# **FACTOR NOTES**

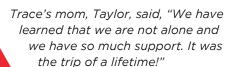
BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

### THE TRIP OF A LIFETIME!

Congratulations to SWOHF participants in the 18th Annual Gettin' in the Game Junior National Championship held in Phoenix, Arizona on November 8-10. The annual competition, created and presented by CSL Behring, brings together more than 120 kids who have bleeding disorders for a weekend full of education and friendly sports competition in baseball, swimming and golf. The focus is on living a healthy lifestyle that includes physical activity.

Our Chapter Nominations for 2019 were Trace Stebelton, who
was accompanied by his brother and parents, and Katie
Hembree, whose mom traveled with her. This year our chapter
was randomly selected by CSL Behring to receive a third nomination; Aiden

King was thrilled to travel to Phoenix with his mom. Trace & Aiden learned more about the fundamentals of baseball. Katie chose golf to learn skills to use on her high school golf team. Each child was recognized for his/her participation.



Katie says, "After being diagnosed with a bleeding disorder, I had to stop playing volleyball and softball because of getting hit. I thought I wouldn't be able to find anything I loved until I picked up a golf club. I fell in love with playing golf and it has helped me in so many ways."

Aiden's mom, Krystal, said, "It was amazing and he

usually available in July.



Presented by CSL Be



had such a good time. He was a little shy and held back at first but by the next day he had friends. He even got an award for most improved with baseball. It was a great opportunity for

If your child (age 7-18 years) would like to be considered

for SWOHF Chapter nomination, watch future Factor Notes for application info or email kay@swohf.org More info is





P. 1 The Trip of a Lifetime!

P. 2 Save the Date

P. 3 Travel Scholarship
Applications Available

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P. 7 Golf Outing

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# SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

3131 South Dixie Drive, Suite 103 Moraine, OH 45439

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# **SAVE THE DATE**

2020 CALENDAR OF SWOHF EVENTS

#### **FEBRUARY**

#### **Teens Only Top Golf**

Saturday, February 15 Top Golf *West Chester, OH* 

#### **MARCH**

#### **Annual Meeting**

Saturday, March 7
Beavercreek Golf Club
Beavercreek, OH

#### **OBDC Statehouse Day**

March 30-31 Columbus, OH

#### **MAY**

#### **Evening Out Casino Night**

Friday, May 1 Dayton Woman's Club *Dayton, OH* 

#### **JUNE**

#### **Family Fest**

June 12-14 Higher Ground Retreat Center *West Harrison, IN* 

#### **JULY**

#### **FAMOHIO**

July 31-August 2 *Columbus, OH* 

#### **AUGUST**

# **Brad Miller Birdie Busters Golf Outing**

Thursday, August 20 Beavercreek Golf Club Beavercreek, OH\_

#### **SEPTEMBER**

#### Bleeding Disorders Awareness 5K

Saturday, September 19 Rice Field *Miamisburg, OH* 

#### **OCTOBER**

#### **Fall Outing**

Sunday, October 4 Young's Dairy Yellow Springs, OH

#### **NOVEMBER**

#### **Women's Day Together**

Saturday, November 14 Golden Lamb *Lebanon, OH*  If you are interested in representing SWOHF and participating in **Ohio Bleeding Disorders Council** 

**Statehouse Day** in March, please contact Kay in the SWOHF Office. Registration will open mid-January. Watch your email for more details!



July 31st through August 2nd Marriott Northwest, Dublin, OH Registration will open in May 2020

Follow us on Facebook at www.facebook.com/Famohio www.famohio.org FAMOhioInfo@gmail.com 614-344-1075



# SWOHF TRAVEL SCHOLARSHIP APPLICATIONS AVAILABLE FOR HFA & NHF CONFERENCES!



#### NATIONAL HEMOPHILIA FOUNDATION

for all bleeding disorders



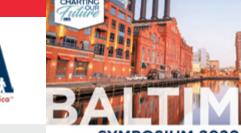
HFA Symposium offers community members the opportunity to learn and grow personally and collectively in becoming strong self-advocates! During their powerful sessions, community members can connect on a personal level with presenters. For more info or to view videos from past years, go to:

https://www.hemophiliafed.org/our-role-and-programs/national-community-events/annual-symposium/



2,590 people attended BDC 2019! NHF 2020 Bleeding Disorders Conference will be in Atlanta, Georgia on August 6-8, 2020.

Check events.hemophilia.org after 12/20/19 for more info.



SYMPOSIUM 2020 • APRIL 23-26



# From SWOHF Staff Kay, Lauren, Brittany



## #1 holiday hack:

When you buy your gifts at smile.amazon.com, Amazon donates.

amazonsmile

Did you know that when you shop for the holidays at smile.amazon.com/ch/31-1527065, AmazonSmile donates to Southwestern Ohio Hemophilia Foundation? This is a simple way for you to support SWOHF while you shop, at no cost to you! Tis the season to be generous!



#### 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.

HEMLIBRA emicizumab-kxwh

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 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

  — cough up blood

  - 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.

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

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 ©2018 Genentech, Inc. All rights reserved.

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



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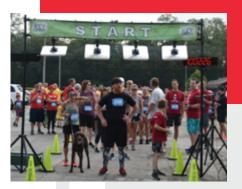
# **5K RAISES 19K!!**

Over 90 individuals came out on Saturday, September 21, to show their support of friends and family with bleeding disorders. Thanks to those who walked, ran or supported those who did, SWOHF raised over \$19,000!!

## BLEEDING DISORDER AWARENESS 5K OVERALL WINNERS:

FEMALE: Molli Courtney 22:04

MALE: Paxton Bostater (age 9) 26:24







#### Other 1st Place Results by Age Groups:

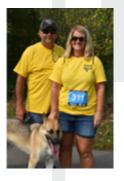
MALES

Shiloh James
Alex Perminov
Jesse Sheets
Steve Bostater
James MacLennan
Grant Donaldson

Rachel MacLennan Ashley Brown Gina Santi Jenny Bostater Janice Palo

Brenda Reichard

**FEMALES** 







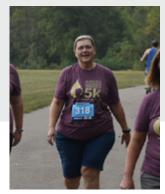




This year two "You Make A Difference Awards" were given. Nick Stebelton was given the award in honor and memory of his father, Randall, who passed away this summer. One of Randall's wishes was to get beehives and have all proceeds from the honey come to the BDA 5K for Team Trace. This year Bee Heavenly Brand Honey helped Team Trace raise over \$2,500! What a wonderful way to honor Trace's Grandpa who was a special fan and support for the 5K team every year.

The second recipient of the "You Make A Difference" award was Lisa Santi, who has three grandsons with hemophilia. SWOHF recognizes the way she has shown consistent and ongoing support of the bleeding disorders community. Her behind-the-scenes support of our events and families does not go unnoticed!





#### SPECIAL THANKS

TO OUR 5K CHAIR DENA SHEPARD AND TO ALL OUR VOLUNTEERS



Committee Members & Volunteers: Ashley Brown, Carolyn Brown, Kim Brown, Steven Brown,

Steve Brown Jr, Denise Croley, Wanda Henninger, Angie Hicks, Teresa Howard, Katie Justice, Larry Justice, Suzi Justice, Susanne MacKenzie, Tina Miller, Sheri Neaves, Alex Perminov, Alison Shofner, Dena Shepard, Greg Vanover, Betty Wyatt





THANKS TO OUR 5K SPONSORS!!





























GROCERYLAND

# **GOLF OUTING**

Another great year for the Brad Miller Birdie Buster's Golf Outing!

On August 15, over 20 teams gathered to play 18 holes, enjoying the beauty of Beavercreek Golf Course and spending time with friends. Afterwards, an Italian dinner was served and awards were given. Congrats to the winning team: Ted Bedrowsky, Jamie Shell, Aaron Bedrowsky and Josh Payne! Door prizes and silent auction baskets totaling over \$2500 raised - thanks to donations from area restaurants and businesses. Over \$12,000 was raised to support our SWOHF programs! Thanks to Dick Miller for chairing this fundraiser that is in its 27th year!





# NHF'S BLEEDING DISORDERS CONFERENCE HIGHLIGHTS



The National Hemophilia Foundation's Bleeding Disorders Conference was held October 3-5 in Anaheim, CA. This signature event brings together affected individuals and their families, NHF Chapter leaders and staff, medical professionals including physicians, nurses, social workers and physical therapists. The conference is broken into 12 tracks tailored specifically to include education and networking based on diagnosis, e.g. VWD, rare bleeding disorders as well as teens, adult men/women, caregivers, parents, spouses. There's truly something for everyone who attends!

Each year SWOHF receives applications for NHF Conference travel scholarships and two were awarded by the SWOHF Board: Graham Carlson and Chloe Henninger.

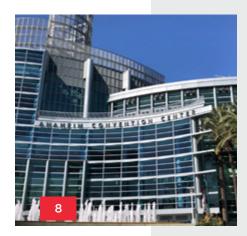


Chloe attended the teen track and learned ways to manage her own bleeding disorder as she prepares to graduate and head to college. She was accompanied by her mom, Wanda. Chloe said, "Attending conference was an awesome experience. We met other people with similar issues. We received new ideas from other people and we made friends."

Our Executive Director, Kay Clark, followed the Chapter Leadership track; our entire Chapter

will benefit as she incorporates information and ideas from valuable workshops and peer-to-peer networking.

Graham's mom, Lindsay said, "I feel like it is very important for my sons to connect with the larger hemophilia community and I am eager to learn about advancements on the horizon." After the conference, she said, "Our attendance was very beneficial for our entire family."





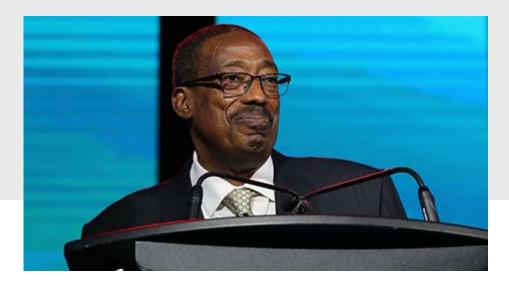




### NHF CEO VAL D. BIAS RETIRES

In the Opening Session, there was special tribute to CEO Val D. Bias who will retire this year. Through the years, he has achieved so much including helping to pass the Ricky Ray Relief Act of 1998, growing NHF's research agenda and increasing awareness and treatment options for women with bleeding disorders. After a moving video that highlighted his life of service, vision and leadership

during the past 11 years in his role as CEO, he addressed the crowd. In his remarks, he reminded us about the importance of speaking up and keeping up. "Making your voice heard," said Bias, "keeps our community together." SWOHF gratefully recognizes his significant contribution and faithful service to all with bleeding disorders.



"The story of the bleeding disorders community needs to be written by us, not for us"

# NATIONAL ORGANIZATIONS COLLABORATE TO ADDRESS PATIENT CONCERNS RELATED TO PRODUCT SAFETY ISSUES

As they become aware of topics of importance to the community, HFA and NHF are looking at areas where collaboration could result in cost and time savings for everyone.

To that end, HFA has recently partnered with NHF to create an inbox for you to share your thoughts, concerns and questions related to product recalls, labeling problems and more. In the future, they will deliver joint letters and statements to the community. **The Patient Voice: Product Safety Issues** is currently accessible through the SWOHF Website Resources (swohf.org)

"Assessing what it means to be both a change agent and an advocate. Our community is built on the voices of many before us and we will need many voices to carry us forward. We are looking at new ways to engage the bleeding disorder community in advocacy to drive change and better care for those we serve." HFA & NHF



# **FALL HAPPENINGS**

# SWOHF FALL OUTING

SWOHF Fall Outing was held on Sunday, October 11, at Young's Dairy in Yellow Springs, Ohio. Over 250 individuals attended – enjoying fried chicken dinner, ice cream, putt-putt, batting cages and door prizes. Dr. Jordan Wright from Dayton Children's HTC gave us an update and Melissa Tucker RN reminded us of the importance of keeping treatment logs.























On Saturday, November 9, SWOHF women including teens spent the day at The Golden Lamb in Lebanon, OH. Our program was "Putting Stress in its Place" and the day was spent relaxing as we talked about priorities, organizing and the importance of "white space" – decluttering. Then we enjoyed a delicious lunch and craft time, along with shopping in historic Downtown Lebanon for "Girls Night Out."

Special Thanks to HFA for sponsoring this event and providing our speaker, Ann LeWalk, VP Education HFA.







# SWOHF WOMEN'S DAY TOGETHER

















# **EXCITING NEWS! GRANT FUNDS ADD FUN TO WOMEN'S DAY TOGETHER!**

SPECIAL THANKS TO:

## CK Colburn Keenan Foundation, Inc.

SWOHF was awarded a \$1000 grant from Colburn-Keenan Foundation for our Women's Day Together that allowed us to provide goody bags with a 2020 Planner for each woman. Door prizes were awarded including the top 10 Amazon-recommended home organization items: a wrapping paper organizer, closet organizers with velvet hangers, drawer organizers, and more for every room in the house! To emphasize our theme, "A place for everything and everything in its place," our special craft was making clutch purses ... out of placemats! Everyone made one to keep and one to give as a gift. They turned out so cute! Put the date on your calendar for SATURDAY, NOVEMBER 14, 2020 to join in the fun!

# **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."





248-660-7384 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

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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.

rinted in USA/September 2018



# **COMMUNITY CONNECTIONS**

On Tuesday, October 22, over 30 individuals gathered at Figlio Wood Fired Pizza Restaurant in Kettering for an education session on HEMLIBRA sponsored by Genentech and hosted by Ami Seligman, Genentech Hemophilia Community Clinical Educator. We heard from Tammuela Singleton, MD, Louisiana Center for Advanced Health, as well as a patient ambassador currently on the product.







Twenty SWOHF community members met for an educational program on Tuesday, November 19, at Bravo Cucina Italiana hosted by Pfizer Patient Affairs Liaison, Chris Liddell. The topic was "Empowered: Tools for Self-Advocacy" and we learned about the importance of speaking up and communicating effectively not just in health care, but in all areas of life. We learned self-advocacy leads to confidence and independence as we face unique challenges.







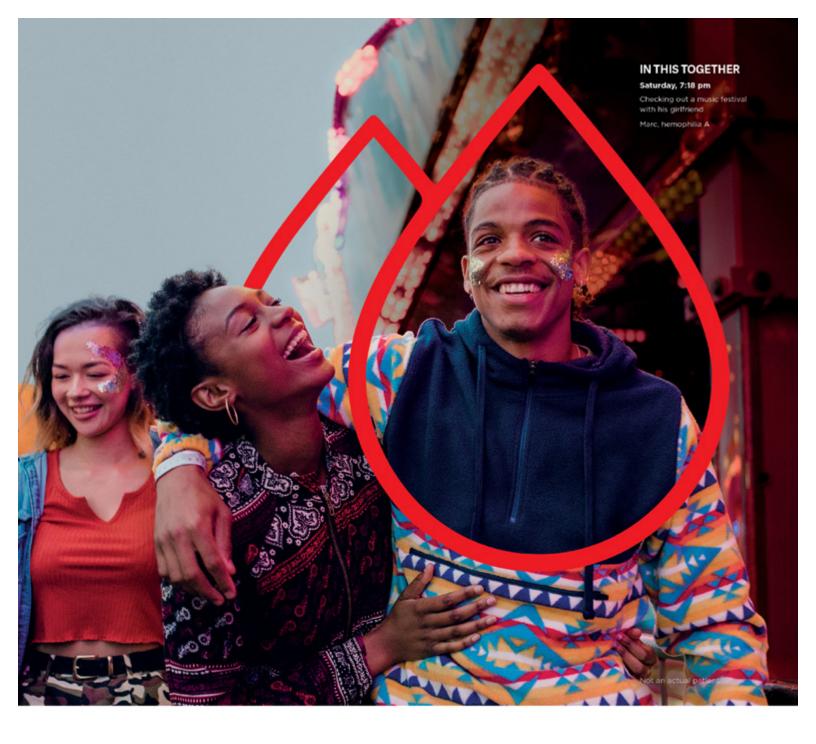
On Saturday, November 23, CSL Behring hosted a program at the Boonshoft Museum of Discovery. John Vieke, a police officer with severe Hemophilia B, spoke as a Common Factors Advocate during this educational program. He talked about overcoming obstacles, taking a proactive approach to your health and the importance of staying physically fit. Over 10 families gathered at

the Museum for lunch and after the program set out to explore the wonderful exhibits at the Museum. Thanks to Gwen Eyerman (CSL Behring Manager of Coagulation Products OH) and Bri Vieke (CSL Behring Community Support Liaison Midwest) for putting this program together just for SWOHF and providing a family day at this premier Dayton attraction.









Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world, is stronger than ever. Let's make today brilliant.

bleedingdisorders.com



BAXALTA AND SHIRE ARE NOW PART OF TAKEDA

# **HTC CORNER**

# SANDY HIBNER RETIRES FROM DAYTON CHILDREN'S

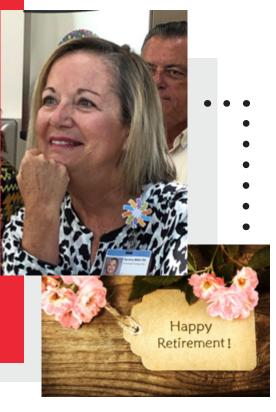
Sandy Hibner started work at Dayton Children's in 1997 as Coagulation Resource Nurse and Research Nurse Coordinator. She was awarded the Nursing Excellence Award for Community Service in 2003 and a Nursing Excellence Award in 2018 for Response to Diversity. She has been part of SWOHF since 1997 and is currently serving on the SWOHF Board. We all wish Sandy a well-deserved and Happy Retirement!

Here's a few words from Sandy ....
"I have been working as a nurse for
almost 46 years. In 1997, I took a leap
of faith and applied for a position at
Dayton Children's Hospital, known
then as Children's Medical Center.
I thought caring for children would

be more challenging than caring for adults. Little did I know that children are the most resilient people in this world and that they would teach and give me more than I could ever teach or give them!

It was a great privilege for me to care for children and their families who experience bleeding and clotting disorders. I have been fortunate to be involved with many of these children from infancy to adulthood. I have watched fearful parents become expert caregivers and to observe children accept their conditions and then conquer the world. You have all taught me something and I thank-you from the bottom of my heart for allowing me to be a part of your lives."







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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