# the BICCON

The Camp Issue

Eagle Journeys: Camp Bold Eagle | Eagle Quest Eagle Expedition | Eagle Outpost

we are today without [HFM] camp."

Anne Henningfeld, MA, CTRS, Co-founder, Beyond Recreation,

"We would not be the community

and Former Camp Bold Eagle Director

Fall 2016 • Serving Michigan's bleeding disorders community





exists to enhance the quality of life for all affecte

by bleeding disorders www.hfmich.org 734.544.0015

INSIDE

- 2 Message from our Executive Director Susan Lerch
- 3 The Home of Bold Eagle
- 5 Camp Health Education
- 6 Walkin' on the West Side
- 7 Walkin' on the Wild Side
- 8 Why I send my child to HFM's Camp Bold Eagle
- 9 Terrifically Transformative Training El verano del campamento
- 12 Eagle Quest
- CBE's Revered Campfire 13 Eagle Expedition
- 16 Eagle Outpost
- 17 In Memoriam: Dr. John Penner Bowling for Bleeders Community Fun Night!
- 19 Worried About Your Child Getting Homesick?Welcoming Us to the Camp Family: A thank you from a med student
- 20 Adoption Opportunities Women's Retreat Weekend with Jeanne White-Ginder
- 24 Upcoming Events 2017 (tentative) Camp Dates

## ...and more!

#### HFM BOARD OF DIRECTORS OFFICERS

Rob Hopper, President Allan Kucab, First Vice President Jim Mohnach, Second Vice President Diane McIntyre, Treasurer

#### DIRECTORS

Ronia Cole Kathy Fessler, MD, PhD Rebecca Malouin, PhD, MPH, MS Dilip Moonka, MD Matt Sterling

#### **EX OFFICIO**

Susan Fenters Lerch



Roshni Kulkarni, MD Megan Procario, Cascade Board

## HFM STAFF

Susan Fenters Lerch, Executive Director

#### COMMUNICATIONS-EVENTS-CAMP

Gwyn Hulswit, MA, Philanthropy Director Janelle Gunn\*, Special Events Manager, West Michigan Carrie McCulloch, Special Events Manager Tim Wicks, Camp Director Torey Allen, MA-TESOL, Associate Camp Director Robin Cook\*, Whitfield Design, **Communications Director** Sarah Procario, Special Projects Coordinator Diana Mathis\*, RN, Camp Bold Eagle Health Officer Sherry Hubble\*, RN, Eagle Outpost Health Officer Jim Munn\*, BS, BSN, MS, Eagle Expedition Health Officer Deep appreciation to Amy Hepper, MD and Aarti Raheja, MD-our two wonderful and highly skilled Medical Directors.

## **OPERATIONS-ADMINISTRATION**

Sharon Ceci\*, Finance and Operations Director Laura Olson\*, Business Manager Ashley Fritsch, Office Manager David Lattas\*, Facility Manager

#### PROGRAM SERVICES-EDUCATION-ADVOCACY

Patrice Thomas, MS, MSW, Program Services Director Lisa Clothier, LLMSW, Outreach & Community Education Manager Tim Wicks, Youth Services Manager Torey Allen, MA-TESOL, Educational Services Manager Shari Luckey\*, Advocacy and Outreach Coordinator Danna Merritt\*, MSW, Senior Social Work Advisor; PEP Executive Director

#### GREAT LAKES HTC NETWORK REGIONAL CORE CENTER

Susan Fenters Lerch, Regional Director Travis Tussing, JD, Regional Coordinator, Federal Grants Director Roshni Kulkarni\*, MD, Medical Director Sue Adkins\*, RN, Regional Core Center Specialist \* Denotes part-time or contractual 2 htmich.org Fall 2016 HFM exists to enhance the quality of life for all affected by bleeding disorders.

# We Are Community

## Dear HFM friends & family,

We've devoted this issue of The Artery to HFM's Eagle Journeys' summer camp programs because these experiences offer the true heart and spirit of our organization's future, as well as our past.

## What makes HFM's camping programs so incredibly special?

From HFM's very first Camp Bold Eagle Highlands for boys with hemophilia 47 summers ago, moving through the years to our most recent summer's Eagle Journeys' camp programs, the extraordinary impact on those involved continues to be life changing. We remain grounded by Camp Bold Eagle, and our other camping programs, as our community's children, teens, and young adults come together in a way that is beyond simple characterization.

Individuals who grow up with HFM's CBE and Eagle Outpost, serve as Counselors-In-Training, and become cabin counselors, program staff, and camp directors, each feel a level of personal ownership that few other experiences bring to our lives. There is joy and tension that comes with this level of commitment, and the devotion and challenge of living up to expectations. Camp has always been a "can do" place-a safe and accepting home where others are like you-and your non-bleeding disorder idiosyncrasies are also readily accepted.

Those who choose to become part of CBE and other camp programs, who are not directly impacted by a bleeding disorder, are welcomed into the fold as they join our community in these meaningful experiences. University of Michigan med students who commit to the full CBE staff training share personal vulnerability and experience a culture of community that fosters intimate friendships. The mutual benefit is pretty astounding.

Through the years, camp has mourned and celebrated those who aren't with us anymore. Traditions are significant and proudly passed down. Kids learning about their bleeding disorders and the history of our community, particularly with leadership who understand, is clearly meaningful. Unconditional acceptance and family, the joy of being with people who accept you, love you, try their best to understand you–maybe even complain about you–yet will truly be there for you no matter what, is the heart of HFM's camping programs. The kids, and adults, who come to camp, create and live that spirit.

HFM's camps encourage each of us to bring and receive joy and acceptance.

With love,

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



PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER.



"The people make it great, they actually understand."



# The Home of Bold Eagle

By Sarah Procario

From the moment you turn down the gravel drive of Pioneer Trails, the overwhelming sensation that you are home washes over you. For over 20 years, Pioneer Trails has been home to HFM's Camp Bold Eagle. Throughout those years, the campground has shaped our favorite camp experiences. The natural beauty and rustic charm of Pioneer Trails has become an integral part of campers' (and counselors') experience at Camp Bold Eagle.

Pioneer Trails offers a beautiful lakefront on Big Blue Lake and acres of woods lined with trails, which offer access for all our campers in wheelchairs and on crutches. Here, campers and counselors alike experience life closer to nature. For many, the camp life can be a step outside of one's comfort zone. We sleep in wood cabins with only fans to cool us off, spend hours in the buggy woods, and swim beside minnows in the lake. This unique lifestyle at camp allows for adventure that is all too uncommon for our kids and offers unique opportunities for growth. Nights away from your parents are sleepovers with best friends. The woods hold trails for nature hikes, materials to create shelters or fires, and a floor to campout under the stars.

Adventure on the lakefront is a favorite for many. Big Blue Lake is a natural spring lake with soft sand and blue water. In our swim area, children get individual swimming lessons with our waterfront director, try to balance on our foam raft, "Jamaica," and search for seashells. Further down our lakefront, we kayak, paddleboard, and fish off the dock! Swimming in the lake is often a challenge for our campers; putting their feet (or head!) in the murky water is sometimes a step outside of their comfort zone. One of our 10-year-old campers not only successfully swam in the lake for the first time this year, he actually swam across the lake. Though the experience was new, and slightly intimidating, he swam with persistence, surrounded by his cabin mates and under the dedicated supervision of qualified lifeguarding staff. His face radiated with pride as he swam the last stretch before touching the beach.

Camper, 16

Not only does the immersion into nature increase the ability for adventure and growth, the simplicity of our camp lifestyle creates an intimate environment for personal connection. Conversations at camp, whether around the campfire, on the dock, or between bunk beds, become some of the most meaningful memories. We are thankful to have such a beautiful home for our camp family at Pioneer Trails.



is now brought to you by

# Aptevo Therapeutics—

a company that's anything but ordinary



## At Aptevo, we pride ourselves on:

Providing high-quality, specialized therapies for people with rare conditions

Connecting with people to learn about their needs

Developing empowering programs that enrich peoples' lives

Learn more at IXINITY.com



Aptevo BioTherapeutics LLC, Berwyn, PA 19312

IXINITY [coagulation factor IX (recombinant)], and any and all Aptevo BioTherapeutics LLC brand, product, service and feature names, logos, and slogans are trademarks or registered trademarks of Aptevo BioTherapeutics LLC in the United States and/or other countries.

©2016 Aptevo BioTherapeutics LLC. All rights reserved. CM-FIX-0061B

## Who is your hero? "Everybody here." 7 year-old CBE camper



Left: Jaylen, 12, prepares to play Eagle Rush in his wheelchair. Middle: Caden, 10, receives his Butterfly Award upon successfully completing his first self-infusion. Right: Camp Director, Tim Wicks, teaches a medical student how to infuse.

The focus on health education at Camp Bold Eagle makes the camp experience essential for children with bleeding disorders.

# Camp Health Education



By Megan Procario

My favorite part of Camp Bold Eagle is that we strive to empower our campers, not in spite of their bleeding disorders, but through learning to manage their chronic illnesses. So, rather than attempting to pretend for a week that hemophilia doesn't exist, we make it an integral part of camp by equipping campers with the information and skills needed to make informed decisions about how they live their lives, both at camp and at home.

The knowledge and skills our staff prioritize throughout camp are officially recognized through health center awards. All campers are eligible to earn these awards by demonstrating a meaningful understanding of their bleeding disorder and how it is treated. The Firefly, Butterfly, and Dragonfly awards, which can only be received once, encourage campers to spend extra time in the health center, working one-on-one with nurses and doctors. The first of these awards, the Firefly award, can be earned by any camper who has demonstrated knowledge of their bleeding disorder by answering a series of questions. Following the Firefly, campers are eligible

to earn one of the two advanced awards, either the Butterfly, for campers who self-infuse or the Dragonfly, for campers who use other methods to address their bleeding disorders. In order to earn either of these awards, campers must answer a series of advanced questions about their bleeding disorder and demonstrate a mastery of the treatment methods that they use. For the Butterfly award, this requires completing their own infusion from start to finish, including mixing the factor, "poking" themselves, and pushing their own factor. The Dragonfly award requires campers to demonstrate understanding of complex medical information related to various bleeding disorders. Our staff recognizes the magnitude of these achievements and we celebrate our campers' success each session at our traditional closing ceremony.

Although the health center staff does much of our health education at camp, some of the strongest lessons are taught by our counselors with bleeding disorders. A nurse can remind a camper the importance of proper self-care, but

our staff leads by example and solidifies the idea. For campers who don't want to miss out on time with their cabin in order to infuse, or who are scared about the procedure, it can be invaluable to have their counselor come and treat at the same time. I am always so proud of the example led by our staff that is on prophylactic treatment, encouraging each other to come participate in "prophy parties" at the health center, another example of the many ways camp creates a sense of family and support. The staff's enthusiasm for self-care and preventing bleeds is contagious, creating a culture of good self-care at camp for the staff and campers alike.

The focus on health education at Camp Bold Eagle makes the camp experience essential for children with bleeding disorders. Not only do children experience the solidarity of our community, they learn how to better take care of themselves and act as their own advocate. Through every challenge, every Eagle Step, we are with them before, during, and after to provide support and encouragement as needed.







## WALK | Volunteer | Sponsor | Donate

\$20 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.

## **REGISTER TODAY!** walk.hemophilia.org/GrandRapids

Click for awesome fundraising ideas! www.hfmich.org/fundraisingideas

## Saturday, October 8, 2016 Fifth Third Ballpark

Home of the West Michigan Whitecaps 9am Check-in opens 10am Walk begins-5k

## Contact Janelle L. Gunn Special Events Manager-West Michigan jgunn@hfmich.org | 616.301.0020

PAID CONSUMER OUTREACH

We're grateful to **Deerfield** Wind Energy for their **\$5,000 Walk** Match! Learn more about how your fundraising can double! (Starts 9/19 'til the funds are depleted!)





PRESENTING SPONSOR



PACESETTER PLUS SPONSOR



OFFICIAL SPONSORS

## Bayer HealthCare Biogen. GRIFOLS octopharma



SILVER REGIONAL SPONSOR



## PRINCIPAL PARTNERS

accredo<sup>®</sup> Speciality Pharmacy



#### FRIENDS OF HFM Aptevo Therapeutics I CSL Behring

Deerfield Wind Energy | Meijer HFM (Hemophilia Foundation of Michigan) does not endorse any specific product or company.

# access solutions



Don't let insurance or financial challenges get between you and your treatment

- Free Trial Program\*: Talk to your healthcare provider about requesting a free trial
- Access to Therapy: You may be able to receive the prescription treatment at no cost if you experience challenges getting insurance coverage for a Bayer product<sup>†</sup>
- \$0 Co-pay Program<sup>‡</sup>: You may be able to receive up to \$12,000 in assistance per year
- Live Helpline Support: Our experts are waiting to help you with any insurance coverage questions you may have<sup>†</sup>

\*The Free Trial Program is available to newly diagnosed patients and patients who are currently using other therapy. Participation in the Free Trial Program is limited to 1 time only. This program is complimentary and is not an obligation to purchase or use a Bayer product in the future. Reselling or billing any third party for the free product is prohibited by law. The program does not guarantee that patients will be successful in obtaining reimbursement. Support medication provided through Bayer's assistance programs is complimentary and is not contingent on future product purchases. Reselling or billing any third party for free product provided by Bayer's patient assistance programs is prohibited by law. Bayer reserves the right to determine eligibility, monitor participation, determine equitable distribution of product, and modify or discontinue the program at any time. \*People with private, commercial health insurance may receive co-pay or co-insurance assistance based on eligibility requirements. The program is not for patients receiving prescription reimbursement under any federal-, state-, or government-funded insurance programs, or where prohibited by law. All people who meet these criteria are encouraged to apply. Bayer reserves the right to discontinue the program at any time.



Bayer and the Bayer Cross are registered trademarks of Bayer © 2016 Bayer. All rights reserved. Printed in USA 03/16 PP-775-US-0085



## By Carrie McCulloch

Before the sun even rose on August 28th, a group of volunteers, sponsors, and staff were hard at work at the Detroit Zoo. Tables of food were laid out, displays were set up, bubbles, chalk, and temporary tattoos were set up in a fun area for kids. Everyone hoped our expected 800 attendees were ready for a great time. Just hours later, the zoo was filled with much more than that! Almost 1,100 attendees came to Walkin' on the Wild Side to show their support for HFM's bleeding disorders community!

The zoo buzzed with excitement as our event pavilion filled with excited families and friends. After a welcome from HFM's Executive Director, Susan Lerch, our "super-walkers," people who have registered both to Walk Wild and Walk West, led the crowd into the zoo.

At 11am walkers returned to find that volunteers were waiting to present them with medals for their fundraising efforts. While enjoying lunch together, participants also learned that together they raised more than \$65,000 to benefit the programs and services offered by HFM! A special thanks goes out to our highest fundraising team: Sticks Arnone, and our highest fundraising individual: Jackson Eckstein.

## Did you miss Walkin' on the Wild Side?

Don't worry! There will be another walk on October 8th at the Fifth Third Ballpark in Grand Rapids. Be sure to register at: walk.hemophilia.org/GrandRapids

## SEE PAGE 6















Baxalta

PRESENTING SPONSOR

## **Baxalta**





OFFICIAL SPONSORS



Biogen.



Pfizer Hemophilia

SILVER REGIONAL SPONSOR



PRINCIPAL PARTNERS

accredo<sup>®</sup>



FRIENDS OF HFM



Aptevo Therapeutics **CSL** Behring Ideal Bite Catering University of Michigan HomeMed

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



**Left:** Jaya, with her cabin, to the left of HFM Executive Director, Susan Lerch. **Middle:** Jetten in the woods during a nature hike. **Right:** Scout, to the right of HFM Executive Director, Susan Lerch, poses with cabin mates for a "girls photo."

# Why I Send My Child to HFM Camp

I sent my children to camp this year for the first time. They were gleaming with excitement and I was as nervous as ever. This was a major milestone in my parenting career; sending my babies away for four nights?! I was comforted by the fact that I had heard many previous campers, now counselors, speak about the amazing self-discoveries made while at camp and how they looked forward to this experience each summer. Hearing the past campers' stories would bring tears to my eyes and made me know that this IS where my kids with bleeding disorders belong! My tip for first time parents would be to take the plunge! You won't regret sending your children to camp. They

will be among children that understand just how they feel and they will come back with so many stories, smiles, and laughs to share. My kids are already talking about next summer's adventures. *-Veronica Shah, Daughter, Jaya, Son, Jetten* 

2 Camp Bold Eagle holds a special place in my husband's life. So, of course, he wanted to share that experience with our daughter, Scout. I wanted Scout to go to camp to gain a different perspective on hemophilia, maybe learn a little more about being a carrier, and make new friends. What came back home was a very happy child with all kinds of new skills. Wow! Since Scout was a first timer, we found that explaining what activities she would do at camp, involving her in packing and preparing, and talking with other kids (and adults) who would be at camp really helped prepare her.

**Parental words of wisdom** – Survival without them is possible. I finally got used to her being gone on the last day and then she was home! I really did survive (as many of my more experienced friends told me I would). And your child, well, let me quote, "I missed you the first day, but then we were so busy and it was so much fun and they didn't give us time to miss you (much)." Oh, and send mail early and often.

-Suzan Higgins, Daughter, Scout

# "The last thing I like is everything."



~ 6 year-old on his favorite part of camp



# Terrifically Transformative Training

By Torey Allen

## What is staff training?

At HFM's Camp Bold Eagle, we pride ourselves in superior staff training. During staff training, our goal is to promote the mission of Camp Bold Eagle (CBE) by educating children about their bleeding disorder and its management, and to safely challenge them to explore and master new skills. While being energetic and interactive, the training is intentional, always connecting back to our purpose while developing future leaders and forward-thinkers.

## Staff training lasts over 40 hours? That's a long time! Why?

We do it for the kids (and for ourselves a little, too!). Staff training sets the foundation for our campers' positive experience at Camp Bold Eagle.

## What do you do at staff training?

Icebreakers and team-building exercises that help form strong bonds of trust and positive communication. Behavior management techniques: Positive behavior is always the goal, and behavior management strategies are learned through various trainings.

Developmental characteristics of different ages: Staff learns to identify the needs of the campers at different ages and stages.

## **Final campfire**

Through personal testimonies and collaborative discussion, new and seasoned staff come together through the shared history of CBE, as well as the dreams about the future for the campers we serve.

Bleeding Disorder Trivia and the "Butterfly Challenge": Through the ruse of a game of trivia, staff learns medical information about bleeding disorders. Then, by poking themselves with a butterfly needle, staff members learn to appreciate the courage and dedication of the young campers. Cabin Leadership and Teachable Moments: Former CBE camp directors focus on preparing and centering staff, conducting effective cabin meetings, and discovering the potential for learning through camp.

Cabin Preparations: We create welcome signs, nametags, bunk tags, cabin themes, and more!

## But seriously, what's so great about staff training?

CBE staff is exceptional, having gained a tremendous amount of knowledge and skills through training each year. Our training is one of the most comprehensive programs in the country, and not only prepares and equips our staff to be better leaders, it is transformative in nature. The culture of CBE, praised by everyone who experiences it, starts at staff training. By the end of training, the staff is transformed into a unified, cohesive, and highly qualified team that is ready to serve the campers.

"The culture of CBE is unlike anything I've ever known."

~ Camp Counselor

## El verano del campamento Por Victoria Allen

El campamento es un lugar especial por ambos niños y adolescentes y este verano no fue la excepción. El campamento proveyó un espacio donde los niños se pudieron experimentar con cosas nuevas, hicieron y cumplieron metas valiosas, y aprendieron información de sus trastornos hemorrágicos.

Durante las sesiones del campamento, los niños se hicieron amistades muy fuertes porque tuvieron muchas cosas en común, especialmente los similitudes de sus trastornos hemorrágicos. Más importante, sin embargo, fue la conexión los niños tuvieron cuando se experimentaban en actividades nuevas, como dormirse en cabañas, jugar Nuk'em, y aún transportar en barco por la primera vez. Además dimos la bienvenida a algunos adolescentes y niños quienes entraron en el campamento por la primera vez este año. Alguno de los adolescentes se fue en canoa, pescó, y nadó en un lago por la primera vez en sus vidas!

El campamento siempre se cambia la vida por los niños que asisten. Este verano, fue una experiencia especialmente maravillosa para los niños.



# Extended protection\* from bleeds

\*ALPROLIX has been proven to help patients prevent bleeding episodes using a prophylaxis regimen.

ALPROLIX is the first factor IX offering prophylaxis infusion schedules starting every 7 or 10 days with the potential to extend based on your response.

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



## 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:

- On-demand treatment and control of bleeding episodes
- Perioperative management of bleeding
- Routine prophylaxis to 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 Product Information on the next page for additional safety information. This information is not intended to replace discussions with your healthcare provider.



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

## **FDA Approved Patient Information**

## ALPROLIX<sup>®</sup> /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.
- Do 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 solution is 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.

Manufactured by Biogen Inc. Cambridge, MA 02142 USA U.S. License #1697 © Biogen 2014-2016. All rights reserved.



# Eagle Quest

For four days my fellow participants and I carried our food, water, clothes, medical supplies, and camping equipment across Michigan's North Manitou Island. With nearly 45 pounds on our backs, we hiked seven miles each day through swamps, woods, and open fields, dealing with the rain and rough terrain. Each time we encountered a lake or stream, we stopped to collect and filter our own water, stopping only midday to

## By Nick Gamber

eat and rest before heading out again to meet our next checkpoint. After each exhausting day of hiking we began our nighttime ritual to prepare our camp and cook dinner. And when we woke up each morning, we cooked breakfast, infused our medicine, broke down camp, re-packed, and started out again. It was a physically exhausting four days and nights; it was also a remarkable four days and nights. Those of us that went to Eagle Quest found an incredible amount of joy each night in those exhaustive days. It was the joy of accomplishment. For individuals who have grown up hearing how we are limited by our disorder, Quest showed us that we are capable. A month later I still feel the joy of each of those days and I know that it will be a joy that stays with me for the rest of my life.



# CBE's Revered Campfire

## By Patrice Thomas

I sat about 15 feet from the fire, watching the flames leap in the air, and swatting away mosquitoes which were munching on my ankles. This was my first Camp Bold Eagle campfire and I wasn't sure what to expect. All the staff members were seated on tree-trunk, wood benches around the campfire. A veteran staff member began by introducing himself and sharing his journey as a boy with hemophilia, through ups and downs with friends and family, until he landed at CBE and the impact it had on his life. His personal testimony set a tone of vulnerability and safety throughout the circle. After he was finished speaking, many others took turns sharing their own stories, sometimes sad and touching, many times funny, but always ending with how CBE has shaped their lives in such a positive, meaningful way.

I heard themes through the stories of "(CBE) is like coming home" and "I know I'm accepted here for who I am." I was particularly struck by a young adult speaking about his experience of growing up at camp, explaining that "[he] never felt like [he] had role models, but at 11 [he] came to camp and found a lot of guys to look up to. Now [he] can be a role model for others, and want[s] to give back."

Time spent at CBE, a week as a camper or three weeks as a staff member, has so many powerful meanings for these youth and adults that I was overwhelmed with emotions too. I feel so lucky to be part of such an amazing community; working at an agency that prioritizes experiences such as this and works so hard to provide these experiences for the children in our community. I now agree with something I had been told many times: you don't know camp until you've been there.



# Eagle Expedition By Torey Allen

Imagine splashing through the rushing river's current as your team tackles a class III rapid, knowing that the only way to keep your raft afloat is by working together. Now imagine paddling furiously against strong winds and salty waves in the San Francisco Bay in a small kayak designed for two people. These are just some of the heart-racing activities that the participants of HFM's Eagle Expedition experienced this summer.

Eagle Expedition is a camp for individuals with bleeding disorders over the age of 16, designed to promote leadership development. This summer the group traveled to California in order to deepsea kayak and white water river raft. The participants slept under the stars in hammocks, and even spent one night in Civil War barracks. They learned how to safely maneuver kayaks and rafts, and then paddled their boats for over five hours each day.

Participants entered on the first day as individuals, sometimes shy and reserved, not always jumping to take risks, but grew and were transformed through the course of the week. Some of the participants had never previously flown on an airplane, and many had never been white water rafting. One participant was especially nervous to attempt kayaking in the rushing river, but could not stop smiling after he chose to attempt a rapid! Other participants took the role as lead guide of the rafts, acting as the captains by instructing their teams to paddle together, to rotate the rafts, and to make their way through the rushing water. They were determined to help their teammates balance while standing on rafts, row the heavy wooden oars of the oar boat, and travel down rapids in small inflatable kayaks. All the food preparation, clean up, and organization of equipment was led by our group members. For some members of the team, learning how to cut melons and sauté vegetables were new experiences, not to mention maneuvering through rapids and waves!

The skills and strengths that our campers developed during Eagle Expedition were that of leadership, communication, teamwork, enthusiasm, and perseverance. Participants were transformed into a confident, communicative team of leaders.

# "You don't create such deep and intimate relationships anywhere else." ~ CBE Counselor



PROVEN PROPHYLAXIS

SIMPLE,\* TWICE-WEEKLY DOSING SCHEDULE

# oments YOUR WAY

## Proven results with ADYNOVATE

 Zero median ABR for joint or spontaneous bleeding episodes with ADYNOVATE prophylaxis<sup>+1</sup>

\* ADYNOVATE allows you to infuse on the same 2 days every week.<sup>1</sup>
<sup>†</sup> Joint: 0.0 (Q1: 0.0; Q3: 2.0) median vs on-demand 38.1 (Q1: 24.5; Q3: 44.6); 2.9 (SD 8.0) mean vs on-demand 34.7 (SD 15.1). Spontaneous: 0.0 (Q1: 0.0; Q3: 2.2) median vs on-demand 21.6 (Q1: 11.2; Q3: 33.2); 2.9 (SD 7.1) mean vs on-demand 26.0 (SD 19.6).<sup>12</sup>

The safety, efficacy, and PK of ADYNOVATE were evaluated in a multicenter, open-label, prospective, nonrandomized, 2-arm clinical study (N=137) that compared the efficacy of a twice-weekly prophylactic treatment regimen to on-demand treatment and determined hemostatic efficacy in the treatment of bleeding episodes.<sup>1</sup>

For patients 12 years and older with hemophilia A

To see if ADYNOVATE may be right for you, visit **www.ADYNOVATE.com** 

ABR=annualized bleeding rate.

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

## Indication

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.

## **DETAILED IMPORTANT RISK INFORMATION**

You should not use ADYNOVATE if you:

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

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

You should tell your healthcare provider if you: • Have or have had any medical problems.

• Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.

BAXALTA, ADVATE and ADVNOVATE are trademarks or registered trademarks of Baxalta Incorporated, a wholly owned, indirect subsidiary of Shire plc. SHIRE and the Shire Logo are trademarks or registered trademarks of Shire Pharmaceutical Holdings Ireland Limited or its affiliates. USBS/MG159/16-0045

- Have any allergies, including allergies to mice or hamsters.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

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

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

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

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

References: 1. ADYNOVATE Prescribing Information. Westlake Village, CA: Baxalta US Inc. 2. Data on file. Baxalta Incorporated.



## غ 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.

Shire Westlake Village, CA 91362 USA U.S. License No. 2020 Issued 11/2015 15E001-ADY-US





"If you are never vulnerable, you can never be brave, and bravery is highly encouraged at Outpost."

# Eagle Outpost By Jennifer Davie, Ph.D.

I have been fortunate enough to have worked with Camp Bold Eagle (CBE) since 2000, which means I have been spending my summers at Pioneer Trails for half of my life. Though I had heard about the Outpost program, I had never thought that it was something I wanted to try. The cabins at CBE seemed rustic enough for me! How mistaken I was to have been missing out for all these years!

The Outpost program is designed for 14-15 year old campers to give them a more independent camp experience than they have at CBE, as well as to develop future counselors-in-training.

At Outpost 2016, I had the opportunity to watch CIT-ITs (counselors-in-training-intraining, self-named by this year's group), some of whom I've known since they were 6 years old, set up tents, plan for and cook fabulous meals, and take on personal challenges. The group encouraged each other to take "Eagle Steps," doing something outside of their comfort zone. What might be easy for one person may be a huge Eagle Step for another, and support was given for Eagle Steps big and small. Many Eagle Steps were achieved in physical challenges, like the climbing pole or high ropes course, and others were social, like learning to work in a team or talk to people that you don't yet know.

~ Jenny Davie

I am so glad that I had the opportunity to see these CIT-ITs grow and develop into young adults that take positive risks and support each other as they learn and grow. I learned so much from them, and even took some Eagle Steps of my own. I now know that I can survive a week in a tent/ rustic bunkhouse, function without a strict schedule, and go higher on a high ropes course than I imagined. Beyond that, I learned that 14-15 years olds can and will surprise you with what they can achieve when they work together in an environment like Outpost. I hope that I get the chance to continue to learn and grow with this group in the future.

1.877.744.5675

and select option 2

## PAID CONSUMER OUTREACH



## Pfizer Hemophilia Connect Call one number to access all of our resources

Rx Pfizer Trial Prescription Program

**THE P** 

Community Resources

Whatever questions you have, we'll help find an answercall Pfizer Hemophilia Connect

Ś **Pfizer Factor** avinas Card

## **The Pfizer Factor Savings Card\***

\$12,000 annual support for eligible patients in 4 simple steps—the card can be used to help cover copay, deductible, and coinsurance costs associated with

## Pfizer RxPathways®+

Eligible patients can save up to \$10,000 with this comprehensive assistance program that provides a range of support services.

٦,

Pfizer RxPathways

#### **Trial Prescription Program<sup>\*</sup>**

A one-time, **1-month supply up to 20,000 IU** of Pfizer product delivered at no cost to your door.

#### **Community Resources**

Learn about support programs like HemMobile™, Patient Affairs Liaisons, scholarship assistance, and the educational speaker series.

\*Terms and conditions apply; visit PfizerFactorSavingsCard.com for complete terms and conditions. For commercially insured patients only. Medicare/ Medicaid beneficiaries are not eligible. The Card cannot be combined with any other rebate/coupon, free trial, or similar offer for the specified prescription. The card will be accepted only at participating pharmacies. This coupon is not health insurance

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, 2250 Perimeter Park

#### <sup>†</sup>The Pfizer RxPathways Savings Card is not health insurance. For a complete list of participating pharmacies, visit PfizerRxPathways.com or call the tollfree number 1.877.744.5675.

There are no membership fees to participate in this service. Estimated savings is 36% and depends on such factors as the particular drug purchased, amount purchased, and the pharmacy where purchased. Pfizer RxPathways is a joint program of Pfizer Inc and the Pfizer Patient Assistance Foundation<sup>™</sup>.

call 1.800.710.1379 or write us at Pfizer Hemophilia Trial Prescription Program Administrator, MedVantx, PO Box 5736, Sioux Falls, SD 57117-5736. You may also find help accessing Pfizer medicines by contacting the Pfizer RxPathways Program.





# In Memoriam: Dr. John A. Penner

By Sue Adkins

Dr. John A. Penner served as an adult hematologist for more than 60 years. A graduate of the University of Michigan's College of Medicine, he had a prestigious career as a Captain in the U.S. Army Medical Corps followed by service as a Professor at the University of Michigan (UM) and then Michigan State University (MSU); for the majority of his career, Dr. Penner served as Director of the MSU Center for Bleeding and Clotting Disorders. He shared his passion for the bleeding disorders community and inspired medical students, residents and fellows, together with other health care professionals, to learn appropriate care and treatment. Dr. Penner was also internationally renowned in the field of inhibitor research and care.

With his life's work dedicated to people with bleeding disorders, Dr. Penner had a particularly profound and significant impact on Michigan's bleeding disorders community. Instrumental in establishing Camp Bold Eagle Highlands in 1969, now known as Camp Bold Eagle, Dr. Penner understood and supported the importance of people with hemophilia developing a "can-do" spirit of independence while creating friendships with other affected children and adults.

Dr. Penner also served as a founding member of what is now known as the Hemophilia Foundation of Michigan (HFM) and was the original grantee for the federally funded Hemophilia Treatment Center (HTC) program for Michigan, Indiana, and Ohio. A staunch proponent of the need and value of comprehensive care for individuals with hemophilia and other bleeding disorders, Dr. Penner also instituted outreach clinics across the region to provide access to care for adults and children. Awarded national and state awards for his endless hours of patient care and research, Dr. Penner impacted countless lives with his professional care and love of his patients and all those in the bleeding disorders community.

Dr. Penner is missed by all who had the pleasure of knowing and working with him.

Memorial contributions to support HFM's Camp Bold Eagle are welcome and appreciated by his family, colleagues, and friends.

John A. Penner, MD, passed away June 28, 2016.

Click here to make a donation to HFM's Camp Bold Eagle in honor of Dr. Penner. Thank you!

# Bowling for Bleeders Community Fun Night

Baxalta





Novo Nordisk



On August 5<sup>th</sup>, community members from the Grand Rapids area "got their game on" at the AMF Eastbrook Lanes. The night began with a warm welcome from Executive Director, Susan Lerch, and was followed by pizza, pop, and yummy desserts. It didn't take long for guests to hit the lanes and start knocking down pins. Smiles were everywhere and new friendships were made. We would like to thank our sponsors: Baxalta, Bayer, Biogen, and Novo Nordisk for providing a fun night for our community!

**Upcoming Bowling Night:** November 18<sup>th</sup> Lansing Stay tuned for more info on Facebook.



## CoRe CONVERSATIONS

We invite you to join us for CoRe Conversations: opportunities for members of the hemophilia community to come together and discuss topics relevant to the issues we may face each day. We'll share stories, ways to navigate issues, and tips and resources to help guide the way.



THE POWER OF EMPOWERMENT CRACKING THE CODE MAPPING YOUR FUTURE SETTING EDUCATIONAL EXPECTATIONS BRAVING CHANGE DECIDING IF YOU'RE CAMP READY UNDERSTANDING THE VALUE OF GENOTYPING GETTING READY FOR WHAT'S NEXT NAVIGATING FINANCIAL AID SPOTLIGHT ON UNAFFECTED SIBLINGS

Get in touch with your CoRe Manager for more information: BiogenHemophilia.com/CoRes



As a first time staff member at HFM's Camp Bold Eagle this year, I can personally say that your child does not have time to get homesick because they are having SO much fun! Yet, at night as the activities are winding down, homesickness can strike. Here are a few tips to help your child overcome feeling homesick:

• Before sending your child to camp, make sure you have a conversation with them about how homesickness is a completely normal feeling. Homesickness means you have a loving family at home and it is normal to miss them.

## HTC CORNER

# Worried about your Child getting Homesick?

By Annie Phillips, MSW, LLMSW, Pediatric Hemophilia Social Worker

- Even if you are having strong feelings of anxiety, do not project those feelings onto your child. Always approach camp with a positive attitude and consistently remind your children about how much fun they will have. Do not say, "If you get homesick I will come get you." This will plant the idea of leaving camp early in your child's mind and cause them to have a negative view of camp before even arriving.
- Encourage your child to have an overnight experience, away from the family, before arriving at camp. This can

help your child gain independence and confidence.

A great way to support your child while they are at camp is to send encouraging mail, highlighting how proud you are of them for going to camp. Mail call is a fun way for kids to know that you are thinking of them and to feel connected to home while they are at camp.

I truly look forward to next summer at HFM's Camp Bold Eagle and can't wait to work with your wonderful children!

## Welcoming Us to the Camp Family: A thank you from a med student

*By Hasanga Samaraweera, 4th year medical student at the University of North Dakota School of Medicine & Health Sciences planning to pursue a career in pediatrics.* 

The brakes squeaked my car to a stop after nearly 1000 miles. I had arrived at HFM's Camp Bold Eagle all the way from North Dakota. I may have been a random medical student from some far off state, but I was greeted with cheers and smiling faces like I belonged. From that moment, I knew I had come to a place that was different. A place that was special. The staff seemed to have a comfort level with each other that you'd only share with your oldest friends or family. "Family" is a word that I heard almost immediately as I arrived at camp, and at first blush, it seemed like a fairytale description that gets thrown around too easily. But the truth of it became more obvious as we went through staff training and was punctuated by the campfire on the last night before the campers arrived. These people, mere strangers to me three days earlier, were sharing stories that you'd

only share with those most dear to you. The overarching theme that struck me was that most would not be the same people, or possibly even alive, if it wasn't for Camp Bold Eagle and the family it creates. And amazingly, they were inviting all the medical students to join in that family.

The first day of camp, the children piled off the bus so full of life. Excitement was all around, yet I had no idea of the challenges that would lie ahead. I don't think I grasped the gravity of a six year old being away from home for the first time or the constant struggle of young boys trying to push the limits of the adults they've realized are not as infallible as they thought. While nothing grand, I think my friendship with a homesick camper helped him to find moments of joy at camp. I was able to watch his experience transform, with each smile



growing bigger than the last. Though this may not seem like a great victory, camp has shown me that such friendships can impact campers throughout their lives—and certainly counselors as well. I began the path to becoming a doctor because I wanted to help kids when they're in need. Though all I could be was a shoulder to cry on, I found that a small act could still have such a profound impact in the future.

By the end of the month, I was inextricably linked to this family through my friendships with other medical students, counselors, and campers. As those before me had been transformed by camp, so had I. So thank you Camp Bold Eagle for making me a better doctor, person, and advocate for those in need. I think and hope I made a difference too.

## **Adoption Opportunities**

Bryan, Miles, and Ari are still waiting for a family of their very own. Help us find forever families for these boys with hemophilia!

For more information on hemophilia adoptions, please contact Shari Luckey at sluckey@hfmich.org.



## Bryan, 9 years old, hemophilia

Bryan is extroverted, sociable, smart and able. He is described as being good-natured, despite the terrible pain he has when he has bleeds. He gets along exceptionally well with other children, and just look at that smile!

## Previously featured on the HFM Facebook page Miles, 8 years old, hemophilia (no photo)

Miles is very outgoing, and loves to help the caregivers take care of the younger children. He is also a little naughty, and likes to climb and jump, both restricted activities, when they are not looking! Miles is eager for a family of his very own to love and care for him!



## Ari, 4 years old, hemophilia

Ari has been diagnosed with moderate Hemophilia A, spinal muscular atrophy–type II, and delayed physical development. Ari is very charming, emotionally mature, sociable, and inquisitive. He loves to sing songs, join in group activities, listen to stories, watch cartoons, and play with cars. Ari is currently at a center in Eastern Europe.

## 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 to 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**.







Susan Fenters Lerch

Sarah Watson, MA, LPC

Register today

for this wonderful

htm's Homen's Retreat Heepend Limited to 30 women!

## HFM's 60<sup>th</sup> Anniversary Sharing our Stories: Look At Us Now!

Saturday, October 22<sup>nd</sup> & Sunday, October 23<sup>rd</sup>

Watch a video of Jeanne & Susan! www.hfmich.org/jeannewhiteginder

## Scrapbooking with Jeanne White-Ginder

Jeanne has been scrapbooking for years and will bring her teacher's heart, as well as her advocate's passion, to this session. All materials provided!

## **Creative Pieces – The Community Coming Together with**

**Sarah Watson, MA, LPC** Sarah will lead a wonderful interactive creative session revealing the healing power of art.

## A Giving Heart, A Doorway to Joy – Susan Fenters Lerch

Susan will inspire you with ways to invite joy into your life.

## Saturday Evening Wine and Roses Reception

**Von Willebrands Disease** identifying types of VWD and learning more about genetics with Sue Kovats-Bell, BSN, RN, Senior Clinical Specialist II U.S. Hematology, Shire

Sun., October 23rd

Includes breakfast.

• Drawings for lovely

• Three informative one

**Women With Joint Pain** with Angela Lambing MSN, ANP, GNP, Hemophilia Clinical Support Specialist Central Region. Bayer HealthCare

hour educational sessions.

## \$40 to participate.

Limited scholarships available. Contact Ashley,HFM Office Manager at 734.544.0015.

## **Retreat Location**

Hilton Garden Inn Plymouth 14600 North Sheldon Rd., Plymouth, 48170

## Sat., October 22nd

- Check-in 9am
- Continental breakfast
- Scrapbooking with Jeanne White-Ginder & healing art with Sarah Watson
- Includes lunch and dinner

## Thanks to our sponsors

## Specialty Pharmacy



Sponsors will be present at this event in the most sensitive way to support a private gathering of women in the bleeding disorders community. Participants will be provided valuable opportunities to connect and learn from companies who support their, and their family's health, and well-being. HFM (Hemophilia Foundation of Michigan) does not endorse any specific product or company.



• Ends at 1:30pm.

#### **To learn more, go to** www.hfmich.org/ womensretreat

To register, go to

www.hfmich.org/ womensretreatreg



Who is invited?

For this event, we welcome

any female member of the Michigan bleeding disorder

community (those with

a bleeding disorder and

the ages of 18 and 118.

caregivers) between





Special thanks to our Beach Day sponsor: CK Colburn Keenan Foundation, Inc.

# Beach Day: A Day at Lake Michigan

By Sarah Procario

During Session Two of Camp Bold Eagle, campers were taken on a trip to Lake Michigan. For children from our bleeding disorders community, "Beach Day" meant much more than just a day at Lake Michigan. As a Camp Bold Eagle counselor, I saw first hand how Beach Day truly was the gift of opportunity for our campers. Opportunity for fun, adventure, growth, challenge. It was no surprise that Beach Day was one of the campers' most favored activities.

Beach day began this year as campers piled onto surprisingly spacious buses and left Pioneer Trails' campground. Campers began to sing songs with their counselors on the way over, the excitement palpable. Upon arrival, many campers felt the familiar sensation that they were returning to a second home at the lake, yet others set foot on a beach and viewed seemingly endless water for the first time in their lives.

The true excitement of Beach Day occurred in Lake Michigan. A few cabins at a time were called to the shore for their chance to swim, protected from the expanse of the lake by a wall of CBE lifeguards on all sides. Like all activities at camp, we practiced inclusivity: wheelchairs or crutches were not a limitation or impediment for our campers to enter the lake. I watched as my co-counselors carried three campers in wheelchairs over the sand to reach the water. I saw a camper with a broken arm, his cast wrapped in plastic, play in the shallow water with his friends. And as I watched each child smile as they played in the waves, a sense of deep appreciation for camp fell over me, knowing that this experience might only happen once a year – when they are at HFM's Camp Bold Eagle.

To learn more about Delta Dental insurance, go to **www.HFMich.org/dentalinsurance**. If you have questions about the program or eligibility contact Lisa Clothier, Outreach and Community Education Manager at Iclothier@hfmich.org or 734.961.3512.







# The Gift of Camp

## By Gwyn Hulswit

There is no doubt that HFM's camp experience is beyond any monetary value. The pride of children and young adults who earn their Butterfly or Dragonfly Awards, the lifelong friendships that form, and the feelings of connection to a greater community are truly priceless. For camp staff, counselors, and medical professionals who participate with HFM's Eagle Journeys it is an immense privilege to share these moments with your children.

Yet, like many worthwhile experiences, there are expenses associated with our camps. Even though we do our very best to ask for donated items, HFM's costs for camp programs this year are more than \$430,000 cash. This is a big bill! While our medical staff donate \$193,000 worth of their time and expertise (thank you!!), everything from fun food at Orange Dinner to lifejackets to staff to renting campgrounds are expenses HFM must cover. We pay \$75,000 for Camp Bold Eagle's site on Big Blue Lake for the month of July, and another \$50,000 for bus and van rentals, food, ancillary items, and other travel costs. The coveted T-shirts for campers and participants are also part of our costs. Expenses for fun Camp Bold Eagle activities (\$17,200), camp brochures (\$810), and specialized insurance (\$2,250) add up as well. We truly need your help to cover these costs.

An \$18 gift could provide three kids with their annual CBE t-shirt. A contribution of less than \$1,000 could impact all our campers as HFM prints our Eagle Journeys detailed camp brochure. Your \$200 donation could be used by Eagle

## "Camp brings out the best version of me." Aaron, Camp counselor



Outpost teens to grocery shop for an evening meal they prepare for their fellow campers.

We would deeply appreciate your help in covering the costs of camp – either directly or through your networks. Do you know of a business, community group, or faith based organization that may help by making a donation? Are you aware of grant opportunities HFM could apply for that support camp programs? Please share your ideas with Gwyn Hulswit at ghulswit@hfmich.org, visit hfmich.org/donate to make a direct camp contribution, or join us in our fundraising events throughout the year. Your help can make HFM's Eagle Journeys a possibility for every child in our community.

On behalf of our campers, thank you.

## PAID CONSUMER OUTREACH

Biotherapies for Life\* CSL Behring

# INTRODUCING IDELVION NOW AVAILABLE



IDELVION is manufactured by CSL Behring GmbH and distributed by CSL Behring LLC. IDELVION® is a registered trademark of CSL Behring Recombinant Facility AG. Biotherapies for Life® is a registered trademark of CSL Behring LLC.

©2016 CSL Behring LLC 1020 First Avenue, PO Box 61501, King of Prussia, PA 19406-0901 USA www.CSLBehring-us.com www.IDELVION.com IDL16-03-0070 3/2016



## HFM's Butterfly Benefit

By Janelle Gunn

HFM's first Butterfly Benefit in May was a big hit in West Michigan. The Butterfly Benefit provided so much to the community: financial contributions, much-needed awareness, and another opportunity to connect with each other.

The Grand Rapids Art Museum served as the perfect venue for an evening of good food, beautiful music, and stories of inspiration and hope, surrounded by magnificent works of art. One hundred guests, together with industry sponsors, achieved our goal of raising enough funds to send 25 kids with bleeding disorders to one of HFM's Eagle Journeys camp programs AND had a ball doing it.

On behalf of everyone at HFM and all the families we serve—we THANK those who attended, volunteered, and donated at this fun-filled evening event. Your support made it possible for 25 kids to have the experience of a lifetime at one of our camps.

Plans are progressing to add this event to our annual fundraising calendar. Stay tuned – you'll definitely want to be there next year. To see some of the fun we had, check out the event photos at: **www.hfmich.org/butterflybenefitphotos** 

## SPECIAL THANKS TO OUR SPONSORS





SOARING EAGLE

# **Baxalta**

FRIENDS OF HFM Aptevo Therapeutics Bayer Healthcare CSL Behring

HFM SUPPORTERS Grifols | Novo Nordisk | Pfizer Hemophilia



## HFM's Swinging For Smiles

By Carrie McCulloch

On June 6<sup>th</sup>, more than 100 golfers on a mission gathered together at Polo Fields in Ypsilanti. They came for a day of fun, a day on the course, and an opportunity to provide a great camp experience to the youth of our community. All funds raised at the golf outing provided camperships for HFM's 2016 Camp Bold Eagle.

In addition to a beautiful day of golf, the day included breakfast, lunch, and a dinner program that allowed our golfers to learn more about the benefits of the very camp that they were supporting. Golfers also had the chance to walk away with some great prizes through a silent auction, basket auction, and 50/50 raffle.

The day consisted of many opportunities to contribute to camp. The putting contest was a fan favorite, where golfers tried their best to sink their ball using a plastic kiddie club. Golfers were putting to win a specific item to be used at camp: life vests for our waterfront! The life vests dangled from a tent nearby as inspiration, later in the summer to be seen on campers as they took an "Eagle Step" on their swim across the lake!

A big thank you to everyone who made HFM's Swinging for Smiles a success. Swinging for Smiles 2017 will be held on Monday, June 5<sup>th</sup>. We hope to see you there! Check out the event photos at: **www.hfmich.org/golfoutingphotos** 

## SPECIAL THANKS TO OUR SPONSORS

**BUTTERFLY KISS** 



SOARING EAGLE



FRIENDS OF HFM Aptevo Therapeutics Bayer Healthcare CSL Behring

## HFM SUPPORTER Pfizer Hemophilia

## UPCOMING EVENTS

## 2016

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

Sat. Oct. 22nd & Sun., Oct. 23rd Women's Retreat with Jeanne White-Ginder Hilton Garden Inn Plymouth, 14600 North Sheldon Rd., Plymouth pthomas@hfmich.org

October 28-30 Bleeder & a Buddy, Teen Retreat Location TBA

Friday, November 11 Butterfly Breakfast The Henry Hotel, Dearborn cmcculloch@hfmich.org

Friday, November 18 Bowling for Bleeders Family Fun Night Lansing, Location TBA cmcculloch@hfmich.org

Saturday, December 3 End of the Year Community Celebration (formerly Holiday Party) Troy High School, Troy, MI cmcculloch@hfmich.org

Saturday, December 17 Camp Holiday Party & HFM's 60th Anniversary All HFM community members, camp staff and campers, 18 and older; family members welcome! Bring a side dish and a white elephant gift (REMEMBER: don't purchase it!) afritsch@hfmich.org

## 2017

April 21-23 SpringFest ~ NEW LOCATION! Ann Arbor Ypsilanti Marriott at EAGLECREST, Ypsilanti pthomas@hfmich.org

May 18 Butterfly Benefit Grand Rapids Art Museum (GRAM) jgunn@hfmich.org

MAY TBA Lansing Day sprocario@hfmich.org

June 5 Swinging for Smiles Golf Outing Ypsilanti cmcculloch@hfmich.org

**TBA Walkin' on the Wild Side** Detroit Zoo, Royal Oak cmcculloch@hfmich.org

**TBA** Walkin' on the West Side Grand Rapids jgunn@hfmich.org

24 hfmich.org Spring 2016

## Kagle Journeys HFM Camping Adventures

## www.hfmich.org/campingprograms

Questions about camp? please contact Tim Wicks or Torey Allen @ 734.544.0015

## 2017 Camp Bold Eagle

**CBE Session One** (Ages 6-10) July 9-13

**CBE Session Two** (Ages 11-13) July 15-22

**CBE Session Three** (Ages 14-17) July 23-29

2017 CIT Program July 3, 4

2017 Staff Training July 5-8 2017 Eagle Quest (Ages 18+) June 3-10

hĪm

2017 Eagle Outpost (Ages 14-15) June 18-24

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

\*Stay tuned to hfmich.org and HFM's facebook page (www.hfmich.org/hfmfacebook) as dates may change.

Follow HFM!

f www.hfmich.org/hfmfacebook

- 🮯 @hfmich
- 💀 www.hfmich.org
- 💙 @hfmich
- www.hfmich.org/campingprograms