

BLOOD TIES

Tri-State Bleeding Disorder Foundation

| 635 W. Seventh Street

| Suite 407

| Cincinnati, OH 45203

2nd Edition 2022



Our Mission

Tri-State Bleeding Disorder Foundation is a chapter of the National Hemophilia Foundation, which is dedicated to finding better treatments and cures for bleeding and clotting disorders and to preventing the complications of these disorders through education, advocacy and research.

Dear TSBDF Friends and Family,

The end 2022 has brought several great events to our community. We had a wonderful Ask-the-Doctor educational program at the Phoenix in November. The young adults in our region enjoyed a day filled with networking, education and fun at Top Golf in October.

We had a great Unite for Bleeding Disorders Walk in August and we are already looking forward to the next walk in 2023. This past spring, our Board of Directors met to develop strategic goals and objectives for our foundation and we discussed plans for updating and redesigning our website. We are excited that the development of our new website is coming soon. The new website is easier to navigate. It will allow for easy online registration for our events, online donations, as well as on-line scholarship applications. We would like to thank board member, Alex Yastrebenetsky, for his generous support of the development of our new website. Visit TSBDF.com to check out the new website when it is available.

We look forward to the New Year in 2023 and look forward to more opportunities for our bleeding disorders community to connect and learn together in the coming year.

Best wishes to you and your families during this holiday season.

Sincerely,
Lisa Littner
President
TSBDF Board of Directors



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2023 Calendar of Events

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Busy Lane Duck Session and Medicaid Managed Care Launch on Deck for Remainder of 2022

BY DANNY HURLEY

With only a handful of session days scheduled after the November Election, Ohio lawmakers are planning to tackle several controversial issues in a short amount of time. High profile issues include a statewide abortion ban, legislation regarding gender affirming care and participation in youth sports by transgender athletes, and a bill to limit teaching of 'divisive concepts' in Ohio schools. OBDC's top priority is enactment of House Bill 135, which is sponsored by State Representatives Susan Manchester (R-Waynesfield) and Thomas West (D-Canton). The bill, which passed the Ohio House of Representatives unanimously in March, would prohibit the use of copay accumulator programs by health plans. Under these programs, health plans will allow copay assistance to be used by a patient but will not apply that assistance to a patient's deductible. It's all hands on deck to get this bill through the Senate this year.

The Ohio Department of Medicaid (ODM) will also be wrapping up their multi-year effort to redesign and reform Ohio's managed care program with the launch of three new plans. ODM began revamping its managed care program in 2019 with a series of listening sessions and meetings around the state. Requests for proposals were released in 2020 and contracts were awarded for vendors in 2021. ODM is implementing key elements of the new program on a staggered basis with December 1st being the last and most notable launch date. On July 1st, ODM launched OhioRISE, a statewide pediatric behavioral health network managed by Aetna; an estimated 60,000 Ohio kids will be served by this program. October 1st saw the start date for the new single statewide pharmacy benefit manager (SPBM) for all managed care patients; ODM selected Gainwell Technologies to serve as the SPBM.

Finally, on December 1st three new managed care plans came online (AmeriHealth Caritas, Anthem, and Humana), joining the four existing plans (Buckeye, CareSource, Molina, United). Additionally, Gainwell will launch a fiscal intermediary function that will allow providers to submit claims and prior authorization requests to a single entity (as opposed to each managed care plan). Overall, these reforms are meant to improve patient experience and service while also easing administrative burdens for providers. ODM will also be releasing details later this year on next year's anticipated redetermination process for Medicaid enrollees. During the COVID-19 pandemic, states were prohibited from removing individuals from Medicaid if their eligibility changed; with the looming expiration of the public health emergency (PHE), Ohio will need to review eligibility for more than 3 million enrollees.

"Overall, these reforms are meant to improve patient experience and service while also easing administrative burdens for providers."

Science Corner

BY RALPH GRUPPO, MD

Gene therapy by BioMarin Pharmaceutical Inc. gains conditional approval for the treatment of Hemophilia A patients in Europe

On August 24, 2022, BioMarin Pharmaceutical Inc. received conditional approval for their gene therapy product valoctocogene roxaparvovec (Roctavian TM) in Europe for the treatment of severe hemophilia A. Approval was granted for adults with no history of FVIII inhibitors and without detectable antibodies to adeno-associated virus serotype 5 (AAV5), the virus vector that carries the Factor VIII gene into the liver cells. In the last issue of Blood Ties the results of BioMarin's Factor VIII gene therapy trial were discussed. Up to 84% of the participants had a significant and sustained rise in Factor VIII levels and were able to discontinue prophylactic Factor VIII infusion therapy. The only significant side effect was a transient rise in liver enzyme levels without associated symptoms. Enzyme levels returned to normal after treatment with steroids or other immune suppression. The average Factor VIII level in the study participants one year after gene therapy was 42% and at two years was 24% demonstrating a gradual fall-off of Factor VIII levels seen over time in most patients.

It was recently announced that the U.S. FDA has now accepted a resubmitted license application from BioMarin and is expected to decide in 2023 on whether or not to approve Roctavian for use in the U.S. BioMarin first requested FDA approval of Roctavian in 2020, but the agency delayed their decision, requesting additional clinical trial data over a longer time period. The resubmitted application now includes two-years of data from its gene therapy trial, as well as five-years of data from a smaller early phase study.

First Gene Therapy for Hemophilia B under review by regulatory authorities in the U.S. and Europe

Earlier this year in May 2022, CSL Behring announced that the U.S. Food and Drug Administration (FDA) had accepted its license application for priority review for etranacogene dezaparvec (ExtranaDez), an investigational gene therapy for the treatment of adults with hemophilia B. The application is supported by results from the pivotal HOPE-B clinical trial, which was last presented at the International Society of Thrombosis and Haemostasis July 2021. The trial uses a modified non-infectious virus called a “vector” that can enter liver cells and carry genetic instructions for producing Factor IX. The vector is an adeno-associated virus called AAV and carries a variant of the Factor IX gene, FIX-Padua, which generates Factor IX protein that is 5-8 times more active than normal. Earlier studies showed that this AAV5-based gene therapy may be clinically effective in a large percentage of hemophilia B patients with pre-existing antibodies to AAV vectors. The Phase III HOPE-B trial evaluated 54 severe/moderate adult hemophilia B patients with/without pre-existing antibodies to AAV5 requiring prophylactic Factor IX infusions. A total of 53 patients completed the study. The results demonstrated that gene therapy resulted in an average Factor IX activity of 39% at 6 months and 37% at 18 months without a fall-off of activity over time and without the need for prophylactic immunosuppression. A total of 98% of the subjects treated discontinued prophylaxis. The majority of adverse events related to the study drug were considered mild. A similar regulatory application was also recently accepted by the European Medicines Agency (EMA) with an accelerated estimated review of about 5 months from the date of application.

Q&A Resource on Shared Decision Making and Gene Therapy

As investigational hemophilia gene therapies move closer to FDA approval, it has been recognized that people with hemophilia and their hemophilia physicians and other health care providers at the treatment center must share in the decision-making process regarding participation in gene therapy.

Differences from patient to patient in the ability to understand complicated medical information about gene therapy may make it difficult for persons with hemophilia to make an informed decision about proceeding with this potentially life-changing therapy. The flood of information on social media (often inaccurate and contradictory), plus direct-to-patient marketing, may also hinder informed decision making. In addition, the health care provider’s perception of what the patient understands may not accurately reflect what the patient actually understands. All of these factors may play a role in the ability of the patient, in collaboration with his health care provider, from making a truly shared informed decision about participating in gene therapy.

In light of these obstacles to informed shared decision-making, an international and multidisciplinary group known as the Council of the Hemophilia Community (CHC) was assembled. The group was composed of independent advisors, hemophilia care providers, and industry and patient representatives. The goal was to fill these information gaps about hemophilia gene therapy through the development of a resource that could help stimulate a discussion between persons with hemophilia and their health care providers.

Three roundtable meetings were held between November 2020 and May 2021. A series of questions and answers were developed which were meant to stimulate discussion about treatment regimens and adherence requirements, treatment predictability and variability, treatment durability (how long the effects of gene therapy will last), and the risks and benefits of participation.

Each of the questions were subsequently assigned to the five stages of the patient “decision making journey.” These included 1) Pre-gene therapy information seeking 2) Pre-gene therapy decision making 3) Treatment initiation 4) Short-term post-gene therapy follow up (less than one year since receiving gene therapy) 5) Long-term gene therapy follow up (more than one year after receiving gene therapy).

A recent paper published online in the journal Patient Preference and Adherence (PPA), describes in greater detail the process of developing this resource. You can access the article “The Hemophilia Gene Therapy Patient Journey: Questions and Answers for Shared Decision-Making” by entering the following into your web browser address bar:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9191577/>

Wang M, et al. The Hemophilia Gene Therapy Patient Journey: Questions and Answers for Shared Decision-Making. Patient Prefer Adherence. 2022 Jun 9;16:1439-1447.



Saturday 1:22 pm
Swinging in the
backyard with mom
Evan, living with
hemophilia A

Not an actual patient

WE'RE IN THIS TOGETHER.

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



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Cincinnati Unite Walk Celebrates 5 years

On August 20th more than 125 people came together at Mt. Echo Park to celebrate 5 years of Unite Walks – and once again we couldn't have asked for better weather! And that view, wow!

The following awards were given out during the Walk ceremony. These numbers are based on registered participants and donations as of Friday evening.

Our top 3 teams by way of registered participants who raised an average of \$25 per person were:

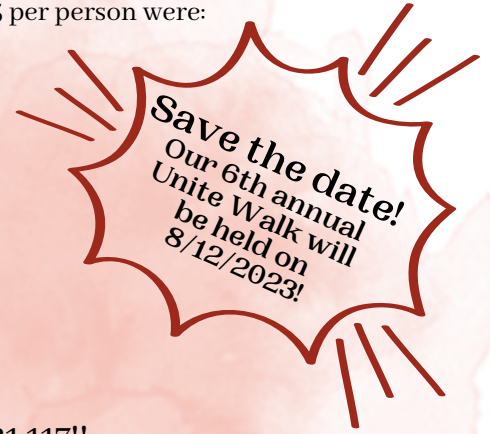
- 3rd place with 7 walkers - Tiffany's ITP Journey
- 2nd place with 8 walkers - The Yaeger Family
- And our 1st place team with 14 walkers is Team Clark

Our top 3 individual fundraisers were:

- 3rd place with \$800 raised - Les Gunzenhauser
- 2nd place with \$1,725 raised - Lindsey Long
- And in 1st place individual with \$3,100 raised is Lindsay Schulte

Our top 3 team fundraisers were:

- 3rd place with \$1,350 raised - Team Gunz Walkers
- 2nd place with \$1,725 raised - Lions, and Tigers and Bears
- 1st place, with \$3,100 raised - Bryn 13



We had 135 participants and raised \$21,117!!

Over these 5 years we have raised more than \$80,000 for our local programs and services...and could not have done it without you.



Dr. Les Gunzenhaeuser



Team Gunzenhaeuser



3rd Place Team Tiffany's ITP Journey



1st Place Individual Lindsay Schulte



2nd Place Team Yaeger



1st Place Team Clark



TSBDF Events

Insurance basics

Premium: The amount you pay for your health insurance every month.

Open Enrollment Period: The one time of year when you can enroll in health insurance or change your existing plan.

Covered Benefit: A service that your insurance company has approved and agreed to pay for.



TSBDF Insurance Education Program 9/8/22

Cincinnati Children's Hemophilia Treatment Center sponsored the Insurance Education Dinner on Thursday, September 8th at Maggiano's. Attendees heard from a panel from CCHMC including Lisa Littner, Tracy Matheny, and Stacie Johnson. The presentation offered great insurance information for those living with a bleeding disorder.

TSBDF Hemophilia Education Program 9/21/22

Genentech sponsored a Hemophilia Education Program on Wednesday, September 21st at Montgomery Inn. Attendees learned about Hemlibra and heard from the mom of two patients who are now taking Hemlibra about their experience switching to the product.



TSBDF Transitioning Youth with Hemophilia Towards Independence 10/12/22

This educational program was sponsored by Bayer on Wednesday, October 12th at Trio Bistro. The presentation offered great information for parents of youth living with Hemophilia to empower their children towards independence while managing their bleeding disorder.



TSBDF Becoming Your Own Best Advocate 10/4/22

Novo Nordisk sponsored an educational program on Tuesday, October 4th at Montgomery Inn Boathouse. The presentation gave great tips to Becoming Your Own Best Advocate living with a bleeding disorder in any situation.

TSBDF Young Adult Program

We held our Young Adult Program at Topgolf on Saturday, October 29th. This program was for anyone with a bleeding disorder ages 18-26. Dr. Kristine Karkoska from UC's HTC presented a great interactive program on what this group will need to know as they transition to the adult HTC.

Education was followed by a few hours of golf with friends. Thank you to everyone who joined us. We can't wait for the next program!

This program was made possible by a grant from the Hemophilia Alliance Foundation.



Thank You to Our Donors

We would like to thank everyone that has contributed to Tri-State Bleeding Disorder Foundation. You have helped to make TSBDF a source of education and support for the bleeding disorder community. This page is only a small token of our appreciation for everyone's contributions, whether they are financial, in kind, or other.

We truly appreciate all that you have given!

ORGANIZATIONAL CONTRIBUTORS

\$15,000 & Up
Sanofi Genzyme

\$10,000 & Up
Bayer Healthcare
CSL Behring
Novo Nordisk

\$5,000 & Up
CCHMC HTC
Genentech USA
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Keith and Victoria Peterson
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\$200-\$499

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Mari Cappel
Kim Dunn
Daniel and Amy Ferguson
Sarah Ferrick
Susan Fine
Dr. Jacob Gunzenhaeuser
Thomas Kropfeld
Lisa Littner
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Haibo Wang

\$100-\$199

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Stacy Bond

Sandy Bond

Tiffany Bond

Glenn Boone

Karl Boppel

Dana and Ryan Brady

Eric Brock

Michele Bunke

Melany Byrd

Rachel Capone

Katie Caster

Natasha Danzilo

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Anita Doyle

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Emily Shade

Michelle Sparto

April Sprague

Marie Stone

Ashley Sulek

Susan Tebbe

June Tebbe

Christian Tucker

Jessica Walker

Tiffany Weigle

Lisa White

Christian Wood

Ann Yaeger

Andrea Yaeger

Donations listed are from 12/21-11/22

TSBDF Scholarship Recipients

Avery Daniels 2022 Gina Stack Scholarship

Q: What are your plans for furthering your education?

A: I am attending Indiana University to study nursing

Q: What experiences have led to you to further your education and future career goals?

A: I am inspired to further my education specifically in nursing for a few reasons. First, my family is full of healthcare providers, my mom and dad both work in the field and even my grandma was a nurse! Within nursing, my goal is to eventually focus specifically on oncology which I have become passionate about since attending Cincinnati Children's Cancer and Blood Disease camp at Camp Joy with my younger brother.

Q: How has having a family member with a bleeding disorder impacted your educational experience?

A: Having a sibling with hemophilia has taught me so many things that I wouldn't have ever learned if he were not affected. I get to witness daily the way he lives his life with the disorder and have even learned of my chances of being a carrier and someday having children of my own who could possibly be affected. Learning how the genetic disorder works and runs through the family is fascinating!

Q: What have been the challenges that you experienced with having a family member with a bleeding disorder?

A: I have only witnessed challenges through my brother living with the disorder. Some challenges for him include having to make decisions based on his condition. For example, not being able to pursue certain sports because of the potential risks. Likewise, seeing him infuse factor and/or make trips to the hospital to be infused has been a challenge. Although I haven't had to face any challenges thus far, challenges could arise in my future family with my potential in being a carrier of the disorder.

Q: What have been the positive aspects of having a bleeding disorder (or having a family member with a bleeding disorder)?

A: Although my brother lives his life with hemophilia, there are certain things that are positive from it. Thanks to Cincinnati Children's and TSBDF, my brother and I were able to attend Camp Joy together for four years. The Tri-State Bleeding Disorder Foundation also does a lot for our family including various educational events to keep our family involved and connected. One of the most positive things about being around my brother's bleeding disorder is that it has heavily influenced my chosen career path!

Lindsey Long 2022 TD Hughes Scholarship

Q: What are your plans for furthering your education?

A: I'm currently working on my second post-graduate certificate at the University of Cincinnati. I have a bachelor's degree in Spanish Language and Literature, a bachelor's degree in Secondary Education, a master's degree in Secondary Education Curriculum and Instruction, a post-graduate certificate for Teachers of Spanish and French and am working towards another post-graduate certificate in Educational Leadership for my principal licensure. I plan to graduate in the spring in 2023.

Q: What experiences have led to you to further your education and future career goals?

A: I've been a Spanish teacher for the past sixteen years. However, raising three sons, it was important to me to make a career move to better support my family. I've accepted the position as Dean of Students at William Henry Harrison for the 2022-2023 school year. This administrative position will allow me the opportunity to work and give back to the community in which I live, and better serve my family's needs. This certificate program in Educational Leadership will open the door for future roles in high school administration.

Q: How has having a bleeding disorder (or having a family member with a bleeding disorder) impacted your educational experience?

A: Having twin four-year old sons with hemophilia has vastly changed my view of education and my educational goals. In the last four years our lives have changed significantly. Though teaching is a great job to have while raising a family, it has been a challenge to balance the inflexibility provided by hemophilia, with the consistent routine required in an educational setting. After the twins were diagnosed, I wanted to learn more about things that impacted our family, and truly began to value everything I've learned from my experiences as an educator. I've found my voice and now want to use it to meet the needs of students in my community through a role in administration.

Q: What have been the challenges that you experienced with have family members with a bleeding disorder?

A: As a mom of twins with hemophilia we've experienced many challenges. We've had to learn to advocate, educate, and support our children (including our son without hemophilia) through a medical lens we were lucky to not have known existed prior to their diagnoses. In addition, one of our sons with hemophilia also has cerebral palsy and Coats' disease (a rare retinal condition). Learning to deal with hemophilia is challenging, but we were diagnosed with two hemophiliacs, at the same time, that bleed differently. Our child with cerebral palsy and Coats' disease is impacted by hemophilia daily. Even simple measurements at weekly physical therapy appointments can have ramifications if not modified. We've had to learn to live on our toes, but not in a bubble, and that there isn't such thing as routine when it comes to raising children with complex and rare diseases/disorders.

Q: What have been the positive aspects of having a family member with a bleeding disorder?

A: The most positive aspect of raising children with a bleeding disorder is that we've been embraced by a community of warriors. The Tri-State Bleeding Disorder Foundation and the HTC community at Cincinnati Children's Hospital have not only given us hope but have afforded us a purpose to give back. We've learned how to find our voices, how to advocate for ourselves and our children, how to navigate the complex world of insurance, and how to share our stories. We're now stronger as a family because we're united for a cause.

Olivia Majors Gina Stack Scholarship Runner-up

Q: What are your plans for furthering your education?

A: I am continuing into my junior year of nursing school and looking forward to the semester ahead of me and the new skills I will

be learning. After graduating with my BSN (Bachelors of Science in Nursing), I intend to gain a few years of nursing experience and then apply to a graduate program to obtain my Master of Science in Nursing.

Q: What experiences have led to you to further your education and future career goals?

A: I have been inspired by my amazing team of doctors and nurses that care for me, and the countless other amazing team members of Cincinnati Children's.

Q: How has having a bleeding disorder impacted your educational experience?

A: Thankfully my diagnoses has not been as severe as others with this disorder. I am very fortunate that it has not negatively impacted me to pursue my education. Rather, this disorder was one of the driving factors of my educational path and pursuing an interest to help others.

Q: What have been the challenges that you experience with a bleeding disorder?

A: Again, I am fortunate to not have many instances in my life where this diagnosis has affected my everyday life. In the past year I did suffer a knee injury that was worsened by my condition. Which raises my self-awareness of how impactful these diagnoses can really be and the challenges it brings.

Q: What have been the positive aspects of having a bleeding disorder (or having a family member with a bleeding disorder)?

A: A positive aspect of having my bleeding disorder was the drive it has given me to pursue nursing. I have also become more empathetic and can relate to those who are living with rare and chronic conditions in a health care setting.

Isabella Ferguson

Gina Stack Scholarship Runner Up

Q: What are your plans for furthering your education?

A: I will be attending my second year of graduate school at Xavier University in the fall to earn my Master's in Health Services Administration.

Q: What experiences have led you to further your education and future career goals?

A: It was my experience with TSBDF that led to my career choice. I have always been passionate about helping and caring for others since I was a little kid. However, it wasn't until I participated in State House Days that I realized there were other ways I could help care for people besides being a nurse or a doctor. It is because of this realization that I began to pursue the healthcare administration field, which in turn led to me choosing to go into the Health Services Administration program at Xavier.

Q: How has having a family member with a bleeding disorder impacted your educational experience?

A: My father having a bleeding disorder has not only impacted my career path, but it has also given me valuable knowledge that will impact my future. Not only has he made a point to prepare me for the future (having kids with a bleeding disorder), but he has also given me a unique perspective that has helped me better understand what I am studying and the career I have chosen.

Q: What have been the positive aspects of having a family member with a bleeding disorder?

A: Having a family member with a bleeding disorder has taught me many valuable lessons. My father is one of the strongest, most resilient and determined people I know. He does not let his bleeding disorder define who he is or how he lives his life. Seeing these qualities in him inspires me and has taught me how to be resilient and determined too.



**Connected
to you.**

As Community Relations & Education Managers, our work with the hemophilia community is deeply personal. It unites us in our efforts to help educate and support you and your family.



Reach out to your local CoRe to learn more.
rareblooddisorders.com
f @HemophiliaCoRes | 1-855-SGZHEME

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National Hemophilia Foundation Conference

By Angel Parrett

“Progress” and “Community”: Two Words That Sum Up My Experience At the National Hemophilia Foundation Conference

From August 25-27, 2022, I had the opportunity to attend the National Hemophilia Foundation Bleeding Disorder Conference in Dallas, TX. This event is typically held yearly, but hadn't been in-person since 2019, so it was a true family reunion for all.

It was my first NHF Conference, but not my first national event. Several years ago, I went to a similar event hosted by the Hemophilia Federation of America.

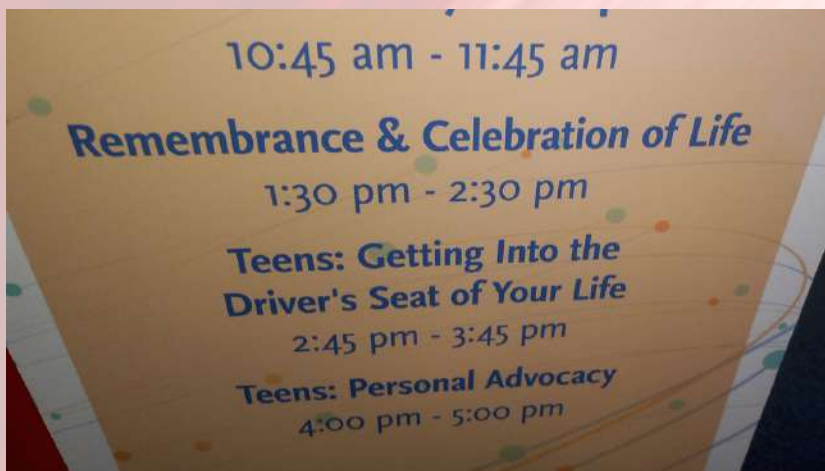
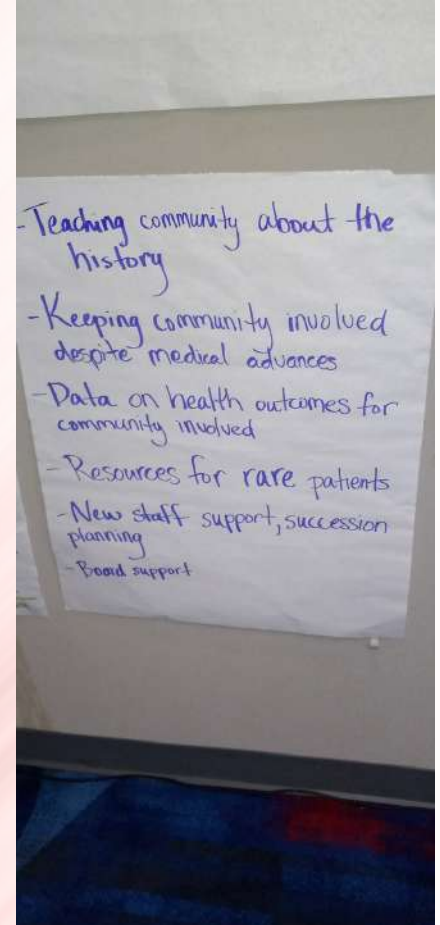
In March, I discovered that travel grants were being given out to various groups. One of these was for “Ultra-Rare” bleeders, which, as a person with factor 1 deficiency, I qualified for and was accepted. That started the journey. Two reoccurring themes seemed to define the weekend: community and progress.

Community was emphasized through finding my tiny segment of the bleeding disorder community, as well as other aspects. Sessions were very informative, from learning more about the various diagnoses, to treatments available, to opportunities for continuing education. I was excited to find out that NHF has stepped up their efforts in reaching out to this population, and my grant was only a part. Other ways “community” represented itself was through relating to various challenges. Poor ER encounters, clueless doctors and impossible insurance challenges were all brought up. Excellent education was provided on how to address all of these.

Progress was highlighted mainly through discussing various treatments and how they have improved. One day, gene therapy will be an option for some. Avoiding intravenous infusions has already become a reality, and more treatments along this line are in research. Hearing (not for the first time) that ultra-rare bleeders actually have factor deserve convenient treatment was very affirming.

An event that brought both of these pieces together was the Celebration of Life. This is a time to remember those in the community we have lost, be it through contaminated product, delayed or missed diagnosis/treatment or mental health. They left a legacy for us all, and I feel compelled to honor that.

Overall, it was amazing. I am grateful to those who paid my way and look forward to attending again.



SAVE THE DATE

FAMOHIO
FAMILY
EDUCATION
WEEKEND

AUGUST
4, 5 & 6, 2023

REGISTRATION AND INFO WILL BE AVAILABLE IN SPRING.
STAY TUNED FOR MORE DETAILS!

WHAT'S
NEXT?
YOU
DECIDE.



At Genentech, we're committed to creating programs for you, with you. From a web series focused on finding the *magic* in life, to a tournament for gamers, to workshops designed to help you think well, do well, and be well, we're here to help you take on what comes next.

VISIT [GENENTECHHEMOPHILIA.COM](https://www.genentechhemophilia.com)
TO SEE HOW WE'RE CREATING
WHAT'S NEXT, TOGETHER.

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M-US-00005064(v1.0) 10/20

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Cincinnati, OH 45203

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Calendar of Events

2023 EVENTS

February 4th - Teen Program at Top Golf

April 17th - World Hemophilia Day

May 7th - Flying Pig Marathon-TSBDF Pork N' Beans Station

June 24th - Family Education Day at Kings Island

July 16th-28th - Camp NJoyItAll

August 4th-6th - FamOhio

August 12th - Unite Walk at Mt. Echo Park

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www.TSBDF.com
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announcements! ”