

Kids are forming life-long friendships and reuniting with fellow campers and staff while parents, grandparents and friends are interacting with one another as memories are being made. And this is important! As a community, we know socialization with others facing similar circumstances has a tremendously positive effect on the well-being of people who are handling chronic health challenges.

We believe HFM's role in fostering friendships and opportunities for community support and understanding are not only nice things to do - they are necessary things to do!

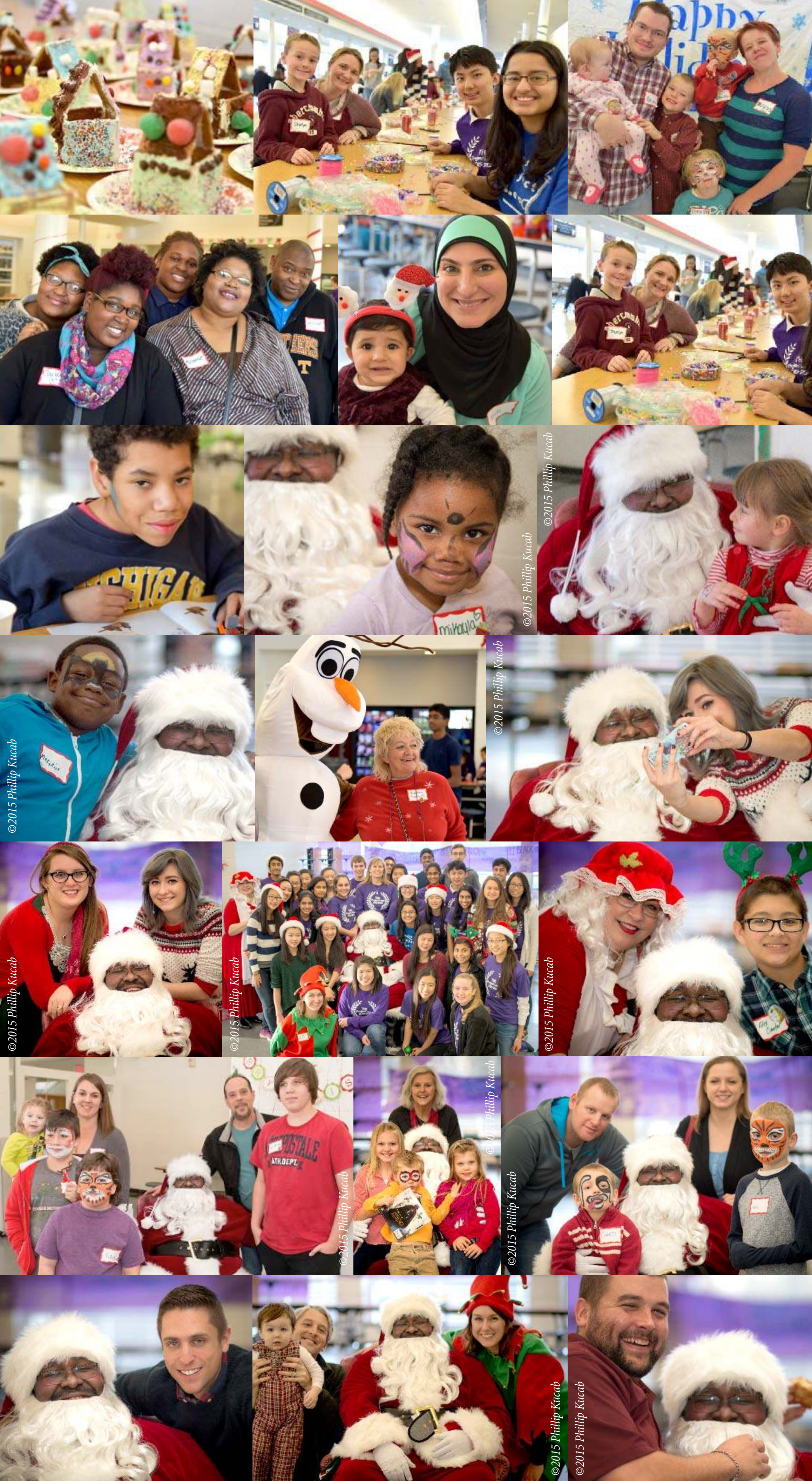
Our HFM family is comprised of community members from a diversity of ethnicities and walks of life who come together with compassion and support for one another whether as a patient, caregiver, care provider, friend or supporter.

We are grateful to have you as an integral part of our extraordinary family.

Wishing you and yours a beautiful holiday season.

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

Click here to see the fun video **of HFM's Holiday Party**



HFM's Annual Holiday Party

December 5th proved to be a very Merry Day for the HFM community! Thanks to the students of Project Lead at Troy High School, families came together to enjoy a day of activities, food, and fun! As festive music played, children gathered together to decorate gingerbread houses. They colored, had their faces painted, and ate as many cookies and pizza as their bellies would allow.

An unexpected guest joined the group: Olaf from Frozen! He was excited to take photos with our kids, and their parents alike! The highlight of the day, however,was our very own Santa-Antonio! Joined by elves, and Mrs. Claus (HFM Executive Director, Susan Lerch), Santa-Antonio dazzled as he welcomed each child to hear their heartfelt wishes.

Once they had met with Santa, each family then entered a special gift area where each child was able to select a special gift for themselves. They were then surprised with the additional gift of a book, courtesy of the Kiwanis Club. We can't wait for next year!

Click here to see the fun video **of HFM's Holiday Party**

ADYNOVATE
[Antihemophilic Factor (Recombinant), PEGylated]

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 used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADYNOVATE is used on-demand to control bleeding in patients 12 years of age and older with hemophilia A. 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

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.

How should I use ADYNOVATE? (cont'd)

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.

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.ADYNOVATE.com 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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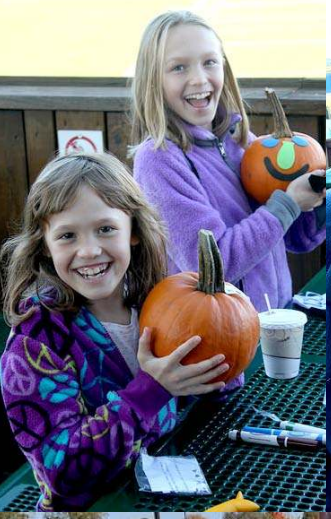
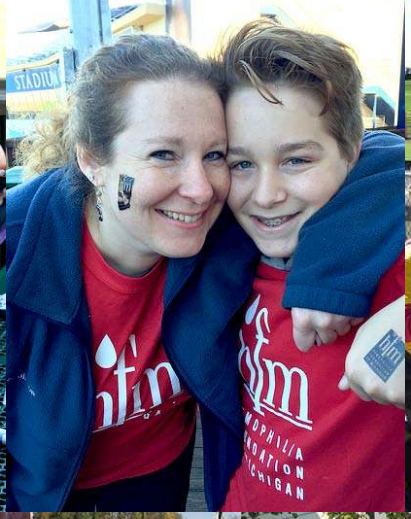

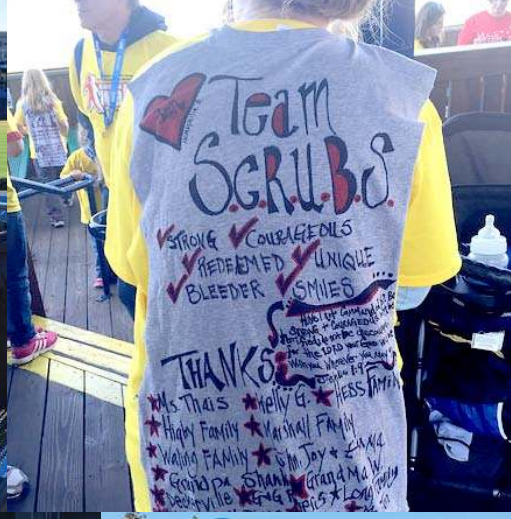


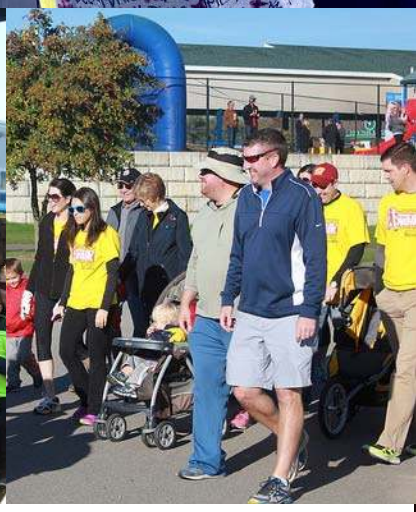

Walkin' on the West Side

HFM's inaugural "Walkin' on the West Side" was a great success in every way. West Michigan showed their support and commitment to HFM's services by raising more than $35,000 with 13 teams and 129 walkers. The theme of this picturesque fall day was FUN! Participants enjoyed family activities such as speed-pitch and pumpkin decorating as well as a beautiful stroll along the Grand River. The Fifth Third Ballpark was the pitch-perfect setting for this first-time event and we can't wait to be back next year. Walkers, volunteers and sponsors came from across the state to be a part of this experience. The event provided the opportunity for those impacted by bleeding disorders to come together in a fun and healthy way. Not only were funds raised to support HFM's much-loved programs, but the personal connections made will have a lasting impact that strengthens our community.

Thank you to everyone who participated in and supported this event including a special team from **Helen DeVos Children's Hospital HTC!** HFM is so grateful for your commitment and dedication to our mission.

Save the date! We **"Walk West"** again, **October 8, 2016**. Stay tuned for more details to come; in the meantime **"click here"** for fun memories from 2015's Walkin' on the West Side.

SPECIAL THANKS TO OUR SPONSORS

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for all bleeding disorders

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Walk Sponsors

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VON WILLEBRAND DISEASE
Bringing Together the Pieces of the Puzzle

This conference was funded through an unrestricted grant from

octapharma®
For the safe and optimal use of human proteins

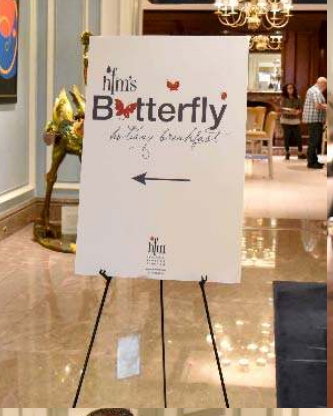
Von Willebrand Disease Conference

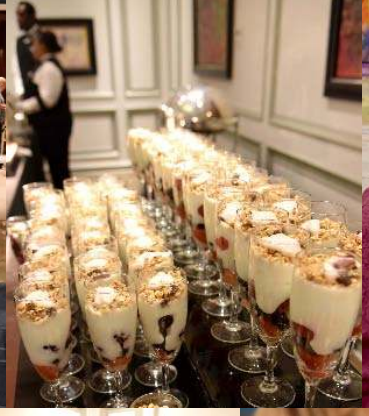
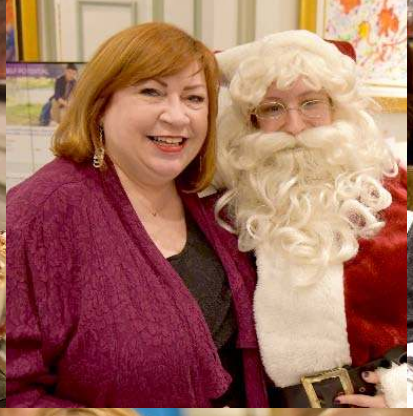
HFM was proud to host the very first regional von Willebrand Disease conference in the Midwest in early November, 2015, in Novi, Michigan. The conference brought together over 100 people from Michigan, Ohio and Indiana who have VWD in their families and were seeking answers to questions regarding diagnosis, care and treatment. A wonderful faculty participated, representing the structure of our HTCs, with doctors, social workers and nurses.

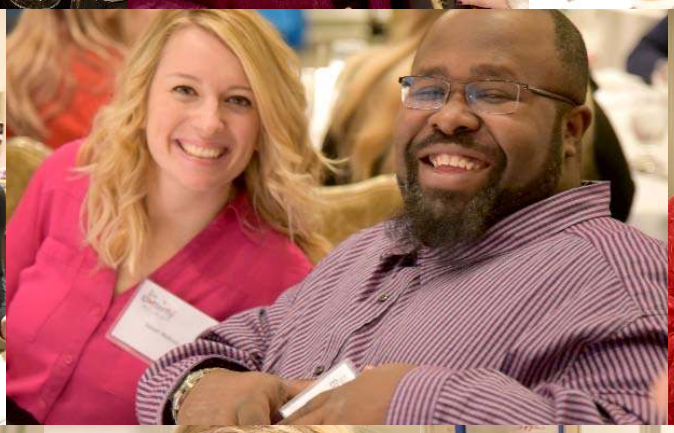
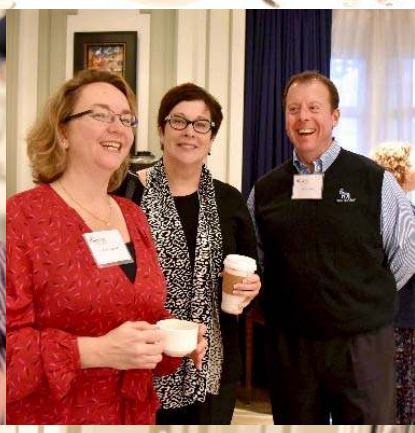
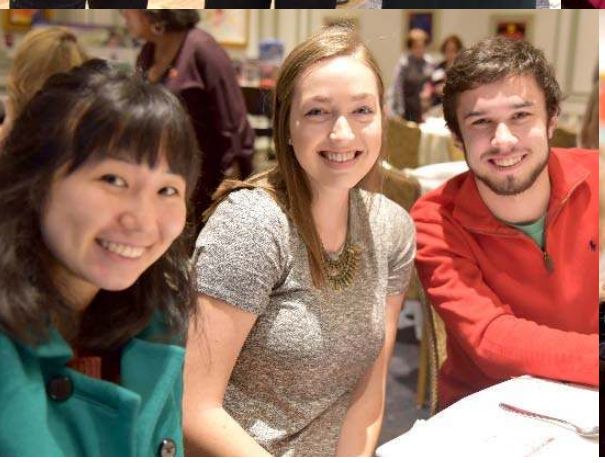
Those in attendance as faculty were: Dr. Steven Pipe (University of Michigan), Dr. Jordan Shavit (University of Michigan), Dr. Meera Chitlur (Children's Hospital of Michigan), Dr. Christopher Walsh (Mt. Sinai, New York), Dr. Robert Sidonio (Children's Healthcare of Atlanta), Jennifer Maahs (Nurse – Indiana Hemophilia Treatment Center), Sue Adkins (Nurse – HFM Regional Core Center Specialist), Danna Merritt (Social Worker – Children's Hospital of Michigan) and Ed Kuebler (Social Worker – Gulf States Treatment Center, Houston).

Attendees participated in general sessions with faculty on Saturday afternoon, including topics on introduction to VWD, diagnosing, and treatment. This was followed by breakout sessions on various topics such as "Genetics: It's all in the Genes" and "Transitioning: Leaving Home in a Healthful Way." Sunday morning followed a similar format, with more attention focused on the future of research and treatment for VWD. Attendees' evaluations rated the weekend event as a success, with 92% stating that they would attend a similar event again in the future. HFM is using the feedback from participants to plan for inclusion of VWD topics during the 2016 year, including organizing at least one all day family VWD event.

If you have any questions or comments, please contact Patrice Thomas, Program Services Director at pthomas@hfmich.org.



"Santa Claus is anyone who loves another and seeks to make them happy."

~ Edwin Osgood Grover

HFM's Butterfly Holiday Breakfast at The Henry

Special thanks to our event sponsors

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Baxalta

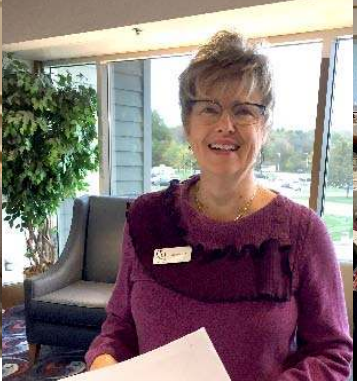
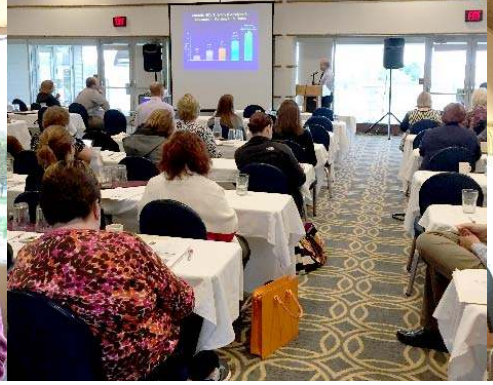
Friends of HFM

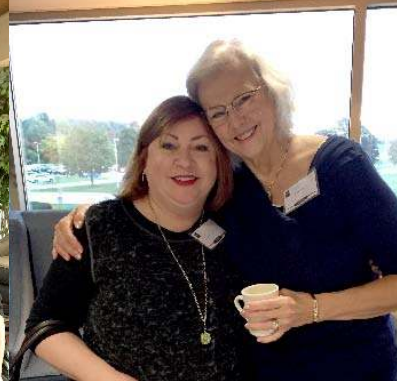
Bayer HealthCare
CSL Behring
CVS/Caremark
Emergent BioSolutions
Grifols
Novo Nordisk
Pfizer

Santa needed help, and the HFM community came to the rescue! Due to an overwhelming demand for toys this year, Mr. Claus was having a difficult time producing enough to provide for both his home deliveries at the end of December, and our Holiday Party on December 5th. Fortunately, the attendees of the HFM Holiday Butterfly Breakfast were quick to respond!

On November 13th, 60 members from the community gathered at The Henry in Dearborn. The morning started with a visit and toy collection from Santa "himself." He was overjoyed with the generosity of those in attendance! The toy collection was followed by a delicious breakfast and time to socialize. The breakfast included a program that highlighted the ways that we can positively affect individuals in the bleeding disorders community from giving at a global level, to local giving. Together, we celebrated the power that we all have to better the world around us through generosity of heart and spirit.

This opportunity to celebrate the start of the holiday season was generously provided by our sponsors. We thank them for recognizing the needs of our community!



Annual Regional Meeting

As the Regional Core Center, the Hemophilia Foundation of Michigan hosts an annual Regional Meeting for our HTC providers. Staff members from all of the Hemophilia Treatment Centers in our region are welcome and encouraged to attend. We offer general education sessions as well as breakout sessions based upon discipline.

We hosted our 2015 Regional Meeting October 11-13 at Maumee Bay State Park Lodge and Conference Center in Oregon, Ohio. Over 100 people attended the meeting, which was the highest attendance we have had in recent years. Additionally, almost 25% of the attendees were either new HTC staff members or first time attendees of our Regional Meeting. We covered a wide variety of topics in our sessions that are relevant to HTC staff. This year we had updates from the American Thrombosis and Hemostatis Network (ATHN), the National Hemophilia Program Coordinating Center (NHPCC), and the Hemophilia Alliance. Our general sessions topics included: "Bleeding Tendencies in Hemophilia Carriers" presented by Dr. Robert Sidonia, Jr. from Emory University, "The Movement Checkup" by Vanessa Lanier from Washington University, and "Hepatitis C-The Good News" presented by Dr. Dilip Moonka. We also had a session covering Quality Improvement, which is one of the goals of the grant program. The Regional Meeting also provided nurses and social workers an opportunity to earn Continuing Education Units towards their licensing requirements.

The Regional Meeting is not all work. We offered time for attendees to enjoy the scenic location and the opportunity to test their trivia knowledge. (Do you know how many local hemophilia chapters there are in Indiana, Michigan, and Ohio? What happened on May 6, 1954? No Googling!) We look forward to seeing even more people next year at the meeting in Indiana!

ALPROLIX®
[Coagulation Factor IX (Recombinant), Fc Fusion Protein]

A treatment for hemophilia B

PROTECTION* FROM BLEEDS

Starting with at least a week between prophylaxis infusions

Dosing regimen can be adjusted based on individual response.

*Protection is the prevention of bleeding episodes using a prophylaxis regimen.

To learn more, contact CoRe Manager **Shelley Gerson** at **shelley.gerson@biogen.com** or call **248-703-3434.**

INDICATIONS AND IMPORTANT SAFETY INFORMATION

Indications

ALPROLIX, Coagulation Factor IX (Recombinant), Fc Fusion Protein, is a recombinant DNA derived, coagulation factor IX concentrate indicated in adults and children with hemophilia B for:

- Control and prevention of bleeding episodes
- Perioperative management
- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes

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

Important safety information

Do not use ALPROLIX if you are allergic to ALPROLIX or any of the other ingredients in ALPROLIX.

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 and all your medical conditions, including if you are pregnant or planning to become pregnant, are breastfeeding, or have been told you have inhibitors (antibodies) to factor IX.

Allergic reactions may occur with ALPROLIX. 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 ALPROLIX, which may stop ALPROLIX from working properly.

ALPROLIX may increase the risk of formation of abnormal blood clots in your body, especially if you have risk factors for developing clots.

Common side effects of ALPROLIX include headache and abnormal sensation of the mouth. These are not all the possible side effects of ALPROLIX. Talk to your healthcare provider right away about any side effect that bothers you or does not go away, and if bleeding is not controlled using ALPROLIX.

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

Biogen

 FIX-US-0427 06/2015

ALPROLIX [Coagulation Factor IX (Recombinant), Fc Fusion Protein], Lyophilized Powder for Solution For Intravenous Injection.

FDA Approved Patient Information

ALPROLIX™ /all' pro liks/ [Coagulation Factor IX (Recombinant), Fc Fusion Protein]

Please read this Patient Information carefully before using ALPROLIX™ 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 ALPROLIX™?

ALPROLIX™ is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital Factor IX deficiency.

Your healthcare provider may give you ALPROLIX™ when you have surgery.

Who should not use ALPROLIX™?

You should not use ALPROLIX™ if you are allergic to ALPROLIX™ or any of the other ingredients in ALPROLIX™. Tell your healthcare provider if you have had an allergic reaction to any Factor IX product prior to using ALPROLIX™.

What should I tell my healthcare provider before using ALPROLIX™?

Tell your healthcare provider about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- are pregnant or planning to become pregnant. It is not known if ALPROLIX™ may harm your unborn baby.
- are breastfeeding. It is not known if ALPROLIX™ passes into breast milk or if it can harm your baby.
- have been told that you have inhibitors to Factor IX (because ALPROLIX™ may not work for you).

How should I use ALPROLIX™?

ALPROLIX™ should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider. Many people with hemophilia B learn to infuse their ALPROLIX™ by themselves or with the help of a family member.

See the Instructions for Use for directions on infusing ALPROLIX ™. The steps in the Instructions for Use are general guidelines for using ALPROLIX™. Always follow any specific instructions from your healthcare provider. If you are unsure of the procedure, please ask your healthcare provider.

Do not use ALPROLIX™ as a continuous intravenous infusion.

Contact your healthcare provider immediately if bleeding is not controlled after using ALPROLIX™.

What are the possible side effects of ALPROLIX™?

Common side effects of ALPROLIX™ include headache and abnormal sensation in the mouth.

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

ALPROLIX™ may increase the risk of forming abnormal blood clots in your body, especially if you have risk factors for developing blood clots.

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

These are not all the possible side effects of ALPROLIX™.Talk to your healthcare provider about any side effect that bothers you or that does not go away.

How should I store ALPROLIX™?

Store ALPROLIX™ vials at 2°C to 8°C (36°F to 46°F). Do not freeze.

ALPROLIX™ vials may also be stored at room temperature up to 30°C (86°F) for a single 6 month period.

If you choose to store ALPROLIX™ at room temperature:

- Note on the carton the date on which the product was removed from refrigeration.
- Use the product before the end of this 6 month period or discard it. not return the product to the refrigerator.
- Do not use product or diluent after the expiration date printed on the carton, vial or syringe.

After Reconstitution:

- Use the reconstituted product as soon as possible; however, you may store the reconstituted product at room temperature up to 30°C (86°F) for up to 3 hours. Protect the reconstituted product from direct sunlight. Discard any product not used within 3 hours after reconstitution.
- Do not use ALPROLIX™ if the reconstituted solutionis cloudy, contains particles or is not colorless.

What else should I know about ALPROLIX™?

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

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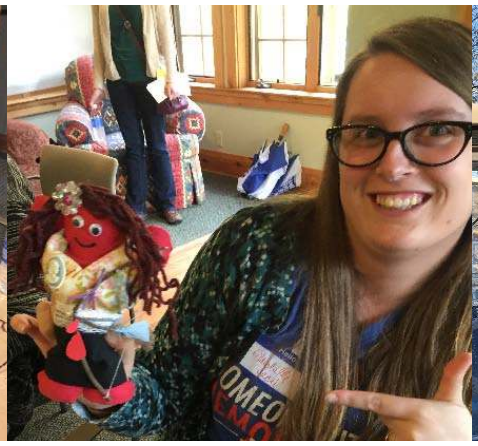


"In this world there is no force equal to the strength of a woman determined to rise."
~ W.E.B. Du Bois

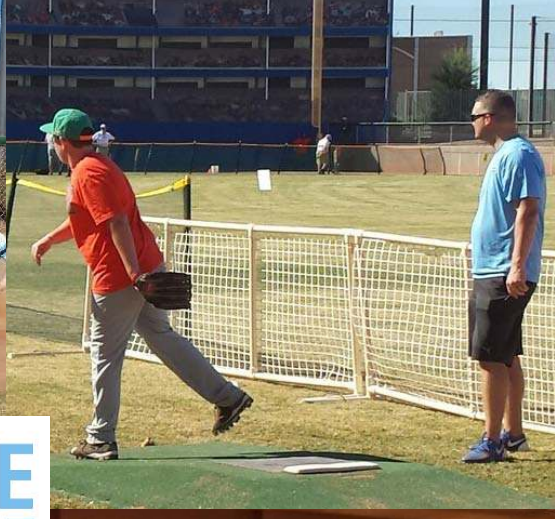
HFM's Women's Retreat

The Hemophilia Foundation of Michigan provided an opportunity for women over the October 24th weekend to participate in an all-women's retreat. Taking place at Yarrow Golf and Conference Center in Augusta, MI, nearly 30 women joined in this event.

Sonja Wilkes from Hemophilia Federation of America joined us to share her story of living with a son who has an inhibitor and to educate on the importance of self-care. In her advocacy efforts she has had the opportunity to meet with President Barack Obama to provide education on the insurance needs of families living with bleeding disorders.

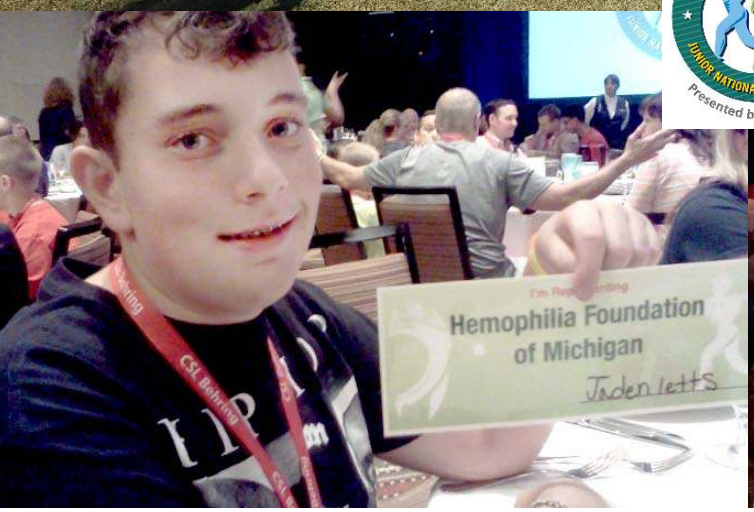
The women participated in numerous activities including the Golf Cart Scavenger Hunt. Everyone was invited to grab a golf cart and participate in finding clues set out along the property. Prizes were awarded for 1st place, best team name, best overall photo and most creative photo!

One major goal of the women's retreat was to enhance connections with previously formed relationships and to establish new connections with other individuals within the bleeding disorder community. HFM is working to build upon these values and objectives now and in the future.



GETTIN' IN THE GAME
JUNIOR NATIONAL CHAMPIONSHIP
Presented by CSL Behring

GAME ON!



Gettin' in the Game

By Dick Letts

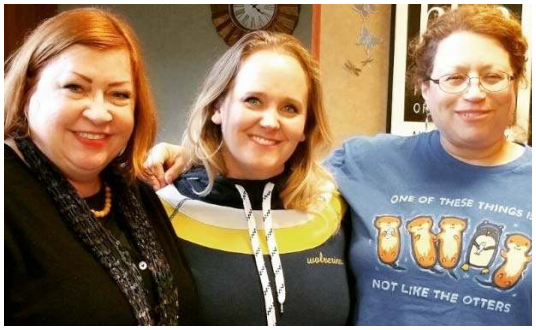
As a parent, it's important to make sure that our children know that the sky is the limit and that anything is possible, even being a professional athlete. Jaden, my 14 year-old son, and I participated in the Gettin' in the Game Junior National Championship (JNC) this fall and we had the chance to meet pro athletes with bleeding disorders. For 14 years JNC has been offering baseball and golf clinics for the bleeding disorders community. The pros, who also have bleeding disorders, make sure that the kids have fun and tell them through role modeling and encouragement that having a bleeding disorder shouldn't hold them back from competition. Perry Parker, an impressive golf pro, really impacted all of the participants with his story about becoming a professional athlete.

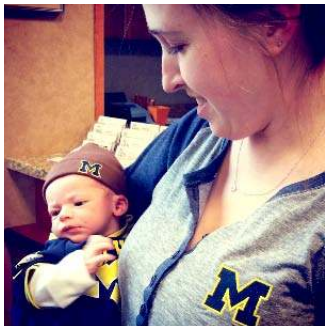
Jaden did a great job throughout the weekend and really enjoyed himself. Jaden fit in quickly and spent a lot of time at the pool with the other boys. I overheard his new friends talking about Jaden being in the "A Team," a reference for boys with Hemophilia A, an instant bond and brotherhood.

My favorite part of the trip (besides seeing Jaden enjoy himself and being in Arizona which was beautiful and warm) was meeting other dads and sharing stories about our sons. It felt good to talk with people who understand what we are going through. It is so meaningful to be able to share our experiences watching our sons grow up as responsible and smart young men and to see them accomplish so many things.

We are thankful to our treatment center for nominating Jaden for the JNC and for all of the opportunities we have had as a family through the Hemophilia Foundation of Michigan. We would like to give a special shout out to Camp Bold Eagle for teaching Jaden how to infuse at age 9; by age 11 he was infusing on his own. Prior to this I always helped Jaden infuse but when he could self-infuse we were able to have his port removed. This was a huge step in Jaden's independence. Jaden self-infused prior to the JNC competition without any problems, and in fact, made it look easy.

As a parent of a child with hemophilia, there are a lot of things you worry about and there are a lot of things our children have to learn in order to manage their hemophilia. Jaden has never let hemophilia hold him back from doing anything and I couldn't be more proud!





photos courtesy of Rhonda Medina

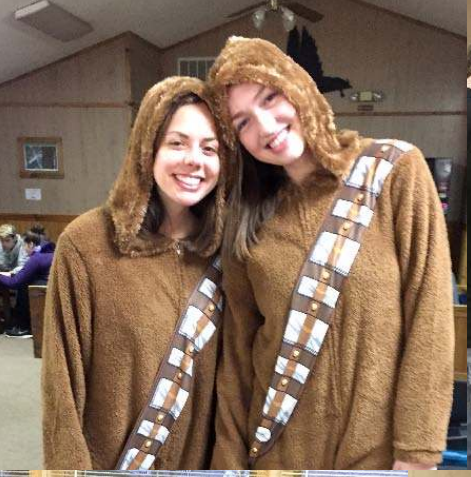
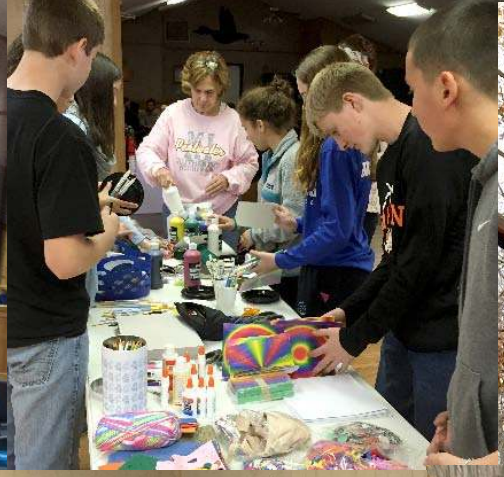
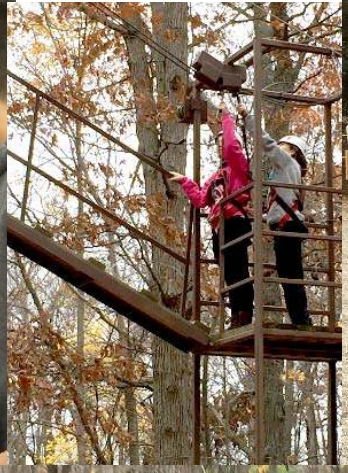
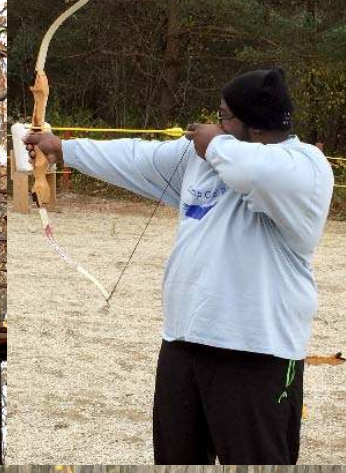
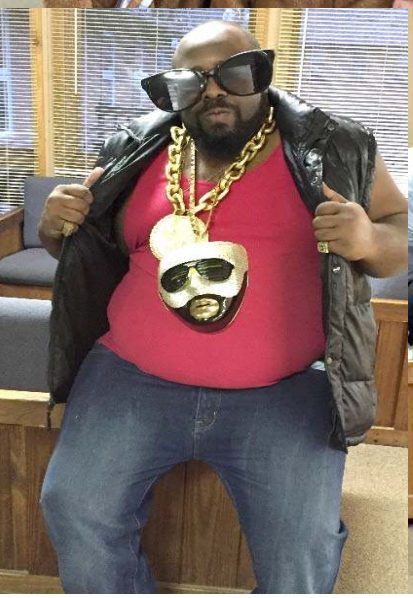
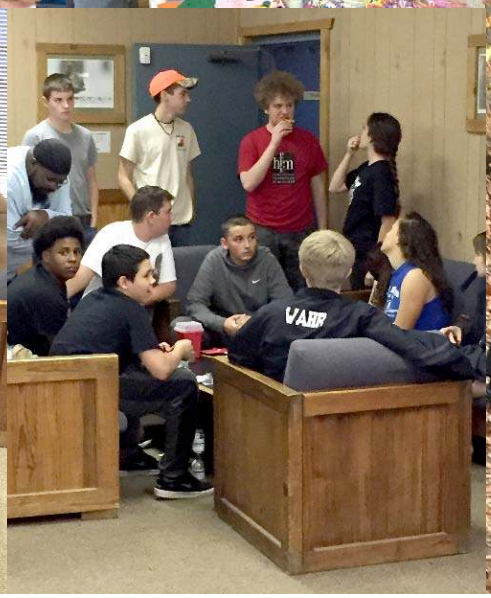
Why do you tailgate?

Is it to stand outside in the cold? Is it to eat food that you could just as easily make at home? Is it to watch a game that you could watch at home? The answer to all of these is, of course, no. You go to a tailgate for your friends. And on an October Saturday, we had our friends – that is anyone who is in the HFM community – join us for a tailgate at our offices to eat and watch Michigan play Michigan State.

HFM provided food and drinks, everyone else provided the entertainment. There were kids running outside, toddlers roaming the halls of the office, friends harassing each other about Michigan or Michigan State, people making new friends, and everyone was enjoying their friends: old or new. The lawn games, the food and the company made the few hours before the game fly by.

The game itself was almost secondary but people became more and more interested in one of the most thrilling games ever. Michigan fans harassed their Michigan State counterparts through the first half but as the second half wore on Michigan fans became more and more anxious. Of course the thrilling last play-where the punter fumbled the snap and Michigan State recovered to score the game winning touchdown-had everyone out of their seats and yelling at the television.

After the game (and the yelling), everyone helped clean up. It was just like at a friend's house. People were cleaning dishes, putting food away and helping to pack up. No one was asked but everyone pitched in. It was a wonderful way to close out a wonderful day.


Bleeder and a Buddy Retreat

Living with a bleeding disorder can be a very lonely life. There are often misconceptions and misunderstandings and many people with bleeding disorders choose not to disclose their diagnosis to others. And because bleeding disorders affect people in such significant ways, this secret creates a barrier to creating close friendships. To break down this barrier, HFM offers our Bleeder and a Buddy program. Teenagers with a bleeding disorder can bring an unaffected friend to this weekend retreat and the friend learns about bleeding disorders while everyone has a lot of fun.

This year at Bleeder and a Buddy we traveled up to Camp Copneconic, the former home of Camp Bold Eagle. Upon arriving Tim, our camp director, took time to lead our 14 bleeders and 14 buddies in icebreakers to get to know one another. Within minutes Tim had the teens laughing, yelling, running, and meeting new people. After only an hour and a half the group was transformed from 14 pairs of strangers to a cohesive group that was getting to know each other.

The next morning the teens were challenged to go outside of their comfort zone as they climbed in the air on the high ropes course. After the high ropes the teens put their archery skills to the test. Our two morning activities pushed the teens physically and showed everyone that individuals with bleeding disorders can do what everyone else does, they just need to take some extra precautions.

In the afternoon the group spent several hours learning about bleeding disorders, discussing what they knew about bleeding disorders and sharing what they would like to know. After the teens talked our nurse, Laura-Jean Siggens, answered their questions and shared some additional knowledge. The teens then mapped out the inheritance patterns for hemophilia and von Willebrand's Disease. Finally, young adults from the National Youth Leadership Institute (NYLI) came and led the group in an art therapy session. The teens designed masks to represent what they show to the outside world and what they keep to themselves. The activity led to a very interesting discussion about how people are perceived and how we perceive ourselves.

Since it was Halloween weekend, we finished the night with a haunted house tour. The teens divided up into small groups and with a staff member traveled through the haunted house. Everyone had a blast and it was a really fun way to finish off a great day. In the morning we ate breakfast and talked about what the teens liked and learned from the weekend. We left to return to HFM, everyone buddies and no one hiding their bleeding disorder.

Nick Gamber of HFM's H.I.R.E.D. shown here preparing to teach Budgeting & Excel.

HFM's H.I.R.E.D.

Do you know what your rights are in the workplace? Do you understand what accommodations you can request, and what accommodations employers are required to give you? Do you feel like you can advocate for yourself in the workplace? Are bleeding disorders covered under the Americans with Disabilities Act? HFM's H.I.R.E.D. program has recently begun focusing on these issues and wants to share what your rights are and what you are entitled to receive.

Employment opportunities and accommodations in the workplace are frequent concerns for those in the bleeding disorder community. A recent H.I.R.E.D. workshop focused on employment issues for individuals with bleeding disorders. The discussion focused on disclosure, self-advocacy, and employment rights. Because of the positive response the workshop received, HFM will host the workshop again on December 20 at the HFM offices. Please join us.

HFM is working on partnering with the HTCs to bring H.I.R.E.D. workshops on the road in the coming year. We plan to hold our H.I.R.E.D. workshops in several locations in 2016. Please keep a look out for updates to see what topics we will be covering and when our workshops will be coming to a location near you!

H.I.R.E.D.'s next workshops:

See Facebook event pages and RSVP to NGamber@hfmich.org

December 20
H.I.R.E.D. workshop
Self-advocacy and employment rights
At HFM, 6pm start time
Pizza will be provided

Anthony's Experience at Camp Bold Eagle

By Anthony Sawyer, MD Candidate, University of Michigan Medical School '17; MPH Candidate, Harvard T.H. Chan School of Public Health '16; BSPH, UNC Gillings School of Global Public Health '10

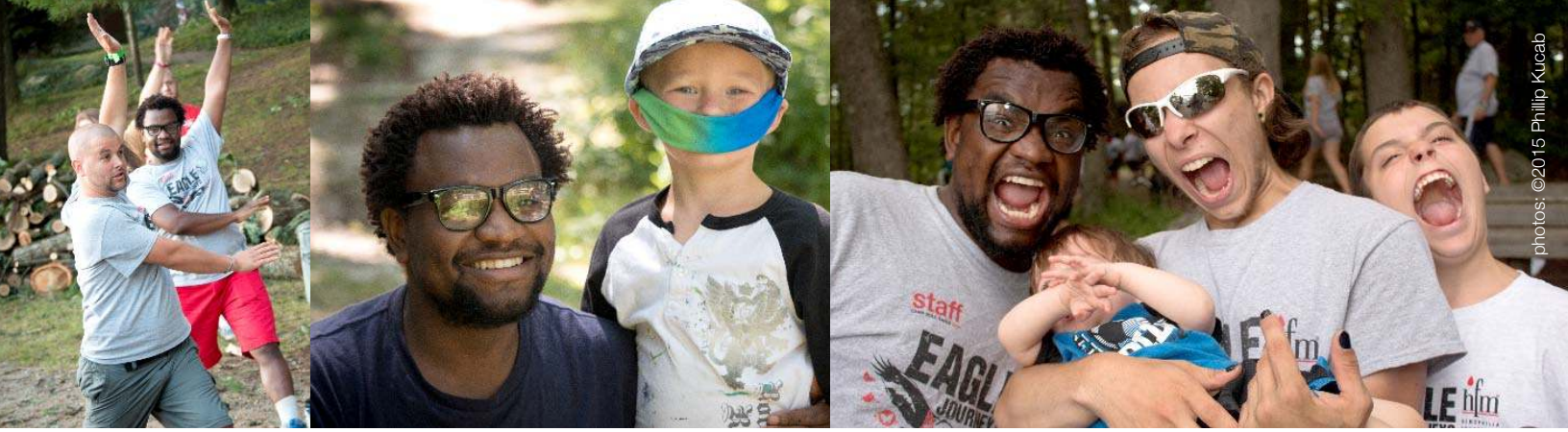
If you've seen me at any point over the past few months, you might notice that there's a bracelet that I wear every day on my right wrist. It's green and blue and made out of plastic. Some people might call it a lanyard or a gimp. On it, my name is spelled out in white beads, except that the A and the O in my name are replaced with plain beads (vowel beads are really popular!), so that it looks like 0-N-T-H-0-N-Y. I love this bracelet not because it is particularly beautiful, but because of what it represents. This bracelet is my constant reminder of my time as a counselor and medical student at Camp Bold Eagle.

From the time that I was a preclinical student at the University of Michigan Medical School, I heard older students raving about what we call "peds camp." I could not understand what all of the hype was about, but no less than five people told me that I should consider participating in this camp as a medical student volunteer during my fourth year. As an aspiring pediatrician, the thought of spending time at summer camp with a bunch of kids while getting academic credit sounded too good to be true, so I jumped at the possibility. I had no idea how the experience would change me for the better.

A week before campers arrived, I arrived to CBE for orientation with another medical student, Kenny. I remember all of the smiling strangers who were there to greet us when we showed up. I remember how young they all looked, only to learn later that most of them were counselors-in-training, and many had been CBE participants just a few years earlier. I also remember how helpful everyone was in getting us acquainted. From that moment on, I knew I was in for an amazing month.

Camp Bold Eagle is a special place where kids and adults alike feel empowered. As an outsider who didn't know much about bleeding disorders before this summer, I was curious to learn what it really looked like to live with hemophilia, von Willebrand Disease, or a platelet disorder. With my limited and often incorrect knowledge, I envisioned frail kids who were afraid to be active for fear of having a debilitating bleed. I could not have been more wrong. Camp Bold Eagle was indeed a place where people felt safe, but not because they were sheltered and protected from any semblance of harm. Instead, they felt safe because they were with their CBE family, and it was a family in the truest sense of the word. From the stories shared to the experiences of being a child with a chronic and frustrating disease,

Anthony's Experience at Camp Bold Eagle continues on page 17



photos: ©2015 Phillip Kucab

Anthony's Experience at Camp Bold Eagle continued from page 16

campers and counselors alike supported each other in an environment that cultivated creativity, collaboration, and a whole lot of fun.

During the first camp session, I was paired with an awesome team of co-counselors and tasked with taking care of the Bannocks, the youngest kids at camp. These five boys, ages 6 and 7, were nothing short of awesome. They had tremendous imaginations and energy for days. They also had a curiosity for their world that I hope never diminishes. Some of them were away from their families for the first time, and I assumed that they would have a difficult time with the separation. While there were some instances of homesickness, what stood out to me more was the fact that these kids really embraced the environment that they were in, and thrived as a result. I loved to watch them learn how to swim with Andy and the waterfront staff, devour food at the mess hall with Karl, and listen intently for directions as we prepared for our "monster hunts." I also saw them demonstrate tremendous bravery every time they had to be "poked," and realized how strong they had to be to deal with their diseases on a daily basis.

During the second camp session, I was a counselor for the Arapaho cabin, and I had a group of 13-year-old boys who were in their final year as campers at CBE. They were the opposite of my Bannocks in many ways; they were all multi-year CBE participants, all but one had already obtained their Butterfly Awards (which is AWESOME!), and they demonstrated a maturity that made it very easy to work with them. They were ready to go to the lake (almost) every morning for the Polar Bear Club. Sometimes, they acted too cool for certain activities, like cabin clean-up, but they really did teach me a lot. They taught me what it really means to understand your bleeding disorder, and why it matters. They demonstrated the independence that comes with being able to infuse factor on your own, and showed great pride in having a bleeding disorder but still being a regular kid. We talked about their goals and dreams, and reflected on the fact that eighth and ninth grade was just over the horizon for them when school was to start up again. During our camp-out, we shared s'mores and laughs (and it seemed like they never wanted to go to sleep because they were laughing so hard!) while playing mystery games. We also endured hard times, as one of our campers experienced a severe bleed that mandated aggressive pain management and factor infusions every six hours.

"Camp Bold Eagle is a special place where kids and adults alike feel empowered."

I watched my campers support each other, from showing tremendous patience and flexibility while the counselors dealt with one camper's bleed to celebrating as another Arapaho successfully obtained his Butterfly Award. I also remember fondly the trip that all of the Arapaho campers and counselors took across the lake on the last full day of camp. We ate, drank, laughed, and enjoyed each other's company. We also reflected not just on that year, but on all of the years that our campers had participated in CBE, and on what their futures would hold. I couldn't have been more proud of those boys than on that day.

For me, camp was a relatively stress-free place, and yet I felt a special tranquility when I entered the arts and crafts area. It was my program area during the second session, and I really enjoyed my time there. Nikki, who ran the program, played the best music, kept a safe and fun environment, and was gracious with all of the kids' – and other adults' – requests. We had a lot of fun. In that cabin, I got to see kids utilize their creativity and ingenuity to create masterpieces. I also gained some insight into who these kids were as individuals: their hobbies, their talents, and their aspirations. I also remember holding a special enthusiasm for my "Science Is Real" crew, from making non-Newtonian fluids and bottle rockets to extracting DNA from strawberries. This was made especially impactful when one of the campers would randomly whisper "science is real" every time he saw me. These represent but a few of the many awesome experiences that I had during my short summer at CBE.

The day that my Arapaho campers left, I cried. I remember feeling a combination of tremendous gratitude and overwhelming sadness. I was grateful that I got to be a part of these kids' lives, even if it was for a short time, and I was sad that I wouldn't see them again for so long, especially since my 13-year-olds were aging out as campers. I also remember feeling guilty that I felt such a connection to a place that I had known for so little time, especially since this was a place where many others had literally grown up. One camper described it as the safest place that he knew. However, what I felt most was excitement, because I knew that I would be back. I wear that green-and-blue plastic bracelet as a reminder to myself of how awesome camp is, and as a commitment to get back to Camp Bold Eagle as soon as I can. Trust me: I will be back!

Get to Know

Camp Bold Eagle's Director, Tim Wicks

How many years have you been HFM's Camp Director and Youth Services Manager?
Since 2010, almost six years.

As a person with a bleeding disorder, can you share what camp means to you?
Camp is a place of understanding and acceptance. Rather than having to explain my bleeding disorder, everyone just gets it. Camp brings out the best in people. We often say that we are the most "real" at camp.

What is your favorite part about being Camp Director?
Going to camp. Before, I would take time off to work at camp, and now it's actually part of my job. Also, seeing campers that I had at age 6, now in leadership roles at camp; just being able to see that growth.

Do staff make fun of you for anything?
Well, I always ride my bike around camp. I wear my camp director hat, and also a helmet over the hat. I started to duct tape a flashlight to the top of my helmet so that I could see at night. Everyone seems to get a good laugh out of that.

You and your wife, Jenna are new parents. Does being a dad change anything about how you look at the importance of camp?
It'll help with my empathy for parents in regards to sending their kids to camp. I can't imagine letting go of my little guy for a day, much less a week. I also feel more confident in the camp; I wouldn't hesitate to send Charlie, even if I wasn't there.

Is there a fun story from camp that you can share with us?
Last year, we needed enough bandanas for everybody at camp. We asked the camp manager to get 100 bandanas while she was out. We realized we needed more for the staff as well, so I sent her a text saying "Could you please try to actually get 120 bandanas?" My phone auto corrected "bandanas" to "bananas." Because cell service is so bad at camp, I didn't get her reply photo of a cart full of 120 bananas until she was pulling down the driveway...

Is there anything you want people to know about you?
My goal is to have some form of camp all year long, I am passionate about camp.

2016 Eagle Journeys
Please check our facebook page or go to www.hfmich.org for more info in January.

Outpost
June 19-25
(14-16 yrs.)

Camp Bold Eagle
Session 1:
July 10-14 (6-10 yrs.)
Session 2:
July 16-23 (11-13 yrs.)

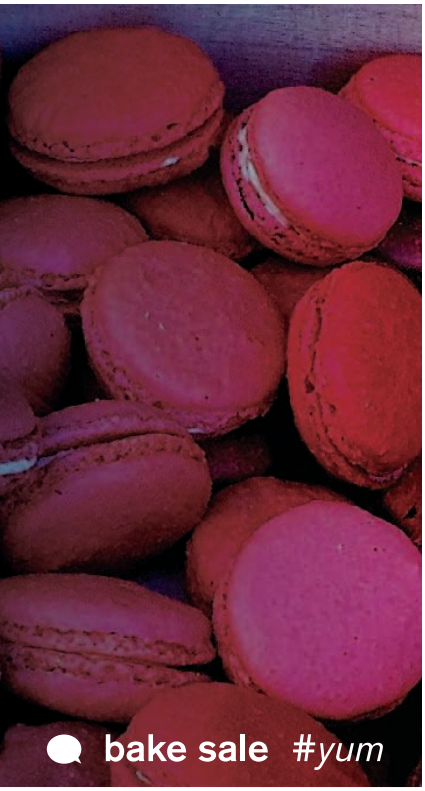
Expedition
TBD (16 yrs. +)

CIT Program
TBD (16 yrs. +)

The Journey, Celebrated

Life is made of small moments that inspire, motivate, and make us feel that our work is worthwhile. As a company, as a team, and simply as individuals, we strive to discover, enable, and celebrate more of them.

Today, possibility is in the air.



Biogen

Get to know us: **BiogenHemophilia.com/CoRes**

/BiogenHemophiliaCoRes /BiogenHemCoRes

The Luckey Family
Top Jay, Shari, Luke (and Clover), Dave;
Bottom: Anya and Isabella

The Luckey's adoption story

Our Journey to our Son

Seven years ago, on November 9, 2008, I had no idea that my son was turning 8 years old, half way around the world in China. I didn't know that in a few months, my husband and I would receive an email that would change our family's, and our future son's, lives forever. The email merely indicated that he lived in China with hemophilia, spending many weeks in the hospital each year, and he needed a home. As a family, we quickly decided we needed to make him ours.

Prior to that email, Pam Thomas, current China Program Director for Across the World Adoptions, was visiting one of her partnership orphanages in Nanjing, China. She went to look at some of the bunk beds her organization had recently donated. She noticed a cute, fragile looking boy, giving her the peace sign with a big grin on his face. She learned that this child had hemophilia, and was therefore considered unadoptable! After returning home she was helping a New York family adopt their little girl when she learned that they had a son with hemophilia. She recalled the charming little boy she had met in China. With encouragement from the NY mom who had a connection in the hemophilia community, she convinced the orphanage to make the young boy "paper ready." Within days of an email going out to the hemophilia community, we had contacted Pam and were getting ready for our new son.

When we were united with Luke on January 25, 2010, he was quite frail and had a slight limp. He had a target right knee that had repeatedly bled over the years and was rather swollen. He spent the majority of his time with us in China in a borrowed wheelchair. When we returned home, we immediately took him to the hematologist for evaluation and he received a dose of factor VIII that day. We then began physical therapy for his knee and prophylaxis twice a week. Over the course of the next several months, Luke made amazing progress, growing physically stronger and regaining full use of his knee. With occasional breakthrough bleeds and school starting in the fall, the hematologist increased his prophylaxis to three times per week.

Now almost six years later, life for Luke is much different. He is physically strong and healthy and he has family and friends who love him. When I asked Luke what he wanted to say about his experience, he said, "The first day I met you, you were strangers, but soon after I felt like I belonged in the family." He is getting excellent grades as a freshman in high school, while playing the violin in his school orchestra, and participating in team sports. He rows on the crew team with his sisters, and enjoys running. Luke's dad, Dave recently commented, "I had thought that our family was complete until Luke. We have been blessed with him in our lives and it is exciting to see him grow into an amazing young man."

Luke learned to self-infuse at Camp Bold Eagle the first summer he was home and is now independent with his infusions. Remarkably he has not had a bleed since starting 4th grade. Luke's older brother Jay says, "It's been exciting to see Luke grow and overcome his hemophilia obstacles." This would not have been possible if he had remained in China.

Since helping our family become complete, Pam has been searching for boys with hemophilia in China and advocating to find families for them. This year alone, she has matched nine boys with hemophilia to their forever families. When Pam locates a boy with hemophilia she contacts myself and several other moms in the hemophilia and adoption communities. We then go to work advocating and searching to find forever families for them. It has been so rewarding to feel that in some small way I can help these boys find the families they deserve and the access to medical care that they desperately need.

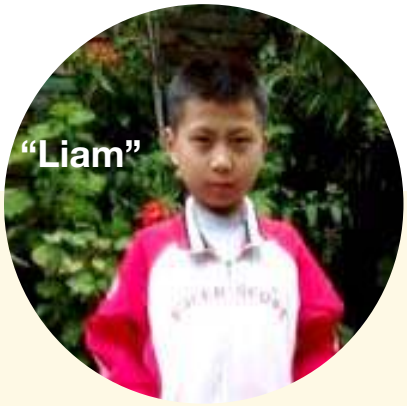
In November of 2014, I learned of "Cody," a young boy in China with hemophilia that was going to be turning 14 in July of 2015. I was told that at age 14 a child "ages out" of the system. Ages out? What does that mean? I had never heard about this before. As it happened, we had just celebrated Luke's 14th birthday three days before. It struck me that if Luke had remained in China, he would have aged out three days earlier! I had to know what would have happened to him. What I discovered was devastating and made my heart ache. For a child with a severe medical condition like hemophilia, aging out typically means the child will be moved from the orphanage to an institution, for the remainder of his life. With severe hemophilia and little to no access to medication, the average life span for someone living with hemophilia in China is only 24 years old. I couldn't believe it! We had to find "Cody" a family! Through a mass effort by Pam, her agency, and the hemophilia and adoption communities, a family miraculously stepped forward for Cody. He has been home five months now and is thriving with his new family and medical care.

Our Journey to our Son continued on page 21

Our Journey to our Son continued from page 20

The blessings we have received from our journey to adopt Luke have been too numerous to count. We have an amazing son whom we love and cherish. He is an integral part of our family and he has impacted each one of us and made our hearts grow. His sister, Isabella, stated, "Even though it wasn't always easy, I cherish getting to build a relationship with my brother." They are truly like any other siblings, they get on each other's nerves one minute and then I will spy Isabella patiently helping Luke with his biology homework. Anya recently said, "I always wanted a little brother, but I didn't know how much he would teach me to appreciate the life that we have here." Anya has developed a passion for Chinese orphans and would like to do a mission trip to China and work with orphans there.

Our journey to Luke has inspired me to advocate for other children with hemophilia in China. Through my advocacy efforts, I have met so many amazing people. One mom who adopted her son a fewyears ago started the Hemophilia Adoption Facebook page. This private group consists of those that have already adopted a child with a bleeding disorder, are starting the process, or considering adopting a child with hemophilia. We are creating a network of advocates, mentors, and experts in hemophilia adoption. I am so blessed to be a part of this, and to witness families finding their forever sons. We are so fortunate to live in this country, where everyone can have access to the medical care that they need and deserve.



Adoption Opportunities

Looking for Forever Families for these two boys

"Liam" will turn 12 in March 2016 and has been waiting a long time for his forever family. From a volunteer who worked with him, "I think Liam's biggest need in life is something that is needed by all children– love. That said, love is not absent in his life because he continually shows love towards the people around him. He loves life and has a way of showing that for others. Liam is an all around great kid who would thrive in a family that supports and loves him." With painful bleeds and little medical intervention for his hemophilia, his life is limited. His time is running out, as he will age out of the system at 14. Could he be the missing piece of your family?

Eight year old "Bryan" has hemophilia and patiently awaits his forever family to find him! His development is excellent, he is outgoing and active– except after he's had a bleed. He loves games, playing with clay, plants and animals, and is very sociable with his little friends.

Both "Liam" and "Bryan" deserve a family to call his own and access to the world's best medical care, so he can live an active pain free life. If you or someone you know is interested in learning more information about these handsome guys, please contact Kendra Allen at Across the World Adoptions at: ***kendi.allen@gmail.com***

Adoption Info

Did you know?

In the United States and other medically developed countries, living with hemophilia is very manageable. Typically, medication that replaces the missing protein in the blood is given through an intravenous infusion 2-4 times a week, allowing the person with hemophilia to live a healthy and active life. In developing and underdeveloped countries, however, medication is not readily available, often making the diagnosis of hemophilia devastating. With recurrent bleeds, pain, and joint damage, hemophilia in many other countries means a daily struggle for the caregiver to protect the child from injury. This typically means the child must live a cautious and sedentary life, still suffering from spontaneous bleeds and bleeds from minor injuries.

Process to Adopt

The process to adopt varies from country to country. For our China adoption, we needed to have pre-approval from China, a home study from a local adoption agency and online training for older and special needs children. We also had to gather various legal papers, fill out many forms, and send everything to China for authorization and approval. Our process took about 9 months from start to finish. The cost associated with a China adoption is currently around $35,000, including travel. These fees are due at different points throughout the process.

The cost to adopt

Many people are frightened by the high cost of international adoption. Don't let that hold you back! Numerous individuals have been able to get grants and scholarships and fundraise enough to cover a large percentage or even the full amount. **Fundraisers I have seen include:** selling T-shirts, on-line auctions, local restaurant donations, garage sales, selling an extra vehicle, merchandise parties, and even a shoe recycling fundraiser.

I LIKE TO STAY ACTIVE.
I HAVE NO PLANS TO CHANGE THAT.

BeneFix has dosing flexibility to help fit your lifestyle

- Individualized dosing schedules
- The flexibility to infuse preventively based on your physical activity
- The convenience of the BeneFix Rapid Reconstitution Kit with a range of dosing options
- Established bleed control in hemophilia B patients
- Safety profile demonstrated in clinical trials

VISIT BENEFIX.COM TO LEARN MORE

What Is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease.

BeneFix is **NOT** used to treat hemophilia A.

Important Safety Information

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your healthcare provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash, or hives.
- Your body can make antibodies, called "inhibitors," which may stop BeneFix from working properly.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are nausea, injection site reaction, injection site pain, headache, dizziness, and rash.

Please see the Brief Summary for BeneFix on the next page.

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.

*BeneFix was approved February 11, 1997.

18+ YEARS* YOUR EXPERIENCE MATTERS

BeneFix®
Coagulation Factor IX (Recombinant)
Room Temperature Storage

BeneFix®
Coagulation Factor IX (Recombinant)
Room Temperature Storage

℞ only

Brief Summary

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.Pfizer.com or call our medical communications department toll-free at 1-800-934-5556.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease.

BeneFix is **NOT** used to treat hemophilia A.

What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.

Tell your doctor about all of your medical conditions, including if you:

- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

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

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take.

Your doctor may need to test your blood from time to time.

BeneFix should not be administered by continuous infusion.

What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

What are the possible side effects of BeneFix?

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

wheezing	fast heartbeat
difficulty breathing	swelling of the face
chest tightness	faintness
turning blue (look at lips and gums)	rash
	hives

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

Some common side effects of BeneFix are nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

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

How should I store BeneFix?

DO NOT FREEZE BeneFix. BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

What else should I know about BeneFix?

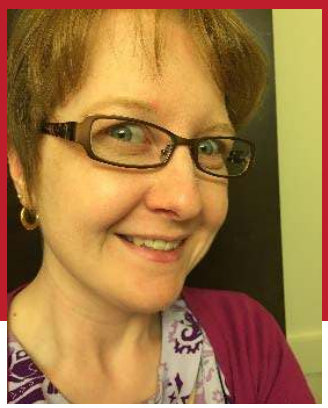
Medicines are sometimes prescribed for purposes other than those listed here. Do not use BeneFix for a condition for which it was not prescribed. Do not share BeneFix with other people, even if they have the same symptoms that you have.

If you would like more information, talk to your doctor. You can ask your doctor for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-9.0, revised August 2015.

Pfizer

“I will strive to do everything in my power to be a fierce, loving advocate for my child.”



“My only dream for “David” is that he have the opportunity to pursue whatever dreams he may have, without untreated hemophilia presenting an unnecessary barrier in his life.”

Adopting a child from China with hemophilia

Alaina Furr’s story

I always wanted to be a mother, and I strongly felt that due to the medical challenges of having von Willebrand’s, I would most likely form my family through adoption. With my bleeding disorder influencing how I will have a family, it occurred to me it could also make me an ideal parent for a child who has a bleeding disorder.

I was inspired by an acquaintance to learn more about adopting a child with hemophilia from China. I contacted the adoption agency to get more information and immediately they shared 10-year-old “David’s” story. “David” has been in an orphanage almost his whole life and is receiving very little treatment for his hemophilia. While I had no intention of starting the adoption process right away, I couldn’t get “David” out of my mind.

After several months, “David” still had not been adopted and I realized that I could be the one to provide him with a forever home.

As a planner by nature, I thought there was no way I would consider adopting until I had all the money I needed saved up. But here I am, moving full steam ahead to make this adoption a reality. The adoption costs, including agency fees, documents, and travel are estimated to be approximately $36,000. I have started a crowd funding site to raise money to cover a portion of these costs.

Please consider making a donation, by **clicking here**, so I can bring “David” home. Thank you. I appreciate your love and financial support as I embark on this journey.

Please consider helping Alaina with her adoption of “David” by donating today!

click here to help

Adopting “David” continued on page 25

"As a prospective adoptive parent, who happens to have a bleeding disorder, I felt like I am in a unique position to be an ideal parent for a child with hemophilia. Plain and simple, hemophilia does not scare me."

Adopting "David" continued from page 24

What are the most important two or three things you want people to know about you?
I am currently 35 years old, single, and was diagnosed with von Willebrand's 20 years ago. I have been connected with the HFM community for about 15 years, primarily through the women with bleeding disorders programming. I was previously the "west side" and mid-Michigan representative for the Women's Information Network (WIN) program, which was a local spin off of the NHF Project Red Flag. We were trained to give presentations to groups about bleeding disorders in women. By trade, I am a Licensed Customs Broker and work in trade (import/export) compliance for a corporation. Though I grew up in Owosso, I have been a "west-sider" during most of my affiliation with HFM, living first in Grand Rapids and now in Muskegon.

Why do you think you'll be a great mom?
I don't think I will focus so much on being a great mom. I think that is a pretty tough standard to live up to. I just want to be the best mom possible to "David." I have had so many positive role models in my life, including my own mom. I will strive to do everything in my power to be a fierce, loving advocate for my child.

Why adopt a boy with hemophilia from China?
When I first started researching my adoption options, one thing that struck me is that these boys with hemophilia really start with three strikes against them.
1. They have a medical condition that tends to scare a lot of prospective adoptive parents. Think about when you or your child was diagnosed, how overwhelming that diagnosis can seem. To an uninitiated prospective parent, the thought of adopting a child with hemophilia must seem pretty intimidating.
2. They are boys. That seems odd to say, but it is well known in adoption circles that prospective adoptive parents, for a number of reasons, tend to prefer girls over boys.
3. Many of them are older. Many prospective parents hesitate to adopt older children, feeling that they will have more "problems" or attachment issues than younger children.

The reason many of the boys with hemophilia available for adoption are older is twofold. First, until recently, many social welfare institutes (public Chinese orphanages) were not making these boys available for adoption, because they believed them to be unadoptable. Second, many of the boys with hemophilia who were made available for adoption were overlooked, likely because prospective adoptive parents were intimidated by their condition.

As a prospective adoptive parent, who happens to have a bleeding disorder, I feel like I am in a unique position to be an ideal parent for a child with hemophilia. Plain and simple, hemophilia does not scare me. Not only do I have knowledge and ability to access the necessary medical resources, but I also have a strong support system and know so many amazing people affected by hemophilia within the HFM community and beyond. This gives me the confidence to tackle what will surely be one of the most challenging undertakings of my life- to be a single adoptive mom to a child with hemophilia.

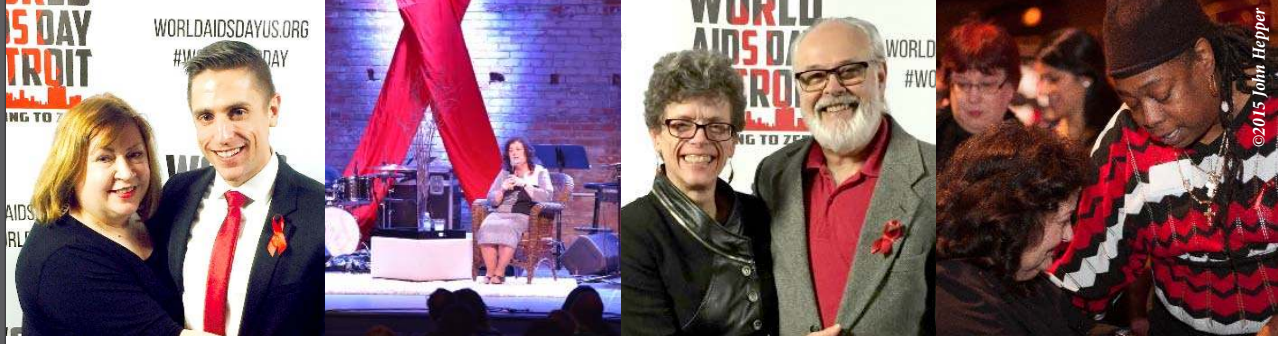
Do you already feel attached to "David"? Can you tell us how you're feeling?
I am not sure that attached is really the right word to use. In the adoption world, attachment is generally used to describe the bonding that happens between parent and child. Since I have not even met him yet, I can't really say that I feel attached, per se. What I can say is that I have felt a certain type of kinship or connection to him, from the time I first heard about him. Though my bleeding disorder is milder than his, not being diagnosed until I was a teenager, I have an understanding of what it is like to live for years without proper treatment of bleeding issues. At some point though, especially after I received the pre-approval from China, I did start thinking of him in a maternal way. There is a long way to go in this process until he is my son in the eyes of China and the United States. However, I do think about him. I wonder if he is alright, whether he has had any recent bleeds, and I hope he is not in pain, etc.

What is it that keeps you hopeful that you'll be able to raise this money?
The topic of raising money is probably the toughest one for me. I am a fairly independent, private person, who has a hard time asking for help. Starting the adoption process now, without all of the funds in hand, is a real leap of faith for me. My hope is that there are people out there who will be touched by our story, and be willing to help "David," a boy with hemophilia, get a permanent, loving home.

Do you have a dream for "David"?
My only dream for "David" is that he have the opportunity to pursue whatever dreams he may have, without untreated hemophilia presenting an unnecessary barrier in his life.

Can you share what's in your heart?
The adoption process is emotional in so many ways. The more I have learned in this process, the more I question at times. So often, adoption focuses on the adoptive parents, and the good that they are doing in their adoptive children's lives. What is not focused on as much is that the children available for adoption internationally have faced so much loss in their young lives. First and foremost, they have faced the loss of their birth families. Once adopted, they also face the loss of their culture, their country, foster families, and any other people they have been connected to. They are the strong ones. They are the brave ones. In a perfect world, "David" would have been able to be raised by his birth family, and have access to much needed treatment for his hemophilia. Unfortunately, that was not the case. I grieve this loss for him. In all reality, I am "David's" Plan B. However, I hope that having a loving mom who is knowledgeable about bleeding disorders, and who will give him access to proper medical care, will be a pretty decent Plan B.

click here to help



A: HFM's Executive Director, Sue Lerch with World AIDS Day Detroit Founder and President, Phil Kucab; B: Jeanne White-Ginder sharing her son Ryan White's story during the World AIDS Day symposium; C: Kathleen Gerus-Darbison and Bill Darbison; D: After her talk, Jeanne White-Ginder listens to people lined up to say hello or share their story.

5th Annual World AIDS Day Detroit event

Phil Kucab, MD, Founder and President, World AIDS Day Detroit

Growing up with hemophilia, Ryan White's story was familiar to me. When I called his mom in 2010 to see if she would come speak to my medical school class I instantly connected with her. I was sitting in the med school cafeteria and the call lasted almost an hour. I loved listening to her stories. I still do. It's like we had known each other for years even though we just met—a feeling that happens quite often with people I meet in the hemophilia community. There's a common bond—an understanding that we share—often without even saying a word.

I was so moved by talking with Jeanne I started telling people here in Detroit that I wanted to bring her here to tell her story. I envisioned people and organizations coming together to listen to the Ryan White Story. After months of planning, World AIDS Day Detroit was born and was the largest collaboration of its kind for World AIDS Day ever in Detroit as far as I'm aware. I remember taking the stage after Jeanne spoke the first year. I was so overcome with emotion I could hardly speak. As I looked out into the crowd, I saw everyone on their feet and I knew instantly that we had made a difference.

It's not just me. Every time Jeanne speaks she captivates and inspires people, young and old, familiar and unfamiliar with her story. I've been with Jeanne many times when she speaks. One of my favorite things to do is to stand off to the side and watch and listen to people approach her after she is finished. People from all walks of life gather to thank her and to share their own stories of how they relate to her or Ryan.

We lost half of our hemophilia community to HIV/AIDS—entire lives snuffed out overnight. There is not a movie we can make, a book we can write, a monument we can build, or a decade that can pass that will ever close that chapter completely. We keep moving forward by setting aside time to honor those affected, to never forget, to learn and grow from it. As sad of a story as this is, my involvement in World AIDS Day is not sad—it's incredibly rewarding. The more I put into it, the more I get out of it. Together, we have been able to honor our loved ones and carry on their legacies by working to eliminate this disease.

Each year World AIDS Day Detroit has grown. The passion and dedication behind the people involved is contagious. From high school students, to medical students, to partner organizations or American Idols—they walk away changed wanting to do more.

We have come such a long way. HIV used to be a certain death sentence, but now people with HIV can have a normal life expectancy. We have all the tools we need to end HIV and AIDS. We are getting closer and closer to a vaccine or cure. Until then, HIV is preventable. For people who are HIV positive, just being on HIV medication can decrease the chances of transmitting the virus by 96%. There is a pill that HIV-negative people can take to reduce their chances of contracting the virus by 99%.

What can you do? Stand with us on World AIDS Day, or any day. Share stories and remember those no longer with us. Speak out about what HIV is today. Get tested. Get treated if you are HIV-positive. Help end stigma by educating yourself and treating others with compassion and understanding.

Chris, Andy, Ryan, Dustin, Nate, Dan, Paul, Todd, Danforth, Louie, Michael, Tim, Greg… and all those that lived with HIV/AIDS and are no longer with us, we love you, we remember you, and we work for an AIDS-free generation in honor of you.

facebook.com/worldaidsdaydetroit
twitter.com/WorldAIDSDayUS
instagram.com/worldaidsday

World AIDS Day continued on page 27

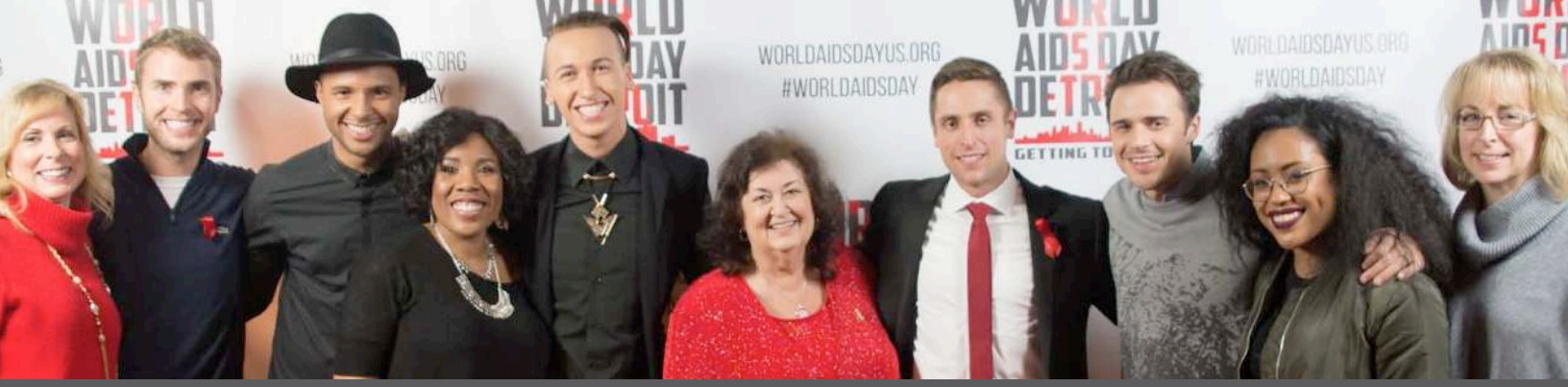
WORLD AIDS DAY DETROIT 12-1-2015
GETTING TO ZERO

For information, contact
Maxwell Cameron
Executive Director
248.227.7079
mcameron@worldaidsdaydetroit.com
worldaidsdayus.org

World AIDS Day Detroit
December 1, 2015

Thank you
World AIDS Day Detroit would like to thank all of our sponsors, volunteers, and partner organizations for their steadfast support of this important event!

2015 Sponsors:
The Hemophilia Foundation of Michigan, The National Hemophilia Foundation, Cascade, Walgreens, Wayne State University School of Medicine, Motivus Healthcare, Gilead, Biogen, BioRX, Broadway Cares, Color Me Rad, Janssen Pharmaceuticals, Viiv, Fox 2 News Detroit, Between the Lines, Professional Med Center and 98.7 AMP Radio.



Dawn Bradley, Shane Bitney Crone, Rayvon Owen, Melinda Doolittle, Devin Velez, Jeanne White-Ginder, Phil Kucab, Kris Allen, Malaya and Theresa Monks

World AIDS Day continued from page 26

What did attending World AIDS Day Detroit 2015 mean to you?

Susan Fenters Lerch

"I've been involved with World AIDS Day Detroit (WADD) since its inception in 2011 because I believe deeply that we cannot forget the devastation of AIDS on so many extraordinary lives. Beautiful people from our hemophilia community were lost to us. During my first years with HFM in the 1980s through mid-'90s, we were in the midst of the AIDS crisis. My heart was broken by the tremendous losses felt by so many people I knew so well. Beyond HFM we worked closely and collaboratively with other affected communities and I met so many wonderful people across Michigan and the country. It was tremendously painful yet actually a privilege to be able to be there for individuals and loved ones when so many were fearful or uneducated about AIDS. I believe it remains quite important to remember the history of AIDS while also working toward an AIDS-free generation which is now truly within reach. WADD provides an important touchstone for so many who continue to be impacted by AIDS or are working to eradicate the virus in our lifetime."

Melinda Doolittle

"I love what I do for a living, but I love it even more when I get to be a part of something so much bigger than me! Being a small part of the amazing effort behind World AIDS Day and the huge difference it makes, is such an honor. I do this for my friend, Missy, who is HIV positive and living her life to the fullest... and for so many others just like her!"

Antonio Jenkins

"For me it's about showing respect to those in the hemophilia community who passed away and fought the long hard battle of HIV/AIDS."

Michelle Leona Cecil

"The reason why events like WADD are so essential is that they raise awareness and they help to erase stigma. They bring together people affected by this terrible illness as well as students, allies and so many others to create connections and have conversations about how the disease can be destigmatized and how we can support one another. WADD is an amazing example of how people and organizations coming together under a united cause can change the world for the better."

Shane Bitney Crone

"Taking part in World AIDS Day was one of the most inspiring and rewarding experiences of my life. From the deeply moving performances of the American Idol stars, to the heart-wrenching stories from those who have lost loved ones to the disease, to the heroic HIV-positive individuals who bravely advocate to end this epidemic, I was inspired and touched by it all. World AIDS Day is a chance to celebrate the progress that has been made, to honor those we've lost, and to give people a chance to speak out. This event also helped me remember that we must treat every day as World AIDS Day in order to erase the stigma surrounding the disease and to help save lives."

Kathleen Gerus-Darbison

"There are many feelings that come over me in regards to World AIDS Day. The first I suppose is how lucky I am that I'm still alive. I became infected in 1984 when there wasn't a lot known about HIV and there were no therapies available. It was a pure and simple death sentence. I watched so many people die from this disease within the hemophilia community and amongst other friends and family members. My late husband died in 1992 at the age of 33. My daughter was only eight years old and these are the only memories she has of him. Fast forward to 2015 and our event December 1st. There's a world of difference from then until now. We are now speaking of getting rid of AIDS, not just treating it. I never thought I would live to see this day.

When I was downtown the other day, the overwhelming feeling I had was love. I was surrounded by people that I've known for years who are still fighting the fight. I got so many hugs and kisses that I thought I would float off of the floor. How blessed I am to have so many wonderful people in my life. But then I see the quilt and the Stitches Dolls and I am reminded of all the people who have died. So my feelings are always bittersweet. I am happy that we have something like World AIDS Day to remind people that this is still a huge problem. And to remember all those who are no longer here.

I suppose when all is said and done the best way I can describe my feeling is gratitude with a capital G. I was diagnosed at age 27 and given 18 months to live. This coming Monday I will be turning 58 years old. I am grateful for so many things. My beautiful daughter who I got to see graduate and get married. I'm grateful that I have always had support from my family. And for the past 17 years that I've been married to my husband Bill; I am beyond grateful for his love and support. I know that I would not have made it this far without all of those things."

Devin Velez

"Where do I even begin? It's such a humbling experience to be able to participate in such a great show for such a great cause. I'm not one to know much about anything, but I know what love is and I know how to love. I know how to smile, and I know how to encourage. I loved being able to not only give that, but receive that from the team that worked so hard to put this event together. Every year, I learn more and more, and I meet someone that impacts me forever. This year I met a woman who had gone through a really rough few years due to having HIV, and still she glowed with joy and remained positive. She has another organization that helps young women with their recouping, and healing process, (mentally, emotionally and physically). She's an educator at a university now, molding minds and influencing and informing young people about these realities in life. She also lost her husband due to HIV/AIDS. But still she fights, she chooses happiness over the circumstance, and I loved being able to just give back with what I've been given. All that I have to give is me. It's an honor to be a part of something this great, can't wait to be back, hoping to do more, and get us to zero."

Upcoming Events

December 19, 2015
Camp Holiday Party
(Open to camp staff and campers.)
3-7pm
HFM Offices, Ypsilanti
For more information, contact twicks@hfmich.org

December 20
H.I.R.E.D.
Self-advocating and employment rights
6pm at HFM
For more information, contact ngamber@hfmich.org

April 15-17, 2016
SpringFest
Bavarian Inn Lodge
Frankenmuth, MI
pthomas@hfmich.org

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

Outpost
June 19-25 (14-16 yrs.)

Camp Bold Eagle
Session 1: July 10-14 (6-10 yrs.)
Session 2: July 16-23 (11-13 yrs.)

Expedition
TBD (16 yrs. +)

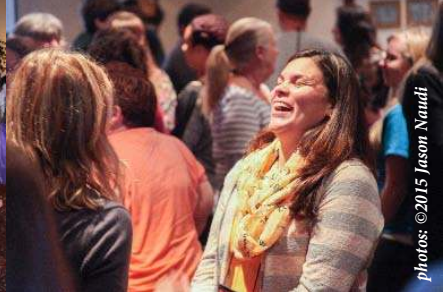
CIT Program
TBD (16 yrs. +)

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

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

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





NEW IDEAS FOR 2016

We're excited to be presenting at least one program in **Spanish**!

We're experimenting with **"tracks,"** where some sessions will follow a theme such as health and wellness.

We're planning an **activity specifically for our young adults**!

Please join us for this special weekend filled with a multitude of **opportunities all designed to support** the men, women and children in our bleeding disorders community.

Save the date!

HFM'S SPRING**FEST**'16

April 15, 16, 17, 2016

Bavarian Inn Lodge
1 Covered Bridge Lane
Frankenmuth, Michigan

Join us for this wonderful weekend and learn from top notch professionals in the bleeding disorders field, participate in fun workshops, and connect with our amazing community.

Over 500 people participated last year and we expect even more in 2016!

Look for more information in early 2016!

Cascade/Hemophilia Foundation of Michigan

DELTA DENTAL PROGRAM

Are you uninsured or underinsured with your dental coverage? If you are, we may be able to help.

In order to be eligible for this program you must meet the following criteria:

- 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.

You are not eligible for this program:

- If you have current Medicaid dental coverage (unless there is a special circumstance – these exceptions are limited and determined on a case by case basis).
- If you have access to dental coverage through your employer or your spouses' employer, even in 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.

Contact your HTC Social Worker for an application or contact **Kayla McMaster** at **kmcmaster@hfmich.org** or **734.544.0015** to receive an application. If you have eligibility questions contact **Lisa Clothier** at **lclothier@hfmich.org** or **734.961.3512**.