

# FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

## VOLUNTEER OF THE YEAR!



2019  
ISSUE #2

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Congratulations to Julie Sampson SWOHF's 2018 Volunteer of the Year. Julie and her family have been involved with the SWOHF community since 2012. In 2018, Julie volunteered for our Casino Night, Family Fest and Golf Outing. She showed her support of SWOHF by attending the Annual Meeting, Fall Outing and Women's Day Together. Additionally, she is faithful to attend our industry-sponsored Community Education dinners throughout the year.

SWOHF counts on Julie's fundraising efforts to provide silent auction items and prize donations. She visits area businesses and personally asks managers for giftcards. She often gets a chance to tell her story as she interacts with the community.

Recognizing she has been given many blessings, Julie chooses to volunteer to GIVE BACK to the community. She wants to set a positive example for her family. She states, "We all have the basic emotional needs of wanting to be loved and cared for. And by volunteering, that example can be set in motion, along with personal actions."

Julie says:

*Especially in the world we live in today, we all need to support each other and make a difference - this is so important! I will not say it is always easy. But the outcome of your time outweighs everything else and should be a priority in our families. If you feel like you want to make a difference, then volunteer.*

**Julie has shown our community what personal strength and commitment looks like! We applaud her dedication!**

**SOUTHWESTERN OHIO  
HEMOPHILIA FOUNDATION**  
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**SATURDAY SEPTEMBER 21, 2019,  
10:00 A.M.**

**Rice Field - Bike Path  
2001 Dayton-Cincinnati Rd.  
Miamisburg, Ohio 45342**

Join the Southwestern Ohio Hemophilia Foundation on Saturday, September 21 at 10:00am for our annual 5K Walk/Run for Bleeding Disorder Awareness. Registration is just \$25 per person and includes bib, timed finish, and T-shirt. Come be a part of making a difference in the lives of those dealing with bleeding disorders as we walk or run our way to victory at the BDA 5K Walk/Run!

For more info, check our website or call the SWOHF Office at 937-298-8000.



# SAVE THE DATE

## 2019 CALENDAR OF SWOHF EVENTS

### JUNE

#### Family Fest

June 14-16  
Higher Ground Retreat Center  
West Harrison, IN

### Brad Miller Birdie Busters Golf Outing

Thursday, August 15  
Beavercreek Golf Club  
Beavercreek, OH

### OCTOBER

#### Fall Outing

Sunday, October 13  
Young's Dairy  
Yellow Springs, OH

### AUGUST

#### FAMOHIO

August 2-4  
Columbus, OH

### SEPTEMBER

#### Bleeding Disorders Awareness 5K

Saturday, September 21  
Rice Field  
Miamisburg, OH

### NOVEMBER

#### Women's Day Together

Saturday, November 9  
Golden Lamb Inn  
Lebanon, OH



## New name, **stronger commitment.**

Over the years, Baxalta and Shire have provided products and services that have stayed in step with the changing needs of the bleeding disorders community. And now as Takeda, we are committed to building on that legacy. We've got a new name, but our commitment to you is stronger than ever.

Alex  
Hemophilia A  
Massachusetts

[bleedingdisorders.com](http://bleedingdisorders.com)



Baxalta and Shire are  
now part of Takeda

# DEDICATION and PERSONAL SUPPORT

**Your Pfizer Patient Affairs Liaison** is a professional dedicated to serving you and the hemophilia community by connecting patients and caregivers with Pfizer Hemophilia tools and resources. We are committed to continuing Pfizer's more than 20 years of listening to the hemophilia community and working to meet its needs.



## Chris Liddell

Southern OH, MI, KY, IN

*"I've worked in rare disease for 15 years, and I have experience collaborating with and advocating for different members of this community."*



PATIENT  
AFFAIRS  
LIAISONS



248-660-7384 [chris.liddell@pfizer.com](mailto:chris.liddell@pfizer.com)

## MY WORK IS GUIDED BY:

### Compassion

Listening to your needs and addressing questions and concerns that you may have

### Commitment

Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more

### Connection

Connecting you with hemophilia advocacy groups and programs like Leading Edge, the National Hemophilia Foundation, the Coalition for Hemophilia B, and others

HemMobile is a registered trademark of Pfizer Inc.  
HemMobile is not intended for curing, treating, seeking treatment for, managing, or diagnosing a specific disease, disorder, or any specific health condition. Pfizer will not have access to any personal information you enter into HemMobile.



# FAMOHIO

## 2019 Conference

### August 2<sup>nd</sup> — 4<sup>th</sup>



Registration deadline is July 12, 2019. For more information, email Lisa at [FAMOhioInfo@gmail.com](mailto:FAMOhioInfo@gmail.com)

Register online at <https://www.eventbrite.com/e/famohio-2019-registration-61769494220>

### GOLF OUTING TO BENEFIT THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

Thursday, August 15 2019 at Beaver Creek Golf Club

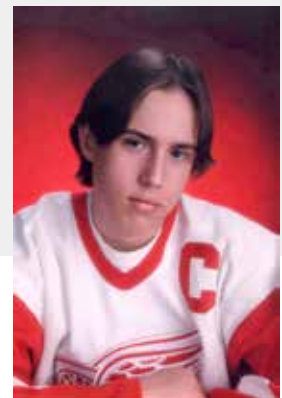
Shotgun Start at 1:00 p.m. with Dinner, Silent Auction and Awards following at 6:00 p.m.

In 2010, the Birdie Busters Golf Outing was renamed in memory of Brad Miller, a member of our hemophilia community who passed away at age 29 in October, 2008. Brad's short life was filled with many health challenges, all of which he faced with courage and strength. We fondly remember Brad's compassion for others and love for family and friends. Brad is the son of Richard and Mary Miller, long-time supporters of SWOHF and brother of Ellyn Miller.

## COMING THIS SUMMER!

Check the SWOHF  
website for more info  
and registration!

Even if you don't golf, tickets for our Italian dinner buffet are available for \$25. Lots of great silent auction items will be available! Don't miss out!



## THE BRAD MILLER BIRDIE BUSTERS

GO SEEK. GO EXPLORE.  
**GO AHEAD.**



Discover your sense of go. Discover HEMLIBRA®.

[HEMLIBRA.com](https://www.hemlibra.com)

#### 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. 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. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). 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.**

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.**

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

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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: 10/2018



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# SWOHF IS COUNTING ON YOU! GIVING IS AS EASY AS 1-2-3!

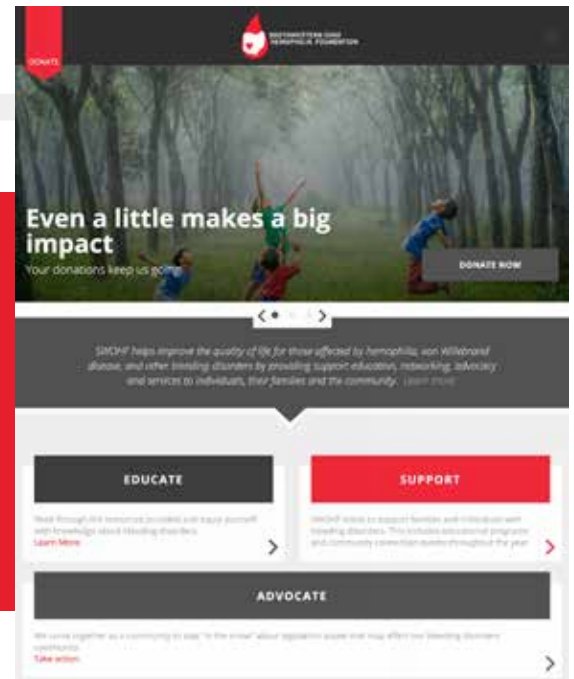
## 1 DONATE ONLINE

Now you can donate to the SWOHF easily and securely online at our website [swohf.org](http://swohf.org). Donations are processed through our Network For Good donor program.

### LINDA BONNER GIVES BACK

"I think that the SWOHF is a wonderful group. They were a great support to me when I didn't where to turn."

Linda recently made a donation online as she was registering to attend a SWOHF event!



## 2 SHARE ON FACEBOOK

To create a fundraiser for a charitable organization click here or follow these steps:

1. Click Fundraisers in the left menu of your News Feed.
2. Click Raise Money.
3. Select Nonprofit/Charity.
4. Select a charitable organization, choose a cover photo and fill in the fundraiser details.
5. Click Create.



### CEDENA HARTLEY GIVES BACK

"I know Blaze doesn't have the problems that many do and we are so thankful his Hemophilia is mild however it is such a part of who he is and who we are. If it weren't for all the work past people have done to learn how to treat it and all of the education and research he wouldn't be alive today. You have no idea how thankful we are to those people and to SWOHF for all they do for people with bleeding disorders. The community means a lot to my husband and I and our family."



# 3 WORK: CORPORATE GIFT MATCHING

An easy way to increase donations is to take advantage of Corporate Gift Matching opportunities. Many employers offer Corporate Gift Matching Programs, where they will match your donations. Some companies even double or triple the amount you donate! Check with your employer to find out if Corporate Gift Matching is an option for you.



## JOSH BOJANOWSKI GIVES BACK

"I work for Alliance Data in Westerville, Ohio. Alliance Data always provides a match to a donation, but in 2018 during their kickoff pledge campaign they are offering a double match! I am happy to designate my donation to Southwestern Ohio Hemophilia Foundation.

I have seen first-hand the impacts and changes that your organization has committed to help those with Hemophilia. Doug Mueller, my brother-in-law, and my nephew Rylee both have Hemophilia. Over the last 20 years I have seen Doug and Rylee manage their medical condition, but can really see the advancements in research and development."



# 4 SHOP: KROGER, AMAZON

We all shop for groceries and buy from Amazon from time to time. It's easy to give back to SWOHF by signing up for Kroger Community Rewards and AmazonSmiles before shopping. Already this year year, SWOHF made \$55 through programs like these.



## An Easy Way to Give Back to the Community!

Sign up at [krogercommunityrewards.com](http://krogercommunityrewards.com) with your Kroger Plus Card and enter our number #DS729 as your organization. Once you're enrolled, you'll earn rewards for SWOHF every time you shop at Kroger and use your Plus Card!



# 5 MEMORIAL

## THE SHOFNER FAMILY GIVES BACK

A memorial gift is a meaningful and lasting way to honor someone special. By making a gift to honor Jerry Shofner, who passed away on August 8, 2018, the Shofner family is paying tribute to his memory and celebrating his life.



SWOHF

# ANNUAL MEETING

SWOHF Annual Meeting was held on Saturday, March 2 at the Beaver Creek Golf Club. Over 70 individuals registered and our morning together included:

- Buffet breakfast with made-to-order omelets
- Industry partner/sponsor displays
- Update from our Dayton Childrens HTC, Dr. Jordan Wright
- Advocacy Initiatives from Ohio Bleeding Disorders Council
- Financial and Program Reports from Board
- Showing our appreciation for all our 2018 Volunteers with a SWOHF backpack
- Honoring our VOLUNTEER of the Year: JULIE SAMPSON

A copy of the 2018 program, including financial reports and event summaries, is available from the SWOHF Office upon request.



THANKS TO OUR **SPONSORS!**



# WE APPRECIATE OUR 2018 VOLUNTEERS!



Kyle Bishop  
 Jenny Bostater  
 Steve Bostater  
 Kim Bostater  
 Rick Bostater  
 Ryan Bostater  
 Kevin Bostater  
 Carolyn Brown  
 Steve Brown  
 Ashley Brown  
 Stephen Brown, Jr.  
 Dan Bucklew  
 Renae Bucklew  
 Lindsay Carlson  
 Jeff Clark  
 Paul Clark  
 Billy Cline  
 Cheryl Coffey  
 Denise Croley

Darla Edds  
 Donna Elson  
 Jim Elson  
 Anastasia Geels  
 Katie Hembree  
 Shellie Hembree  
 Wanda Henninger  
 Sandy Hibner  
 Brian Howard  
 Larry Justice  
 Suzie Justice  
 Katie Justice  
 Deb Kremer-Smith  
 Audra Lamb  
 Nick Lamb  
 Andrea Marler  
 Brian Marler  
 Chris Marler  
 Dick Miller

Mary Miller  
 Ellyn Miller  
 Sheri Neaves  
 Ellen Poti  
 Jason Poti  
 Matt Sampson  
 Julie Sampson  
 Josh Griffin  
 Gina Santi  
 Craig Schnelle  
 Susan Schnelle  
 Amber Shawen  
 Eric Shepard  
 Katherine Shepard  
 Rick Shepard  
 Dena Shepard  
 Alison Shofner  
 Leah Shofner  
 Seth Shofner  
 Alicia Snyder  
 Pam Snyder  
 Nick Stebelton  
 Taylor Stebelton  
 Christy VanBibber  
 Elise VanBibber  
 Becky Walker  
 Amanda Weaver  
 Dan Weaver  
 Peggy Wilcox  
 Timothy Wilcox  
 Betty Wyatt  
 Dr. Jordan Wright  
 Carole Zeiter  
 Les Zeiter

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 to step up to the challenge  
 with **Jivi<sup>®</sup>**

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Ask your doctor if Jivi may be right for you.

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**Your Health. Your Voice. Our Future.**

# ADVOCACY EVENTS



## **NATIONAL HEMOPHILIA FOUNDATION WASHINGTON DAYS: MARCH 27-29, 2019**

NHF Washington Days! More than 400 participants joined together to advocate for our community. Each voice is important and adds a face to the policy issues being debated in Congress.

SWOHF Chapter and Dayton Children's HTC advocates (Kay Clark, Sandy Hibner, Monica DuShane) joined with others from the Ohio chapters to talk to our legislators regarding these policies:

- Oppose short-term insurance plans and support people with pre-existing conditions by co-sponsoring HR 1010 or introducing companion legislation to rescind the 2018 regulation that expanded short-term plans
- Support federal hemophilia programs at CDC, HRSA and NIH that support the bleeding disorders community

**In the House, HR 1010 has already added several more co-sponsors since Washington Days! Together we can make a difference!**

## **OHIO BLEEDING DISORDERS COUNCIL STATEHOUSE DAY: MARCH 13, 2019**

Over 70 individuals attended from all five Ohio chapters and SWOHF was well represented at our State Capitol Building. After training, we set off for meetings with our state legislators to discuss BCMH and Medicaid funding, as well as insurance issues like copay accumulator programs. How exciting it was to get our picture taken with newly elected Rep Randi Clites after introduction in Chambers!

# Let's get together to talk about IXINITY<sup>®</sup>

My passion for and commitment to the bleeding disorders community is driven by the strength, compassion, and sense of family with everyone I meet. It warms my heart and inspires me every day.

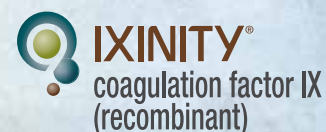
—Arica DeSilvestri, your resource for all things IXINITY



► Contact Arica at 614-519-3052 or [desilvestria@apvo.com](mailto:desilvestria@apvo.com)



Aptevo BioTherapeutics LLC, Berwyn, PA 19312  
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On February 1, SWOHF teens gathered for a 2019 planning meeting and trip to Top Golf in Cincinnati. The teens enjoyed indoor golf, giveaways, great food--even injectable donut holes! (see pic below) What a fun time together! **Our next teen event is in the works - watch for email updates!**

## COMMUNITY CONNECTIONS:

# TEENS TOP GOLF





## COMMUNITY CONNECTIONS: **EDUCATION NIGHTS**

This spring, several SWOHF families enjoyed delicious dinners and time getting to know others in the Greater Dayton community during our industry-sponsored dinners.

Sanofi-Genzyme presented “Cognitive Conversations for Parents & Caregivers” highlighting insights from the field of behavioral science and how they can be applied in conversations and behaviors related to managing Hemophilia.

Bayer presented their Jivi® Patient Program. Hemophilia A patients and their families had the opportunity to learn from a Bayer Clinical Support Specialist who provided safety and bleed protection information for Jivi.

**We are grateful for their generous support of education events for our chapter!**



# HTC CORNER

The staff of Dayton Children's HTC is pleased to introduce Monica DuShane, MSW, LISW-S. Monica joined the hemophilia team in January filling the role of the social worker.

Monica is native to Minnesota, but has lived in OH since 2010. She reports that "life is warmer in Ohio" and by that she is referring to the weather and warmth of the people. Monica is married with three adult children and four grandchildren.

Monica received a Bachelor of Science-Social Work from Augsburg University in Minneapolis, MN in 2007 and a Master of Social Work from University of Cincinnati in 2014. Being a life-long learner is a priority for Monica!

Monica meets with patients and family members during clinic visits and provides support and assistance as needs arise. She has further integrated herself by joining the Ohio Bleeding Disorder Council and attending her first Washington Day!

Monica states, "I feel fortunate to be part of the hemophilia team and to partner with you. I look forward to seeing you at events. Our collective efforts and voices can make a difference for those affected by bleeding disorders!"



*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.*

## 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

Kay Clark

## SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

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