

FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

EXCITING NEWS FOR THE BLEEDING DISORDERS COMMUNITY!

The history of bleeding disorders will be archived in the Smithsonian Institute's National Museum of American History in Washington, D.C.

The Hemophilia Federation of America (HFA) announced they have made an initial donation including historical artifacts, personal journals, newspaper articles, as well as photographs and oral histories. This is the first step in preserving the history of the bleeding disorders community for future generations!

The Smithsonian has over 25 million visitors per year and is the world's largest museum, education, and research complex, with approximately 154 million artifacts and specimens in its trust for the American people.

The goal for Phase 1 is \$65,000 and to date \$56,600 has been raised. SWOHF joined with other local chapters, national organizations and individuals to contribute to this meaningful project.



2019
ISSUE #3

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PHOTO: The Hemophilia Alliance made a financial contribution and was recognized for their generous support at HFA's annual Symposium in San Diego on April 5, 2019.

To stand in community and help preserve our bleeding disorders history, the SWOHF Board voted to support this initiative with a Chapter donation of \$1000. Further personal or organizational financial contributions to the bleeding disorders history project are welcome as additional donations/phases of this project continue. Contributions are being accepted at <https://give.onecause.com/hfa> or text HFA to 243725.

Support the
Smithsonian Institute
Bleeding Disorders
Collection.

Text HFA
to 243725



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SWOHF FALL OUTING

REGISTER ONLINE at www.swohf.org BY THURSDAY, OCTOBER 3

Sunday, October 13, 2019

1:30 to 5:30 pm

**Young's Dairy
6880 Springfield-Xenia Road
Yellow Springs, OH 45387**

Join us for great food, vendor displays, awesome activities and ICE CREAM! Plenty of time to chat with new families, industry reps, HTC Staff, SWOHF Board members and staff. Our picnic and entertainment package includes fun for the whole family.

This event is open to SWOHF families who are treated for a bleeding disorder at Dayton Children's HTC or a Greater Dayton hematologist. Thanks to our industry partners' sponsorship, this event is FREE for immediate family members only. Children must be supervised by an adult at all times. For more info, call the SWOHF Office 937-298-8000 or email kay@swohf.org



SWOHF 5K

THERE'S STILL TIME TO REGISTER
ONLINE @ WWW.KEYSPORTS.NET



**Southwestern Ohio
Hemophilia Foundation**

Women's Day Together

**Saturday, November 9, 2019
10:00 a.m. to 3:30 p.m.**

**The Golden Lamb (Meeting Room 2nd Floor)
27 S. Broadway St, Lebanon, OH 45036**

"Self-Care: Putting Stress In Its Place"

Speaker: Ann LeWalk, VP Communications, HFA

Take a break, do something for yourself and join us for this special day! We'll get to know each other, enjoy a delicious luncheon, learn why self-care is so important, and still have plenty of time for chatting and other fun, relaxing activities (Prizes!)

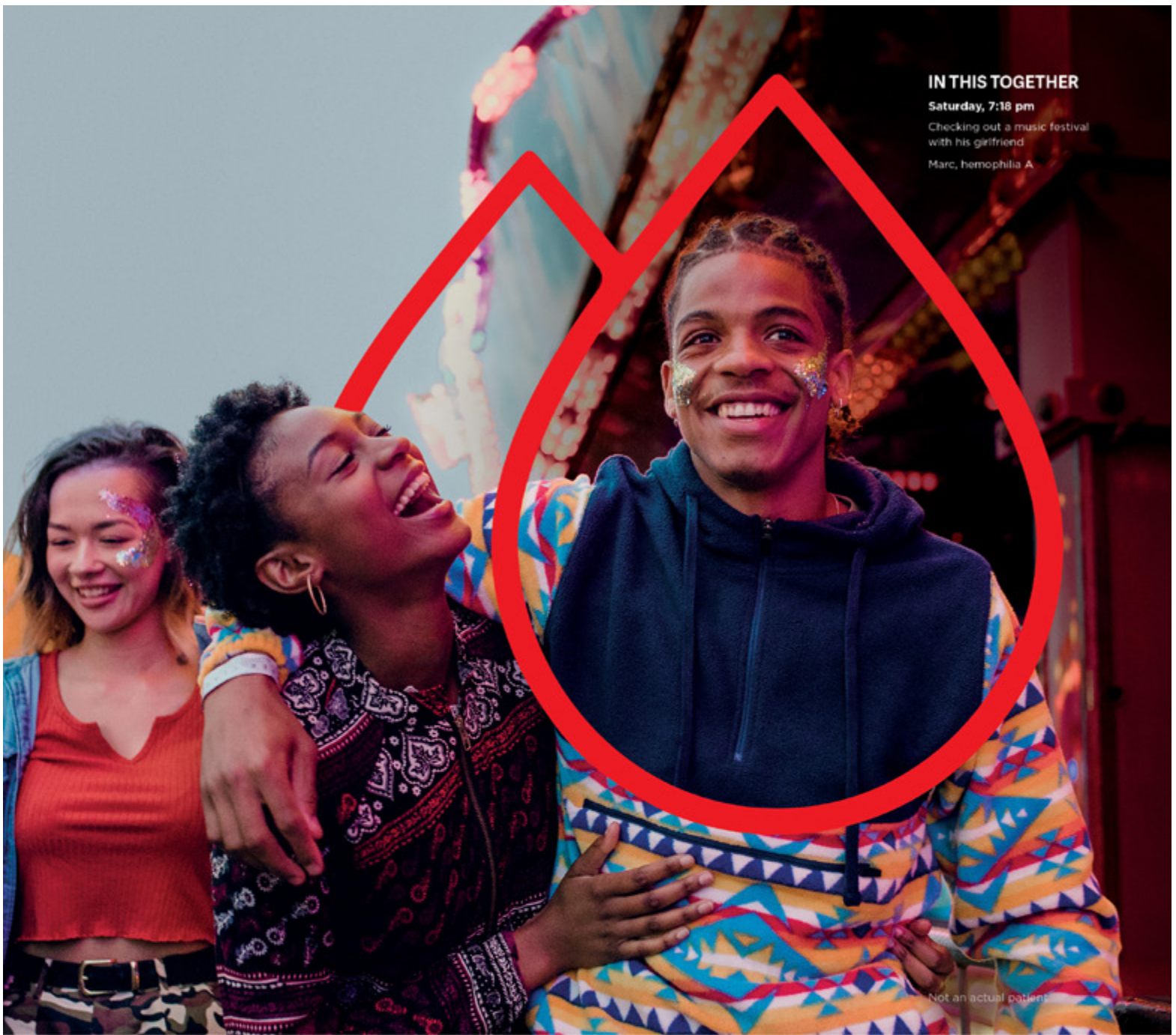
ONLINE REGISTRATION WILL OPEN IN OCTOBER!

IN THIS TOGETHER

Saturday, 7:18 pm

Checking out a music festival
with his girlfriend

Marc, hemophilia A



Not an actual patient.

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
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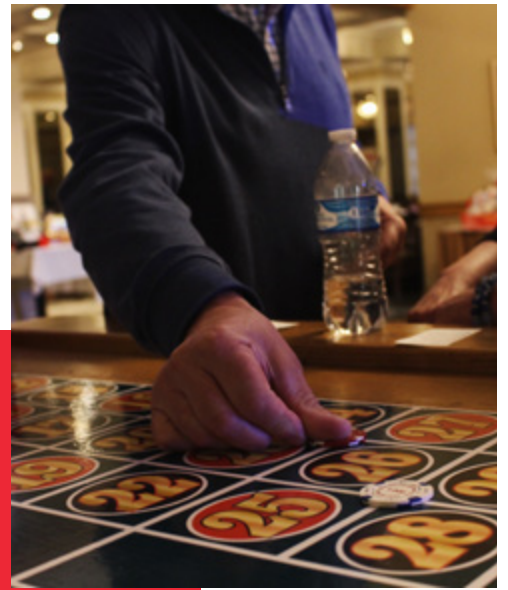
ALL IN!

CASINO NIGHT

2019 "ALL IN" CASINO NIGHT FUNDRAISER WAS "THE REAL DEAL"

SWOHF's Casino Night fundraiser was a great success! A fun time was had by all who attended!! The Dayton Woman's Club was the perfect venue and the Cincinnati Circus Company professional dealers doubled as entertainers. For games, we had roulette, craps, blackjack, Texas hold 'em. Even those who had never played before enjoyed the excitement among friends around the tables.

With the generous support from local businesses, we had 29 awesome baskets in our Silent Auction that sold for a total of \$1665. The event raised over \$7000 for SWOHF Programs.



Throughout the evening, as individuals contributed toward our MedicAlert ID funding, they received a light-up sports bracelet to wear. Only those with bracelets were able to play our "Light-up Bracelet Heads or Tails Showdown." The winner received a Fitbit! In 2019, SWOHF has purchased Medic Alert bracelets for 47 individuals and we are grateful to have raised \$450 during this event specifically for those bracelets. Raffle prizes were awarded at the end of the evening!

BIG THANKS to our volunteers and to all who attended and brought friends.

**MARK YOUR CALENDAR FOR
FRIDAY, MAY 1, 2020**





- **SILENT AUCTION DONORS**
- Al's Smokehouse Bar & Grill
- Angela Lambing
- Beavercreek Golf Club
- BIBIBOP (UD location)
- Bravo! Cucina Italiana
- BreakOut Dayton
- Buffalo Wild Wings
- Carillon Historical Park
- Cincinnati Art Museum
- Cincinnati Nature Center
- Cincinnati Reds
- Cincinnati Shakespeare Company
- Cincinnati Zoo
- City BBQ
- Cleveland Cavaliers
- Columbus Blue Jackets
- Dayton Dragons
- Dayton Society of Natural History
- Dewey's Pizza
- Don Patron Mexican Grill
- Donato's Pizza
- Dream Dinners
- Esther Price
- Evans Original Bakery
- Flemings Prime Steakhouse & Wine
- Flying Ace Car Wash
- Flying Pizza
- Frickers
- Frisch's Big Boy
- Funny Bone Comedy Club
- Gigi's Cupcakes
- Goldshot, Lamb & Hobbs CPA Firm
- Graeters
- Greek Isle Deli
- Hollywood Gaming
- Hot Head Burritos
- Kings Island
- Miami Wine and Liquor
- Mike's Carwash (Beavercreek location)
- Northstar Cafe (Liberty Center)
- Ohio Expo Center & State Fair
- Pedal Wagon Dayton
- Philly Pretzel Factor (Centerville)
- Ray's Drive-Thru
- Rock & Roll Hall of Fame
- Rooster's Restaurant
- Scoops Ice Cream
- Shoot Point Blank
- Square 1 Salon & Spa
- Sweet Treats Bakery
- SWOHF Board
- Wanda Henninger - Norwex
- Woodhouse Day Spa
- Young's Jersey Dairy

THANK YOU TO OUR CASINO NIGHT SPONSORS!

ACE-KING SPONSORS



GOLD SPONSOR



GRANTS



DESSERT TABLE SPONSOR:

The Shofner Family



FAMILY FEST 2019

LOOKING UP!
RESPECT, RESILIENCE,
RESEARCH, REACHING OUT

Our weekend at Higher Ground Conference Center kicked off with industry partner displays, dinner and a brief program by Honey Blankenship, Senior Clinical Specialist for Takeda, who spoke about “Mindfulness” and the importance of a caring community.

On Saturday, the program “Honoring Our Past, Building Our Future” was presented by Catherine “Andy” Anderson, HFA Project Coordinator. These sessions were eye-opening, informative and inspiring and showcased the resilience of our community. Following the sessions, Sandy Hibner, Dayton Children’s, led a rap session about the continued importance of research & resilience. A BIG THANK YOU to HFA’s Eric Burgeson and SWOHF’s Lauren Jager, who led the children’s activities & education sessions.



We ended the day with our “Team-Building/ Bike-Building” family activity where we had fun competitions between teams and ultimately each team worked together to build a bike to “give back” to our Greater Dayton Community. Bikes were donated to the Life Enrichment Center (see pictures next page)!

Special Thanks to our Sponsors and our Planning Committee: Deb Smith, Lindsay Carlson and Julie Sampson ... and all our wonderful volunteers.

SEE YOU NEXT YEAR!
MARK YOUR CALENDAR NOW!
JUNE 12-14, 2020

THANK YOU TO OUR SPONSORS!



GIVING BACK

THANK YOU SWOHF!

On behalf of the LEC, we thank you for the donated bicycles and your commitment to fueling our "Earn a Bike" program where students learn the fundamentals of bike repair, safety and hands-on experience in the maintenance of a bike. Together we can continue to have more impact as champions in helping others transform their lives, their families, and ultimately our communities.

-- Karen Jackson, Program & Marketing Director, Dayton Life Enrichment Center



BOUNCING FOR ... RESEARCH!

During Family Fest 2019, 20 individuals participated in our SWOHF Bouncing for Bucks (B4B) fundraising event for a total of 18,231 bounces. Each year our bouncers are encouraged to ask friends and family for donations to support this worthy cause as they bounce a basketball for 10 minutes trying to get as many bounces as they can. There were prizes for the top three who collect the most in donations, as well as prizes for most bounces for male and female in each age category.

2019 RESULTS: \$590 donation to Judith Graham Pool Fellowship

Since the program's inception, NHF has funded almost 100 scientists whose projects have produced vital insights into hemophilia and other bleeding disorders. JGP research fellowship award projects have contributed to the development of safer concentrates, enhanced methods of testing and screening, and have laid the groundwork for current advances in gene therapy for hemophilia. JGP is sustained solely by the generosity of the bleeding disorders community including chapters, individuals and foundations.



TOP MONEY EARNERS:

Miles Lamb, Holden Lamb, Josh Griffith, George & Graham Carlson

TOP BOUNCERS:

Under 5: Logan

5-8: Graham and Lexi

9-12: George and Kiley

13-18: Chloe Henninger and Josh Griffith

Over 18: Julie Sampson and Patrick Toller

NATIONAL SERVICE DOG MONTH

DID YOU KNOW?

September is National Service Dog Month, a time set aside to raise awareness about these animals and the service they provide people in their care. Service dogs include guide dogs for the blind, hearing dogs for the deaf and mobility assistance dogs.

Fortunately, both federal and state laws offer protections for the use of service animals in various situations, including places of public accommodation, like restaurants. However, before a person who needs a

service animal can have any of the legal protections, he or she must have a disability, which is defined by each of the pertinent laws.

Many people don't realize there are actually **rules of etiquette** when you're in the presence of a service dog. There are helpful articles online you can reference for more information - check out "8 Do's and Don'ts for Behavior Around a Service Dog Team" at healthypets.mercola.com, as well as "7 Guide & Service Dog Do's and Don'ts" on parade.com



The general rule for service dogs is this: DON'T TOUCH OR DISTRACT THEM.

At SWOHF events, we value the special assistance that the service dog provides the owner; equally important is the safety of all individuals in attendance.

Children should never approach a service dog. If you are at a SWOHF community event/program and are concerned about a service dog, please notify SWOHF Staff or Board members immediately. A service dog's owner may be asked to remove the dog if it is out of control and the owner does not take effective action to control it or if the animal is not housebroken. If properly excluded for one of these reasons, the individual would be asked to leave the event and could return without the service animal.

In some states, there are laws that make it a misdemeanor to represent an untrained dog as a service animal and fines up to \$500 for an incident. Because there is currently no certification or official national registry of legitimate service dogs, there is no way to verify whether a dog has undergone rigorous training to become a service animal. However, trained service dogs don't go off-leash, bark, knock things off shelves, jump on people, play or fight with other dogs, or grab food off tables, trainers say.

Here's some info from a website that is a great resource to check out about service dogs in the State of Ohio -- www.disabilityrightsohio.org/service-animals

What is the definition of a service animal under Title III of the ADA (Americans with Disabilities Act)?

A service animal is a working animal, **not a pet**. Regulations under Title III of the ADA define a service animal as any dog that is individually trained to do work or perform tasks for the benefit of an individual with a disability.

Are emotional support, therapy, comfort, or companion animals considered service animals under the ADA?

No. These terms are used to describe animals that provide comfort just by being with a person. Because they have not been trained to perform a specific job or task, they do not qualify as service animals under the ADA.

What are the responsibilities of a person who uses a service animal in a place of public accommodation?

The service dog's handler must maintain control of the animal, and the animal must have a harness, leash or other tether. However, if a disability prevents the person from using those or if a tether would interfere with the performance of the dog's job, then the dog's owner must maintain control through other effective means, such as voice control or signals.



DO'S AND DON'TS

- Always speak to the dog's owner, not the dog.
- Do teach your children that service dogs are working and should not be petted.
- Never touch the dog without asking the owner first. Don't be offended if the owner says "no"
- Keep your own dog away from a service dog at work.
- Don't offer food to a service dog.
- Don't stare at or directly approach the dog. Don't whistle or clap your hands to get the dog's attention. Don't point at or come rushing up to the dog.
- Don't ask the owner of a service dog personal questions about his/her disability.
- Be respectful and show courtesy to those with service dogs when entering buildings or in crosswalks.
- Don't assume a sleeping dog is off duty or that service dogs never get to play like other dogs—they do!
- Do not expect to see a special ID, tag or harness identifying service dogs at work.

"Service Dog Etiquette" researched on the internet for this newsletter by Timothy Wilcox.



This summer we have enjoyed two Community Education Dinners. In June, Pfizer hosted **"Step It Up! Being More Active With Hemophilia"** at The Chop House. SWOHF families enjoyed a delicious dinner and learned the importance of regular physical activity for those with bleeding disorders. Information including variation in dosing requirements depending on activity level, types of activities generally preferred for those with bleeding disorders and the need for constructive communication in families.

The SWOHF community also gathered at Salar Restaurant in August. Takeda offered the program **"Making The Grade"** stressing the importance of open lines of communication with school personnel to help manage a child's health specifically related to bleeding disorders.

COMMUNITY CONNECTIONS: EDUCATION DINNERS



Discussion about Preparedness for Natural Disasters

ARE YOU PREPARED?



Fourteen years ago, “Hurricane Katrina” slammed into New Orleans causing severe damage.³ The disaster left millions homeless. Many displaced people were without medications and health care equipment; some with hemophilia were without factor and access to care.

Fast forward to Dayton, Ohio on May 28, 2019. Headlines the following day read:

“Tornado Outbreak Devastates Ohio Communities with Winds up to 140 mph.”¹ Were you prepared? **Dayton Children’s HTC** urges you to review the following recommendations (from Steps for Living located on the NHF website).

EMERGENCY PLANNING

Whether you are planning for a major disaster or an unexpected trip to the emergency room (ER), planning for an emergency is essential.

Here are essential steps people with bleeding disorders should take to prepare for an emergency:

- Wear a medical alert ID bracelet or necklace
- Pack a go-bag with factor and supplies to be ready at all times so you can grab it and go
- Keep multiple ice packs in the freezer
- Keep extra cash in a safe and consistent place so you will remember where it was stored.
- Keep as much factor and supplies on hand as your health insurance will allow
- Take factor and supplies with you when you leave home

- Keep important phone numbers (e.g., your HTC, home care company, physician’s office, insurance company, local ER) in multiple locations: on the fridge, in your wallet, in your go-bag, and with your car registration papers
- Teach extended family/friends how to administer factor in case you are unable to do it yourself
- Keep a family manual—a notebook containing pertinent medical information, directions on mixing/infusing factor, maps showing the location of your HTC/hospital, important phone numbers, diagnosis and treatment regimens, and location of a backup HTC
- Keep an infusion log and take it with you in case you must evacuate your area
- Rotate supplies regularly according to expiration dates
- Add 1-800-42-HANDI (1-800-424-2634) and your HTC number into your cell phones in case you have to evacuate and need information on available HTCs in other areas
- Contact your local emergency management office or public health department for information on shelter-in-place and other safety procedures for your area²

References (retrieved by Sandra Hibner):

- 1) Romo, P. & Chappel, B., (2019). Tornado outbreak devastates Ohio communities with winds up to 140 mph., Retrieved from <https://www.npr.org/2019/05/28/727439670/multiple-tornadoes-touch-down-in-dayton-ohio-catastrophic-damage-reported>
- 2) National Hemophilia Foundation (NHF). (2019). Steps for living: Emergency preparedness. Retrieved from <https://stepsforliving.hemophilia.org/step-up/treatment/emergency-preparedness>
- 3) Zimmerman, K.A. (2015). Hurricane Katrina: Facts, damage, & aftermath. Retrieved from <https://www.livescience.com/22522-hurricane-katrina-facts.html>

SWOHF RECEIVES AWARD AT FAMOHIO CONFERENCE 2019

The six founding fathers of FAMOHIO were active and strong advocates of the bleeding disorder community. These brave men knew firsthand what having a bleeding disorder entailed in a time when treatment was very limited. These founders realized **EDUCATION is POWER!** To honor FAMOHIO's great founders and current advocates, a series of awards have been created and are awarded annually. The **William R. Dennis Award recognizes an organization that has made a significant contribution to the well-being of Ohio's bleeding disorder community.**

This year the award was presented to the five Ohio Hemophilia Chapter/Foundations including SWOHF.

Sandra Hibner, FAMOHIO Board Member, said: "The recipients of the William R. Dennis award can be described as the backbone of hemophilia community. Why is that you may ask? A backbone is needed every day for one's lifetime in all developmental stages of life. These recipients provide ongoing education and support to patients/families across the lifespan. The support given by these organizations

is impossible to quantify. But, I bet each and everyone in the audience has experienced a positive interaction provided by this year's recipients" said Sandra Hibner, FAMOHIO board member.

The 28th educational conference was held in Columbus on August 2-4, 2019 with an attendance of over 320. The theme was **See Us Soar, Hear us Roar.** Educational topics included exercise and fitness, Medicare, taking control, medical marijuana, sharing your story, advocacy, new products and the future of hemophilia treatment. Attendees also viewed *Bombardier Blood* and visited the Columbus Zoo. This event is made possible by countless hours by volunteers of the FAMOHIO board, event planner Lisa Raterman and her staff, and the generous financial support of industry partners.



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

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