FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

2022

ISSUE #3

SWEATER WEATHER IS BETTER TOGETHER

There is a chill in the air, so it must mean the Annual Women's Day Together is just around the corner. Join us **Saturday, November 12** from 11:00 a.m. to 3:00 p.m. Once again, we will be coming together at the beautiful and festive Golden Lamb in historic Lebanon, Ohio. Lunch and dessert will be served. We are fortunate to host Anna Bell CFSA, child and family services advocate, who will speak to us on the Mind, Body -Heart Connection and Taking Care of You. These timely messages are certain to inspire new ways of thinking about coping and empowerment. We will also have a wonderful card-creating craft sponsored by Creative Memories. It is such a relief to have a card on hand to say the right thing at the right time and attendees will leave with 12 cards "Made by You." Following our time together, stay to enjoy Main Street Lebanon's "Girls Night Out" for food tastings, holiday previews, prizes and an opportunity to gather and make memories. Can't wait to see you there! Register online at swohf.org by November 4; space is limited.

JUDITH GRAHAM POOL

A TITAN OF RESEARCH! CELEBRATING 50 YEARS!

The National Hemophilia Foundation recently celebrated the 50th anniversary of the Judith Graham Pool (JGP) Postdoctoral Research Fellowship. Since the program's inception, NHF has funded numerous scientists whose projects have produced vital insights into hemophilia and other bleeding disorders. Their commitment to research and the inheritable blood disorders community has laid the groundwork for current advancements in treatments and cures. Along with other chapters across the country, SWOHF is proud to support the JGP Research Fellowship program each year. We couldn't do it without the generous support of our community. Please join us in celebrating the JGP Fellowship and the impact our support has in shaping research for generations to come.

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SUMMER CAMP
MEMORIES 2022

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To shop at AmazonSmile simply go to smile.amazon.com from the web browser on your computer or mobile device. Search "Hemophilia" and scroll down to find Southwestern Ohio Hemophilia Foundation or type in "Southwestern Ohio Hemophilia" and select SWOHF as your charity.

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KROGER COMMUNITY REWARDS

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've 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.

RESEARCH AT DAYTON CHILDREN'S HEMOSTASIS AND THROMBOSIS CENTER

In addition to comprehensive care, the staff at Dayton Children's Hemostasis and Thrombosis Center (HTC) offer research possibilities to those who are interested and who fit the research inclusion criteria. The patients at Dayton Children's HTC have been subjects in many different clinical trials and research studies that have contributed to the development of products such as recombinant hemophilia factor to the current longer acting hemophilia factor products. Hemophilia and other bleeding disorders are rare and therefore research participation from this group is necessary to improve care. Some research is clinical and involves receiving a new product and having labs drawn, whereas others are observational. Observational studies usually involve surveys or chart review for database entry. The number one reason our subjects participate is they want to be a part of developing better care options for themselves and other patients with hemophilia.

Dayton Children's HTC is currently involved in the following studies (more information available at ClinicalTrials.gov on the Novo Nordisk studies):

A Research Study Investigating Mim8 in People with Hemophilia A (Frontier1)

SPONSOR: Novo Nordisk A/S

SUMMARY: This study is investigating how Mim8 works in people with hemophilia A, who either have inhibitors or do not have inhibitors. Mim8 is a new medication that will be used for prevention of bleeding episodes. Mim8 works by replacing the function of the missing clotting factor VIII. Mim8 will be injected with a thin needle in the skin of the stomach, using a pen-injector. This study will last for up to 44 months. It consists of a main phase (part 1 and part 2) and an extension phase. We were only involved in part 2 and the extension phase. In part 2 and the extension phase participants will get and Mim8 injection weekly or monthly.

A Research Study Investigating Mim8 in Adults and Adolescents with Hemophilia A With or Without Inhibitors

SPONSOR: Novo Nordisk

SUMMARY: This study is investigating how Mim8 works compared to other medicines in people with hemophilia A, who either have inhibitors or do not have inhibitors. Mim8 is a new medication that will be used for prevention of bleeding episodes. Mim8 works by replacing the function of the missing clotting factor VIII. When and how often participants will receive Mim8 is dependent on their previous treatment-but is otherwise decided by chance. Mim8 will be injected into a skinfold on the stomach with a thin needle either once a week or once a month. The study will last 54-124 weeks depending on how long participants will be followed in run-in before they start treatment and if they continue in the follow period or transfer to an open label extension study. Participants will have 12-17 clinic visits.

ATHN 10: Leveraging the ATHN dataset to Document the State of Rare Coagulation Disorders in the United States

SPONSOR: American Thrombosis and Hemostasis Network

The main purpose of this project is to document genetic data on the rare blood disorder population. We will test your blood and look at your genotype (also called genetic testing). We will look at your DNA to potentially see what change in your genes is causing your rare bleeding disorder. Disorders that qualify are Factor VII, Platelet Function Disorders, and other rare bleeding disorders. Hemophilia and vWD are not covered in this study.

ATHN Community Counts

SPONSOR: American Thrombosis and Hemostasis Network

The main purpose is to check for inhibitors to factor products. This study is for patients with Hemophilia A and B.

CHAT 1901: Prospective validation of a venous thrombosis risk assessment model in critically ill children from the CHAT Registry. Children’s Hospital Acquired Thrombosis (CHAT)

SPONSOR: Hemostasis and Thrombosis Research Society funded by Takeda Pharmaceuticals

This is a multicenter observational project under the Children’s Hospital-Acquired Thrombosis Consortium. The primary aim of this study is to validate a model that will be able to predict children who are at risk of developing a venous thrombolytic event (VTE). **Inpatient only.**

We also have a few projects on the horizon. Please reach out to the HTC research staff at 937-641-3207 if you have any questions about any of the studies or if you have information on a study you would like to see Dayton Children’s HTC bring to the area.

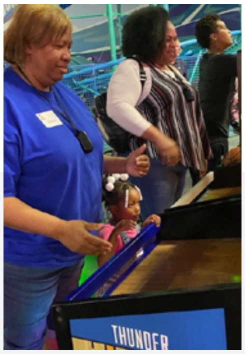
FAMILY FEST 2022

Pivot was the name of the game as the SWOHF Board made the decision to move Family Fest to a local venue and change some existing programming. Family Fest at Higher Ground Conference and Retreat Center has been a mainstay of the Southwestern Ohio Bleeding Disorders community for many years. These fantastic memories we hold in our hearts forever. But with so many enormous changes in our lives as of late, we quickly realized that we must make a change. In doing so, opening the door for a new normal. In a very few weeks we managed to organize something new and spectacular!

Family Fest subsequent edition proved to be a huge success. We had over 102 participants at Scene 75/Dayton Dragons event. Cottrill's Pharmacy provided a fantastic educational program hosted by John Duddleston, Hemophilia A consumer and an Award-Winning endurance athlete. We played energetic games, made some new friends, and created a wellness space that could be emulated in our own homes. The focus of the program was fitness with an emphasis on joint health and mindful mobility--a crucial element in the management of bleeding disorders. It was a well-received message with benefits for us all.

A scrumptious Mexican Buffet was served and then the festivities of Scene 75 were open for all. From the Merry go Round to Glow-in-the-Dark Mini Golf and a million other marvelous activities in between. The Fun was on overdrive! The pictures say it all. Who says you can't have a good time and learn a thing or two in the process?

On Saturday evening, we went to the Dayton Dragons game. Yummy Stadium snacks were on tap, as we rooted for the home team. While the Dragons didn't win that night, it was a glorious celebration of community and a wonderful, although warm, topper to an amazing weekend.



SPECIAL THANKS TO OUR 2022 FAMILY FEST INDUSTRY PARTNERS & PROGRAM SPONSORS

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CONSORTIUM

WE'RE IN THIS TOGETHER.

Friday 6:26 pm
Sharing stories by the campfire with friends

Isaac, living with hemophilia B

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 | Takeda

RECIPIENT OF
2022 BRAD MILLER MEMORIAL SCHOLARSHIP
PATRICK TOLLER

This year the amount of the Brad Miller Memorial Scholarship was raised to $2000 and was awarded by the SWOHF Board to Patrick Toller who is attending Wright State University pursuing a degree in Organizational Leadership.

Patrick's end goal is to one day own his own business. He sees business relationships as a great way to spread awareness of hemophilia for an entire city, state, or country depending on how large the business gets.

Having been diagnosed with hemophilia as a child, he is grateful to have met medical staff who have always been encouraging to him. As a child and teen, he especially enjoyed going to camp and getting to know camp leaders. Patrick states, "These people come to camp talking about how they change the world every day at their jobs which is something I've always wanted to do."

He also wants to impact the next generation of children with bleeding disorders and these are his wise words: "One thing I would like to share to the younger generation is don't let your bleeding disorder limit your options, especially with athletics. You can accomplish any goal. You can always make yourself better. If you want to remain healthy your entire life, then stay in motion. Things that stay in motion remain in motion. Continue to make yourself a better human being every day. Ask yourself: did you make yourself better today? If not, then you lost today, and we don't have very many days to lose."

Certainly when thinking of Brad Miller, we cherish memories from the past. It is clear from Patrick's goals, we are also looking to the future. Providing financial assistance to a deserving student with a bleeding disorder is a way to remember Brad and honor his legacy for years to come. If you have a bleeding disorder and plan to attend college or trade school after high school, watch your email next spring or check our website for more information about the application process and requirements.

LOOKING FOR HIGH SCHOOL TEENS INTERESTED IN LEADERSHIP OPPORTUNITIES

Participate in interactive activities and learn some valuable things along the way about becoming more independent and empowered. Meet new friends with bleeding disorders.

One-hour monthly Zoom meetings will begin in January 2023 culminating in a mystery fun activity in the Fall of 2023.

The first meeting will include both parents and teens to learn more about the program.

No cost involved with this program.

Please register to get on the mailing list for this program. Registering does not commit you to the program. If internet is a difficulty, please note on the Jotform.

Comments from 2022 participants included, "I enjoyed the breakout rooms and talking to others in there." "The games were fun." "I liked meeting new people."

To receive further information, complete the JotForm by scanning this QR code with your phone camera.

Great Lakes Region
Hemophilia Network

Sponsored by the Great Lakes Region Hemophilia Network

Do you know your **on-demand treatment** options for hemophilia A?

Stay informed of product choice by speaking with your doctor and learning more about a prescription treatment option by visiting **OnDemandHemophiliaA.com**

PP-XYN-USA-0496-03 June 2022

Pfizer

NEW BOARD TREASURER

MEET CAROLYN BROWN

SWOHF BOARD TREASURER

Carolyn Brown is an Ohio native. She is married and has two adult children. She loves animals, nature, and gardening, as well as photography...often taking pictures of nature and gardening.

Carolyn has known Dena Shepard, 5K Chair & Board VP, for about 20 years. She first volunteered to help with the SWOHF 5K in 2014. Shortly after that, her mom was granted guardianship of her niece and her half siblings – one was 18 months old at that time and diagnosed with Hemophilia. She was assigned as a back-up caregiver through Children Services to help when needed. This was her first experience with the bleeding disorders community. Ever since then, she has been a volunteer for the 5K.

Carolyn has always been very active with kids sports fundraising and organizing activities.

Once her children both graduated high school, she found herself with a lot of extra free time. She wanted to fill the free time with something that means something--more than just a time filler. So, she went to our SWOHF website and submitted an application to be a volunteer. The Board Vice President contacted her about the Board member opportunity.

Carolyn was originally an “outsider” of this community, but now feels very welcome. She states, “I could not think of a better use of my time than to support this community.”

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HEMOPHILIA FOUNDATION

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.

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