FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

2022

ISSUE #1

ARE YOU FEELING LUCKY?

The SWOHF Casino Night is back! **On May 6th** we will hold our 3rd Casino Night at the beautiful Dayton Woman’s Club in downtown Dayton from 7-11 PM. Please join us for a wonderful night out. Again this year, there will be professional gaming tables, Silent Auction, DJ, Appetizers, Drinks and amazing camaraderie with our community and friends. Ticket cost is $60 per person. **Register by April 1st and receive bonus chips.** Invite your friends and family--it will be a night to remember! You can purchase tickets on our website at *swohf.org/programs-events*

Please remember that SWOHF relies on the generous donations from corporate and industry partner sponsors and individual donors to fund our programs like camp, scholarships, Women’s Day, Family Fest, educational programs, and special assistance. Every bit helps and we thank you for your support!

A JEANIUS IDEA!

JEANS DAY DONATIONS TO SWOHF

Special Thanks to all the team members at The Uhl Agency for wearing jeans in 2021! Each year they choose a charity and then donate the proceeds from their Friday Jean Fund ($1 per person for each week for wearing jeans to work). The Uhl Agency matches the money raised and a contribution is made to a local charity. We are so grateful they chose us!

Does your business have a nonprofit they support? Could you organize a jeans day? Sounds easy, right? Call the SWOHF office for more information.

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HEMOPHILIA FOUNDATION**
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SWOHF
ANNUAL MEETING

GOOD Morning
SWOHF
Thank you!
SPONSORS FOR OUR SWOHF
2022 ANNUAL MEETING

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We were so relieved to have our first live event of the year and hear from the SWOHF Board on the events from 2021 and look to the plans of 2022. Sandy Hibner and Paul and Deb Smith gave a presentation on Gene Therapy; Sandy from the point of view of a research nurse and the Smiths as parents of a child that participated in a gene therapy trial. Cheryl Coffey-HTC nurse and Donna Caires-HTC LSW provided valuable information regarding the HTC. We recognized our incredible volunteers and enjoyed a delicious breakfast from Christopher's Catering. **Thanks to our sponsors and all who attended!**

2021 VOLUNTEERS, WE APPRECIATE YOU!

Office/Mailings
Lisa Geers

5K Committee
Carolyn Brown
Steve Brown
Teresa Howard
Katie Justice
Larry Justice

5K Comm. (cont'd)
Suzi Justice
Barry Linder
Sheri Neaves
Angie Hicks
Denise Croley
Dena Shepard
Betty Wyatt

2021 Board
Cheryl Coffey
Deb Kremer-Smith
Lindsay Carlson
Dena Shepard
Dick Miller
Sandy Hibner
Katie Mullins

Women's Day
Jenny Bostater
Ava Linder

5K Fundraising Teams
Taylor Stebelton
Lindsay Carlson
Dena Shepard

2021 BOARD REPORT

"Small steps back to normal" is how we would describe the year that was 2021. We began the year in hopeful anticipation that in-person events may happen, however just as the world was unsure of when this would be a reality, so were we. The winter and spring months kept us in the virtual space; between the Annual Meeting, Family Fest and several Industry Sponsored Events, we looked at our friends across the screen (certainly not our ideal way to come together, but together at least!)

The stress of COVID life brought an uncommon amount of Special Assistance needs -- reminding us all that we are in this storm together. Fortunately, with consistent grant support, SWOHF was available to fund these extraordinary requests. Once the warm days of summer arrived, so did the opportunity to slowly emerge (albeit at a safe distance) to real-life events. We were able to host the Bombardier Movie at the Neon Theatre, The Bleeding Disorders Awareness 5K, The Fall Outing at Youngs's Dairy Farm and our Women's Day at The Golden Lamb. Then back in hibernation we went.

Here we are, though, together again as a community and enthusiastically and realistically planning for a full calendar year of in-person events in 2022. We are excited to see you and plan for a 2022 that shows our commitment to our strategic plan, providing services to our community.

2022 EVENTS

APRIL

Sanofi Genzyme
World Hemophilia Day Dinner
Wednesday, April 6
Coco's Restaurant

HFA Symposium
Wednesday-Saturday, April 20-23
San Antonio, TX

MAY

SWOHF Evening Out
Casino Night Fundraiser
Friday, May 6
Dayton Woman's Club

HEMA Biologics Dinner
Wednesday, May 18
Location TBD

JUNE

Bayer and Cottrills
Women's Night Event
Thursday, June 16
The Pub at The Greene

JULY

SWOHF Family Fest
Friday-Sunday, July 8-10
Higher Ground Retreat Center
West Harrison, IN

AUGUST

FAMOHIO Annual Conference
Friday-Sunday, August 5-7
Columbus Marriott (TBD)
Columbus, OH

NHF Bleeding Disorders Conference
Thursday-Saturday, August 25-27
Houston, TX

SEPTEMBER

SWOHF Bleeding Disorders Awareness 5K
Saturday, Sept 17
Rice Field
Miamisburg, OH

OCTOBER

SWOHF Fall Outing
Sunday, October 9
Young's Dairy
Yellow Springs, OH

NOVEMBER

SWOHF Women's Day Together
Saturday, November 12
The Golden Lamb Inn
Lebanon, OH

Check swohf.org or the newsletter for updates!

A **ONCE-WEEKLY** TREATMENT OPTION FOR HEMOPHILIA B.

HOW DOES THIS FACTOR IN?

To find out about a prescription option, talk to your doctor or visit **OnceWeeklyForHemophiliaB.com**

February 2021

REMEMBERING
VAL BIAS

NHF MOURNS THE LOSS OF LONG-TIME CEO, VAL BIAS

MARCH 20, 1958 – DEC. 30, 2021

SWOHF joins with NHF and chapters around the country in mourning the death of Val Bias. Val overcame the effects of a bleeding disorder that disabled him as a child and successfully pushed on a national level for better health care for those with hemophilia and HIV/AIDS. Val retired in 2019 as CEO of the National Hemophilia Foundation.

Val was diagnosed with severe Hemophilia B at birth. “He was a boy that liked to play,” his wife Robin Bratton-Bias said, “but he would fall and shatter his kneecaps. He spent a lot of time as a child in hospitals.”

When the first hemophilia summer camp was established, he became a counselor and went on to be the camp’s program director. He developed a leadership program that trained counselors and continued serving as director until he moved to New York City in 2008.

Having contracted hepatitis from blood transfusions and HIV from a clotting factor infusion, he became co-chairman of the National Hemophilia Foundation’s Blood Safety Working Group and encouraged the Federal Drug Administration to mandate testing on all blood donations.

A member of the National Hemophilia Foundation board of trustees, he was sent to Washington, D.C., in 1994 to represent the foundation as a lobbyist. He pressed Congress for a compassionate relief fund for those living with bleeding disorders and HIV/AIDS, which led to the passage of the Ricky Ray Hemophilia Relief Fund Act of 1998.

“It didn’t take him long to understand the politics of D.C.,” said former National Hemophilia Foundation president Mark Skinner. “Very few people have (his) skill set and a personality that can get along with everyone, from congressmen, government agency heads, advocacy group leaders and patients.”

From 1999 to 2003, he was an advocate and consultant on bleeding disorders with the Centers for Disease Control and Prevention in Atlanta and the University of California, San Francisco.

He served as board chairman of the National Hemophilia Foundation in the early 1990s. As the foundation’s CEO from 2008 to 2019, he was in the thick of the debate over health care reform. He pushed strongly to provide insurance for those with pre-existing conditions in the Affordable Care Act and to eliminate caps on lifetime coverage. His colleagues at NHF said his biggest achievement came in 2009 with the creation of ACT (Access to Care Today, Achieving Cures Tomorrow), which strengthened the organization at the local chapter level and encouraged research. He led the creation of a program offering free genetic testing for people with hemophilia to confirm potential carriers of the disorder.

A celebration of his life is planned this spring in the Hemophilia Memorial Circle, which he helped establish in memory of those with hemophilia who lost their lives to AIDS, in the National AIDS Memorial Grove in San Francisco’s Golden Gate Park.

THE FUTURE OF HEMOPHILIA CARE AND TREATMENT

“A world without bleeding disorders begins with research” (National Hemophilia Foundation (NHF), 2022). Most agree that research is the engine that moves the train forward to better treatments and ultimately a cure for hemophilia and other inherited blood disorders. Accordingly, the NHF has made the commitment to engage the patient-community to best determine what research is most desirable to bring lasting betterment to their lives. Leonard Valentino, MD, CEO of the NHF, “The National Hemophilia Foundation, as the largest national organization dedicated to improving lives for people with inherited bleeding disorders, is embracing our role, and responsibility, to champion this effort and serve as the conduit through which the research and patient community can come together to create a national blueprint of patient-centered research with quantifiable outcomes” (NHF, 2022).

With this initiative in mind, members of the Southwestern Ohio Hemophilia Foundation (SWOHF) board and Dayton Children’s Hemostasis and Thrombosis Center (HTC) staff are collaborating to provide a series of articles regarding research. These articles will appear in each of the quarterly newsletters in 2022.

Many of you are involved in research studies and clinical trials at the HTC either presently or in the past. Your involvement and commitment are most appreciated. Granting permission to enroll in a research study is a thought-provoking decision and one that should be considered very carefully. An enrollee gives informed consent only after being informed about all aspects of the trial including the steps of the trial and all possible risks and benefits. The informed consent process is extensive and will be reviewed in detail in a future article.

People choose to become involved in a clinical trial or research study for many different valid reasons. Some agree in order to obtain needed treatment at no or minimal cost, some are interested in the detailed tests and/or frequent check-ups required, and many simply express a true altruistic motive; the desire to help improve treatments for those in the future. Whatever the motivation, when one chooses to participate in a clinical trial, one becomes a partner in scientific discovery. Major medical breakthroughs could not happen without the generosity of clinical trial participants (NIH, 2022).

References

Study Types in Research - Bing images
https://www.bing.com/images/search?q=Study+Types+in+Research&mmreqh=C5yJLZyJmP6E7fjmsqjXZwGgwOhxpp1%2fPI4NYBX02AU%3d&form=INLIRS&first=1&tsc=ImageHoverTitle

What Are Clinical Trials and Studies? | National Institute on Aging (nih.gov)
https://www.nia.nih.gov/health/what-are-clinical-trials-and-studies

Research | National Hemophilia Foundation
https://www.hemophilia.org/research

What Are the Different Types of Clinical Research? | FDA
https://www.fda.gov/patients/clinical-trials-what-patients-need-know/what-are-different-types-clinical-research

RESEARCH STUDIES AND CLINICAL TRIALS

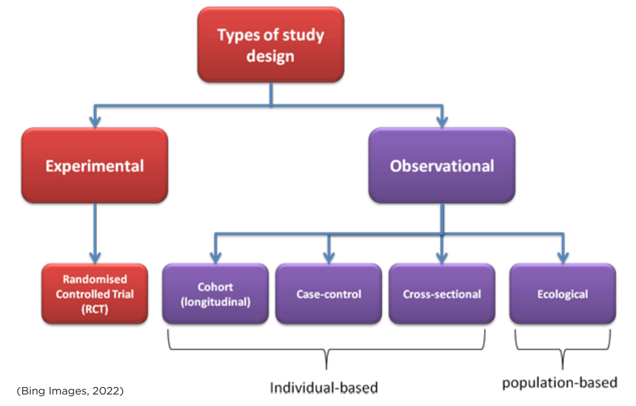
What exactly is a research study? A research study is a process designed to evaluate the effects of interventions on health-related biomedical or behavioral outcomes. A variety of different types of research studies are used to investigate a hypothesis, prove safety and efficacy of a treatment or drug, gain general information on a specific subject or even to gather opinions.

Clinical research is medical research involving people. There are two types, observational studies and clinical trials.

Observational studies observe selected people in normal settings. Researchers gather information, group volunteers according to broad characteristics, and compare changes over time. For example, researchers may collect data through medical exams, tests, or questionnaires about a group of people with bleeding disorders over time to learn more about the effects of different lifestyles on joint health. These studies may help identify new possibilities for clinical trials.

Clinical trials are research studies performed in people that with the goal of evaluating medical, surgical, or behavioral interventions. They are the primary way that researchers find out if a new treatment, like a new drug or diet or medical device (for example, hemophilia factor) is safe and effective in people. Often a clinical trial is used to learn if a new treatment is more effective and/or has less harmful side-effects than the standard treatment (National Institute of Health (NIH), 2022)."

Both experimental (clinical trials) and observational studies are further divided into which design method is utilized. The following diagram demonstrates the different types of design methods.



(Bing Images, 2022)

PHASES OF CLINICAL TRIALS

Clinical trials are divided into phases that occur in orderly fashion. There are rules and regulations for each phase of the clinical trial process.

- **Pre-Clinical** – Performed in a lab, generally with animal models
  - Goal: determine safety, toxicities, and major side effects
- **Phase 1** – Small group of people for the first time, sometimes using healthy volunteers
  - Goal: determine safety, dose, and identify side effects
- **Phase 2** – Large groups of people affected by the disease/condition being studied
  - Goal: determine effectiveness and further study safety
- **Phase 3** – Larger groups of people affected by the disease/condition being studied
  - Goal: confirm effectiveness, monitor side-effects, compare standard or similar treatment
- **Phase 4** – Post marketing analysis using subjects using the product or treatment
  - Goal: follow-up on side-effects, efficacy, use, and cost

Approval of a drug or treatment generally takes about eight years; however, many trials fail and are then shut down. Some most marketing follow-up data collections continue for decades.

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Factor My Way Events

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Factor My Way Learning

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Join Today! factormyway.com

For personalized assistance, contact your local Octapharma Representative:

Bri Vieke

Phone | 551.502.7007

E-mail | briana.vieke@octapharma.com

"I have a passion for making a difference. As a Patient Experience Manager at Octapharma, I get to do that every day! I am dedicated to providing education and support for people living with bleeding disorders and their families. I'm proud to work for a company that shares the same mission and commitment to making a difference in the bleeding disorders community."

Date of preparation: 8/2021. NUW-0415-CAD

octapharma

CAMP BOLD EAGLE

For children with bleeding disorders, camp is a place where they can learn the valuable skills they need to become independent teens and adults. They will learn from each other and from their counselors (many of whom live with bleeding disorders themselves) about ways to manage their disorder both medically and socially. 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. For more information about camp opportunities and requirements, check out the Hemophilia Foundation of Michigan's website at *https://hfmich.org/camp*

Camp Bold Eagle registration is open now! SWOHF and Dayton Children's HTC partner to make going to camp a wonderful experience for your child. For directions regarding the application process, please contact Joy Linder, Executive Director SWOHF via email at *joy@swohf.org* **by May 18, 2022**. Once the application is submitted through the HTC as required, SWOHF will make travel arrangements for campers as well as processing scholarships provided through grant funding and generous supporters. If you have questions, contact the SWOHF office at 937-298-8000.

SESSION 1: (Ages 6-9) 5 days, 4 nights (July 10-15, 2022)

SESSION 2: (Ages 10-12) 7 days, 6 nights (July 17-23, 2022)

TEEN CAMP: (Ages 13-17) 7 days, 6 nights (June 26-July 2, 2022)

BECOME AN ADVOCATE!

There is so much change in healthcare access in both Ohio and in Congress. Patient voices have never been so important at the decision-making table. Sharing your story to impact change is very empowering.

Randi Clites was recently recognized at the 2021 Rare Voice Awards as a Finalist in the State Advocacy Patient/Organization category by the EveryLife Foundation for Rare Diseases. Nominations were made by the rare disease community for their amazing advocates who give rare disease patients a voice in government and have worked to create and pass state legislation.

Randi became an advocate for affordable access to healthcare for medically fragile children when her son Colton was born in 2002 with hemophilia and also diagnosed with leukemia a short time later. She began her advocacy efforts chairing the parent advisory councils at both Akron Children's Hospital and Ohio's Title V Program – Children with Medical Handicaps. In 2012, she represented Ohio as a Family Scholar for the Association of Maternal and Child Health Program. She has been the advocacy coordinator for a coalition of providers, patients, and non-profits serving bleeding disorders patients for over 10 years. She joined the Little Hercules Foundation in 2021 as the Rare Disease Policy Director, after taking her passion of working on policy to public office, serving as State Representative for the 75th Ohio House District in 2019-2020. While serving she was able to pass legislation to establish a Rare Disease Advisory Council.

Congratulations, Randi!

ADVOCACY
WASHINGTON DAYS

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Virtual **Washington Days** was held the first week of March. Once again families affected by bleeding disorders appealed to the representatives across the country to address the needs faced by so many in the community. The main issue remains -STOP Co-pay accumulator adjustor policy (CAAP). This plan can be thwarted by regulating insurers practices so that #ALLCopays Count. Support bleeding disorder programs at CDC, NIH, and HRSA. They help ensure that specialized care is accessible to our community.

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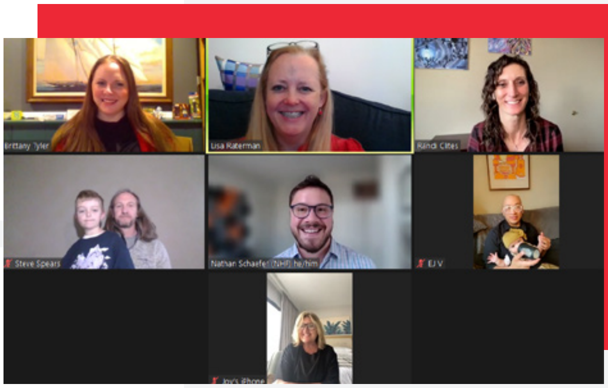

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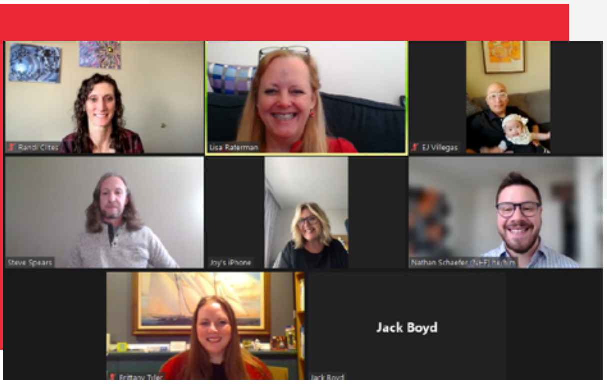

Save the Date!

FAMOHIO

& better than ever!
Back in person

FAMOHIO Conference
August 5th - 7th 2022

For additional information

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

MEDICAL ID'S

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]

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SWOHF
SOUTHWESTERN OHIO
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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