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THE ARTERY

FALL 2025

THIS ISSUE

HFMICH.ORG ♦ SERVING THE BLEEDING DISORDERS COMMUNITY

DEAR HFM FRIENDS,

WFH Comprehensive Care Summit with NBDF NYLI representative Quinn Kennedy and Eliza VanZweden, former NYLI and current member of the NBDF Research Committee (pictured left to right with Susan Fenters Lerch, HFM Executive Director, in the middle).. Quinn participated with HFM's Eagle Expedition camp program this summer, Eliza serves on HFM's Board of Directors.

In this Fall 2025 issue of the Artery, we're celebrating the joy and impact of camp and the opportunity to share HFM's National Women's Conference globally, while also looking at changes in state and federal policies and funding that will affect families with bleeding disorders. Advocacy is at the heart of HFM's work, helping protect resources, support families, and do our best to improve the quality of life for Michigan's bleeding disorders community.

There are significant changes at both the state and federal level that will directly impact Michigan's bleeding disorders community, and your involvement has never been more important.

At the state level, we are continuing our work with several coalitions to reduce patient out-of-pocket costs and to remove barriers to health care access. A continuing priority is to introduce a bill to end harmful copay accumulator policies. We have been working on this effort for several years, running up against inaccurate information being presented by other entities to our state legislators. Without this change, many families will unexpectedly face thousands of dollars in out-of-pocket costs before they can access needed treatments. We are also working to reform step therapy and prior authorization rules, which can delay, or block prescribed therapies. Protecting funding for Children's Special Health Care Services (CSHCS) also remains a priority, as this program supports both children and adults with bleeding disorders and provides crucial medical and financial assistance.

At the federal level, lawmakers in Washington, D.C. passed H.R. 1 in July, and the bill was signed into law shortly thereafter. This new law makes drastic cuts to Medicaid and is expected to make Medicaid and marketplace insurance less accessible and more expensive. These federal cuts make state-based advocacy even more important to ensure patients in Michigan can access care.

The decisions made today will shape access to treatment and quality of life for years to come. Add your voice by meeting with legislators, sharing your story, or joining us at advocacy events like Lansing Days. Together, we will assure Michigan's bleeding disorders community is heard.

Heartfelt appreciation,

Susan Fenters Lerch

HOW YOU CAN GET INVOLVED

- Contact your legislators – ask them to protect access to care.
- Stay connected – follow HFM for updates and share advocacy alerts with friends and family. Visit www.hfmich.org or contact Dana Brendecke-Carrier at dbrendeckecarrier@hfmich.org to be added to our mailing list.
- Speak up – your personal experiences make the biggest impact!
- Join us for Lansing Days March 24 - 25, 2026 – meet with lawmakers and share your story.
- National Bleeding Disorders Foundation Washington Days March 4 – 6, 2026.

Front Cover: © Brian Sevald Photography

IN THIS ISSUE

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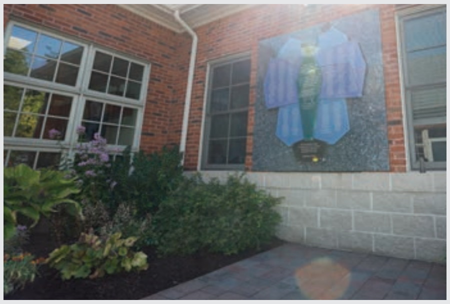
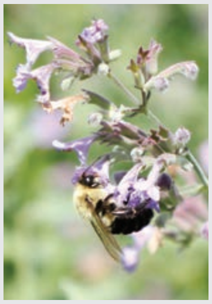
PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER

HONORING MICHIGAN'S LEGACY:

THE BUTTERFLY MEMORIAL GARDEN PROJECT





The Butterfly Memorial Garden at the Hemophilia Foundation of Michigan's (HFM) Ypsilanti office is a place of remembrance for Michigan's bleeding disorders community affected by HIV/AIDS. At its heart is a stunning blue glass butterfly inscribed with the names of 303 patients and advocates.

The original butterfly with 103 names was dedicated in 2005 when HFM moved into its new building. In June 2019, it was updated and recreated in the original image alongside the creation of a garden designed to educate, inspire, and commemorate. The garden features plants and flowers selected to attract and support butterflies. These winged creatures, with their transformative journey from caterpillar to butterfly, serve as a powerful metaphor for resilience.

In 2024, HFM launched a renovation project with support from a grant from Ann Arbor Farm & Garden (AAFG). While initial work was completed in the spring, excessive summer rainfall led to flooding that damaged the courtyard, boardroom, and surrounding areas. Swift action was taken, including upgrading gutters, replacing brick pavers, and regrading the garden to improve drainage. Plants were carefully removed and later replanted to preserve the garden's integrity.

By November 2024, outdoor repairs were completed, marking a major milestone despite the setbacks. While further developments were temporarily paused over the winter, work was resumed this spring, thanks to an extension to utilize remaining funds from the AAFG grant. The next phase includes purchasing additional plants, seeds, soil, compost, and fertilizer to fulfill the garden's original vision.

A special thank you goes to Larry Nisson, whose generous donation allowed fellow glass artist Anne Rogers to craft a custom monarch butterfly. This stunning artwork will serve as a lasting tribute within the garden, symbolizing transformation and renewal.

The Butterfly Memorial Garden Project not only honors the past but also cultivates a lasting legacy of resilience, advocacy, and hope. It stands as a testament to the strength of community spirit, the transformative power of remembrance in healing hearts, and inspiration to future generations. More than just a garden, the Butterfly Memorial Garden is a living tribute to the indomitable human spirit and a beacon of hope for years to come.

© Brian Sevald Photography

THANK YOU TO THE COLBURN-KEENAN FOUNDATION AND THE GALENS MEDICAL SOCIETY

The success of our camping programs relies on many things: caring staff, campers who embrace the spirit of their experience, sponsors and donors, our campgrounds at Pioneer Trails, and so much more. But what we don't always see are the very important in-kind contributions that make their mark on camp.

Thanks to organizations such as the Colburn-Keenan Foundation and the Galens Medical Society, a medical student organization from the University of Michigan, our camps have been gifted with supplies that enrich the camping experience for everyone involved.

These organizations have supported us in unexpected ways. From helping us transport our gear by contributing funds for a new trailer; to allowing us to zip around camp in a much-needed golf cart; to supplying basic needs such as menstrual products, toiletries, and replacement items such as sheets, swimsuits, and flip flops, these groups support camp necessities, fun, and comfort.

If you would like to contribute with an in-kind donation for the 2026 camp season, look for a wish list later in the year. We would love your support of camp!

Colburn Keenan Foundation, Inc.

galens
tag days

DOGS AT CAMP BOLD EAGLE

At Camp Bold Eagle, the wagging tails and happy barks of our canine companions are as much a part of the summer as campfire songs and s'mores. This year, we fondly remember Jack, a beloved camp dog who has crossed the rainbow bridge but whose spirit remains through our sun-dappled grounds. Winnie continues to bring her joyful presence to camp, alongside the playful new puppy Ziggy.

Jack, a beloved Camp Bold Eagle companion, may have crossed the rainbow bridge, but his gentle spirit and loyal heart will always be part of our camp family.

What do dogs love most about Camp Bold Eagle? For starters, it's the ultimate swim spot! From a refreshing dip in the beloved Big Blue Lake on a hot afternoon to playful splashes, the water is a canine paradise. Then there's the unparalleled joy of greeting campers in the morning for the flagpole songs.

Of course, no camp day is complete without a sun-drenched nap, often strategically positioned to catch the warmest rays or to enjoy a gentle breeze. As evening falls, the daily ritual of saying goodnight to the cabins, with a final wag and a comforting presence, ensures everyone drifts off to sleep with a sense of security and belonging. The dogs of Camp Bold Eagle aren't just pets; they're cherished members of our camp family, embodying the joy and spirit of summer.

Ziggy and Winnie, Camp Bold Eagle's dynamic duo, soaking in the sunshine and sharing a quiet moment on their daily adventures through the woods.

© Brian Sevald Photography

DRAWING CALM:

HOW NEUROGRAPHIC ART SUPPORTS MENTAL WELLNESS

ELIZABETH WILSON FISCHER, ART EDUCATOR AT BRILLIANT HUES AND THRIVE LEARNING CENTER, GRAND RAPIDS, MI

© Box of Light Photography

As an art educator, I've long believed in the healing power of creativity. For those living with bleeding disorders and other chronic health conditions, mental and emotional support is an important part of overall wellness. That's where neurographic art comes in.

Neurographic art is a simple, meditative drawing technique that blends psychology and creativity. Developed by psychologist Pavel Piskarev, it involves drawing freeform lines and softening their intersections. Where all the intersections create a "V," the angle is rounded to make a "U" shape, creating abstract, organic compositions. The repetitive process helps quiet the mind, reduce stress, and give form to emotions we may not have words for.

Recent studies, including one published in *Art Therapy: Journal of the American Art Therapy Association*, show that even brief creative activity can significantly lower stress hormone levels and improve mood. For individuals managing chronic conditions, this kind of self-expression can be a powerful tool for resilience.

What I love most about neurographic art is that anyone can do it, no art experience is required. It can be done with any medium, paint, colored pencils, even crayons. It's not about making something beautiful. It's about being present, expressing yourself, and letting your nervous system settle. 🩸


© Brian Sevald Photography

Willie helps his daughter Josie cast her line during a peaceful afternoon of fishing at Eagles Nest Family Camp.

EAGLES NEST FAMILY CAMP
2025

Willie Gibbs, a former Camp Bold Eagle counselor, returned to camp this year for a new experience: his very first-time attending Eagles Nest Family Camp alongside his wife, Nicki, and their seven-year-old daughter, Josie.

For Willie, walking the familiar grounds of Pioneer Trails was deeply nostalgic. “Everywhere you go, you’re remembering something—you’re smiling to yourself just wandering around,” he said. But this trip was more than a walk down memory lane. It was a chance to introduce Josie to the camp community that has meant so much to him.

Watching Josie adjust to the new environment—from sleeping in a cabin for the first time to telling a joke at dinner—was a meaningful experience. “She’s opening up, she’s speaking louder, she’s making connections. That kind of growth in just a few days is amazing,” Willie shared.

Eagles Nest also gave the Gibbs family something they hadn’t found at other events: uninterrupted time together in community. “At SpringFest, we’re usually separated; Nicki and I are in sessions, and Josie is in childcare. Here, we get to experience everything together,” he said. “It’s deepened our bond as a family and our connection to the bleeding disorders community.”

From lake dips to surprise letters and shared laughter, Willie said the true highlights were the many moments of pure joy on Josie’s face. “Those are the smiles you don’t forget.”


© Sonja Sevald Photography

Josie takes off running during a game of kickball at Eagles Nest Family Camp, soaking up summer fun and making memories that will last a lifetime.

WATCH THE FULL INTERVIEW BY SCANNING THE QR CODE

COMMUNITY NIGHT:

I CAN'T SEEM TO GET AHEAD

On March 14, amidst the ongoing challenges of high living costs and health-related expenses, thirteen families gathered virtually for an insightful and interactive workshop aimed at empowering their financial journeys. Facilitated by Caroleen Verly, owner of Untangle Your Money, the session delved into practical strategies for saving, spending wisely, and cultivating a healthy money mindset.

The workshop began with an exploration of effective ways to trim expenses without sacrificing quality of life. Participants learned how to redirect their financial resources towards meaningful goals, whether securing their children's education, planning for retirement, or investing in personal growth.

Caroleen highlighted common pitfalls that can hinder financial progress, such as impulsive spending, neglecting savings, and overlooking long-term financial planning. Through interactive discussions, families discovered proactive steps to avoid these traps and maintain financial stability.

A significant portion of the session focused on the psychological aspects of money management. Attendees examined their own money beliefs and learned techniques to overcome limiting beliefs that may hinder financial growth. By fostering a positive money mindset, participants gained confidence in making sound financial decisions.

The workshop concluded with a vibrant discussion where families shared personal insights. The event equipped attendees with practical financial tools and fostered a supportive community focused on achieving long-term financial security.

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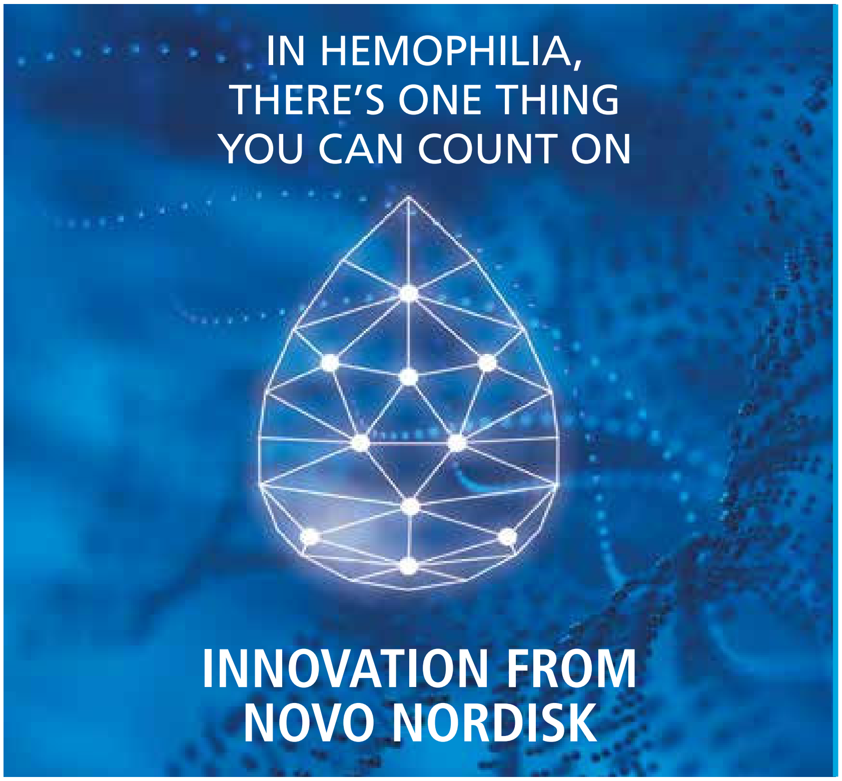

PAID CONSUMER OUTREACH

HEROIC STORIES UNITE AT SPRINGFEST2025

> "BONDING WITH THIS COMMUNITY!"

> "I TRULY ENJOYED THIS WEEKEND AND LEARNED A TON! THANK YOU HFM FOR ALL YOU DO!"

> "WE ENJOYED THE SOCIALIZATION, NETWORKING, SEEING OLD FRIENDS, MAKING NEW FRIENDS, AND LEARNING NEW, VALUABLE INFORMATION."

The Hemophilia Foundation of Michigan's SpringFest 2025 was held in April at the Detroit Marriott in Troy, uniting 350 members of the Michigan bleeding disorders community for a weekend of education, connection, and celebration. Centered around the theme "Heroic Stories: Uniting Our Powers," the event offered dynamic programming for all ages. Family-friendly sessions encouraged learning and connection across generations, while an interactive scavenger hunt inspired attendees to explore sessions, meet others, and connect with sponsors. The silent auction and raffle highlighted the community's creativity and generosity, with proceeds benefiting HFM's mission.

The weekend kicked off with an inspiring plenary, "Mission Possible: Heroes Unite," featuring Dr. Daicia Price of the University of Michigan in full Wonder Woman attire. Sessions throughout the weekend explored a variety of topics, including bleeding disorders management, emotional wellness, clinical trials, and family stress, alongside hands-on and self-care activities like a visual history project and yoga. Highlights included "Aqua Work-It Out," the HFM Scholarships & Awards ceremony, and the beloved Kids Cape Parade. Children and teens found empowerment through the Heroes Circle's non-contact martial arts program. The event concluded with a strong sense of connection and inspiration, leaving attendees energized by the heroic spirit of the community.

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> "I ALWAYS ENJOY MEETING NEW FRIENDS AND MY OLD FRIENDS AND HAVING GOOD TALKS."

SAVE THE DATE FOR SPRINGFEST 2026 AND OUR FIRST IN-PERSON VWD SYMPOSIUM: APRIL 17–19 AT THE RADISSON PLAZA HOTEL AT KALAMAZOO CENTER.

Join us Friday for the VWD Symposium, followed by SpringFest on Saturday and Sunday. Thank you to everyone who made SpringFest 2025 a success—we'll see you next year!

TAMAR
HEMLIBRA PATIENT SINCE 2019

DEVON
HEMLIBRA PATIENT SINCE 2020

MIRANDA
HEMLIBRA CAREGIVER TO TWIN SONS
TRISTAN & TALAN (AGE 11) SINCE 2018

VERONICA
HEMLIBRA CAREGIVER TO SON
IAN (AGE 7) SINCE 2020

HEMLIBRA: TRUSTED BY THE COMMUNITY FOR 7 YEARS AND COUNTING

SOREN
HEMLIBRA PATIENT SINCE 2022

HARVEY
HEMLIBRA PATIENT SINCE 2016

MARIA
HEMLIBRA CAREGIVER TO SON
CARLOS (AGE 16) SINCE 2019

OLIVIA
HEMLIBRA CAREGIVER TO SON
ARLO (AGE 6) SINCE 2018

First approved in 2017.*
Over 8,100 patients
in the US treated with HEMLIBRA.†

SCAN TO HEAR STORIES FROM THE COMMUNITY

*November 2017: FDA approval for adults and children with hemophilia A with factor VIII inhibitors.

†Number of patients with hemophilia A treated with HEMLIBRA in the US as of March 2024.

INDICATION & IMPORTANT SAFETY INFORMATION

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.

These serious side effects include:

- **Thrombotic microangiopathy (TMA),** a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events),** which may form in blood vessels in your arm, leg, lung, or head

Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. If aPCC (Feiba®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (Feiba®) total.

Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (eg, increase in bleeds).

Please see Brief Summary of Medication Guide on following page for Important Safety Information, **including Serious Side Effects**.

HEMLIBRA®
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

Medication Guide
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (e.g. increase in bleeds).

See "**What are the possible side effects of HEMLIBRA?**" for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See "**What is the most important information I should know about HEMLIBRA?**"

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

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

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 03/2023

HEMLIBRA®
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

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Women's RETREAT

HARNESSING THE HEALING POWER OF WATER

Muskegon, Michigan served as the serene backdrop for a women's retreat held on May 17 and 18, with the inspiring theme, "Harnessing the Healing Power of Water." This unique event offered attendees a deeply restorative experience, inviting them to connect with the calming and revitalizing properties of water and, as always, with each other.

Retreat attendees had the opportunity to unleash their creativity in a watercolor class taught by Liz Wilson-Fischer of Brilliant Hues, transforming the beauty of the lakeshore into artistic expressions. The retreat included an energetic water aerobics session at a local gym, providing a fun and invigorating way to engage with water, promoting physical well-being and a joyful spirit and supporting joint health. There were also educational sessions aimed at expanding the women's toolboxes for taking care of their bleeding disorder, or a family members' bleeding disorder.

A significant highlight of the weekend was a peaceful, albeit windy, walk at Pere Marquette Beach. This allowed the group to immerse themselves in the expansive beauty of Lake Michigan, feeling the sand beneath their feet and experiencing the profound sense of tranquility that only a natural waterfront environment can offer.

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We're so excited to host next year's Women's Retreat at North Star Reach in Pinckney, Michigan. Registration will open in January 2026.

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TINY CLOT CHRONICLES

Welcome to the Tiny Clot Chronicles! Discover your Camp Bold Eagle name, then have fun with a birds of prey word search!

WHAT'S YOUR CBE NAME?

At Camp Bold Eagle, all of our cabins are named after birds of prey and now you can find out your CBE name using your birthday!

Here's how it works:

1. Find your birth month in the blue header row.
2. Look for the day range that includes your birthday.
3. Your CBE name is the word above the day range + the bird name below it.

Example:
If your birthday is March 10, your CBE name is Dazzling Merlin!

January	February	March	April	May	June
Amazing	Fantastic	Dazzling	Super	Magical	Glorious
1-2	3-4	5-7	8-9	10-11	12-13
Condor	Falcon	Hawk	Caracara	Merlin	Vulture

July	August	September	October	November	December
Bold	Fearless	Mighty	Brilliant	Sparkling	Awesome
14-15	16-19	20-22	23-25	26-28	29-31
Buzzard	Kite	Harrier	Owl	Kestrel	Osprey

WORD SEARCH

R	J	I	B	B	O	L	D	C	J	Z	L	R	J	G	G	X	O
K	X	T	K	G	V	N	D	H	O	E	H	A	M	U	N	H	D
U	W	W	B	I	U	O	C	T	V	C	A	E	J	M	B	M	X
N	B	S	H	I	L	Y	W	A	V	K	O	G	Q	C	U	B	M
P	L	G	A	C	A	M	P	X	R	U	C	N	L	E	Z	G	H
K	Y	W	R	Y	U	E	B	P	Y	A	L	P	D	E	Z	C	U
N	I	K	R	J	U	T	K	Z	K	V	C	T	E	O	A	G	H
E	F	T	I	H	H	A	W	K	D	Z	J	A	U	K	R	I	V
X	J	Z	E	F	F	M	E	R	L	I	N	Z	R	R	D	I	G
R	T	C	R	S	D	G	F	A	L	C	O	N	B	A	E	L	Y
O	S	P	R	E	Y	V	O	W	L	L	Z	Y	C	B	T	G	U
G	Q	O	R	D	K	Z	K	E	S	T	R	E	L	T	N	F	Z

Find the following words in the puzzle.
Words are hidden ➔, ↓, and ↘.

CARACARA
HARRIER
KESTREL
VULTURE
BUZZARD
OSPREY
MERLIN
FALCON
CONDOR
EAGLE
HAWK
KITE
CAMP
BOLD
OWL

STAFF UPDATES

HFM is pleased to welcome three new staff members to our team: Dana Brendecke-Carrier, Office and Database Manager; Ariana Herrera-Wilder, Regional Executive Assistant; and Shawna Norris, Program Services Manager.

DANA BRENDECKE-CARRIER

Since moving to Michigan in 2016, Dana has continued her passion working with Raiser's Edge and not for profits. Achieving professional level certification, Dana is experienced in Database Administration, Operations, and Management for nonprofit agencies and is experienced in partnering and growing relationships with a vast array of organizations.

When she is not running reports and queries, Dana is the cheese coordinator at her local co-op. She also enjoys spending time with her boys, her dog, and going to see live music.

ARIANA HERRERA-WILDER, MPA

Ariana is a Certified Nonprofit Professional whose work has focused on mental health, maternal/infant health, early childhood education, and community health. While at Eastern Michigan University completing her Masters in Nonprofit Management, Ariana was nominated for the CAS Wanda J. Monks Staff Member of the Year Award and received a "Thank-An-Eagle Award". When not serving her community, Ariana enjoys spending time with her family, working on a jigsaw puzzle, or reading.

SHAWNA NORRIS

Shawna is HFM's Program Services Manager. She brings more than twelve years of experience in the event planning industry, including ten years as a business owner organizing events throughout the Metro Detroit area and beyond. After taking her business full-time for four years and successfully running a 5-star rated company, Shawna decided to close its doors and return to her true passion: planning events for nonprofit organizations. She finds great fulfillment in using her skills to give back to the community and create meaningful experiences. In addition to her professional achievements, Shawna is a proud mother to her young adult daughter. When she's not planning events, Shawna's second passion is traveling the world. Her favorite destinations include South Africa, Rome, and Egypt.

THANK YOU TO LAURA OLSON: A LEGACY OF SERVICE AND COMMITMENT

Throughout her years at the Hemophilia Foundation of Michigan, Laura Olson was a constant source of reliability, warmth, and care. Often the first person to greet visitors or answer the phone, Laura welcomed everyone with genuine kindness and a willingness to help. As Business Manager, she played a vital part in the organization's daily operations, handling challenges of all sizes with thoughtfulness and grace.

From resolving technical issues to creating and managing HFM's database, Laura approached each task with dedication and heart. Her calm presence and steady leadership made her a trusted colleague and a deeply valued member of the HFM community.

Laura's retirement marks the close of a remarkable chapter of service with HFM and in the nonprofit sector. Her contributions have left a lasting impact on HFM and on all who had the privilege of working alongside her. We are truly grateful for her commitment and wish her the very best as she begins this next chapter spending time with her beloved granddaughter, family, and friends.

COMMUNITY MEMBER FEATURE

EMMA BAKER

I first attended Camp Bold Eagle when I was 11 years old. Newly diagnosed, I didn't know anyone, but was welcomed with open arms by kind, patient counselors and I quickly made several good friends I couldn't wait to see the following year. Over the years, I participated in Session 2, Teen Camp, and Outpost. It felt incredible to be part of a community that gave me a true sense of belonging. What kept me coming back each summer were the friendships I formed and the unique experiences and activities that were offered. Camp Bold Eagle was also my first overnight summer camp, and it provided peace of mind for my mom. She knew I was in good hands, surrounded by medical students, nurses, and counselors who had extensive knowledge of bleeding disorders. She didn't have to worry about whether activities were safe for me—I could just be a kid. Camp remains a safe haven for me, just as it is for so many others.

Growing up with multiple medical conditions, including von Willebrand Disease, I faced frequent bullying throughout grade school. By the time I was in high school, I came to realize that my classmates weren't being cruel out of spite, but the real reason was because there was a lack of understanding and education on what was happening with me and why I couldn't participate in the same activities they could. I struggled to find resources that were kid-friendly and educational materials that explained medical conditions in a way I could understand and relate to. At 17 years old, already a published illustrator, I decided that I wanted to help change that. I began not only illustrating but also writing books. At 18, I published my first book about Juvenile Arthritis, becoming a published author. Since then, I have written and illustrated four other books, including my fifth on bleeding disorders. My goal as an author is to spread awareness and foster empathy by educating the next generation of children about less common medical conditions so that understanding replaces judgement, and compassion takes the place of fear.

I am currently enrolled in the Recreational Therapy Program at Grand Valley State University. The curriculum focuses on working with youth at risk, older adults, pediatric clients, and individuals with physical and cognitive disabilities. Recreational therapy uses recreational activities to enhance an individual's overall quality of life. Rather than viewing the body as separate parts, recreational therapists approach care holistically—by addressing physical, mental, emotional, and spiritual wellbeing. Having completed my first year in the program, I participated in fieldwork this summer at Camp Bold Eagle, building skills by working with children and teens while also developing my leadership and teamwork abilities. This opportunity allowed me to observe a recreational therapist in action and deepen my understanding of the profession, while spending time with my bleeding disorders community.

Check out Emma's newly published book, where Dee takes readers on an educational and empowering journey through bleeds, clotting, treatment, and more!

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WORLD FEDERATION OF HEMOPHILIA CONFERENCE

In 2024, HFM was encouraged by Dr. Roshni Kulkarni, emeritus director of the Michigan State University Bleeding and Clotting Disorders Clinic, to submit an abstract to the World Federation of Hemophilia's (WFH) 2025 International Comprehensive Care Summit. Dr. Kulkarni serves on the WFH Women and Girls with Inherited Bleeding Disorders Committee and continues to be a tremendous advocate of women with hemophilia and other bleeding disorders receiving access to appropriate care. We refer to Roshni as the Fairy Godmother of HFM's annual National Conference for Women with Hemophilia and Other Rare Factor Deficiencies initiated in 2018. Dr. Kulkarni, together with HFM's Susan Fenters Lerch, Shari Luckey, Gwyn Hulswit, and NBDF's Samantha Carlson, authored the abstract. Subsequently, HFM was invited to present a poster during the 2025 WFH Comprehensive Care Summit that took place in Dubai, UAE. The dates of the Summit coincided with HFM's annual SpringFest educational weekend, so only Susan served as our representative. Physicians, community members, and advocates from across the world gathered to discuss issues facing patient care challenges and opportunities. The summit offered an amazing opportunity to share the dynamic impact HFM's conference has made for women as well as the opportunity to share strategies and awareness to a global audience.

Susan Fenters Lerch in Dubai for the conference.

Sharing HFM's work with the global community at the WFH conference poster session.

Susan Fenters Lerch, Antonio Gomez Cavallini, Deniece Chevannes and Eliza VanZweden representing their organizations during the WFH conference in Dubai.

Ganga Wijewardana and Susan Fenters Lerch, reconnecting after collaborating during HFM's visit to Sri Lanka for the WFH Twinning Project.

NATIONAL CONFERENCE FOR WOMEN

EMPOWERING CHANGE: TRANSFORMING AWARENESS, ADVOCACY AND CARE FOR WOMEN WITH HEMOPHILIA AND RARE FACTOR DEFICIENCIES

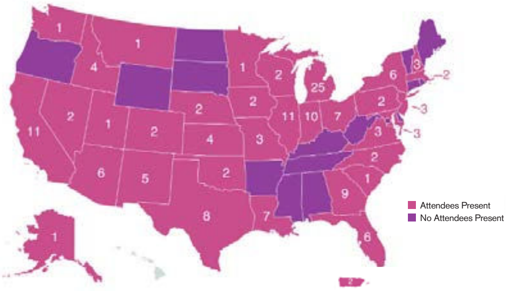
ABSTRACT ID: 2010443

NATIONAL WOMEN'S CONFERENCE (NWC)

HFM initiated the National Conference for Women with Hemophilia in 2018 with 100+ attendees from around the United States. The conference is offered at no cost to participants, so numbers are limited. Each year since 2018 conference attendance increased, with the need for attendee waiting lists; during the COVID pandemic HFM offered virtual participation with boxes delivered to participants providing content and materials for use. Participation increased to include women from across the country as well as Puerto Rico and New Zealand. 209 individuals participated with the 2024 national conference.

Registration and Attendance

- **217** applied to this year's conference
- **130** women participated in-person and 30 women participated virtually
- **15** HFM staff members
- **27** speakers
- **209** eligible attendees selected from 34 states and Puerto Rico
- **17** community professionals
- **13** volunteers
- **13** industry representatives



PLANNING AND INCLUSIVITY

- The initial planning committee included hematologists from various HTCs as well as Lived Experience Experts (LEEs) to determine program content. This process has continued and grown, with advanced leadership training available via application from LEEs.
- Recruitment via HTCs, national partner organizations, social media, NBDF chapter and HFA member organizations
- Emphasis on diversity: geography, diagnosis, race, age, history
- Hybrid format: In-person and virtual attendance
- Inclusive features: Spanish translation, social work/nursing support, welcoming space

CONFERENCE GOALS

Since its inception, the goals of HFM's National Conference for Women with Hemophilia have been demonstrating methods of self-care and bleed management, enhancing self-advocacy in medical and community settings, and to increase community connections among women with hemophilia and rare factor deficiencies.

2024 Goals

- Promote Advocacy for Healthcare Equity
- Foster Resilience and Build Support Networks
- Address Barriers to Diagnosis and Treatment through Education
- Advance Research and Data Collection for Informed Care

2024 CONFERENCE PRESENTERS

Meera Chitlur, MD; Mina Nguyen-Driver, Psy.D; Kerry Funkhouser, EdD; Kathleen Gerus-Darbison, MA; Andra H. James, MD, MPH; Rebecca James, MD, MPH; Jill Johnsen, MD; Roshni Kulkarni, MD; Lynn Malec, MD, MSc; Ann-Marie Nazzaro, PhD; Daicia Price, PhD, LMSW, OMHP; Jessica Richmond; Kaite Scott, LLMSW; Sarah Watson, LPC, CST; Angela Weyand, MD; LEEs and HFM staff

AUTHORS

Susan Fenters Lerch, HFM; Shari Luckey, MA, HFM; Gwyn Hulswit, MA, HFM; Roshni Kulkarni, MD, MSU CBCD Emeritus Director; Samantha Carlson, MSW, LMSW, National Bleeding Disorders Foundation.

WHY THIS MATTERS

- **Historically Overlooked**: Women have typically been considered only carriers of hemophilia consequently misclassified as only genetic carriers, leaving their medical and emotional needs unmet.
- **Undiagnosed and Unsupported**: Many women remain undiagnosed or under-treated, leading to serious impacts on **quality of life, reproductive health, and mental well-being**.
- **Raising Awareness = Better Outcomes**: Recognizing that women can and do have hemophilia or rare factor disorders is critical for **accurate diagnosis, care, and support**.

KEY TOPICS PARTICIPANTS VALUE MOST

- Access to diagnosis and treatment
- Understanding disease burden
- Mental health and psychosocial support
- Navigating reproductive health with bleeding disorders
- Community and connection

CONFERENCE EVOLUTION

In assessing the conference from 2018 through 2024, the following themes have emerged:

- **2018** Recognizing similarities through the sharing of individual stories
- **2019** Contending with naming, representation, and the debate surrounding 'carrier' versus 'woman with hemophilia'
- **2020** Moving the conversation to advocacy and creating a collective voice
- **2021** Discussing the importance of research, embracing the need for health equity, addressing medical inequities
- **2022** Examining structural problems that impact misdiagnosis and delay in appropriate care
- **2023** Embracing a more refined understanding of the multifaceted challenges faced by women and recognizing a growing demand for specialized care, nuanced research, and a more comprehensive approach to addressing needs throughout women's different life stages
- **2024** Growing awareness of the importance of testing women for hemophilia and rare factor deficiencies as delays in diagnosis are now recognized as contributing to increased bleeding episodes and lower quality of life. However, factor levels alone can fail to accurately reflect the symptoms experienced by women. The marginalization and dismissal of women's symptoms are deeply entrenched. Misdiagnosis, or absence of a diagnosis, can lead to inappropriate treatment, delayed care, or even no treatment at all. The best practice model involves establishing multidisciplinary clinics dedicated to women and girls to enhance early identification—especially in families with a known history—to improve overall health management. Efforts to further educate medical professionals, advocate for better care, and raise awareness highlight a growing push for systemic change. This includes a renewed focus on acknowledging women's experiences and promoting greater participation in patient registries.

RESULTS THAT MATTER

- **96%** of participants felt more supported by the bleeding disorders community.
- **91%** learned new, actionable medical information.
- **97%** would recommend the conference to others.
- Many attendees reported plans to make **positive changes in their healthcare** after attending.

NWC IMPACT & FUTURE DIRECTIONS

- The NWC has elevated the national conversation around women with hemophilia and rare factor deficiencies
- Ongoing education, awareness, and annual programming are essential:
  - Breaking stigma
  - Increasing self-advocacy
  - Driving healthcare equity for women with hemophilia
  - Further data specific to women with hemophilia and rare factor deficiencies
  - Foster hope and meaningful change

HFM's National Conference for Women poster shared at the conference.

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PAID CONSUMER OUTREACH

CIT SPOTLIGHT

KIMMIE MARTIN, 2025 CIT DIRECTOR


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The 2025 CIT Group with Kimmie Martin.

Camp Bold Eagle is often referred to as a magical place where those with bleeding disorders can relax and be themselves without worry of being defined by their health condition. At Camp Bold Eagle, we want to help foster this love for camp and help our campers and youth in the community learn valuable life and job skills.

The Counselor in Training (CIT) program has been around for almost as long as the camp and is one of the most important opportunities offered during the camp season. Former campers, typically ages 16-17, exhibiting strong leadership skills can apply for the specially designed training program that acts as a stepping-stone to a full staff position. We teach these ambitious teenagers what happens at camp and how to be a Cabin Counselor who will leave a lasting positive impression on the campers. We do this through programming and activities that focus on positive behavior management, time management, team building, and maintaining a safe and happy environment for campers.


© Misty Lyn Photography

Kimmie with her daughter Serena.

Having the CITs come out for 2 days of specific training prior to the staff orientation helps build camaraderie and community with the teens in our community. This feeling of having a team of peers learn and grow with you often leads to increased staff retention as many CITs will return to help create memories for new campers and see their fellow CITs for years to come.

If you're interested in learning more about HFM's CIT program, visit **www.hfmich.org/camp** for more information and the application.

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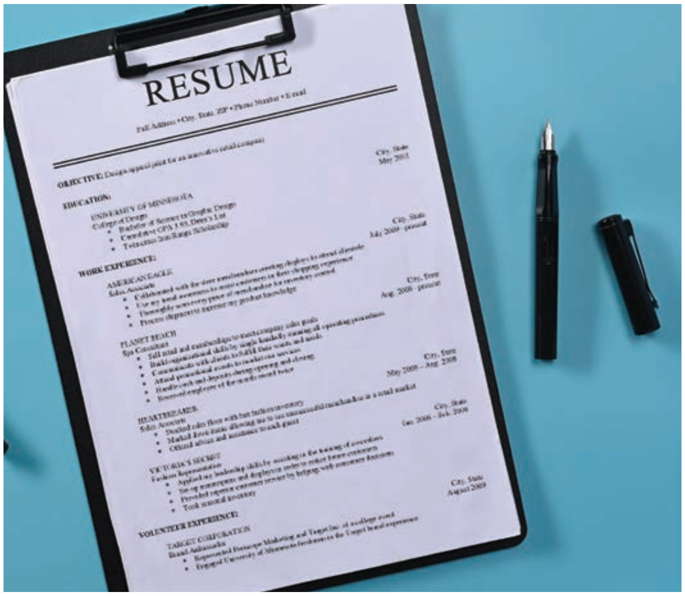
LAUNCH


RESUME

On Saturday, May 3, HFM welcomed seven community members to our office in Ypsilanti to attend LAUNCH Day, an in-person workshop designed to assist community members in their job search. This event offered hands-on assistance with resume writing to help community members create a resume that stands out. Attendees also had the opportunity to hone their interview skills with questions tailored to their career interests. All these topics were discussed with our guest speaker, Jim Ritz, the Career Services Advisor at Lawrence Technological University. Jim shared his experience and expertise with us in regard to many topics ranging from answering difficult interview questions to how to deal with applicant tracking systems.

Amidst the networking with fellow job seekers, community members had the chance to update their professional image with a complimentary headshot. HFM staff provided valuable insights to help attendees find a job that fits their needs and shared information about HFM’s job training and certification program.

If you would like to learn more about **LAUNCH** and how the program might assist you with your career goals, please visit **hfmich.org/launch**

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SINCE 1994

A NURSE'S VIEW:
CAMP BOLD EAGLE THEN AND NOW

MISSY FREY, RN

When I first arrived at Camp Bold Eagle in 2004, the health center was a whirlwind of activity. As nurses, we managed a full schedule of infusions, sometimes 6-8 a day, just to keep campers on their prophylaxis regimens. A camper with severe hemophilia usually infused 3 times a week then. Today, thanks to extended half-life products and subcutaneous options, a camper might only need to treat once, or not at all during their stay.

It's remarkable how science has changed the way we care for kids at camp. Camp Bold Eagle has grown from four sessions to eight over the years, stretching across nearly the entire summer. The energy is still there at every session.

And yet, despite all the changes, so much has stayed the same. Karl still remembers every camper's name and makes each meal special, Tim and Antonio are camp staples, and Big Blue Lake still reflects the same wonderful memories. The health center still sees its share of bee stings, rashes, scraped knees, homesickness, teaching how to infuse, and everything in between.

My favorite saying is, "Camp popsicles and ice packs fix a lot of things at camp!" Camp is still camp. It holds space for growth and laughter, as well as independence and friendship. And for a nurse like me, it's still one of the greatest honors of my year to participate and gives me the utmost pleasure seeing a new camper at age 6, now a fully independent counselor at age 18. 💧

KARL SPOTLIGHT

© Brian Sevald Photography

"Goooooooooooooood morning, Camp Bold Eagle!"

Each morning, Karl greets us with these words, and we reply, "Good morning, Karl!"

Karl is the Director of Camp Services at Pioneer Resources. But that title doesn't encapsulate all that he does at camp. Karl welcomes us to Pioneer Trails with a smiling face every year and always greets campers by name. You can find him in the mess hall getting meals ready, driving his Kubota around, doing the daily dumpster dance, mowing the activity field, and even participating in our evening program activities! Read more for our exclusive interview with Karl.

Q: How long have you been at Pioneer Trails?
A: Long enough to know better. I thought I had been addicted to the hokey pokey, but then I turned myself around.

Q: What is your favorite thing about CBE?
A: My daily greetings with the campers and their responses!

Q: What is your favorite orange food item?
A: Jello!

Q: How do you remember everyone's name?
A: I don't. What is your name?

Q: Where do you get all of your jokes?
A: The joke store.

Q: What do you do when Camp Bold Eagle isn't at Pioneer Trails?
A: I dream of you all coming back to camp.

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SCHOLARSHIP/LIFETIME AWARD WINNER SPOTLIGHT

Brooklyn Michalak

This year at SpringFest, we were able to award two deserving students with the annual HFM scholarship. Congratulations to Hannah Ketterer and Brooklyn Michalak! We were also thrilled to award Lynn Ray Allen with a Lifetime Legacy award.

Hannah Ketterer is attending Wayne State University where she is pursuing a major in chemical engineering. Upon graduation, she is interested in pursuing a career in the medical field to create pharmaceuticals. Hannah shares: "my whole goal with my degree is to be able to help others the best that I can by changing lives with medications that they did not have before."

Following graduation from Coopersville High School, Brooklyn Michalak will be attending Grand Valley State University. Her intention is to major in pre-medicine and minor in Spanish. Brooklyn shares her "aspirations for a career in the medical field stem from her grandmother's resilience battling her bleeding disorder."

We wish both Brooklyn and Hannah all the best of luck with their studies this year and appreciate their career plans to support people in the bleeding disorders community.

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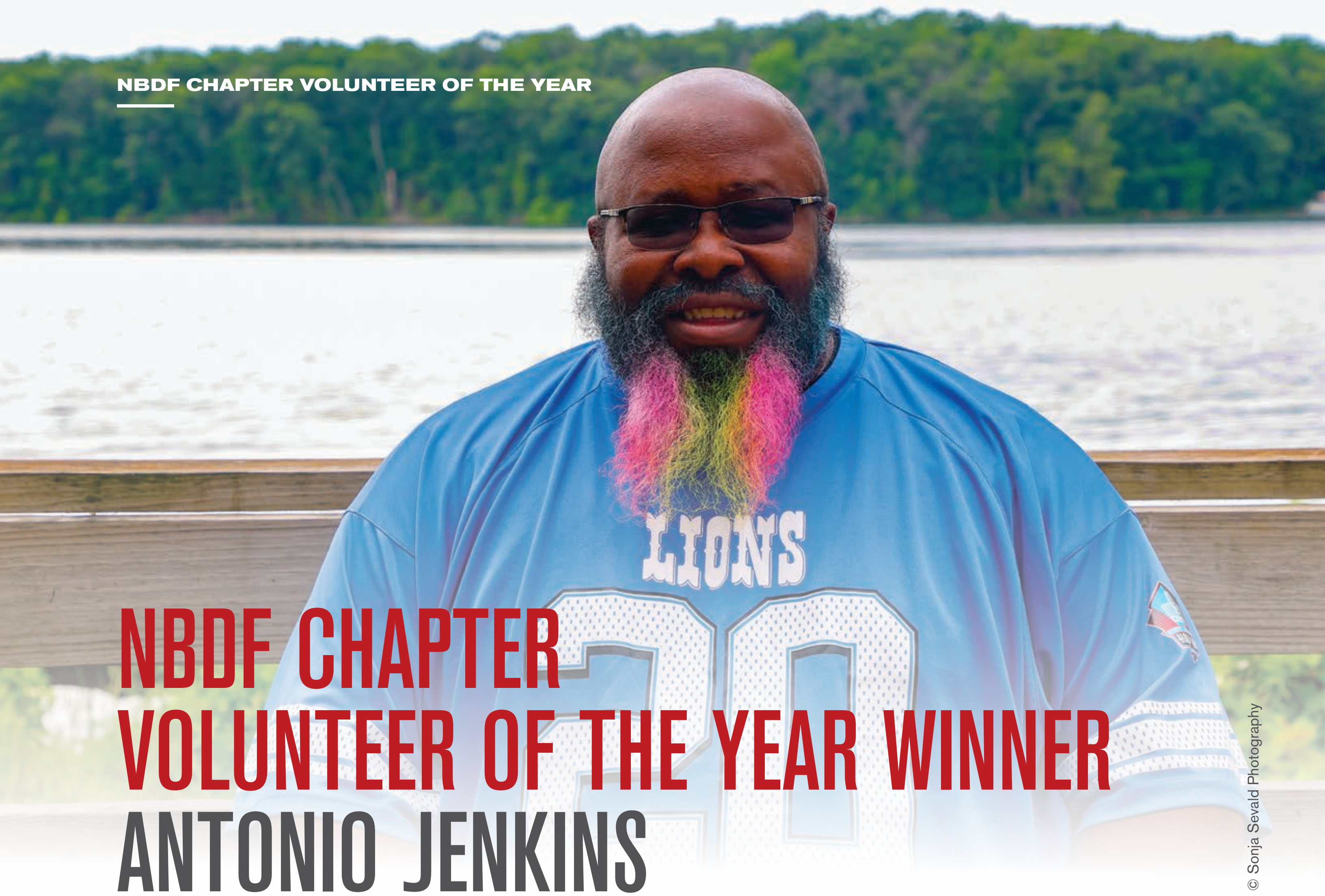
Lynn Ray Allen's Lifetime Legacy award is almost an understatement when we consider the many ways that Lynn has supported individuals in the bleeding disorders community. Lynn held various roles at Camp Bold Eagle starting in 1970, including Counselor in Training, Indoor Recreation Director, and Cabin Counselor. In 1982, Lynn joined the board of the Hemophilia Foundation of Michigan and rose to become the President of the board. Lynn has been a longtime participant in Lansing Days to advocate for the community.

Thank you, Lynn, for all that you've done for the Michigan bleeding disorders community – your impact is truly immeasurable.



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NBDF CHAPTER VOLUNTEER OF THE YEAR WINNER

ANTONIO JENKINS

HFM wants to congratulate Antonio Jenkins for receiving the National Bleeding Disorders Foundation's Chapter Volunteer of the Year Award! Antonio is a longtime volunteer with HFM, having been an involved member of the community since 1990. Each year Antonio volunteers as Santa for our End of the Year Community Gathering, greeting attendees and having families take photos with "Santonio."

Antonio has also been an essential part of our Eagle Journeys Camping Programs, including as staff at our traveling camp, Eagle Outpost, and our residential camp, Camp Bold Eagle. He is always ready with new ideas, especially in camp program activities, and is a very important figure that both campers and staff look up to at Camp Bold Eagle. Outside of camp, Antonio has joined us as staff for both our Bleeder and a Buddy teen retreats, and our Spring teen retreats.

Antonio carries on the history of camp, dating back to the time when he attended as a camper. Despite the challenges that Antonio has faced, he continues to share his knowledge about the history of camp, traditions, and his experience with hemophilia with a smile on his face.

We are so grateful for Antonio's generosity, commitment to our youth, and service to our chapter. Congratulations Antonio for receiving this award and thank you for your years of selfless dedication to the bleeding disorders community!

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UPCOMING 2025 EVENTS

FOR MORE INFORMATION AND
OTHER UPCOMING HFM EVENTS,
PLEASE VISIT **HFMICH.ORG/EVENTS**

💻 Virtual
👤 In-person
(18+) 18 and older

October 3-5
National Conference for Women 👤
The Westin Detroit Metropolitan Airport

October 16
Blood Buds: Virtual Escape Room 💻 (18+)

October 17-19
Bleeder & A Buddy 👤
North Star Reach

October 23
Get to Know Your Insurance
(So That it Works the Best for You!) 💻

October 28
Ruby Connection 💻 (18+)

November 3
Men's Support Group 💻 (18+)

November 7
Community Night: Incredible Mo's 👤
Traverse City, MI

November 20
Blood Buds: Virtual Cards Night 💻 (18+)

November 25
Ruby Connection 💻 (18+)

December 6
Year End Community Gathering 👤
Troy, MI

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