

FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

MARK YOUR CALENDARS!!!

SEPTEMBER 19, 2020

5K Your Way! It's virtual! It's not too late to sign up!

The SWOHF Annual Bleeding Disorder walk celebrates 10 incredible years. We may not be walking together in 2020, but we are still walking and want you to be a part of this milestone event. Please join us to make a difference in the lives of those affected by bleeding disorders.

You can walk anywhere; you can choose anytime. The race fee is \$20, however it is a **BOGO** buy one registration and get one free! Thanks to **Cascade Hemophilia Consortium!**

If you register online before September 12, you will be guaranteed a t-shirt. Post pics on social media for prizes! Practice safe protocols and walk on!

Easy online registration and payment with credit card (\$3 processing fee for each registration) at:

<https://bleedingdisorderawareness5k.itsyourrace.com>

Payment by mail: Make check payable to *Southwestern Ohio Hemophilia Foundation*, mail along with registration form to: *SWOHF 5K, 3131 South Dixie Drive, Suite 103, Moraine, OH 45439*



2020

ISSUE #3

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CHANGES AT SWOHF

Our dear Kay Clark has decided to step down as Executive Director. Kay has decided to spend more time with her lovely family and beautiful grandkids. While we are thrilled for her, she will certainly be missed. Her warm smile and caring demeanor are only a few of the wonderful things about Kay. She has been a tremendous asset to the bleeding disorders community in Southwestern Ohio. We wish you well friend.

The Board of Directors would like to announce that after an exhaustive search we have hired a new Executive Director. Joy Linder has returned to SWOHF. She was our first Executive Director over 20 years ago. She is excited to be back working for the bleeding disorders community and getting reacquainted with some old friends. "It is exciting to see how this community has developed over the years. The same spirit is still here." She recalls attending Family Fest, The Golf Outing, and the K-12 art event among others. We offer Joy a welcome return as she begins her second round of new adventures with us.



**SOUTHWESTERN OHIO
HEMOPHILIA FOUNDATION**

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5k GOING VIRTUAL!

Your Walk - Your Way. Choose your location, date and time. Walk, run or jog with family and friends practicing social distancing. Register by **9/12/20** for T-shirt and special promo. Check website for more info!



Fall Outing at Young's Dairy POSTPONED TO 2021 !

SWOHF 2020 FALL CALENDAR UPDATE



Women's Day Together GOING VIRTUAL?

Ladies, Save the Date!
Saturday November 14
More details to come.

Check website
for updates
www.swohf.org



Contact us:
937-298-8000
Email Joy
joy@swohf.org

FAMILY

EDUCATION

NIGHT

OCTOBER 16, 2020



FOR ADDITIONAL INFORMATION

EMAIL FAMOHIOINFO@GMAIL.COM OR CALL 614- 344- 1075

SAY HELLO TO JAMES

He has hemophilia A and has gone through two major surgeries while keeping to his factor regimen with the support of his hemophilia care team

“RECOVERY WAS TOUGH,
BUT I LEARNED I HAD
MORE SUPPORT THAN
I THOUGHT POSSIBLE.”

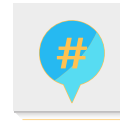


Read stories like James' in
Hello Factor magazine:
BleedingDisorders.com



THINKVWD.COM

SOCIAL CHALLENGE VIDEO



REMEMBER TO #THINKVWD ON ALL YOUR SOCIAL MEDIA CHALLENGE POSTS!

HERE ARE THE 5 STEPS TO PARTICIPATING IN THE CHALLENGE:

1.) COME UP WITH A FUNNY ACRONYM FOR VWD.

Once you come up with a funny acronym, be sure and tell people what VWD actually stands for, which is von Willebrand Disease.

"Velociraptors with Dentures"



2.) PROVIDE PEOPLE WITH A FACT ABOUT VWD

- Please use one of the following facts:
- VWD is the most common inherited bleeding disorders and is underdiagnosed.
 - VWD affects 1 out of every 100 people.
 - Common signs of VWD include frequent or hard to stop nosebleeds, easy bruising & heavy or longer than normal menstrual cycles.

3.) ENCOURAGE PEOPLE TO VISIT THINKVWD.COM

Be sure to say "To Learn More, visit thinkvwd.com!"

4.) RECORD A SHORT VIDEO WITH ALL ABOVE ELEMENTS

Try to make your vide short and sweet - no more than 30 seconds.



5.) POST TO YOUR SOCIAL MEDIA AND CHALLENGE OTHERS TO DO THE SAME.

Post your video on Facebook, Twitter, or Instagram, and call out and tag your friends to take the challenge. Let's make this go viral!

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

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.

SWOHF CARES



SWOHF
SOUTHWESTERN OHIO
HEMOPHILIA FOUNDATION

What is our purpose?

It is to strengthen a caring community for those impacted by bleeding disorders!

Our Values

COMMUNITY: Education, Programs, Special Events and Partnerships like those with the Hemophilia Treatment Center, National Hemophilia Foundation, and the Hemophilia Foundation of America

AWARENESS: Advocacy, Communication via Newsletters, Email, Website, Social Media, Direct Mail

RESOURCEFULNESS: Staff, Industry/Business Partnerships, Fundraising

ENGAGEMENT: Volunteer Opportunities, Board Leadership

SUPPORT: Special Assistance, Camp, Travel Scholarships

This year has obviously been a different experience for us all. Covid has turned the world upside down and our plans have certainly taken a detour. Cancellations and virtual realities are the new norm. However, through it all we remain true to our core values and continue to represent **CARES** as our mantra for serving the bleeding disorders community.

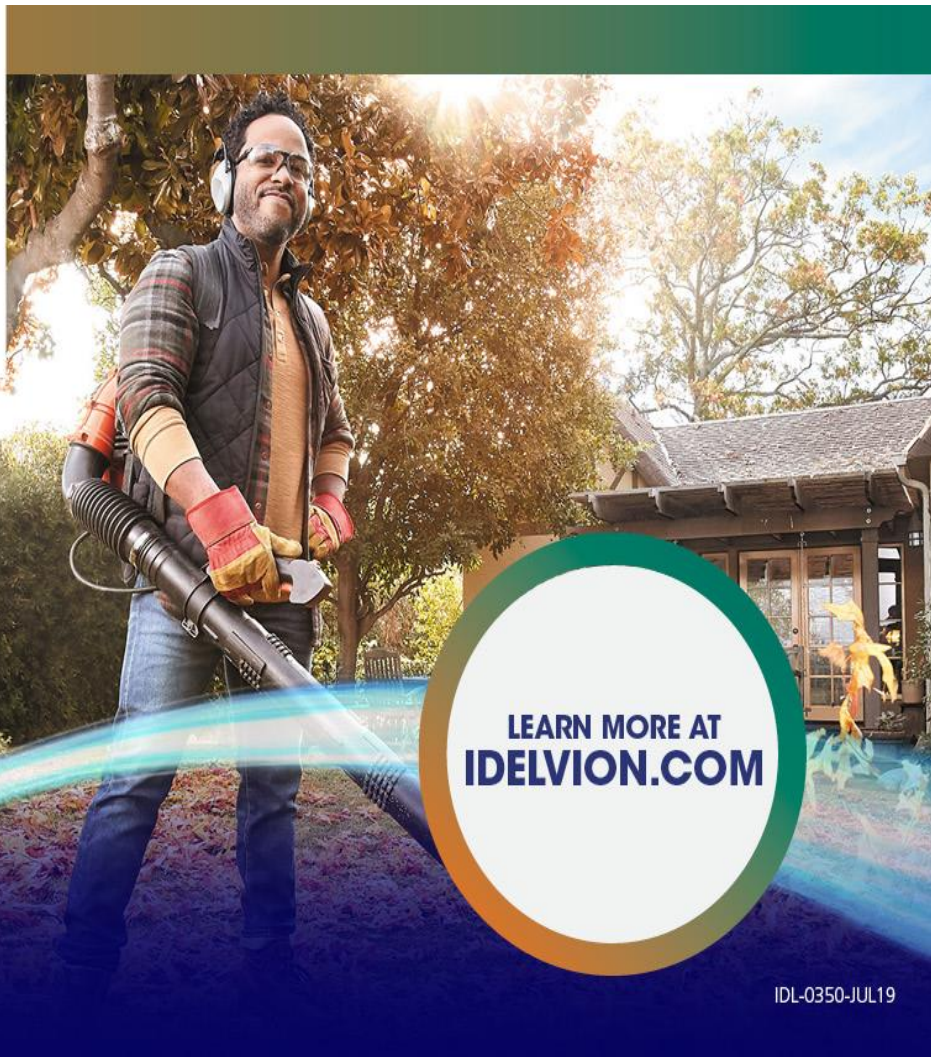


While we may not be able to gather as an in-person community, we continue to be committed to our bleeding disorders family. Our planning may require some out of the box ideas in the short term, but until we meet again, we will reinvent activities and programs to stay connected. Do not forget to join us online when possible and to plan for a future that is full of all the fantastic face-to-face programs that have defined us.



IDELVION[®]

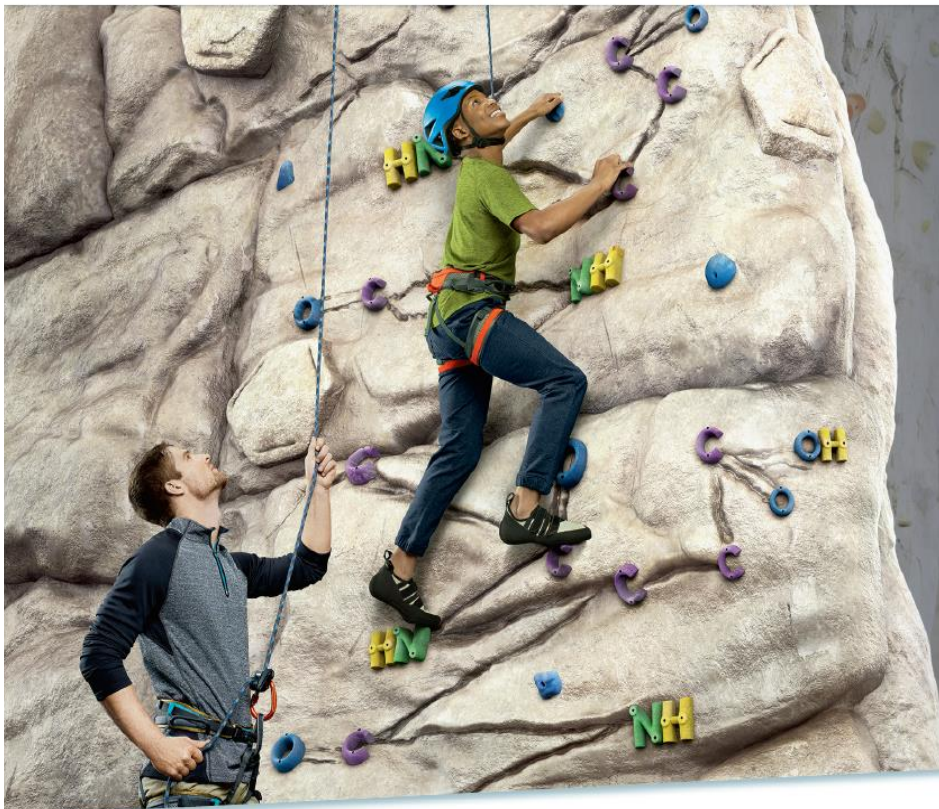
Coagulation Factor IX (Recombinant), Albumin Fusion Protein



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IDL-0350-JUL19

Biotherapies for Life[®] **CSL Behring**



Learn more at
AFSTYLA.COM

AFSTYLA[®]
Antihemophilic Factor
(Recombinant), Single Chain

AFS-0198-JAN18

OHIO BLEEDING DISORDERS COUNCIL

The Ohio Bleeding Disorders Council (OBDC) is a statewide advocacy coalition with the mission to work together to ensure and enhance the quality and accessibility of comprehensive care and services for children and adults with hemophilia and related bleeding disorders through information sharing, public education and advocacy. The OBDC is made up of consumers, five local chapters of the National Hemophilia Foundation and eight regional Hemophilia Treatment Centers.



Ohio Bleeding Disorders Council

HISTORY OF OBDC

Beginning in 1988, the Ohio network of Hemophilia Treatment Centers (HTCs) and chapters came together as the Ohio Hemophilia Action Coalition (OHAC) to promote the interests of Ohioans with hemophilia. The Ohio Department of Health (ODH), which provided direct grant funding to hemophilia treatment centers, also provided staff support and coordination for the coalition, which was very successful and productive.

In 2002, the state of Ohio eliminated the state hemophilia program, including \$1 million in direct funding to support the HTCs and ODH staff dedicated to central coordination and support for OHAC. As a result, the network ceased meeting in an organized way for nearly two years. In October 2004, the network re-convened to discuss a variety of issues of concern to the bleeding disorders community, most importantly the pending funding cuts to federal and state programs. Based on the serious impact of these cuts, the network committed to meet on a regular basis. It elected officers and took the name of "Ohio Bleeding Disorders Council" (OBDC).

OBDC MEMBERS

OBDC members share responsibility for all governance, program activities and fiscal agency responsibilities. The following organizations are involved with OBDC:

National Hemophilia Foundation Chapters

- Central Ohio Chapter of NHF
- Northern Ohio Hemophilia Foundation
- Northwest Ohio Hemophilia Foundation
- Southwestern Ohio Hemophilia Foundation
- Tri-State Bleeding Disorders Foundation

Other Hemophilia-Related Organizations

- FAMOHIO, Inc.
- HHS Hemophilia Region V-East

Hemophilia Treatment Centers

- Akron Children's Hospital
- Cincinnati Children's Hospital Medical Center
- Nationwide Children's Hospital (Columbus)
- Dayton Children's Medical Center
- Northwest Ohio Hemophilia Treatment Center
- Ohio State University Medical Center
- UH Cleveland Medical Center
- University of Cincinnati Medical Center

A man and a woman are jogging together in a park. The man is wearing a blue t-shirt and black shorts, and the woman is wearing a maroon long-sleeved top and maroon leggings. They are both smiling and looking at each other. A large red outline, resembling a stylized leaf or drop shape, is drawn around them. The background shows a green lawn, trees, and a body of water under a clear blue sky.

WE'RE IN THIS TOGETHER.

Sunday 2:16 pm

Jogging in the park
with his girlfriend

Ben, living with
hemophilia A

Not an actual patient

Let's make today brilliant.

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.

bleedingdisorders.com



TOP 10 REASONS

YOU SHOULD WEAR AN EMERGENCY MEDICAL ID

- 1 Medical identification is your voice if you can't speak.
- 2 First responders know who to contact in an emergency.
- 3 Life saving procedures can be explained about your health.
- 4 Medical records can be easily accessed by hospital staff.
- 5 Allergies or medical conditions can be communicated clearly.
- 6 Delays are prevented in life saving treatment.
- 7 Misdiagnosis can be prevented.
- 8 Time is of the essence, identification saves time.
- 9 It looks good on you.
- 10 It is smart!



esperoct[®]
*antihemophilic factor (recombinant),
glycopegylated-exei*

Discover more at [Esperoct.com](https://www.esperoct.com).

HTC CORNER



In collaboration with Dayton Children's HTC, SWOHF has recently switched to a new provider for our Medical ID's. We are happy to announce our partnership with American Medical ID. They offer a great variety of quality products at a discount to Chapters. Additionally, their Customer Service is exceptional, their shipping is fast and their prices are significantly less than MedicAlert (our previous supplier).

Free products are included with every order: An emergency medical ID card, a small ID charm and an exclusive engraved rectangular "InCase" phone ID that easily attaches to your cellphone case or any flat object, such as a suitcase, briefcase or laptop.

SWOHF is grateful for grant funding and donations that facilitate these purchases on behalf of our Greater Dayton Bleeding Disorders Community. So when you go to the HTC for your next visit, you can view sample products available and complete a form to request a new bracelet or necklace according to Chapter guidelines.



[Phone not included]



JOY@SWOHF.ORG



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CONTACT US



WE WANT TO HEAR FROM YOU!

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

Joy Linder

DISCLAIMER

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.

Southwestern Ohio Hemophilia Foundation

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