

FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

VOLUNTEERS OF THE YEAR!

Congratulations to Jenny & Steve Bostater who were chosen as SWOHF's 2017 Volunteers of the Year and honored at our Annual Meeting. The Bostater family has been involved with the SWOHF community since their son, Paxton, was diagnosed with hemophilia as an infant.

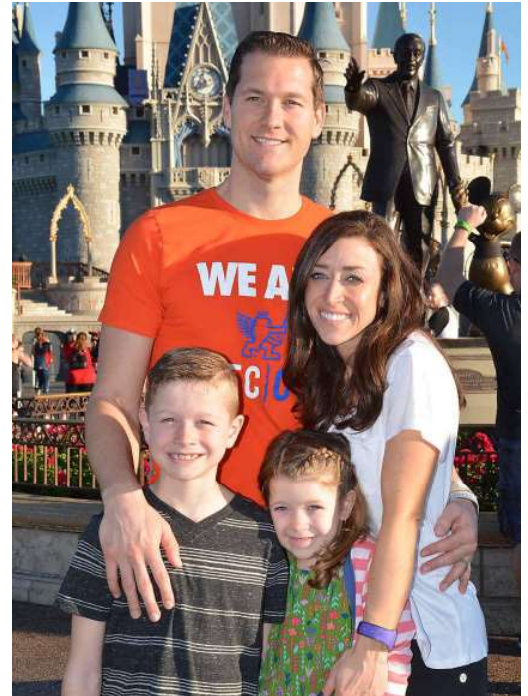
We are thrilled to acknowledge this couple's dedication to SWOHF as they have clearly demonstrated:

A desire to build community and awareness, a desire to share their gifts and talents, and a desire to make a difference!

What has now become our BDA 5K was their vision and they made it happen! That's why it's not surprising to see the entire family standing shoulder to shoulder rallying support for our community at that event.

For the past several years, Jenny and Steve have both given countless hours to assure the success of SWOHF's Evening Out Fundraiser events which raised thousands of dollars for SWOHF's programs! Additionally, Jenny has been on the SWOHF Board of Directors for 7 years and Steve has volunteered at numerous other events

- p.1 **Volunteers of the Year**
 - p.3 **SWOHF Annual Meeting**
 - p.4 **FamOhio Save the Date**
 - p.5 **Coming this Summer**
 - p.6 **Advocacy in Action**
 - p.8 **We Will Never Forget**
 - p.10 **VWD Education**
 - p.11 **Give back at Kroger**
- including Family Fest, Golf Outings and 5K's. Jenny has said, "There are emotional aspects of living with a life-long condition that can only be addressed by the support of a community that walks in your same shoes every day. We are so thankful for this community." Steve & Jenny have shown our community the strength of a family's love. We applaud their dedication and commitment through the years.



In this
ISSUE

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

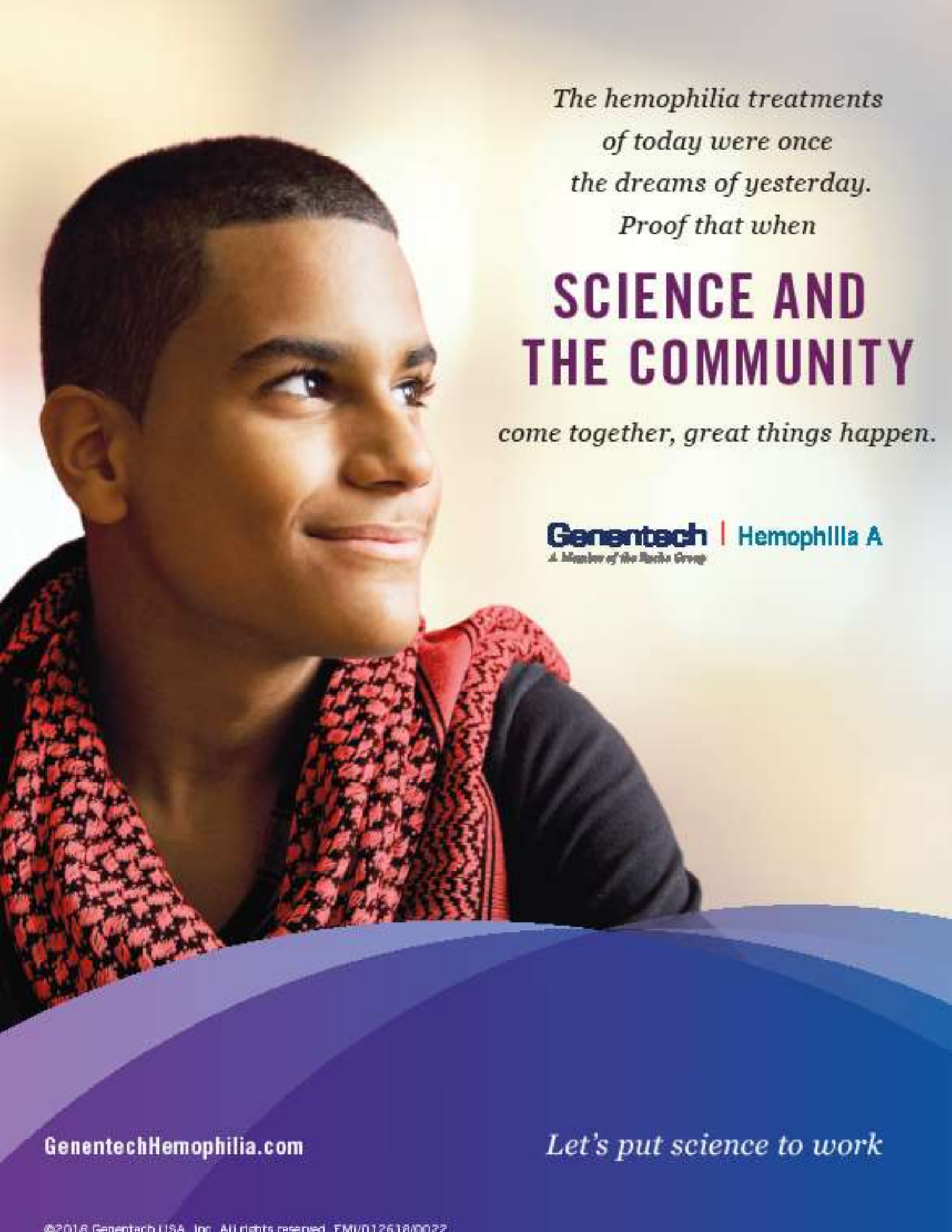
Issue #2 2018

Remembered. Always.

Remember someone
you love in a special way.
Make a gift in their memory.



Special thanks to the Deitsch Family who recently made a gift to SWOHF in memory of Lee's mother, Rosemary. "Rosie" was a loving mother, grandmother and great grandmother and cherished her family. What a wonderful way to honor her love and kindness!



*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

THANK YOU!

WE LOVE
OUR VOLUNTEERS



Our Annual Meeting was held on Saturday, March 3. Many of our Greater Dayton community came to spend the morning together. We enjoyed a delicious waffle bar.

- Vendor displays
- Update from our Dayton Childrens HTC, Sandy Hibner
- Update from Ohio Bleeding Disorders Council, Randi Clites
- Financial and Program Report from Board
- Showing our appreciation for all our 2017 Volunteers with a small gift
- Honoring our VOLUNTEERS of the Year

If you were unable to make it, we want you to know how much we appreciate each and every one of you!

- | | |
|-------------------|----------------|
| Les Zeiter | Jim Elson |
| Matt Sampson | Julie Sampson |
| Lindsey Carlson | Deb Smith |
| Chad Shellabarger | Denise Croley |
| David Brookman | Johanna Miller |
| Eric Shepard | Carolyn Brown |
| Audra Lamb | Steve Brown |
| Nick Lamb | Sheri Neaves |
| Jenny Bostater | Betty Wyatt |
| Steve Bostater | Teresa Howard |
| Tracie Johnson | Katie Justice |
| Daniel Hughs | Suzie Justice |
| Leah Hughs | Marcus Lowen |
| Tanya Hunnewell | Kim Bostater |
| Bill Hunnewell | Shelia Hobbs |
| Sandy Hibner | Leah Shofner |
| Nancy Duffy | Rick Shepard |
| Ellen Poti | Ryan Bostater |
| Jason Poti | Alicia Snyder |
| Andrea Marler | Dena Shepard |
| Rick Bostater | Austin Marler |
| Sarah Wartinger | Mary Miller |
| Chris Marler | Alison Shofner |
| Rena Bucklew | |
| Dan Bucklew | |
| Dick Miller | |
| Paul Clark | |



WE APPRECIATE OUR ANNUAL MEETING SPONSORS!

<<< • SAVE *the* DATE • >>>

FAMOHIO

Together as One

20 | AUGUST | 18
3-5

Columbus Marriot Northwest
5605 Blazer Parkway | Dublin, OH 43017



REGISTRATION OPENS MAY 14TH AT WWW.FAMOHIO.ORG



Pfizer Hemophilia

DEDICATION AND PERSONAL SUPPORT

The Patient Affairs Liaison role was created based on community feedback about the importance of helping to connect patients and caregivers with Pfizer Hemophilia tools and resources.



Working for you—From the home of Motown to the Bluegrass State

Name: Chris Liddell

Home state: Michigan

Fun fact: If I'm watching TV, it's most likely sports-related. Go Tigers!

Ideal vacation spot: Anywhere quiet, unplugged from all electronics

What past experiences can you bring to this job?

I've worked in hemophilia for over 10 years, so I've collaborated with and advocated for different members of this community.



To get in touch with Chris, call Pfizer Hemophilia Connect 1.844.989.HEMO(4366)

What we do:

- ✓ Provide helpful information about Pfizer Hemophilia programs and services
- ✓ Serve as a resource to hemophilia treatment centers to help patients obtain access to Pfizer medicines
- ✓ Serve as a primary point-of-contact for local advocacy groups
- ✓ Participate in local and national events and programs
- ✓ Upon request, meet with patients and caregivers to answer questions related to Pfizer Hemophilia resources

“IT'S IMPORTANT TO CONNECT ON ALL LEVELS: HTC's, PATIENTS, FAMILIES, THE WHOLE COMMUNITY.”

—Chris Liddell

COMING THIS SUMMER!



SWOHF Family Fest Camp

June 22-24, 2018

**Higher Ground
Retreat Center
West Harrison, IN**

REGISTRATION IS NOW OPEN FOR FAMILY FEST 2018!

Check the website at www.swohiohemophilia.org and click on the PROGRAMS/EVENTS tab, then Family Fest for all the educational program info and to pay for registration. This event is sponsored by our industry partners, along with grant funds, and is open to individuals in the Greater Dayton community diagnosed with bleeding disorders and their immediate family members. Space is limited so REGISTER EARLY. Contact SWOHF Office with questions.



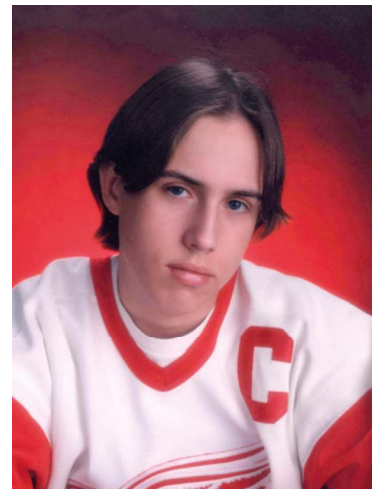
THE BRAD MILLER BIRDIE BUSTERS

Thursday, August 16 2018 at Beavercreek Golf Club

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 Elynn Miller.

Golf Outing to Benefit the Southwestern Ohio Hemophilia Foundation.



**Check the SWOHF
website for
registration for
these events!**

**We look forward to
seeing you!**



ADVOCACY IN ACTION

March was a busy month for SWOHF as community members traveled to Washington DC and to Columbus, Ohio to build awareness and relationships with our lawmakers. Our SWOHF ambassadors used their voice and their story to remind legislators to consider the bleeding disorders community when making important decisions on behalf of the residents of their district.

In Washington, DC, according to our fitness app, we walked 5.7 miles (that's 13,333 steps!) to meet with our Ohio legislators including: Senator Rob Portman, Senator Sherrod Brown, Representative Michael Turner.

This year the two big "talking points" included access to healthcare and maintaining funding for the Hemophilia Treatment Centers (HTC's). With all the proposed changes to healthcare, it is important that people with bleeding disorders are able to maintain adequate insurance coverage. In Columbus, we met with Senator Lehner (District 6, Representative Butler (District 40), Representative Antani (District 42), Representative Strahorn (District 39), Representative Perales (District 73), Senator Hackett (District 10) and Senator Beagle (District 5).

We were reminded that "Advocacy is not just putting on a suit for one day in DC." SWOHF partners with Ohio Bleeding Disorders Council (OBDC) as we work alongside other Ohio chapters and HTC's throughout the year on behalf of the bleeding disorders community. This year in Columbus, OBDC was recognized and applauded from the Floor of the Ohio House of Representatives and the Senate.

The Patient and Parent Advocacy Ambassadors are a small group of trained advocates that work on issues throughout the year that directly impact bleeding disorder patients locally, statewide and federally.

If you are interested in participating in the Advocacy Ambassadors program and representing SWOHF for next year's Advocacy events, please email kay@swohiohemophilia.org or contact Kay Clark in the SWOHF office for more information.



In honor of Bleeding Disorders Awareness Month, Senator Bob Hackett (R-10th District) wore the red tie we had given him.



SWOHF Advocates at Statehouse Day in Columbus, OH

Meet Carol, your CoRe Manager



Hello! I'm Carol DeMatteis and I am a CoRe Manager for Bioverativ. It is my job to connect you with others in the community, introduce our educational programs, and to support you on your journey. I am here so we can take action together! I also have a lifetime of experience living with hemophilia as an affected carrier and as a mom to a son with severe hemophilia.

.....

Contact me!

carol.dematteis@bioverativ.com | 781.663.2110

.....



 Connect with Us @BioverativCoRes

We Will Never

The Hemophilia Memorial Circle



In the early 1980's thousands living with Hemophilia were affected by HIV/AIDS simply by using their treatment product. Through tainted blood and inexcusable inaction, these champions lived with courage, valor and determination. This dark time in our history is filled with pain, anger and incredible loss. As a community, we have worked together to make tremendous strides in the safety of blood products and the protection of those living with bleeding disorders. **We will never forget.**

In 2017, a permanent hemophilia memorial was created within the National AIDS Memorial Grove in San Francisco. They partnered with the National Hemophilia Foundation and the Hemophilia Federation of America to build the memorial which was dedicated in September 2017 and serves as a place where the hemophilia community can grieve and remember those lost during the early days of the AIDS epidemic.

"The tragedy that struck this community is one that cannot be forgotten. It is our duty to find a way to provide a place for people to remember those who lost their lives, and this memorial does just that. We are honored to be able to partner with organizations that share this mission." —Val Bias, CEO, NHF

"This memorial will serve as a permanent reminder of the lives that were lost and will pay tribute to the bravery and activism of a community that has suffered so dearly." -- Kimberly Haugstad, President/CEO, HFA

SWOHF Executive Director, Kay Clark, recently returned from the 2018 NHF Chapter Leadership meeting which was held in San Francisco, California. The location was chosen intentionally to invite Chapter leadership from all across the country to join together at The Hemophilia Memorial Circle in order to remember our past and stand together for our future.

r Forget



A moving address focused on healing was presented by Jeanne White-Ginder, Ryan White's mother, who has been a tireless advocate and champion for HIV-positive hemophilia patients since the early days of Ryan's illness, and has made the realization of this Memorial her life's work.

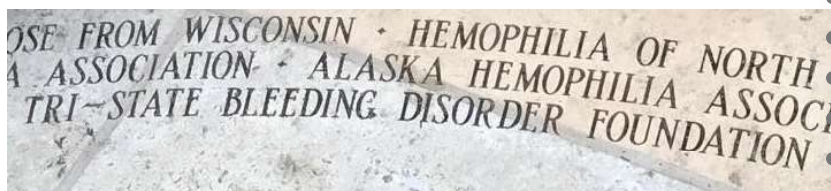
"For decades, I have worked side-by-side with brave and dedicated people to tell Ryan's story and stories of those like him. The construction of this memorial is a long overdue acknowledgment of those in the Hemophilia community who lost their lives so tragically. Our story will be remembered. The Hemophilia Memorial will ensure we never forget those we loved but lost."



The Hemophilia Memorial is engraved with over 200 names of members of the Hemophilia community who have been touched by AIDS including members of the hemophilia community who lost their lives, in addition to their family members and friends. Names also include community leaders and activists to honor their tireless work to ensure that America's blood supply became safe.

Also engraved are names of nationwide hemophilia organizations. The SWOHF Board has recently made arrangements to have our Chapter name engraved at the Hemophilia Memorial Circle to honor courageous individuals in our community and to ensure that the roles played by hemophilia advocates in the early years of the crisis are never forgotten or ignored. Our goal is to preserve our history and pass it on to future generations, to promote continued blood safety and to preserve memories of our fallen heroes.

"Our hearts bled from love, pain and suffering, from fear and isolation. We battled on the fringe. Warriors fighting stigma, ignorance and inaction. We came together, as families, communities and fierce friends, to build community and protect one another. We felt betrayal. We learned resilience. We promise this will never happen again." -Engraving in the Hemophilia Memorial Circle

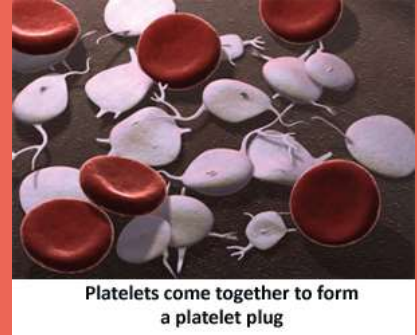


Staff from Hemophilia Foundation Chapters across the USA joined together for a time of remembrance and a celebration of life.

Community Education Night for VonWillebrand Disease

On March 19, many individuals from our community affected by VonWillebrand disease met for an educational dinner “Hello Talk” presented by Shire. Von Willebrand Disease (VWD) is believed to be the most common bleeding disorder. Up to one in every hundred people has VWD. Von Willebrand factor is what allows platelets to stick to the blood vessel wall and to each other. VWD is more likely to cause easy bruising and nosebleeds; women with VWD can have very heavy menstrual periods.

One young woman attending the program remarked at the end of the evening, “I know the statistics say I’m one in a hundred, but tonight I didn’t feel that way.” Response to this event was so positive and encouraging -- we plan to offer more education in the future for families whose lives are impacted by this bleeding disorder.



IT'S THAT TIME OF YEAR!

We want to say “Congrats” to all in our community who are graduating from high school. Many scholarships are available to those within the bleeding disorders community who go on to college or vocational-technical school. While some deadlines for applications have passed, there is still time to apply for the HFA Educational Scholarship, the HFA Parent/Sibling/Child Educational Scholarship, the HFA Medical/Healthcare Services Educational Scholarship and The Kevin Child Scholarship.

For a list of available scholarships, check HFA or NHF website or www.kelleycom.com/scholarships.html to see all scholarships that will be offered in 2019. Here's some that were offered this year.

- Aptevo B More Scholarship
- Shire Education Advantage Scholarship Program
- Hemophilia of North Carolina Educational Scholarships
- Beth Carew Memorial Scholarship
- Hemophilia Foundation of Michigan Academic Scholarship
- BioTek reMEDys Educational Scholarship
- Calvin Dawson Memorial Scholarship

An Easy Way to Give Back to the Community!



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'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

3131 South Dixie Drive #103

Moraine, OH 45439

Phone: 937-298-8000

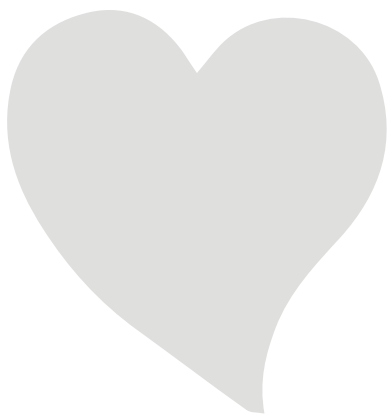
E-mail: info@swohiohemophilia.org



SWOHF

Southwestern Ohio Hemophilia Foundation

Southwestern Ohio Hemophilia Foundation
www.swohiohemophilia.org
3131 South Dixie Drive., Suite 103
Moraine, OH 45439



SWOHF
Southwestern Ohio Hemophilia Foundation