FACTOR NOTES

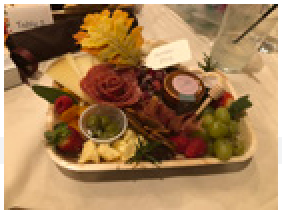
BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

2021

ISSUE #4

WOMEN'S DAY … OH WHAT A DAY!

It was such a DELIGHTFUL reunion as over forty of our SWOHF ladies reconnected over good food and friendship. The Golden Lamb was once again *le resto de choix* for this lovely gathering. We checked all the boxes for a fantastic day! Jenny Bostater, our guest speaker and mother of a son with a bleeding disorder, shared their very personal journey. Beginning with the discovery of diagnosis, connecting with the community, and now advocating and supporting others in their journey. Afterward we enjoyed a delicious lunch and learned how to make our very own yummy charcuterie boards. Can anyone say salami roses? Finally, we shopped till we dropped at the Lebanon *Girls Night Out*. It was truly a joyous occasion, and we are so excited to make plans for next year. Special thanks to Cascade Hemophilia Consortium and the Keenan Colburn Foundation for making this event possible.



SOUTHWESTERN OHIO
HEMOPHILIA FOUNDATION
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Moraine, OH 45439

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www.swohf.org joy@swohf.org

2022 EVENTS

SWOHF 2022
ANNUAL MEETING
NEW LOCATION!

JOIN US for
breakfast!

MARCH 2022

NHF Washington Days VIRTUAL
Tuesday-Wednesday, March 1-2

SWOHF Annual Meeting
Saturday, March 5
The GEM
Dayton OH

APRIL 2022

HFA Symposium
Wednesday-Saturday, April 20-23
San Antonio, TX

MAY 2022

SWOHF Fundraiser (TBD)

JULY 2022

SWOHF Family Fest
Friday-Sunday, July 8-10
Higher Ground Retreat Center
West Harrison, IN

AUGUST 2022

FAMOHIO Annual Conference
Friday-Sunday, August 5-7
Columbus Marriott (TBD)
Columbus, OH

NHF Bleeding Disorders Conference
Thursday-Saturday, August 25-27
Houston, TX

SEPTEMBER 2022

SWOHF Bleeding Disorders Awareness 5K
Saturday, Sept 17 (TBD)
Rice Field
Miamisburg, OH

OCTOBER 2022

SWOHF Fall Outing
Sunday, October 9 (TBD)
Young's Dairy
Yellow Springs, OH

NOVEMBER 2022

SWOHF Women's Day Together
Saturday, November 12 (TBD)
The Golden Lamb Inn
Lebanon, OH

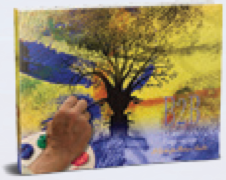
DECEMBER 2022

Teens Event (TBD)

Check swohf.org or the newsletter for updates!

Emotional Wellness as a Mature Adult:

Discussing the Unique Challenges of Living With Hemophilia



For more information, visit b2byourvoice.com to download *Learn from Experience: A Guide for Mature Adults.*

This content is brought to you by Pfizer.

How Hemophilia Affects Mature Adults

Mature adults may look back and recognize how living with hemophilia has influenced who they are today. Persevering through the challenges of being a child diagnosed with hemophilia when less was known about the condition, and navigating the issues of being a young adult with a bleeding condition can shape one's perspective. Knowledge and wisdom are some of the benefits that accrue with age, but along with these can also come additional health concerns such as high blood pressure, diabetes, and arthritis; depression and stress; and financial planning and retirement concerns. For those who have lived with hemophilia for many decades, the task of managing these concerns of older age may seem to be less important. However, there are some key points to keep in mind when addressing the effect hemophilia can have on mental health.

The Risk of Clinical Depression

Mature adults living with hemophilia typically have experienced substantial challenges related to their disease throughout their lives. In some instances, hardships may contribute to the development of clinical depression, which is more common among people living with hemophilia than the general population. The results from one study conducted at a hemophilia treatment center showed that 37% of a sample of patients met the criteria for depression. Of that 37%, 20% had moderate to severe symptoms, and 66% reported having functional impairment due to their depressive symptoms.[1] The authors of the study concluded that the comprehensive care of adults with hemophilia should include depression screening for the potential to improve overall health outcomes.[1]

Education and support for people living with bleeding disorders and their families is one component of managing psychological wellness. Having control over life decisions and self-advocacy can also be important. For some living with hemophilia, past experiences may serve as a motivator to continue to work toward personal objectives. Others may find the journey more difficult to navigate. Self-help seminars and support groups are some of the resources that may help adults set and attain realistic goals.

> "[A reminder to] older adults that there is always somewhere to turn, even in times of immense hardship. All you need to do is ask, and you should never feel ashamed for doing so."
>
> — Judy Bagato
>
> RN, BSN, Hemophilia Specialist

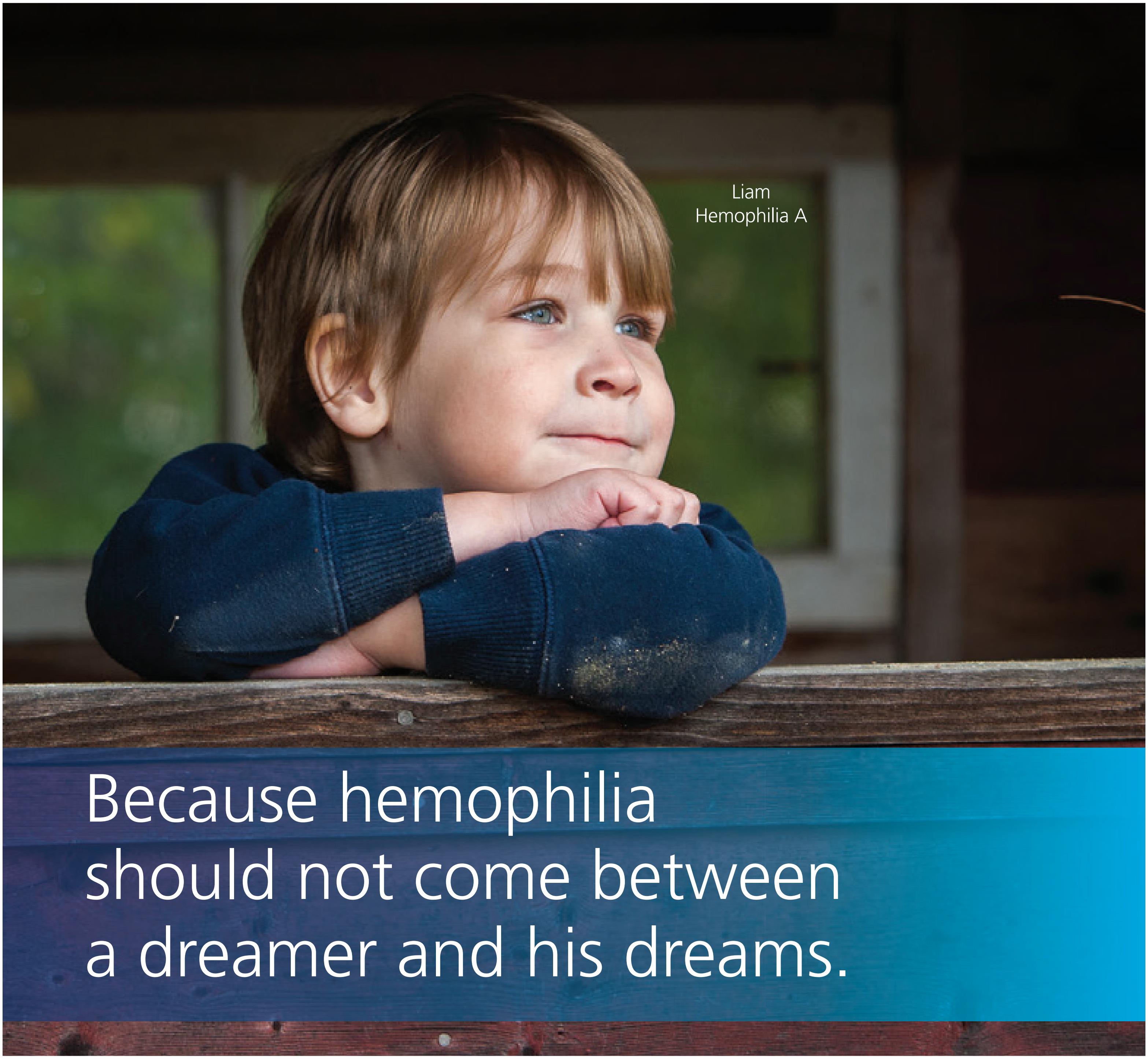
Finding Support for Complex Issues

For people who acquired human immunodeficiency virus (HIV) and/or hepatitis C (HCV) from virally contaminated blood products, there may be feelings of anger and resentment. The adversity caused by a lack of family or social support during younger years or changes later in life, such as changes in one's capacity for employment or altered family dynamics, may also contribute to these feelings. Learning effective ways to cope with the stresses of living with hemophilia in older age may help an individual to be resilient to these challenges. If you are experiencing stress that is affecting your day-to-day outlook, it is important to seek help. Reach out to your treatment team to discuss your situation and learn about what help and support may be available.

Reference: 1. Iannone M, Pennick L, Tom A, et al. Prevalence of depression in adults with haemophilia. *Haemophilia.* 2012;18:868-874. doi: 10.1111/j.1365-2516.2012.02863.x.

PATIENT AFFAIRS LIAISONS

Patient Affairs Liaisons are Pfizer employees who are dedicated solely to providing support to the community. Your Pfizer Patient Affairs Liaison is available to help you access the support and information you need. To find your Patient Affairs Liaison, go to hemophiliavillage.com/support/patient-affairs-liaison-finder or call Pfizer Hemophilia Connect at 1.844.989.HEMO (4366).


Liam
Hemophilia A
Because hemophilia should not come between a dreamer and his dreams.

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Change the way you picture living with Glanzmann's thrombasthenia

Novo Nordisk is changing the way people like Cathy write their stories

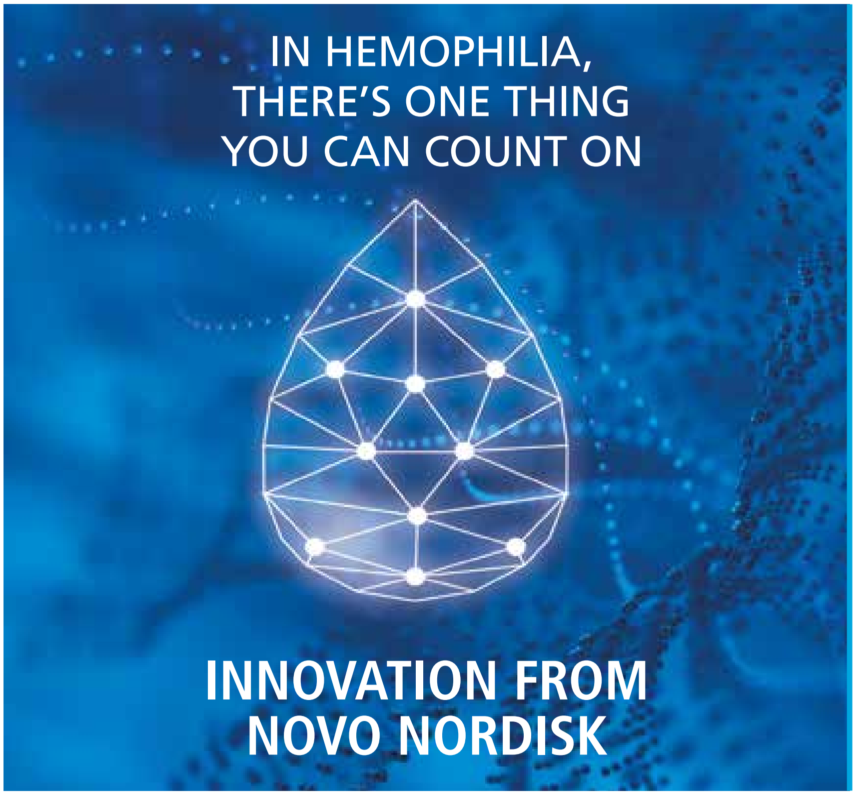
That's why we are continuously seeking new ways to help support and educate the bleeding disorders community. Because, at Novo Nordisk, we're always committed to helping you make your potential possible.

Connect with us at Facebook.com/ChangingHemophilia

Cathy has Glanzmann's thrombasthenia with refractoriness to platelets.

changing hemophilia®

novo nordisk®



We strive to help improve the lives of people with hemophilia

For 30 years, Novo Nordisk has been a driving force for people living with rare bleeding disorders. We take pride in striving for innovative solutions to help improve patients' lives. This motivates us to uphold the highest standards in our product research and development. This vital research is just the beginning of our commitment in hemophilia.

We will continue our research and connect with people with hemophilia and health care professionals to ensure we understand and respond to the specific needs of the hemophilia community.

With a rich history, Novo Nordisk remains at the forefront of discovery. We are poised to continue to develop innovative solutions that can help improve the lives of people with hemophilia in the future.

Please visit www.rarebleedingdisorders.com or find us on Facebook at www.facebook.com/cpih.us.

changing hemophilia™

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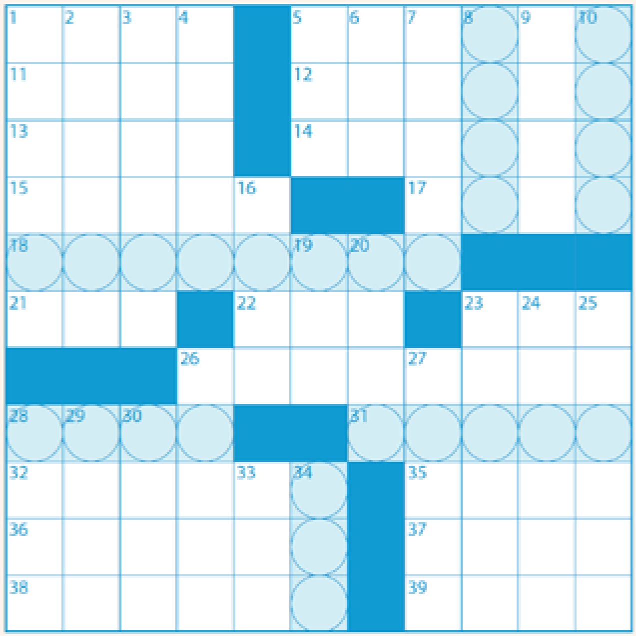
CAN YOU SOLVE

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 hemophilia A*

*According to IQVIA claims data from various insurance plan types from October 2019 to November 2020 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
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. _____ 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. eyelet,
35. Otoe, 36. ariose, 37. tall, 38. lessen, 39. oles
Down: 1. catchy, 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. mortal, 24. Creole,
25. steels, 26. polos, 27. photo, 28. zeal, 29. Eyre,
30. Reis, 33. ESE, 34. ten

[†] Number of people with hemophilia A treated as of February 2021.

Discover more at 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.**

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.

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

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: 10/2018

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

Genentech
A Member of the Roche Group

2021 5K

3.23
Miles

22'26" Avg. Pace
1:12:31 Time
159 Calorie

178 ft Elevation ain
-- ♡ Avg. Heart Rate
105 Cadenc

WINNERS

OVERALL

Female - Mollie Courtney
Male - James MacClennan

AGE 60 AND OLDER

Female - Melodie Eads
Male - Grant Donaldson

AGE 50-59

Female - Angie Suggs
Male - Matt Sampson

AGE 40-49

Female - Amanda Koch
Male - Curt Rupp

AGE 30-39

Female - Jen Rupp
Male - Jack Griner

AGE 20-29

Female - Carissa Smith
Male - Anthony Whitaker

AGE 14-19

Gracie Vanover

AGE 10-14

Rachel MacClennan

AGE 5-9

Female - Carly MacClennan
Male - Jameson MacClennan

WE ARE BACK!

Thanks to everyone who participated in the 2021 Bleeding Disorders Awareness 5K. It was a perfect late summer weekend. Our deepest heartfelt appreciation to all who supported SWOHF we raised over $19,000!!! We couldn't do it without you. A special recognition to our board chair, Dena Shepard, for organizing this amazing event. Her tireless, year-round effort makes it go off seamlessly. We also want to give a shout out to the YOU MAKE A DIFFERENCE recipients Anthony Whitaker and Sheila Hobbs. How fortunate are we to count on your smiling faces. Truly you do MAKE A DIFFERENCE....Thank you!!!

THANK YOU
2021 SPONSORS!

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* * * * * * * * * * * *

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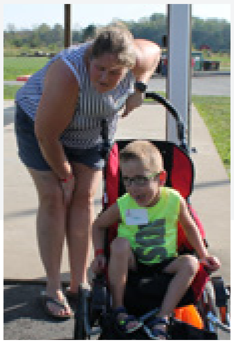
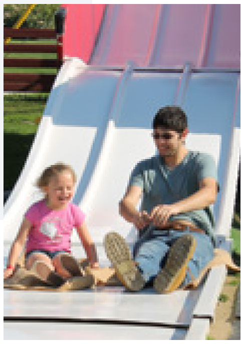
RE/MAX

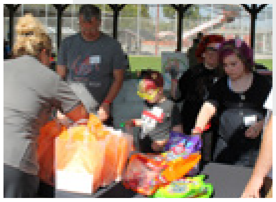
VINTAGE BLISS
EVENTS

FALL OUTING

It was such a sunny day at Young's Dairy Farm for the fall outing. The weather was matched only by the terrific company that attended and supported our Annual Autumn Shindig. Over 100 participants enjoyed the day and the farm festivities. The grub was delicious as always, and the homemade ice cream was icing on the cake. It was a glorious reunion with families, the HTC and SWOHF board staff. We all enjoyed Dr. Wright's talk on recent advancements in care and treatment of bleeding disorders. The feedback was so positive that we already have it on the calendar for next year. **SAVE THE DATE October 9, 2022!**







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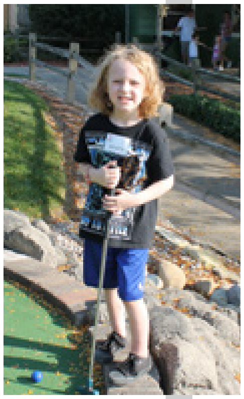

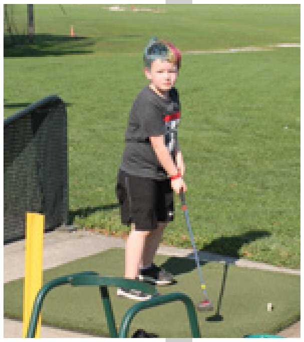

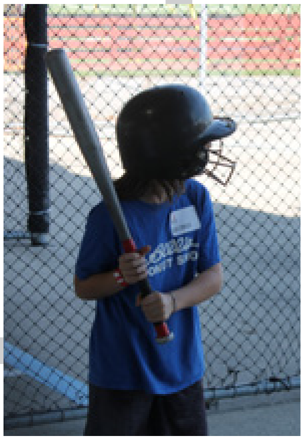

Judy Doyle

Patient advocate

About Judy

Judy is a Novo Nordisk Hemophilia Community Liaison with 18 years of experience supporting those with bleeding disorders. She loves the passion of the hemophilia community to get things done and not let things stand in their way.

Connect with Judy

JDDL@novonordisk.com
(216) 217-4197

Hemophilia Community Liaison

OH, IN

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ARE YOU ELIGIBLE FOR THE OHIO DENTAL PROGRAM COVERAGE?

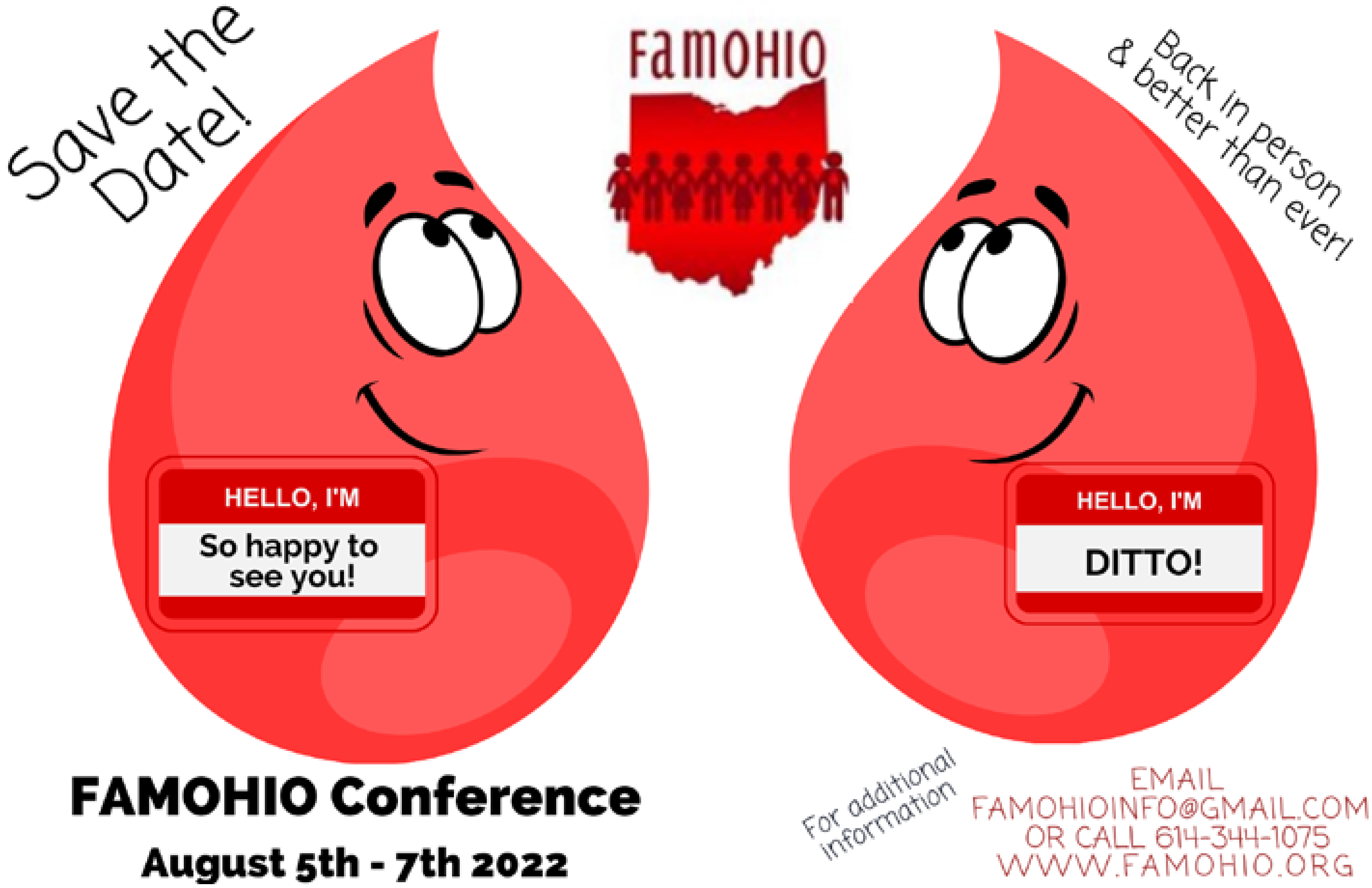
Who is eligible? The Ohio Dental Program is open to all bleeding disorder patients in Ohio who have NO AVAILABLE dental coverage through any other source.

Where does the plan coverage come from? The Northern Ohio Hemophilia Foundation acts as the fiscal agent for all Ohio chapters and HTCs 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 HTCs 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 for more info. Call the program manager, Randi Clites, at 330-730-1259 for more information.



Save the Date!

FAMOHIO

Back in person & better than ever!

FAMOHIO Conference

August 5th - 7th 2022

For additional information

EMAIL
FAMOHIOINFO@GMAIL.COM
OR CALL 614-344-1075
WWW.FAMOHIO.ORG

A **ONCE-WEEKLY** TREATMENT OPTION FOR HEMOPHILIA B.

HOW DOES
THIS FACTOR IN?

To find out about a prescription option, talk to your doctor or visit **OnceWeeklyForHemophiliaB.com**

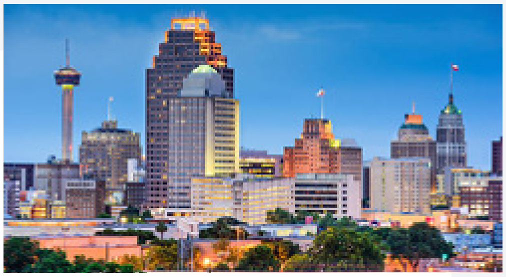
PP-HEM-USA-1424-01

February 2021

SWOHF TRAVEL SCHOLARSHIP APPLICATIONS AVAILABLE FOR HFA SYMPOSIUM 2022

Shine those boots and saddle up; HFA is heading to San Antonio for what is shaping up to be the biggest and best Symposium yet. Mark your calendars April 20-23, 2022, and plan to attend this in-person Symposium.

SWOHF is pleased to offer scholarship opportunities for travel to our national organization conferences. These scholarships are awarded by the SWOHF Board after review of all applications received. The scholarships are open to individuals in our community diagnosed with a bleeding disorder who live in the Greater Dayton area and are treated at Dayton Children's HTC or by a Dayton area hematologist. The scholarship is for one individual affected by a bleeding disorder and one immediate family member only.

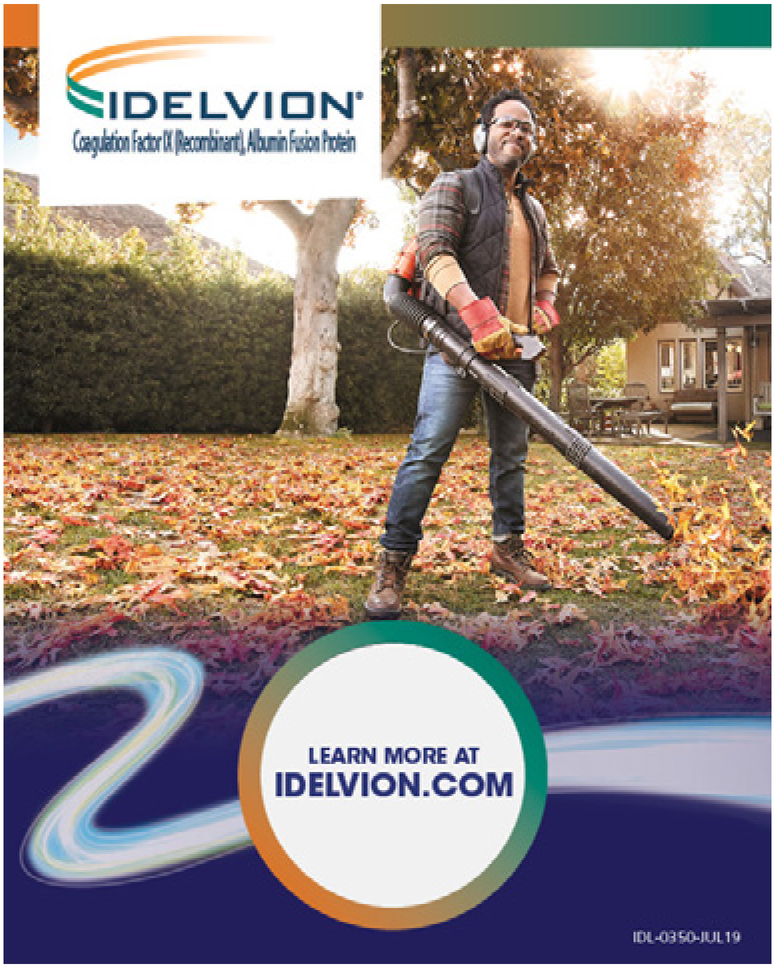


This scholarship award is intended to solely cover: Registration to the HFA Symposium; Airline Reservations and Hotel Accommodations. Before you apply, please be aware that there will be other costs to attend; for example: meals, taxi/shuttle, baggage, and other miscellaneous expenses. SWOHF is not responsible for any additional expenses of the trip.

Email joy@swohf.org for an application or more info. Check our website swohf.org under Resources to download a Travel Scholarship Application Form. Forms must be completed and submitted to SWOHF by the deadline indicated for Board review and decision notification. Not all applicants are awarded scholarships.

HEMOPHILIA FEDERATION OF AMERICA
SYMPOSIUM

APRIL 20-23, 2022 IN SAN ANTONIO, TEXAS



ADVOCACY

AD-VO-CATE

NOUN **- A PERSON WHO PUBLICLY SUPPORTS OR RECOMMENDS A PARTICULAR CAUSE OR POLICY.**

VERB **- PUBLICLY RECOMMEND OR SUPPORT.**

ADVOCACY IS A DECISION

1. Stay informed.
2. Practice your message.
3. Know what you are asking for.
4. Introduce yourself to lawmakers.
5. Identify your type of action.
6. Be honest.
7. Determine your story and how to tell it.
8. Be confident.
9. Network.
10. Offer yourself as a resource.
11. Learn about the community you represent.
12. Ask questions.
13. Document everything.
14. Follow up.
15. Use social media,

OHIO UPDATE

Our top priority remains passage of House Bill 135, which would prohibit the use of copay accumulator adjuster programs. Sponsored by State Representatives Susan Manchester (R-Lakeview) and Thomas West (D-Canton), the bill passed the Ohio House Health Committee unanimously in March and has been awaiting a floor vote since. There is some lingering concern among House leadership, though we are actively working to address their concerns and remain confident that HB 135 will become law before the end of next year when the 134th General Assembly comes to a close. Just behind our priority list is House Bill 153, which is aimed at stopping non-medical switching of drug coverage by health plans. The bill has received three hearings in the Ohio House Insurance Committee and conversations are occurring behind the scenes to get the bill moving out of committee. Once enacted, HB 153 would ensure that patient access to prescription drugs is not interrupted during a plan year due to non-medical reason, such as a change in the manufacturer rebate provided to the health plan.

Another bill we are hoping to see enacted in the 134th is House Bill 212, which is sponsored by State Representatives Mark Frazier (R-Newark) and Beth Liston (D-Dublin). HB 212 would expand eligibility for the Children with Medical Handicaps program under the Ohio Department of Health to age 26. HB 110, the State Operating Budget enacted earlier this year, included a temporary increase in CMH eligibility to age 23, however HB 212 is needed to ensure this is a permanent change. The bill passed the Ohio Families, Aging and Human Services Committee unanimously, but must also pass the Ohio House Finance Committee since it contains an appropriation. Finally, we are optimistic that legislation designating March as Bleeding Disorders Awareness Month will be enacted this year. Sponsored by State Representative Bride Sweeney (D-Cleveland), House Bill 185 passed the Ohio House of Representatives unanimously and has received an initial hearing in the Ohio Senate Health Committee. There are many other bills that we continue to monitor, though HB 135, HB 153, and HB 212 will be the most impactful to the population we serve.

On the Medicaid front, we are closely monitoring the Ohio Department of Medicaid's multi-year push to reform its managed care program. Under this new system, which will launch on July 1st, 2022, there will be seven statewide managed care plans for patients to choose: Anthem BCBS, AmeriHealth Caritas, CareSource, Buckeye Health Plan, Molina Healthcare, United Healthcare, and Humana. An open enrollment period will occur prior to July 1st for patients to change plans or to select a new plan if currently enrolled in Paramount. It is important to note that Paramount is currently in court attempting to overturn ODM's decision not to award them with a new contract. The new managed care system will also include a single statewide pharmacy benefit manager for all of Medicaid and a statewide fiscal intermediary that will serve as the sole point of contact for claims and prior authorizations. Gainwell Technologies will perform both of these roles. During the first half of 2022, we plan to meet with these vendors and ODM staff to prepare patients and providers for the transition.

WASHINGTON DAYS

SAVE THE DATE

NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

NHF's Washington Days is an opportunity for people affected by bleeding disorders to advocate for issues that are important to them. Washington Days 2022 will be a virtual experience. Washington Days programming will take place during the dates of March 1-4. More programming details will be announced soon. Contact joy@swohf.org or subscribe to SWOHF email updates for more information as the event approaches.

SWOHF RECEIVES BRONZE MEDAL

WFH
WORLD FEDERATION OF HEMOPHILIA

In honor of our commitment to support the hemophilia community around the world, SWOHF was recently presented with a Bronze Medal in the NHF Chapter Challenge by the World Federation of Hemophilia USA. This honor included recognition on October 21, 2021, at their US celebration of "Compassion in Action." SWOHF remains dedicated to transforming lives of those with bleeding disorders--not only in the Greater Dayton area, but around the world. We are grateful for this acknowledgment and join WFH in believing individuals with bleeding disorders are champions every day!

MEDICAL ID'S

American Medical ID

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]

COVID-19 and Hemophilia

Preparedness and Self-Care in a Pandemic

This information is provided for educational purposes only and is not intended to replace discussions with a health care provider. Speak to your treatment team if you have any questions about your/your child's care.

This content is brought to you by Pfizer.

The COVID-19 pandemic brought with it many lessons that can be carried into the future, including ones on preparedness, health care provider (HCP) communication, and self-care.

HCP Communication

Good communication with your hemophilia treatment center or care team can be an important part of living with hemophilia. During a pandemic, your team can help you understand possible risks based on your condition, as well as advise on treatment and vaccination.

Being prepared and proactive in hemophilia care[1]

One of the lessons of the COVID-19 pandemic is that it is important to be prepared, and that also applies to the hemophilia community. National Hemophilia Foundation's (NHF's) Medical and Scientific Advisory Council recommends:

- Having a 14-day supply of factor products available during crisis for those who treat at home
- If an ER visit is required, call in advance so staff knows you are coming and why; this will help them prepare
- Staying in contact with your doctor's office or hemophilia treatment center (HTC). They can explain what to do if you need to visit in person or can help get you connected with telehealth appointments, if available

Caring for yourself[2]

Events such as the COVID-19 pandemic can create uncertainty for many, which can stir up emotions such as anxiety, fear, anger, sadness, discouragement, or a sense of being out of control. Self-care is important to help you address these feelings. Here are a few tips you can use to take care of your mental health:

- Set and maintain a routine
- Focus on things you can control
- Use technology to maintain social connections with your loved ones
- Focus on reasons to be grateful
- Read books or listen to music
- Take a break from news and social media if it makes you anxious
- Look for ways to help your community
- Acknowledge and appreciate what others are doing to help

Further information

Many of the larger advocacy groups have sites to keep you in the know, see below:

- **The Coalition for Hemophilia B**
  hemob.org
- **Hemophilia Federation of America**
  hemophiliafed.org
- **Hope for Hemophilia**
  hopeforhemophilia.org
- **National Hemophilia Foundation**
  hemophilia.org
- **World Federation of Hemophilia**
  wfh.org

These websites are neither owned nor controlled by Pfizer. Pfizer does not endorse and is not responsible for the content or services of these sites.

Be sure to also inquire of your local chapter/advocacy organization and speak to your HTC's social worker for more information about available assistance programs.

References: 1. Supplemental MASAC statement regarding home delivery and refill under state of emergency declaration. National Hemophilia Foundation website. Published March 30, 2020. Accessed July 27, 2021. https://www.hemophilia.org/news/supplemental-masac-statement-regarding-home-delivery-and-refill-under-state-of-emergency-declaration **2.** Reichert S. Self-care tips during the COVID-19 pandemic. Mayo Clinic Health System website. Published April 7, 2020. Accessed March 30, 2021. https://www.mayoclinichealthsystem.org/hometown-health/speaking-of-health/self-care-tips-during-the-covid-19-pandemic

RARE DISEASE PATIENT AFFAIRS

Patient Affairs Liaisons are a team of non-sales, non-promotional field-based professionals. Pfizer's Patient Affairs Liaisons are dedicated to serving the rare disease community by connecting patients and caregivers with Pfizer Rare Disease tools, including educational resources, access support, and community events in your area.

Visit www.pfizerpal.com to connect with your Patient Affairs Liaison.

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To shop at AmazonSmile simply go to 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.

AmazonSmile

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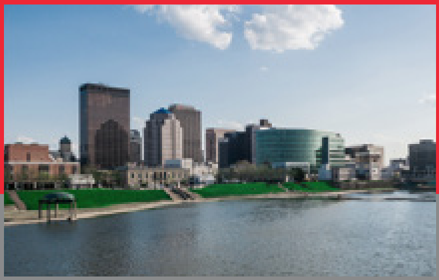
Did you know you can support our SWOHF community just by shopping at Kroger? It’s easy when you enroll in Kroger Community Rewards! To get started, sign up at krogercommunityrewards.com with your Kroger Plus Card and enter our number **#78558** as your organization. Once you’ve enrolled, you’ll earn 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.

Kroger community rewards

JOY@SWOHF.ORG



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SWOHF
SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

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.

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