

# FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION



## 2022 ISSUE #4

- P. 2 Ohio Dental Program, Youth Leadership (NYLI)
- P. 4-5 The Future of Research
- P. 6-7 Bleeding Disorder Awareness 5K
- P. 8 Gettin' In The Game
- P. 9 Women's Day
- P. 12-13 Fall Outing
- P. 14 Scholarship Recipient, AmazonSmile & Kroger Rewards
- P. 15 Medical ID's

The New Year is almost upon us, and we are preparing for a very special one. March 4th is our Annual Meeting and Volunteer Breakfast. This year we are thrilled to host at the beautiful Top of the Market in downtown Dayton. Afterward we will distribute tickets to Carillon Historical Park. This park has been a mainstay in Dayton since the 1940's, and its rich history is clearly on display. The park has continued to evolve, and we are excited to enjoy an afternoon reacquainting ourselves with this Dayton Gem.

Other memorable events for the year include the Casino Night, Family Fest at Scene 75 and Dayton Dragon's Game, The BDA 5K, Fall Outing, and Women's Day. In addition, we will hold several other events TBD. If you haven't participated in a SWOHF event, please consider joining us in 23. New friends and fun are just around the corner.

## SAVE THE DATE

- MARCH 4** Annual Meeting  
*Top of the Market & Carillon Historical Park Outing*
- MARCH 8-10** NHF Washington Days
- APRIL 13-16** HFA Symposium *Orlando*
- MAY 5** Cinco de Mayo Casino Night *Dayton Women's Club*
- JULY 7** Family Fest Weekend *Scene 75*
- JULY 8** Dayton Dragons Game
- AUGUST 17-20** NHF Bleeding Disorders Conference  
*Washington, DC*
- SEPTEMBER 16** Bleeding Disorder Awareness Walk  
*Rice Field, Miamisburg*
- OCTOBER 8** Fall Outing *Young's Dairy*
- NOVEMBER 11** Women's Day  
*The Golden Lamb, Lebanon*

**SOUTHWESTERN OHIO  
HEMOPHILIA FOUNDATION**  
3131 South Dixie Drive, Suite 103  
Moraine, OH 45439

P: (937) 298-8000  
www.swohf.org

F: (937) 298-8080  
joy@swohf.org

## ARE YOU ELIGIBLE FOR THE OHIO DENTAL PROGRAM COVERAGE?

**Who is eligible?** The Ohio Dental Program is open to all bleeding disorder patients in Ohio who have NO AVAILABLE dental coverage through any other source.

**Where does the plan coverage come from?** The Northern Ohio Hemophilia Foundation acts as the fiscal agent for all Ohio chapters and HTC's for the Ohio Dental Program. NOHF coordinates coverage with Delta Dental.

**What does it cost?** There is an annual \$25 per person enrollment fee for a person with a bleeding disorder and \$50 each for additional family members with a \$200 per family maximum. Each enrollee will also have a \$100 deductible due to the dentist for services over and above exams/cleanings. Each family has an annual maximum of \$300 out of pocket. The monthly premium costs will be paid out of grants that were written and supported by all Ohio Chapters and HTC's from Cascade Hemophilia Consortium and United Way Summit County.

**What is the coverage?** Two free cleanings per year per enrollee. Also includes \$1250 in services per enrollee.

**When can I sign up for coverage?** The applications are available year-round and placement in the program is done throughout the year based on availability. Contact your HTC or email [joy@swohf](mailto:joy@swohf) for more info. Call the program manager, Randi Clites, at 330-730-1259 for more information.



## YOUTH LEADERSHIP (NYLI)

### The next generation of leaders in the bleeding disorders community

**Are you ages 18-24 and a member of the bleeding disorders community, or know someone who is? Consider applying to the National Young Leaders Institute (NYLI) and become a part of the National Hemophilia Foundation's (NHF) next generation of leaders in this exciting two-year program.**

Anyone who has a blood or bleeding disorder – or anyone who has an immediate family member with a blood or bleeding disorder – and is 18-24 years of age are welcome to apply. (Applicants must graduate from high school no later than June 15, 2023).

Select applicants will interview with the NYLI applications committee in mid to late March 2023, and a final cohort will be announced in April 2023.

What are the benefits of joining NYLI? Members will make friends, memories, and build professional skills. Plus, NYLI members attend the annual Bleeding Disorders Conference and get an in-depth experience learning about how different departments at NHF support individuals with bleeding disorders. Many other opportunities, such as speaking engagements and participating in working groups, are also available.

**The NYLI section of NHF's website has more detailed information about the program [www.hemophilia.org/educational-programs/training/youth-leadership-nyli](http://www.hemophilia.org/educational-programs/training/youth-leadership-nyli) or you can reach out to NYLI Manager Heather Hicks at [hhicks@hemophilia.org](mailto:hhicks@hemophilia.org) if you have any questions!**



Do you know  
your **on-demand**  
**treatment** options  
for hemophilia A?



Stay informed of product choice by speaking with your doctor and learning more about a prescription treatment option by visiting **[OnDemandHemophiliaA.com](https://OnDemandHemophiliaA.com)**



# THE FUTURE OF RESEARCH

During the past year, members of the Southwestern Ohio Hemophilia Foundation (SWOHF) board and staff at Dayton Children's Hemostasis and Thrombosis Center have collaborated to develop the Clinical Research Series detailed in each edition of Factor Notes. The following articles have been published:

- ***Research in General, Types of Research, Phases***
- ***What to Expect in a Clinical Trial***
- ***The History of Research at Dayton Children's Hemostasis and Thrombosis Center***

In this edition, we will discuss, ***The Future of Research including Gene Therapy.***

## GENE THERAPY: AVAILABLE

### HEMGENIX (ETRANACOGENE DEZAPARVOVEC)

Recently the treatment of gene therapy to treat hemophilia B (congenital factor IX deficiency) has been approved by the U.S. Food & Drug Administration (FDA). Hemgenix (etranacogene dezaparovec), an adeno-associated virus vector-based gene therapy, is available for the treatment of adults with hemophilia B:

- who currently use factor IX prophylaxis therapy
- have current or historical life-threatening hemorrhage
- have repeated, serious spontaneous bleeding episodes (FDA, 2022)

“Gene therapy for hemophilia has been on the horizon for more than two decades. Despite advancements in the treatment of hemophilia, the prevention and treatment of bleeding episodes can adversely impact individuals' quality of life,” said Peter Marks, M.D., Ph.D., director of the FDA's Center for Biologics Evaluation and Research (FDA, 2022). Thus, this newly approved hemophilia B treatment is considered a major advancement for those seriously affected by Hemophilia B. Cost constraints are being evaluated as the one-time infusion of Hemgenix is priced at \$3.5 million dollars (Drugs, 2022). How payors will handle this cost remains a significant question.



## TREATMENTS FOR HEMOPHILIA ON THE HORIZON

When asked to describe treatment options for hemophilia or other rare blood conditions that are not FDA approved, but are anticipated within the next year, Steven W. Pipe a professor of pediatrics and pathology at the University of Michigan, Ann Arbor and medical director of the Pediatric Hemophilia and Coagulation Program, answered the question by reviewing the history of hemophilia treatment and how that history led to the types of treatment options being studied (AJMC, 2022).

The functional problem facing those with hemophilia is risk for bleeding, not just into soft tissues but primary joints. Those affected deal with the temporary pain of swelling to the development of severe hemophilic arthropathy and major disabilities. A breakthrough in the treatment of hemophilia occurred with the introduction of clotting factor in the 1970s. This factor was made with human plasma obtained from donors. Many patients contracted the human immunodeficiency virus (HIV) and/or hepatitis B/C from this early factor. Methods to make the factor safe and clinical trials to develop new ways to make factor were successful. In the 1990s, a recombinant version of both factor VIII and factor IX was developed which allowed future improvements of the molecule. These improvements included extended half-life concentrates, which stay in one's circulation longer. However, infusions generally must be given at least weekly, and the intravenous (IV) infusion process remains a huge burden. The complicated IV access is the only route of administration.

Dr. Pipe acknowledges that one of the greatest innovations he experienced in his time caring for patients as their hematologist has been the availability of a new substitution therapy for factor VIII. Efficizumab, a bispecific antibody, substitutes for the clotting function of factor VIII in the body. This medication can be given subcutaneously, and dosing is once weekly, once every two weeks, or sometimes even

monthly. "The lower burden of administration has really transformed the lives for patients" according to Dr. Pipe (AJMC, 2022).

Another category of treatments for hemophilia is termed **hemostatic rebalancing agents**. The blood clotting system can be viewed as a balance between procoagulants and anticoagulants. If an anticoagulant is missing, one has hemophilia. It makes sense to target a procoagulant, but the rebalance can also occur by targeting the natural anticoagulants. There are three natural anticoagulants in one's blood clotting system. They are antithrombin, activated protein C, and tissue factor pathway inhibitor (TFPI). Each of these natural anticoagulants has a biologic target that's being investigated in the clinics. By either neutralizing those functions or knocking down their activity or the levels, it shows a rebalancing of the hemostatic system. Such treatments are being explored in hemophilia. Studies are showing that these can be effective prophylactic agents, even without giving factor VIII or factor IX.

The other beauty of this class of agents is they work on the natural anticoagulants, they are effective for patients with hemophilia A, hemophilia B, with or without inhibitors. It's like a cross-platform type of therapy. According to Dr. Pipe "If these get approved, these will also have the advantages of subcutaneous delivery, steady state hemostatic effect, and long duration, so the intensity of the burden of administration will be quite low" (AJMC, 2022).

Gene therapy trials are ongoing with outcomes being positive. Patients who have received gene therapy have shown sustained increase of factor VIII or factor IX, but more research is needed as to the longevity of these treatments. It is important to look at all the options, the side effects, and the goals of the patient with hemophilia to assess whether the research study is appropriate. Jordan Wright, MD, director of Dayton Children's Hemostasis and Thrombosis Center would love to discuss some of the options at your next comprehensive visit.

### References

**Dr Steven Pipe: What to Watch for in the Hemophilia Therapy Pipeline**

<https://www.ajmc.com/view/dr-steven-pipe-what-to-watch-for-in-the-hemophilia-therapy-pipeline>

**A Gene Therapy for Hemophilia, Hemgenix, That Costs \$3.5 Million Gets FDA Approval**

<https://www.drugs.com/news/gene-therapy-hemophilia-hemgenix-costs-3-5-million-gets-fda-approval-109171.html>

**FDA Approves First Gene Therapy to Treat Adults with Hemophilia B**

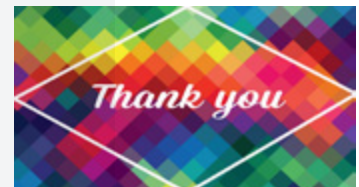
<https://www.fda.gov/news-events/press-announcements/fda-approves-first-gene-therapy-treat-adults-hemophilia-b>



# BLEEDING DISORDER AWARENESS 5K

September 18, 2022 was a great day for the 12th Annual Bleeding Disorder Awareness 5K. Over 120 individuals participated raising their own quality of healthy living, as well as, increasing awareness of how bleeding disorders affect individuals and families. Individuals walked and ran, virtually at their own chosen location or in person at Rice Field/ Greater Miami Valley Metro Park bike path. Beautiful weather and an atmosphere of comradery among individuals participating blessed the event. The 12th Annual BDA 5K raised over \$16,300. Funds go directly to support the vision and mission of the Southwestern Ohio Hemophilia Foundation. We appreciate everyone who participated and donated to make this day a great success.

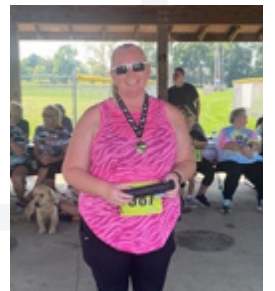
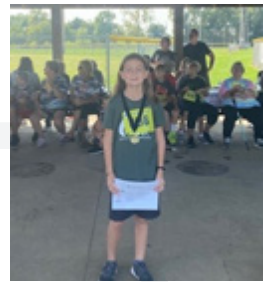
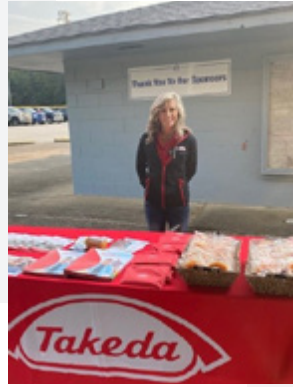
Medals and prizes went to overall first place winners male and female and for six age categories. Times and effort were impressive! Congratulations to George Carlson (24:06:1) and Carly MacClennan (29:05:3) the overall 1st place winners.



A special thank you to the sponsors of the event: Takeda, Novo Nordisk, Bayer, Butler Heating and Air Conditioning, CSL Behring, Octapharma, Martin Welding, Elite Iron, Environmental Doctor, Arpp, Root & Carter Funeral Home, Vintage Bliss, Groceryland of New Lebanon and Heavenly Touch Cleaning.

Thank you to the volunteers: Steve Brown, Carolyn Brown, Teresa Howard, Sheri Neaves, Katie Justice, Larry Justice, Suzi Justice, Betty Wyatt, Denise Croley, Angie Hicks, & Barry Linder.





# GETTIN' IN THE GAME

## JUNIOR NATIONAL CHAMPIONSHIP



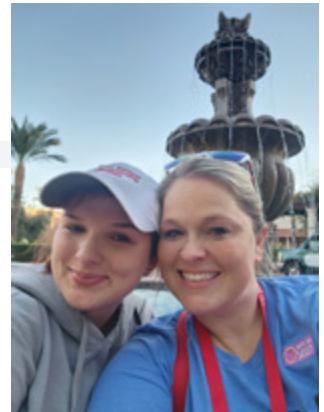
October 27–30, 2022 Phoenix, Arizona

Congratulations to ALL participants in the 20th Annual Gettin' in the Game Junior National Championship! You should be very proud of your achievement in representing your chapter in this time-honored event. We hope that you will take this experience with you as you continue to "Stay in the Game." We would also like to recognize and thank all the bleeding disorders chapters who partnered with us! Thank you for your dedication and commitment in helping us promote education and physical fitness within the community.

Allie Shawen was our SWOHF representative for the 2022 CSL Junior National Championship Gettin in the Game sponsored by CSL Behring. She was accompanied by her mom, Amber Guy, who expressed her gratitude for being able to attend this event which was filled with so much information and support. The event had lots of information for caregivers and patient care. Allie participated in the baseball competition and was able to build bonds with another child from Ohio. Allie was so excited and extremely grateful to have had this experience.

Developed by CSL Behring, the Gettin' in the Game (GIG) Junior National Championship (JNC) was the first and currently only national sports competition designed specifically for the bleeding disorders community. The program gives children with bleeding disorders an opportunity to learn golf, baseball and swimming and provides education and information-sharing opportunities for participants and their parents/caregivers.

- More than 50 children and their caregivers representing 54 chapters across the country, traveled to Phoenix, Arizona on October 27–30, 2022 to participate in this annual event.
- Attendees learned the fundamentals of baseball, golf, or swimming, participated in friendly competition, and connected with their peers. Educational seminars focusing on the importance of physical fitness and other related topics were provided on site.
- At the conclusion of the JNC, each child was recognized for his or her participation and the champions were announced.





# WOMEN'S DAY

We were so grateful and fortunate to have Anna Bell, LISW to attend our Women's Day event this past November. Her Intentional Messages of Taking Care of You, and Mind Body Heart just simply resonated with the room. The day was capped off with a Creative Memories Card Class and welcoming the Holidays at the Lebanon Girls Night Out Event. This event isn't to be missed!

**SAVE THE DATE—NOVEMBER 11, 2023**

## COMMENTS FROM SOME OF OUR GUESTS

*The topic was personal and easy to implement.*

*Fantastic Speaker!*

*Loved the Humor.*

*Ms. Bell's knowledge and experience really made it sink in!*

*Very Talented and informative speaker with an appropriate message for a female audience.*

*Would not change a thing.*

*Useful info for emotional health, tips, advice, self-reflection.*

*Self-care knowing I'm worth it.*

*Tips to deal with stress, thought reframing.*

*The day was perfect!*



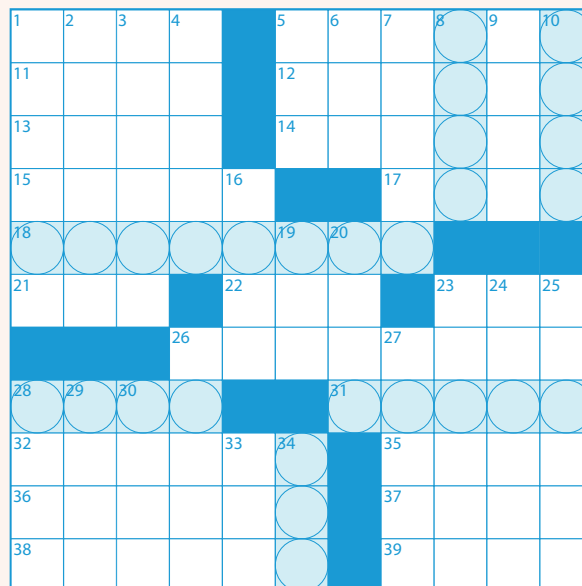
CK Colburn Keenan Foundation, Inc.

CAN YOU SOLVE

# FOR A DIFFERENT HEMOPHILIA A

TREATMENT?

Test your HEMLIBRA knowledge



## ACROSS

1. Wine barrel
5. Deep fissures
11. Mideast gulf port
12. District
13. Ripped
14. Familiar with
15. Mean
17. Roost
18. The #1 prescribed prophylaxis for people with hemophilia A without factor VIII inhibitors\*

\*According to IQVIA claims data from various insurance plan types from April 2020 - May 2021 and accounts for usage in prophylaxis settings in the US.

21. Calendar divs.
22. Regret
23. Banquet hosts (abbr.)
26. International travel necessity
28. Check out the \_\_\_\_\_ treated bleeds data with HEMLIBRA
31. Number of dosing options HEMLIBRA offers

†Number of people with hemophilia A treated as of October 2021.

32. Small hole in lace cloth
35. Central Plains tribe
36. Melodic
37. Towering
38. Reduce
39. Spanish cheers

## DOWN

1. Memorable, as an earworm
2. Devotee
3. Medical fluids
4. Prepare to propose, perhaps
5. PC's "brain"
6. Owns
7. Concert venue
8. See Medication Guide or talk to your doctor about potential \_\_\_\_\_ effects
9. Winter hrs. in Denver and El Paso
10. HEMLIBRA is the only prophylactic treatment offered this way under the skin

16. Pre-Euro currency in Italy
19. Subway alternative
20. Relax
23. Human
24. New Orleans cuisine
25. Mentally prepares
26. Collared shirts
27. Instagram post
28. Ardent enthusiasm
29. Brontë heroine Jane
30. Old Portuguese coins
33. Opposite of WNW
34. More than \_\_\_\_\_ thousand patients have been treated with HEMLIBRA worldwide†

## SOLUTIONS

Across: 1. cask; 5. chasms; 11. Aden; 12. parish; 13. tore; 14. used to; 15. cruel; 17. nest; 18. HEMLIBRA; 21. yrs; 22. rue; 23. MCS; 26. passport; 28. zero; 31. three; 32. eyelid; 35. Oreo; 36. anise; 37. tall; 38. lessen; 39. oles  
Down: 1. catnip; 2. adorer; 3. serums; 4. kneel; 5. CPU; 6. has; 7. arena; 8. side; 9. MSTs; 10. shot; 16. lira; 19. bus; 20. rest; 23. moral; 24. Creole; 25. steels; 26. polo; 27. photo; 28. zeal; 29. Eyre; 30. Reis; 33. ESE; 34. ten

Discover more at [HEMLIBRA.com/answers](https://www.hemlibra.com/answers)

## 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

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



**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 (eg, 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,  
1 DNA Way, South San Francisco, CA 94080-4990  
U.S. License No. 1048

HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan  
©2021 Genentech, Inc. All rights reserved.

For more information, go to [www.HEMLIBRA.com](http://www.HEMLIBRA.com) or call 1-866-HEMLIBRA.  
This Medication Guide has been approved by the U.S. Food and Drug Administration  
Revised: 12/2021



HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.  
The HEMLIBRA logo is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.  
The Genentech logo is a registered trademark of Genentech, Inc.  
All other trademarks are the property of their respective owners.  
©2022 Genentech USA, Inc. All rights reserved. M-US-00011998(v2.0) 03/22

**Genentech**  
A Member of the Roche Group

# FALL OUTING

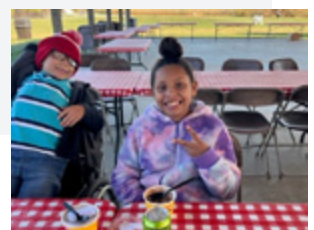


Once again Young's Dairy was the place to be this past October. It was truly a beautiful autumn day for a picnic with so many friends from our community. Thanks to all of our sponsors! Accredo, Bayer, BIOMARIN, CSL Behring, CVS/specialty, Cascade Hemophilia Consortium, Genentech, HEMA Biologics, NovoNordisk, Octapharma, Parago Healthcare, Pfizer, Sanofi Genzyme, Takeda and The Dayton Childrens HTC Staff. Special thanks to Donna Caires, our speaker.





## 2022 SWOHF FALL OUTING SPONSORS



**RECIPIENT OF  
2022 BRAD MILLER  
MEMORIAL SCHOLARSHIP  
PATRICK TOLLER**

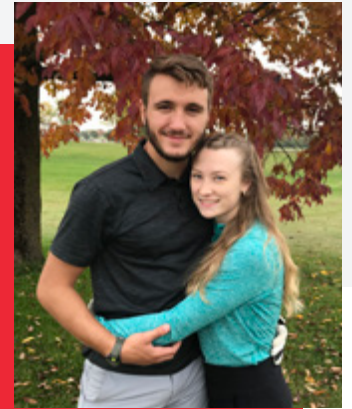
This year the amount of the Brad Miller Memorial Scholarship was raised to \$2000 and was awarded by the SWOHF Board to Patrick Toller who is attending Wright State University pursuing a degree in Organizational Leadership.

Patrick's end goal is to one day own his own business. He sees business relationships as a great way to spread awareness of hemophilia for an entire city, state, or country depending on how large the business gets.

Having been diagnosed with hemophilia as a child, he is grateful to have met medical staff who have always been encouraging to him. As a child and teen, he especially enjoyed going to camp and getting to know camp leaders. Patrick states, "These people come to camp talking about how they change the world every day at their jobs which is something I've always wanted to do."

He also wants to impact the next generation of children with bleeding disorders and these are his wise words: "One thing I would like to share to the younger generation is don't let your bleeding disorder limit your options, especially with athletics. You can accomplish any goal. You can always make yourself better. If you want to remain healthy your entire life, then stay in motion. Things that stay in motion remain in motion. Continue to make yourself a better human being every day. Ask yourself: did you make yourself better today? If not, then you lost today, and we don't have very many days to lose."

Certainly when thinking of Brad Miller, we cherish memories from the past. It is clear from Patrick's goals, we are also looking to the future. Providing financial assistance to a deserving student with a bleeding disorder is a way to remember Brad and honor his legacy for years to come. If you have a bleeding disorder and plan to attend college or trade school after high school, watch your email next spring or check our website for more information about the application process and requirements.

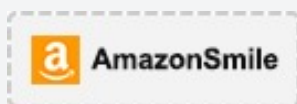


## AMAZONSMILE

If you are an Amazon shopper, please consider supporting SWOHF every time you purchase from Amazon through AmazonSmile.

To shop at AmazonSmile simply go to [smile.amazon.com](https://smile.amazon.com) from the web browser on your computer or mobile device. Search "Hemophilia" and scroll down to find Southwestern Ohio Hemophilia Foundation or type in "Southwestern Ohio Hemophilia" and select SWOHF as your charity.

**TO SUPPORT SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION, ALWAYS SHOP AT SMILE.AMAZON.COM**



*Bookmark AmazonSmile*

**Create a bookmark** or shortcut to [smile.amazon.com](https://smile.amazon.com) and always start your Amazon search by typing in [smile.amazon.com](https://smile.amazon.com)



## KROGER COMMUNITY REWARDS

Did you know you can support our SWOHF community just by shopping at Kroger? It's easy when you enroll in Kroger Community Rewards! To get started, sign up at [krogercommunityrewards.com](https://krogercommunityrewards.com) with your Kroger Plus Card and enter our number **#78558** as your organization.

Once you've enrolled, you'll earn rewards for SWOHF every time you shop at Kroger and use your Plus Card!

Kroger is committed to helping our communities grow and prosper. Year after year, local schools, churches and other nonprofit organizations earn millions of dollars through Kroger.



# MEDICAL ID'S

In collaboration with Dayton Children's HTC, SWOHF has recently switched to a new provider for our Medical ID's. We are happy to announce our partnership with American Medical ID. They offer a great variety of quality products at a discount to Chapters. Additionally, their Customer Service is exceptional, their shipping is fast and their prices are significantly less than MedicAlert (our previous supplier).

Free products are included with every order: An emergency medical ID card, a small ID charm and an exclusive engraved rectangular "InCase" phone ID that easily attaches to your cellphone case or any flat object, such as a suitcase, briefcase or laptop.

SWOHF is grateful for grant funding and donations that facilitate these purchases on behalf of our Greater Dayton Bleeding Disorders Community. So when you go to the HTC for your next visit, you can view sample products available and complete a form to request a new bracelet or necklace according to Chapter guidelines.



[Phone not included]



JOY@SWOHF.ORG



3131 SOUTH DIXIE DRIVE, SUITE 103  
MORAIN, OH 45439



937-298-8000



## CONTACT US

WE WANT TO HEAR FROM YOU!

### MISSION STATEMENT

SWOHF helps improve the quality of life for those affected by hemophilia, von Willebrand disease, and other bleeding disorders by providing support education, networking, advocacy, and services to individuals, their families and the community.

### EXECUTIVE DIRECTOR

Joy Linder

### DISCLAIMER

*The material provided in Factor Notes is for your general information only. SWOHF does not give medical advice or engage in the practice of medicine. SWOHF under no circumstances recommends particular treatment for specific individuals, and in all cases recommends that you consult your physician or treatment center before pursuing any course of treatment.*

Southwestern Ohio Hemophilia Foundation  
3131 South Dixie Drive, Suite 103  
Moraine, OH 45439

