

FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

SWOHF JOINS HFA

SWOHF Joins HFA as a Member Organization

Hemophilia Federation of America (HFA) exists to assist and advocate for those living with a bleeding disorder. Achieving this mission is accomplished in many ways, including delivering quality programs collaboratively through HFA Member Organizations.

HFA invites our SWOHF community to discover what they have to offer through many programs, services, events, outreach and advocacy education by checking their website for more information www.hemophiliafed.org



In this
ISSUE

Get Involved: Participate in HFA's educational, financial and wellness programs, designed to help the bleeding disorders community stay healthy, informed, and supported. Develop meaningful connections within the bleeding disorders community and find support at both the local and national levels. Check out HFA's Programs and Services and discover how you can get involved today!

Attend HFA Meetings and Events: HFA's annual Symposium, designed specifically for people with bleeding disorders and their families, brings the bleeding disorders family from across the country together. An estimated 600 attendees participate in rap sessions, networking, and receive education from top national speakers and educators. The 2019 Symposium will be held April 4th to 6th in San Diego, California. If you are an active SWOHF member who is treated for a bleeding disorder at Dayton Children's HTC or other Greater Dayton hematologist and if you are interested in applying for travel scholarship as an advocate from SWOHF, watch for more information in future newsletters!

Be an Advocate: Get involved in HFA's Advocacy initiatives. If you are new to the bleeding disorders community or have years of experience championing this community, HFA welcomes you! Join their outreach and advocacy education efforts! Working together and supporting each other, we can make a difference for people with bleeding disorders.

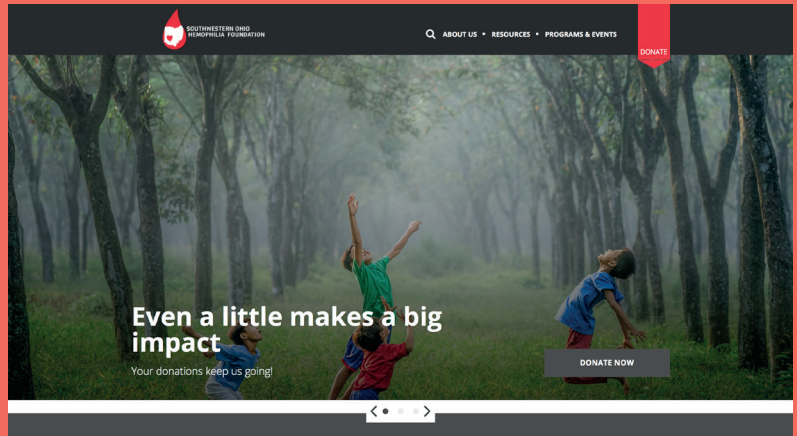
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Southwestern Ohio Hemophilia Foundation
www.swohf.org
3131 S. Dixie Dr., Ste. 103
Moraine, OH 45439
P: (937) 298-8000 F: (937) 298-8080
E: info@swohf.org

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SWOHF WEBSITE GETS A NEW LOOK!

Thanks to a grant from the Hemophilia Alliance Foundation, SWOHF recently updated and refreshed our website! Check us out: www.swohf.org
We were also able to shorten our email address to reflect the new change! Our new emails in the SWOHF office are: kay@swohf.org; info@swohf.org; director@swohf.org



LADIES, SAVE THE DATE! SATURDAY, NOVEMBER 10, 2018

Plans are currently underway for a “new-to-SWOHF” event:

WOMENS DAY TOGETHER: Women’s Day Out at The Golden Lamb in Lebanon, Ohio

Join us for a special day set aside just for women! Moms, Wives, Daughters, Sisters ... All welcome. We will enjoy special group activities including inspirational sessions by HFA Programs, as well as a delicious lunch at The Golden Lamb and time to shop in beautiful historic Lebanon afterward. (It’s actually Girl’s Night Out in Lebanon with special coupons, prizes, samples, tastings!)



Our goal is to enable and empower women in the hemophilia community to

- enjoy some “me” time
- learn self-care and family care
- build support networks
- bond with others in similar situations
- grow stronger personally

Invitations will be mailed and registration will be online. Want to help with this event? Contact Kay in the SWOHF office kay@swohf.org



BLEEDING DISORDER AWARENESS RUN/WALK 5K



Saturday September 22, 2018
10:00 a.m.
Rice Field - Bike Path
2001 Dayton-Cincinnati Rd.
Miamisburg, Ohio 45342

Join the Southwestern Ohio Hemophilia Foundation on Saturday, September 22 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 blood disorders like hemophilia and Von Willebrands 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



SWOHF FALL OUTING

Sunday, October 7, 2018
1:30 to 5:30 pm
Young's Dairy

Please 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.

This event is open to SWOHF families who are treated for a bleeding disorder at Dayton Children's HTC or a Greater Dayton hematologist. It is completely FREE for immediate family members only, but you must RSVP. For more info, call the SWOHF Office 937-298-8000 or email kay@swohf.org

OVER 20,000 BOUNCES!

Top Money Earners

Miles Lamb
Holden Lamb
Josh Griffin

Top Bouncers

5 & under:	Graham ...	334
6-8:	George ...	1077
9-12:	Brianna ...	2062
13 & over:	Trinity ...	2405

During Family Fest 2018, 23 individuals participated in our SWOHF Bouncing for Bucks (B4B) fundraising event for a total of 20,996 bounces.

As in years past, all proceeds raised go to the National Hemophilia Foundation Research Fund to support finding cures and better treatments for those living with bleeding disorders.

This was our 17th year hosting B4B which was created by one of our own, Dr. Eric Shepard. To date over \$30,000 has been raised by our bouncers and lives have been changed because of it.

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.

This year we raised a total of \$662 and we received this "Thank You" from NHF Research:

I wanted to extend my heartfelt thanks to you and your chapter for donating to JGP this year. Your chapter has consistently supported NHF's premier research program each year and we are so grateful for the level of support you have given to it.

Without the support of our chapters we wouldn't be able to fund the JGP fellows. And JGP is so important because it's the first step in looking at possible cures for bleeding disorders in the future.

Thank you again for your commitment to research. And I look forward to providing updates on JGP to you and other chapters in the future.

Best, Kristin Hokoyama
Senior Manager of Development & Special Events



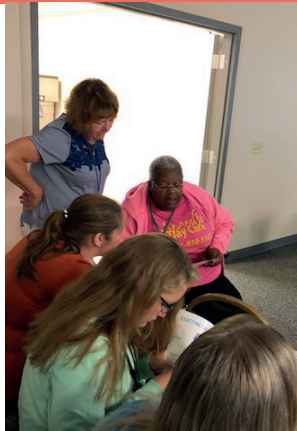


FAMILY FEST

2018

Our weekend at Higher Ground Conference Center kicked off with industry partner displays and chances to win prizes by checking in with all 12 reps throughout the afternoon on Friday, June 22. There were 16 families registered to attend and we all enjoyed the beautiful park-like setting in Indiana, plenty of delicious food, as well as time spent together in fun and games.

Our Friday evening speaker was Captain Guy Gruters, US Air Force, who shared his experience as a POW in North Vietnam from December 1967 to March 1973 (over five years). His story of courage and the importance of family inspired us as he encouraged us to “Stop complaining” and challenged us to live with contentment, gratitude and faith. You can learn more of his story by visiting his website www.guygruters.net



Saturday there were education sessions by Genentech rep, Diana Caito and Dana Norris from StoryClub Cleveland. Special programs were also provided for children and teens. A BIG THANK YOU to NHF’s Kate Nammacher for the Art Workshop “Artistically Speaking” where creativity inspired both adults and children to understand our individuality and identity.

On Saturday evening, we enjoyed a Family “Bond-fire” and were reminded of the importance of being connected and involved in our community. There was plenty of time to chat with friends, play ball and make s’mores.

Thanks to Deb Smith, our Event Chair, and her team of wonderful volunteers. We especially appreciate Andrea Marler taking pictures so we could share the experience via this newsletter!

This event is specially designed for those with Hemophilia A/B living in the Greater Dayton area and affiliated with our Dayton Children’s HTC or a hematologist in our area. If you meet these qualifications, we hope you will join us next year. This educational program is scheduled for Friday, June 14 to Sunday, June 16 at the Higher Ground Conference Center in West Harrison, Indiana. Be sure to check “Factor Notes” and register early to guarantee your family will be part of the fun next year!





SWOHF's 1st ever 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. The Cincinnati Circus Company was the real deal when it comes to throwing an amazing casino party - their professional dealers doubled as entertainers -- even the DJ was juggling! They brought in seven awesome game tables -- we had roulette, craps, blackjack, Texas hold 'em. Even those who had never played casino games before enjoyed the exciting experience among friends around the tables.

With the generous support from local (and out-of-town) businesses, we had 25 baskets in our Silent Auction and SWOHF made over \$1700 as items were purchased. Some of the donated items included:

- Tickets to Dayton Dragons, Cincinnati Reds, Kings Island, The Beach, FCC Soccer, Cincinnati Zoo, Kings Island, COSI, the Ohio State Fair, and even Dollywood!
- Restaurant gift cards to: Dewey's, Chuy's, Coopers Hawk Winery, Buffalo Wild Wings, Bob Evans, Flyboys Deli

THANKS TO OUR SPONSORS FOR THIS EVENT!!

GOLD SPONSOR: NovoNordisk

Ace King Sponsors:

CSL Behring
Butler Heating & Air Conditioning

Grant Funds:

Cascade Hemophilia Consortium
Allstate -- Dan Bucklew & Associates

Dessert Table:

Chip James Real Estate - KW Advantage

Throughout the evening, as individuals contributed toward our MedicAlert bracelet 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, Lisa Santi, received an Alex & Ani bracelet (valued at over \$100)!! So far in 2018, SWOHF has purchased Medic Alert bracelets for 36 individuals and we are grateful to have raised \$475 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. We plan to repeat this event in 2019 and hope you can join us for a fun and exciting SWOHF community fundraiser!

AUCTION DONORS

Beavercreek Golf Club
 Cincinnati Reds
 Cincinnati Zoo
 Dewey's Pizza
 FCC Cincinnati
 Graeter's Ice Cream
 Rock n' Roll Hall of Fame
 Scene 75
 Square 1 Salon & Spa
 The Beach
 Hollywood Gaming
 COSI
 Cleveland Browns
 Buffalo Wild Wings
 Cedar Point
 Dollywood
 Ohio State Fair
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 Snow Trails
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 Jenny Bostater
 Darla Edds
 Flyboy's Deli Restaurant
 Tik's Thai Restaurant
 Flying Pizza
 Don Patron Mexican Grill
 Jerri's Catering & Restaurant
 Tony's Italian Kitchen
 Bob Evans
 Harrison's Restaurant
 Expressions Studios
 Grismer
 Sam & Ethel's Restaurant
 Get Air Trampoline Park
 Company 7 BBQ
 Rapid Fire Pizza
 Chipotle
 Brio Tuscan Grille
 Mod Pizza



CSL Behring

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CONSORTIUM





CAMP BOLD EAGLE

Every year we partner with the Hemophilia Foundation of Michigan to send interested individuals (ages 6 to 17) to their summer camps. This year, from our SWOHF community, Anthony Wilson attended Eagle Outpost and Chloe Henninger, attended Camp Bold Eagle.

“My first year at camp was a blast. I had so much fun and made a ton of new friends that I still talk to now. At first I was a little nervous to be away from my family for a week, but as soon as I got there the nervousness went away. There was never a dull moment and there was always something to do and keep us busy. The counselors and campers there were all super nice and made me feel welcome on my first year there. It was a super fun week and one of the highlights of my summer. I can’t wait for next year!” - Chloe Henninger

At Camp Bold Eagle, kids experience a traditional summer camp environment complete with archery, arts and crafts, canoeing, swimming in a lake, and nature walks. Campers and counselors stay in rustic cabins in the woods and eat meals together in the dining hall. They play full-camp games, roast marshmallows over a campfire, and sing silly songs before meals.

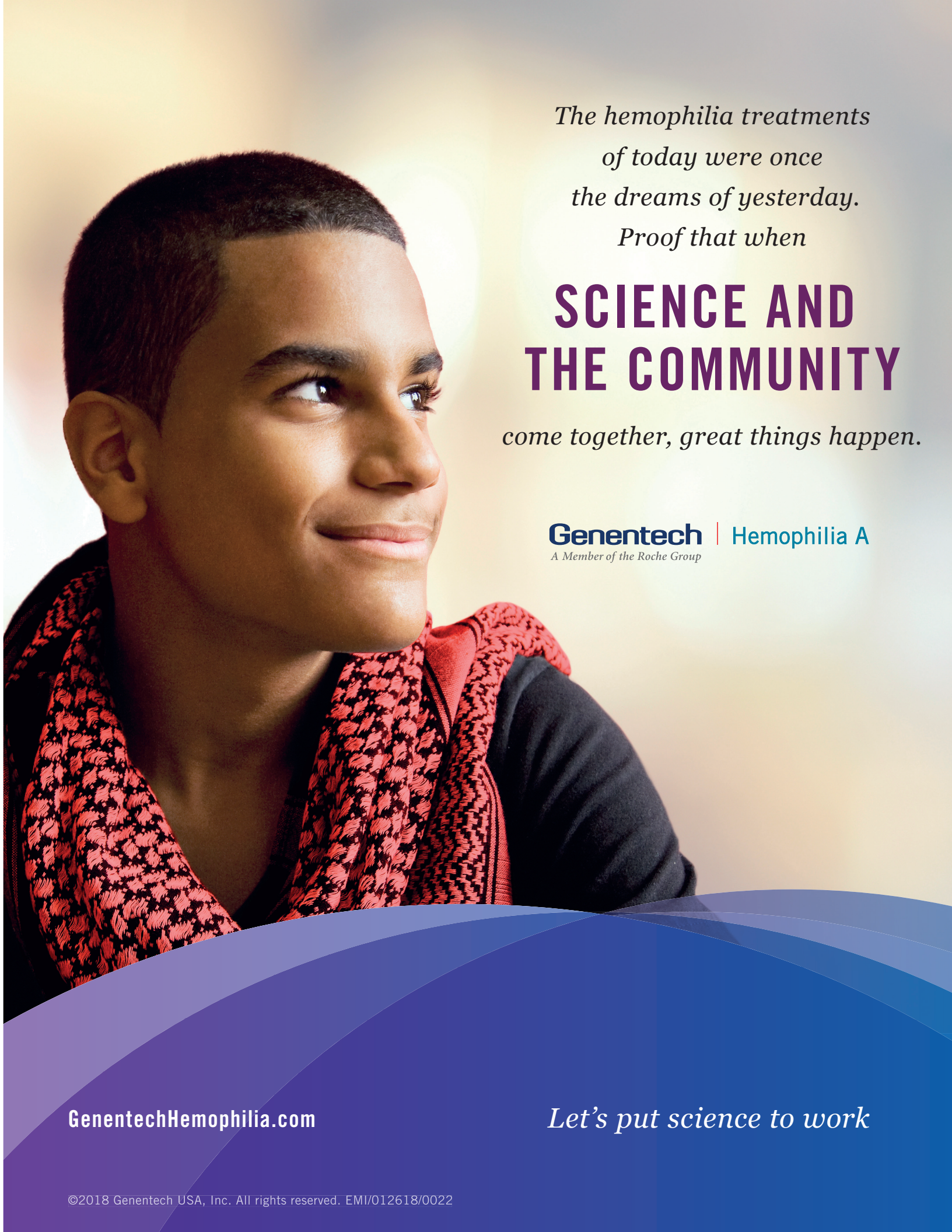
For children and teens with bleeding disorders, camp is a place where they can learn the valuable skills they need in order to become independent. They learn from each other, from their counselors (many of whom live with bleeding disorders themselves), and from many adult volunteers about ways to manage their disorder both medically and socially.

Campers are surrounded by peers who have also faced the challenges of living with a bleeding

disorder. Camp is a place where kids who sometimes feel like outsiders find themselves on the inside. Campers at Bold Eagle tend to return year after year and together graduate to HFM’s other camping programs. Many become lifelong friends and find themselves in the middle of one of the strongest support systems available.

For more information about camps, check the HFM website
<https://www.hfmich.org/camp-front-page/>

If your child or teen is interested in a camp session for 2019, be sure to check in with Dayton Children’s HTC next spring for more info or email
kay@swohf.org



*The hemophilia treatments
of today were once
the dreams of yesterday.
Proof that when*

SCIENCE AND THE COMMUNITY

come together, great things happen.

Genentech | Hemophilia A
A Member of the Roche Group

GenentechHemophilia.com

Let's put science to work



Embracing the Future,
Remembering the Past.

Send us your historical records, clippings, and more from our community's history.

Email content to history@hemophiliafed.org.



Lest We Forget

HFA is preparing to remember the history of the bleeding disorders community and recognize their 25 years serving the community in 2019 with a collection of history. You can help by telling them what you might have to contribute.

Email history@hemophiliafed.org to tell us what you have to share!

OPPORTUNITY FOR WOMEN DIAGNOSED WITH HEMOPHILIA

Created and hosted by HFM
(Hemophilia Foundation of Michigan)

APPLICATION PROCESS OPEN!

Go to www.hfmich.org/conf-apply

2018 National Conference Being Visible: Women with Hemophilia

For women who have hemophilia and/or are symptomatic carriers

November 9-11, 2018
Amway Grand Hotel | Grand Rapids, Michigan

Women who are eligible to join us will experience an amazing weekend learning from national expert health care providers, and have opportunities to connect with other attendees who each bring their own unique wisdom and experience of living with hemophilia.

- There is **NO CHARGE** for this weekend.
- For conference faculty & session information, go to www.hfmich.org/womens-conference
- **Questions?** Contact Patrice Thomas at pthomas@hfmich.org, 734.544.0015.

Founding Sponsor



HFM does not endorse any specific product or company.

Regional Sponsor



Hemophilia Foundation of Michigan exists to enhance the quality of life for all affected by bleeding disorders.

www.hfmich.org

An Easy Way to Give Back to the Community!



**PLEASE NOTE: Our Organization Number has changed for Kroger Community Rewards
New Number is DS729**

Did you know you can support our SWOHF community just by shopping at Kroger? Right now we only have a few families who have signed up for this easy way to support SWOHF for our Kroger shoppers.

To get started, sign up at krogercommunityrewards.com with your Kroger

Plus Card and enter our SWOHF Organization number #DS729 as your organization of choice.

Once you're 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 Community Rewards®.

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.

PUBLISHER

Southwestern Ohio Hemophilia Foundation

EDITOR/DESIGNER

Jessica Steiner

EXECUTIVE DIRECTOR

Kay Clark

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.

SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

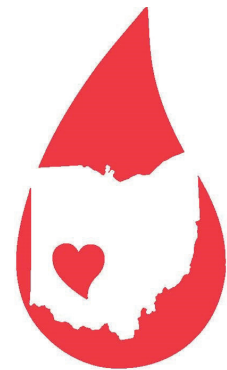
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Moraine, OH 45439

Phone: 937-298-8000

E-mail: info@swohf.org

director@swohf.org



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