

Connection, education, community,
belonging, hope & fun await you!

SpringFest 2021

VIRTUAL around the world



Presented Online via Socio

Thursday, April 15 (6-9pm)

Friday, April 16 (5-9pm)

Saturday, April 17 (9:30am-6pm)

(GooseChase begins on Monday, April 12)



We're looking forward to
seeing you **online** soon!

HFM exists to enhance the quality of life for all affected by bleeding disorders.

W www.hfmich.org

 [www.hfmich.org/ig](https://www.instagram.com/www.hfmich.org/ig)

f [www.hfmich.org/facebook](https://www.facebook.com/www.hfmich.org/facebook)



SpringFest 2021

G U I D E L I N E S

SpringFest 2021 Theme: Virtual Around the World

What has always made SpringFest magical is the chance to journey to a space of education and acceptance. We have decided that being virtual is actually our chance to take YOU on the grandest journey of all: a trip around the world! Let's escape together to lands unknown, and experiences that can only be achieved in the virtual world. Your "travel" itinerary follows. Your flight is included via the animated plane on these pages, or if you registered by March 25, by the plane in our SpringFest box. Your presence is requested. Let's Go!

SpringFest is a positive, community affirming event. Community members and HFM staff have planned a conference filled with social interaction, education, and camaraderie. In this spirit, we appreciate everyone

participating in activities to demonstrate respect for different opinions and methods of self-care. We have much more in common than we have differences, and so much to learn and share with each other. Enjoy your fellow community members!

Our SpringFest Online Platform: Registration and Logging In

HFM will be using an online platform called Socio. To participate in SpringFest programming, we will need email addresses for each individual logging in to the site; email addresses are collected during the registration process. A link to the Socio site will be sent the week of SpringFest. Once the link has been sent, you are welcome to log on to Socio ahead of the start of SpringFest to familiarize yourself with the platform and interact with fellow attendees.

Ways to Earn Prizes at SpringFest

Round Robin Discussion with Industry Partners BINGO

Earn a chance to win prizes by attending the **Friday 8:05pm** and **Saturday 2:30pm Round Robin Discussions with Industry Partners** and filling out the bingo card that came in your SpringFest box. Instructions for playing and how to submit your card are on the back of the bingo card.

GooseChase Scavenger Hunt – our family SpringFest game!

The game begins on **Monday, April 12**. You will receive an email the week prior to

SpringFest providing instructions on downloading the app and joining our group. We will email instructions to the email address that you used when you registered for SpringFest.

The activities in GooseChase are called "missions" – these are instructions for a fun task to accomplish to gain points. After you sign up the week of April 12, you will find your first mission to complete!

Earn Prizes!

We are planning adventurous and creative activities, and you can earn gift cards while competing for bragging rights! Login each day to submit your missions, and to see what your fellow community members are up to!

VIRTUAL around the world



About Industry Support

The Hemophilia Foundation of Michigan (HFM), in conversation with both the National Hemophilia Foundation and the Hemophilia Federation of America leadership, agrees that industry has a place in supporting our efforts in Michigan. HFM believes that SpringFest is an opportunity to share and receive information and education in the way that is most beneficial and comfortable for you and your family.

We invite you to visit our SpringFest industry partners throughout the weekend through the many opportunities available. In addition to meeting with representatives in the “round robin” sessions on Friday and Saturday, you may also use the messaging feature during SpringFest to reach out to sponsors to initiate a conversation (please note, not all sponsors will be available via messaging). You will find contact details on the “Meet Your Reps” document that will be emailed

prior to and during SpringFest, and you can find both company resources and educational materials, as well as local representative information, on the SpringFest sponsor site. If you wish to have further conversations after SpringFest, you are free to share your contact information, however you are under no obligation to do so. If at any time you feel unduly pressured to provide personal information, please inform a member of the HFM staff immediately.

It is our commitment to be transparent in relation to all HFM activities including industry support. As always, we encourage medical decisions be made under the advice of your treating physician and care team.

HFM does not endorse any specific product or company.

 SpringFest 2021

Support

734-544-0015 | hfm@hfmich.org

If you need **technical support** during SpringFest, please feel free to reach out via **phone** or **email** during the following times:

Thursday, April 15
9am-8pm

Friday, April 16
9am-8pm

Saturday, April 17
9am-5pm

MAKE TAKEDA YOUR FIRST DESTINATION AT HFM SPRINGFEST!



We're here to support you **EVERY MILE OF THE JOURNEY** as you manage your bleeding disorder.

FIND YOUR DRIVE WITH TAKEDA AT HFM SPRINGFEST!

Visit our virtual booth to learn more and chat with Takeda reps!
Join our Educational Session where you will hear directly from members of the Bleeding Disorders Community!

SIGN UP TO STAY CONNECTED ON YOUR JOURNEY

Go to www.hematologyoptin.com and sign up to receive the latest Takeda Bleeding Disorders news and information.



Copyright ©2021 Takeda Pharmaceutical Company Limited, 300 Shire Way, Lexington, MA 02421. 1-800-828-2088. All rights reserved. TAKEDA and the TAKEDA logo are trademarks or registered trademarks of Takeda Pharmaceutical Company Limited. US-NON-4573v1.0 02/21

Thursday, April 15

6-7:30pm **Opening Night Extravaganza!**

➔ **Main Room**

6pm **Welcome**

■ **Speaker:** Susan Fenters Lerch, Executive Director, Hemophilia Foundation of Michigan, Regional Director, HTC Network, Region V-East

6:15pm **Our Trip Around the World Begins...**

Our trip around the world begins with Michael Jay Garner and Anne Henningfeld introducing us to amazing Cirque du Soleil performers who demonstrate their incredible talents. Performances by:

① **William Wei-Liang Lin, Diabolo:**

William was born in Taiwan, and he won Golden Awards in the Cirque du Soleil in 2008. He began his circus life with Cirque du Soleil in 2012. Before the pandemic he was on tour with Cirque du Soleil's Kooza as a featured artist.

② **Ayoub Merabet, Roue Cyr:**

Ayoub was born in Morocco, and currently lives in Salé, about 60 miles northwest of Casablanca. He has performed in festivals across Morocco and Tunisia, and held an artistic residency at the Cultural Space of Tabadoul. In 2019 Ayoub earned a diploma from the National School of Circus SHEMS'Y, which in Arabic means "the sun."

③ **Ninjin Altankhuyag and Sender Enkhthur, Duo Contortion:**

Ninjin and Sender are from Mongolia. They have performed together for many years as part of a contortion trio with Cirque du Soleil's Kooza. Sender and Ninjin both studied at the Mongolian National University of Arts and Culture.

Also hear brief pre-recorded interviews and conversations with performers from Australia, Japan, Israel, and Mexico.

■ **Our Guides:** Anne Henningfeld, MA, CTRS, Managing Partner, Beyond Recreation, NC; Michael Jay Garner, BA, Creative Director, Beyond Recreation, NC

7:45-8:45pm **Doing What Moves You: Staying Active – A Takeda Symposium**

➔ **Main Room**

Gain a unique perspective and inspiration in this HELLOChat from both the health-care provider and the patient point of view, including insights on staying active with hemophilia.

■ **Speakers:** Dezarae Tate, Nurse Coordinator, South Texas Comprehensive Hemophilia Treatment Center, San Antonio, TX; Honey Blankenship, Takeda Senior Clinical Specialist, Hebron, KY; Tony, Patient, Boston MA

◆ Session sponsored by Takeda.

VIRTUAL around the world 



Opening Night Extravaganza!

Friday, April 16

5-5:30pm **HFM Membership Meeting**

➔ **Main Room**

■ **Speakers:** Jim Mohnach, HFM Board President

5:30-5:35pm **Welcome!**

➔ **Main Room**

5:35-6:35pm **World Federation of Hemophilia (WFH) USA Presentation**

➔ **Main Room**

In honor of World Hemophilia Day, we will have a wonderful presentation facilitated by staff and volunteers from the World Federation of Hemophilia USA. They will share with us how their inspiring work is changing the lives of those most in need and how you can get connected to the global community.

■ **Speakers:** Roddy Doucet, Community Outreach Manager, World Federation of Hemophilia (WFH), Montreal, Quebec, Canada; Roshni Kulkarni, MD, Professor Emerita of Pediatrics and Human Development, and former Director Michigan State University Center for Bleeding and Clotting Disorders, Lansing, MI; Philip Kuriakose, MD, Senior Staff Physician, Hematology, Henry Ford Cancer Institute, Detroit, MI; Jennifer Laliberte, National Director, World Federation of Hemophilia (WFH) USA, Montreal, Quebec, Canada; Eric Stolte, President, World Federation of Hemophilia (WFH) USA, London, Ontario, Canada

7-8pm **Educational Breakout Sessions**

➔ **Zoom Rooms (Choose One)**

1 Aging Well: Living your best life!

Now, more than ever, people with bleeding disorders are surviving and thriving! What are the keys to aging well and safely? We want to share ideas to help you continue to "Live your best life!" Join a discussion about tools, resources, and community support around issues that we all face as we get older including fall prevention.

■ **Speakers:** Samantha Carlson, LMSW, Director of Area Agency on Aging 3A; Kalamazoo County Health & Community Services, Kalamazoo, MI; Sherry Herman-Hilker, PT, MS, Physical Therapist, University of Michigan Hemophilia and Coagulation Disorders Program, Ann Arbor, MI

2 Investing in Your Potential: Transition Strategies for Young Children through Early Adulthood

In this highly interactive session we will focus on the partnerships parents have with their children to help them become responsible for their own care. Learn from each other by examining and sharing strategies:

- What have you found to be effective?
- What has worked, what hasn't?
- What might have been missed?
- How has your HTC assisted you with transition or have there been missed opportunities?

Take away positive approaches to help your child transition and gain independence in managing a bleeding disorder.

■ **Speakers:** Karen Boyd, LMSW, ACSW, DCSW, Social Worker, Olin Health Center, Michigan State University, Lansing, MI; Dave Rushlow, LMSW, Program Manager, Bleeding Disorder Center, Munson Medical Center, Traverse City, MI

3 Give it a Shot: A Different Type of Hemophilia A Therapy

Join us for a one-hour discussion about HEMLIBRA (emicizumab-kxwh) and its use in people with hemophilia A with or without factor VIII inhibitors. This program will be presented by Jen Maahs, who will discuss the efficacy of HEMLIBRA; how HEMLIBRA works; and the HEMLIBRA safety profile. We invite you to join what promises to be a robust and engaging dialogue!

■ **Speakers:** Jen Maahs, MSN, PNP, RN-BC, Director of Bleeding Disorder Care and Coordination, Indiana Hemophilia and Thrombosis Center, Indianapolis, IN; Zac, Patient Educator

◆ Session sponsored by Genentech.

4 Nurturing Couple Relationships

This session assists parents in how to put your child's bleeding disorder in its place and take your relationship with your partner or spouse off the back burner.

■ **Speakers:** Dave Robinson, PhD, LMFT, Director of the Marriage and Family Therapy Program at Utah State University, Logan, UT

8:05-9:05pm **Round Robin**

Discussion with Industry Partners

➔ **Zoom Rooms**

Fill in your **BINGO cards** to earn prizes!

Saturday, April 17

9:30-10am **Welcome!**

➔ **Main Room**

10-11am **Children's Fun Activity**

■ **Facilitator:** Annie Phillips, LMSW, Healing Home Counseling Group, Community Therapist, Bloomfield Hills, MI

➔ **Main Room**

11:05-12:05pm **Educational Breakout Sessions**

➔ **Zoom Rooms (Choose One)**

1 Update on Access to Skilled Nursing Facilities for Patients with Bleeding Disorders

Medicare reimbursement for skilled nursing facilities (SNFs) has historically limited access to these facilities for patients with hemophilia and other severe bleeding disorders following an inpatient hospital admission. The Hemophilia SNF Access Act, passed in December 2020, rectifies this long-standing problem to improve access to SNFs for Medicare beneficiaries with bleeding disorders. Learn how the bleeding disorders community accomplished this advocacy victory and what it means for you.

■ **Speaker:** Johanna Gray, MPA, Principal, Artemis Policy Group, Federal Policy Advisor, National Hemophilia Foundation and Hemophilia Alliance, Washington, DC

2 The BIG Secret

In this virtual escape room, participants will race to solve a family mystery with their fictional best friend. Follow clues and solve puzzles to figure out the BIG secret before it's too late!

■ **Facilitator:** Anne Henningfeld, MA, CTRS, Managing Partner at Beyond Recreation, NC

3 VWiD – A Session by Takeda

Our goal is to continue to educate the VWD community with impactful, relevant VWD programs. The VWiD program provides the opportunity for members to hear stories, receive information, and connect with other members of the community.

All attendees must be 18 years of age or older.

■ **Speakers:** Honey Blankenship, Takeda Senior Clinical Specialist, Hebron, Kentucky; Leslie, Speaker for Takeda

◆ Session sponsored by Takeda.

4 Advocating for Better Healthcare for Yourself and Your Daughter: Let Your Voice Be Heard

This session is for all women with and without bleeding disorders. In this session, the presenter will discuss tips for promoting engaging conversation with your healthcare providers about your concerns and needs. Advantages of care provided at Hemophilia Treatment Centers for women and girls with bleeding and carriers of all ages will be discussed.

■ **Speaker:** Laura Gusba, CNP, Henry Ford Health System, Hemophilia and Thrombosis Treatment Center, Detroit, MI

5 8 Tips to Survive Adulthood

Have you ever wondered if you will survive 'adulthood'? Are you looking for tips to help? Come listen to a presentation that will give you eight tips to survive adulthood!

■ **Speaker:** Dana Clemmans, Hemophilia Community Liaison, Novo Nordisk, Chicago, IL

◆ Session sponsored by Novo Nordisk.

12:15-1:15pm **New Kids on the Block: Overview of New Treatments**

➔ **Main Room**

Basic Science of Hemostasis as it Relates to Novel Therapies

■ **Speaker:** Eric Mullins, MD, Hemophilia Treatment Center, Cincinnati Children's Hospital, Cincinnati, OH

1:30-2:30pm **Educational Breakout Sessions**

➔ **Zoom Rooms (Choose One)**

1 Impact of COVID on Families

Coping with a bleeding disorder can be difficult, and coping during a pandemic made it even more difficult. This session will look at the impact of COVID on different ages and stages across the lifespan, including varying situations and roles. We will discuss ways of coping with challenges and growing and developing resilience. Attendees will come away with ideas to incorporate into their routines.

■ **Speakers:** Alice Cakebread, LLMSW, Social Worker, Children's Hospital of Michigan, Detroit, MI; Ellen Kachalsky, LMSW, Social Worker, Henry Ford Health System, Detroit, MI

2 Crear Conexiones: Buscar Apoyo en un Momento de Distanciamiento Social

en español

La pandemia mundial ha generado desafíos imprevistos para nuestra salud y bienestar. Aprendan cómo manejar un trastorno sanguíneo en medio de los mandatos de confinamiento y distanciamiento social, al mismo tiempo que crean y mantienen relaciones de apoyo.

■ **Oradora:** Patricia Espinosa-Thomson, Community Liaison, USBU Hematology, Takeda Pharmaceutical Company Limited, Lexington, MA

◆ Session sponsored by Takeda.

3 The Hope of Innovation: My Family's Journey

Kayla Klein is the Senior Manager of Patient Advocacy at Sigilon Therapeutics and is passionate about innovation and technology

for rare diseases. Kayla also has a deep connection to the bleeding disorders community—her young son has hemophilia A as did her late father. In this presentation, Kayla shares how innovation throughout the decades has played a transformative role in managing her family's hemophilia and how, thanks to the ongoing relationships between community members and biotechs, the next generation of novel therapies are being developed for patients living with a chronic disease.

■ **Speaker:** Kayla Klein, Manager, Patient Advocacy, Sigilon Therapeutics, Inc., Cambridge, MA

◆ Session sponsored by Sigilon.

4 Community Counts! CDC Data Collection from the HTC's

Community Counts is a public health monitoring program that gathers and shares information about common health issues, medical complications, and causes of death that affect people with bleeding disorders cared for in US Hemophilia Treatment Centers (HTCs). The project is funded by the Centers for Disease Control and Prevention (CDC) through a cooperative agreement awarded to the American Thrombosis and Hemostasis Network (ATHN) in partnership with the US Hemophilia Treatment Center Network (USHTCN). Men and women with hemophilia are eligible for and enrolled in Community Counts. This presentation will provide an overview of the data collected in the project, a demonstration of how to access public facing data on men and women with bleeding disorders, and discussion of how Community Counts data can be used to help us understand issues and outcomes affecting men and women with hemophilia.

■ **Speaker:** Vanessa R. Byams, DrPH, MPH, Team Lead, Bleeding Disorders Team, Epidemiology and Surveillance Branch, CDC/NCBDD/Division of Blood Disorders, Atlanta, GA

2:30-3:40pm **Round Robin Discussion with Industry Partners**

➔ **Zoom Rooms**

Fill in your [BINGO cards](#) to earn prizes!

3:50-4:50pm Care Available Via HTC's: What They Do, How They're Funded

➔ Main Room

Join us for a panel presentation and discussion of HTC's and the care that they provide. Learn how HTC's are funded and the roles of the multidisciplinary team members. You will hear from HTC team members from across Michigan as well as our Regional Hemophilia Network staff members. Join us for another perspective on what your HTC does for you.

■ **Speakers:** Michael Altese, PharmD, Pharmacy Director, Cascade Hemophilia Consortium, Ann Arbor, MI; Susan Fenters Lerch, Executive Director, Hemophilia Foundation of Michigan; Regional Director, Great Lakes Region/Region V-E, Ypsilanti, MI; Becky Hauke, University of Michigan Hemophilia and Coagulation Disorders Program, Ann Arbor, MI; Travis Tussing, JD, Regional Coordinator, Hemophilia Foundation of Michigan, Ypsilanti, MI; Nancy Inverso, RN, Hemophilia Program Manager Bronson Hemophilia Treatment Center, Kalamazoo, MI; Sherry

Herman-Hilker, PT, MS, Physical Therapist, University of Michigan Hemophilia and Coagulation Disorders Program, Ann Arbor, MI; Stephanie Raymond, Executive Director, Cascade Hemophilia Consortium, Ann Arbor, MI

4:55-6pm SpringFest 2021 Wrap Up!

➔ Main Room

We'll be presenting recognition awards to some wonderful community members. We'll also see a fun GooseChase video and find out who our prize winners are!

■ **Facilitators:** Tim Wicks, Camp Director and Youth Services Manager, Hemophilia Foundation of Michigan, Ypsilanti, MI; Anne Henningfeld, MA, CTRS, Managing Partner, Beyond Recreation, NC; Michael Jay Garner, BA, Creative Director, Beyond Recreation, NC

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.



company stories

We are very pleased to welcome our industry sponsors as true partners at this year's SpringFest. Each and every one is making a unique contribution to the success of the conference by setting a tone of support, respect, education, and understanding. **We encourage you to visit each of the online sponsor pages,** and to take the many opportunities available throughout SpringFest to learn more about each company and their commitment to the bleeding disorders community. We invited our industry sponsors to share a few words with you about who they are.

SPRINGFEST PRESENTING SPONSOR

Takeda

For over 70 years, Takeda has been committed to the Bleeding Disorders Community. You have trusted us to provide support and education along your journey. As the road ahead evolves, we will continue to work with and for you, focusing on advancing hematology treatments for today and innovating for tomorrow.

Our passion and pursuit of potentially life-changing treatments for patients are deeply rooted in over 230 years of distinguished history in Japan. Our vision is of a world with healthcare that is accessible to all, where prevention measures are exponentially advanced, and billions are freed of disease. We are committed to achieving this goal together with the global community.

With well-established treatments and an eye toward potential future solutions, Takeda is committed to the Bleeding Disorders Community. Patients are always at the forefront of everything we do, and we have your back as you manage your unique bleeding disorder. Because at Takeda we believe your journey is our journey, and we always move forward with your long-term health in mind.

SPRINGFEST SOARING EAGLE

Genentech

Genentech is a leading biotech company. Our partnership with the hemophilia community began over 30 years ago when we developed the first cloned, virus-free, nonblood-derived version of the factor VIII protein.* Since then, we haven't stopped working toward our goal of advancing and improving treatment. But this partnership goes far beyond developing medicines.

Genentech is committed to advancing all aspects of life with hemophilia A, starting with patient care. We strive to provide **Treatment for All** who need it, including underserved communities around the globe.

We Support the Person through education, resources, and tools designed to help individuals thrive throughout their treatment journey.

We Connect the Community through active engagements that help bring these individuals together to learn and grow.

Each day, we work alongside the community to improve life with hemophilia A by creating what's next together.

**Genentech outlicensed worldwide production and marketing of factor VIII.*

HFM HAPPY CAMPER

Novo Nordisk

At Novo Nordisk, with each new treatment we develop, and every new patient we meet, we are expanding our commitment to helping people live better lives. Together with patients and the people who care for them, we are working toward bigger goals and visions for our world. For more information, visit www.novonordisk.us.

SPRINGFEST FRIENDS

Pfizer

The Pfizer focus on rare disease builds on more than two decades of experience, a dedicated research unit focusing on rare disease, and a global portfolio of multiple medicines within a number of disease areas of focus, including rare hematologic, neurologic, cardiac and inherited metabolic disorders. Pfizer Rare Disease combines pioneering science and deep understanding of how diseases work with insights from innovative strategic collaborations with academic researchers, patients, and other companies to deliver transformative treatments and solutions. We innovate every day leveraging our global footprint to accelerate the development and delivery of groundbreaking medicines and the hope of cures.

Sanofi Genzyme

At Sanofi Genzyme, treating rare blood disorders isn't just what we do—it's who we are. Because rare is in our blood. It's why we do everything we can to make a difference in the lives of patients, caregivers, and physicians. It's why we pursue the best possible therapies, services, and resources. Why we research, develop, and discover groundbreaking advancements. Why we use our global scale to create a true, lasting difference. From pipeline to patients, we know that our commitment has the power to truly transform. To shift the trajectory. To change lives.

SPRINGFEST SPONSORS

Accredo

At Accredo, we understand it can be difficult to live with a chronic or complex illness.

As one of the nation's leading and largest providers of specialty pharmaceuticals, our dedicated therapy teams work diligently to coordinate solutions for those living with a bleeding disorder.

With accurate and timely delivery of medication, as well as expert guidance through ongoing therapy directives, you can trust Accredo to provide experienced care.

Please visit www.hemophilia.com for more information.

Bayer Healthcare

Bayer is dedicated to providing treatment options for people living with rare, serious and life-threatening diseases. Bayer has been a committed partner to this community delivering therapeutic options, educational and support programs and continuing research designed to meet the needs of patients throughout their life journey.

BioMarin

BioMarin is a global biotechnology company operating in over 70 countries around the world and on six continents. We aim to develop and commercialize innovative therapies for people with serious and life-threatening rare disorders. Please visit our website: www.Hemdifferently.com.

CSL Behring

CSL Behring is a global biotherapeutics leader driven by our promise to save lives. We meet patients' needs using the latest technologies to develop and deliver innovative therapies. CSL Behring manufactures and markets a range of recombinant and plasma-derived products for the treatment of hemophilia, von Willebrand Disease and other bleeding disorders. We are proud to be able to sponsor chapter programs such as HFM's SpringFest. For more information, please visit www.cslbehring.com.

SPRINGFEST SPONSORS CONTINUED

CVS Specialty Pharmacy

At CVS Specialty, we are passionate about serving the Michigan bleeding disorder community and have been doing so for more than 40 years. We have a dedicated CareTeam made up of pharmacists, nurses, and educators who have bleeding disorder expertise, standing ready to help you.

Hema Biologics

Hema Biologics is a privately held biopharmaceutical company focused on the rarest bleeding disorders. We aspire to support patients living with these disorders, partner with the broader community that cares for them, and bring meaningful treatments and services to help better their daily lives.

Sigilon Therapeutics, Inc.

Sigilon Therapeutics is a biotech company based in Cambridge, MA. We are developing functional cures for patients with chronic diseases such as rare blood disorders, lysosomal diseases and Type 1 diabetes through our Shielded Living Therapeutics™ platform. We initiated our first clinical trial in hemophilia A in 2020 and are working hard every day to build your trust and to bring new therapies to the clinic. Please visit www.sigilon.com to learn more.

Spark Therapeutics

Spark Therapeutics is creating the path for advancements in hemophilia gene therapy research. We are dedicated to challenging the inevitability of genetic disease by striving to discover, develop, and deliver treatments in ways unimaginable – until now. Join us in the sponsor section to Explore the Science of Gene Therapy Research.

uniQure

uniQure is a leader in the discovery, clinical development, and manufacturing of gene therapies for rare diseases, and we want to ensure that the voice of the rare disease community runs through the DNA of our clinical programs. We understand the impact of the disease and engage with the communities that we work with to help shape internal programs and create opportunities for the patient voice to be heard.

SPRINGFEST PARTNERS

Cascade

Cascade is proud to have provided excellent and personalized service for the bleeding disorder community in Michigan, Indiana, and Ohio since 1994. We are considered part of your HTC network, and our team is dedicated to providing you the best individualized care and quickest delivery possible.

As a non-profit 340B pharmacy most of our revenues go to the community to fund services such as educational programming, consumer financial assistance, HTC medical staff, and camp programs. In fact, we have provided \$56,673,000 in total support to the community for over 25 years. We hope to continue providing these services to you for the next 25 years and beyond.

Have a great SpringFest! ...The Cascade Staff
www.cascadehc.org

Hemophilia Alliance

Our Mission

The Hemophilia Alliance works to ensure member Hemophilia Treatment Centers have the expertise, resources and public support to sustain their integrated clinical and pharmacy services for individuals with bleeding and clotting disorders.

Our Vision

Through the work of the Hemophilia Alliance, the clinical and pharmacy programs of the Hemophilia Treatment Centers are integrated, stable and sustainable within a changing healthcare environment. They are trusted and respected as the preferred way to provide people with hemophilia and other bleeding disorders access to the full range of care they need.

Share your selfies on our SpringFest wall—it's fun!

Posting photos is a great way to connect with your friends, and to make new connections with people in Michigan's bleeding disorders community. Never posted photos on a wall before? **We can help!** See page 3 of this booklet for ways to connect with our technical support team.





Altese



Blankenship



Boyd



Byams

Vulnerability is the birthplace of innovation, creativity and change.

~ Brené Brown

Michael Altese, PharmD, Pharmacy Director, Cascade Hemophilia Consortium, Ann Arbor, MI

Mike has been Cascade's Pharmacy Director since 2007. He manages the daily operation of the pharmacy, working with patients and treatment center staff to manage patients' pharmacy needs and care. He also manages the inventory for Cascade and our six contract Hemophilia Treatment Center partners. Mike enjoys this area of work because of the strong relationships within the bleeding disorder community.

Mike received his Doctor of Pharmacy from the University of Michigan. He is a huge fan of University of Michigan Athletics, and is an avid runner, having completed three marathons and multiple half-marathons. He also loves hiking, particularly in Glacier National Park in Montana.

Honey Blankenship, MSN, MBA, RN, CCM, CPN, Senior Clinical Specialist, Takeda, Hebron, KY

Honey has been a Senior Clinical Specialist with Takeda since September 2018. Prior to joining the Takeda team, Honey spent four years managing a case management team at the Cincinnati Children's Hospital. Honey also spent four years as a Nurse Care Manager at the Cincinnati Children's Hospital Hemophilia Treatment Center. During that time Honey enjoyed educating patients and families and advocating for the bleeding disorder community. Honey received a Master's in Nursing Leadership and Management and a Master of Business Administration degree from Walden University. Honey is also a Certified Case Manager and a Certified Pediatric Nurse.

Karen Boyd, LMSW, ACSW, DCSW, Social Worker, Olin Health Center, Michigan State University, Lansing, MI

Karen Boyd is a licensed clinical social worker and has been privileged to work with the bleeding disorders community for over 17 years. She was instrumental in creating retreats for men, women, couples, and families to learn more about their disorder. Karen has conducted research focusing on children with chronic illness and its impact on the family. She has been involved in conducting research for the National Impact Quality of Life on Pain Study in conjunction with sponsoring treatment centers. As a therapist, she is privileged to work with families and adults who are impacted by a chronic health condition. Karen's priority in working with the bleeding disorder community is facilitating collaboration between consumers and providers and enhancing intimate relationships. When away from her busy professional life, Karen enjoys a delicious cup of coffee, ballroom dancing, gardening, entertaining, and travel.

Vanessa Byams, DrPH, MPH, Team Lead, Bleeding Disorders Team, Epidemiology and Surveillance Branch, Division of Blood Disorders, Centers for Disease Control and Prevention, Atlanta, GA

Vanessa Byams joined the Centers for Disease Control and Prevention (CDC) in September 2001 and has worked with the bleeding disorders community for her entire tenure. She began her CDC career as a fellow working on a women with bleeding disorders multisite treatment and management study. Currently as a Team Lead within the Division of Blood Disorders, she provides scientific direction and guides programmatic decisions related to bleeding disorders surveillance and health promotion



Cakebread



Carlson



Clemmans



Doucet



Espinosa-Thomson

projects. Dr. Byams collaborates with colleagues on scientific projects within the Bleeding Disorders team including the Community Counts surveillance project, as well as the health promotion cooperative agreements currently awarded to the National Hemophilia Foundation and the Hemophilia Federation of America. She lives in the Atlanta area with her husband, two kids (ages 13 and 10), and two cats.

Alice Cakebread, LLMSW, Social Worker, Children's Hospital of Michigan, Detroit, MI

Alice has been working as the hemostasis and thrombosis social worker at Children's Hospital of Michigan in Detroit for a year now. Alice is dedicated and passionate about connecting patients and families to resources to help them navigate the world with a bleeding disorder. She has an orange cat named Figgy, enjoys spending time outside and up north with friends (in non-Covid times), and loves exploring Ann Arbor.

Samantha A. Carlson, LMSW, Older Adult Services Director, Area Agency on Aging Region 3A, Health & Community Services Department Planning Section Chief – Covid-19 Vaccination Response, Covid-19 Pandemic Incident Command Long Term Care Facility Task Force Lead, Kalamazoo, MI

Samantha received her undergraduate and graduate degrees in clinical social work at Western Michigan University, practicing in West Michigan since 1998. Samantha is currently the Director of the Area Agency on Aging 3A through the Kalamazoo County Health & Community Services Department. Her clinical and administrative practices focus on brief integrative therapy, family and patient goals and patient centered care, and empowering patients to participate in their health-care and wellness. She has spoken locally, regionally, and nationally regarding palliative

care, psychosocial impact of cancer and blood disorders, volunteer management and ethics, cancer survivorship and pain management.

Dana Clemmans, Hemophilia Community Liaison, Novo Nordisk, Chicago, IL

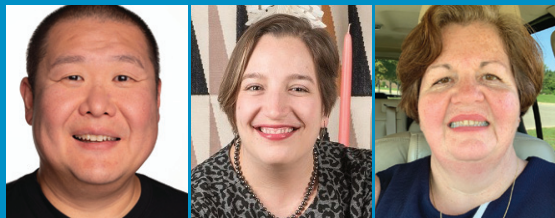
Dana is driven by her passion to help patients. Her greatest contribution comes from letting people living with bleeding disorders know she is there for them as a resource when they need it. In her spare time, Dana enjoys cooking and attending sporting events.

Roddy Doucet, Community Outreach Manager, World Federation of Hemophilia (WFH), Montreal, Quebec, Canada

Roddy is the Community Outreach Manager with the World Federation of Hemophilia. It has been his honor to serve the global bleeding disorder community and work alongside patients, families, and healthcare professionals in pursuit of our shared vision of Treatment for All.

Patricia Espinosa-Thomson, Community Liasion, USBU Hematology, Takeda Pharmaceutical Company Limited, Lexington, MA

Patricia obtuvo su licenciatura en Antropología de la Universidad de los Andes en Bogotá, Colombia. Durante ese tiempo, su deseo de entender los matices multiculturales entre los diferentes grupos étnicos llevó a la experiencia de investigación práctica tanto viviendo como trabajando junto a las remotas tribus indígenas de la Amazonía. Esta investigación se convirtió en la base de su carrera en conectividad humana y comprensión cultural. Patricia tiene una maestría en Administración de Recursos Humanos de la Universidad



Garner

Gray

Gusba

The journey of a thousand miles begins with a single step.

~ Lao Tzu

Nova Southeastern en Florida en 1977, un estado que ha llamado hogar desde entonces. Durante casi tres décadas, Patricia ha trabajado en el campo de la salud especialmente en el área de salud mental proporcionando apoyo, educación y liderazgo en una variedad de roles. Esta pasión por la educación y el desarrollo comunitario la ha llevado a su trabajo actual como "Enlace Comunitario" en Takeda desde 2007.

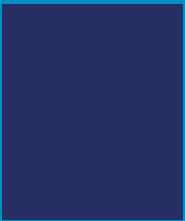
Michael Jay Garner, BA, Creative Director, Beyond Recreation, NC

Michael started his performing career like many who pursue this type of work: by accident. He received a BA in psychology from Emory University, where he also learned how to juggle, play various musical instruments, and find comfort and joy playing on stage as a four-year cast member of the nation's oldest college improv troupe. After college, Michael worked in the corporate world, but took many side gigs as a performer. And while preparing an audition piece for The Big Apple Circus, he realized that by assembling this random assortment of skills, he had inadvertently been training to be a clown for ten years — without even realizing it. Since then, Michael's life has been a swirling vortex of clowning and circus arts — from working as a hospital clown with The Big Apple Circus Clown Care Unit, to being the Resident Clown at The Hole In The Wall Gang Camp (a children's medical camp founded by Paul Newman). He has also toured with Britney Spears on her World Circus Tour and has been touring internationally with Cirque du Soleil since 2016, playing the Handyman clown in KOOZA. Michael is also very proud to work with Cirque du Monde, an outreach program of Cirque du Soleil that teaches circus arts to

at-risk and underserved youth. And finally, he would like to apologize for the camera being too close to his face in the posted profile photo.

Johanna Gray, MPA, Principal, Artemis Policy Group, Federal Policy Advisor, National Hemophilia Foundation and Hemophilia Alliance, Washington DC Johanna is a Principal at Artemis Policy Group, a health policy and association management firm in Washington, DC. She works with clients, including patient advocacy groups and associations of specialized treatment centers, to develop and implement successful advocacy strategies involving Congress and federal public health agencies. She has served as a federal policy advisor to NHF since 2007 and the Hemophilia Alliance since 2011. Johanna began her career as an intern for then-Senator Barack Obama and held several policy analysis and government affairs positions prior to starting Artemis with her partners, Ellen Riker and Elizabeth Karan, in 2020. She received an MPA from the Maxwell School at Syracuse University and a BA in public policy studies with honors from the University of Chicago. Outside of work, she reads a lot to keep up with two book clubs and enjoys trying new restaurants and exploring DC with her husband, Dave, and rescue pup, Indy.

Laura Gusba, CNP, Henry Ford Health System, Hemophilia and Thrombosis Treatment Center, Detroit, MI Laura is a native of Michigan and has many nurses in her family. She married, and moved to Windsor, Canada and completed her BSN at the University of Windsor and then went on to earn her master's degree. She has been working at Henry



Hauke



Henningfeld

What you do makes a difference,
and you have to decide what kind
of difference you want to make.

~ Lao Tzu

Ford Hospital since 1994 and spent most of her career working in labor and delivery and women's health. In 2015, she took on the challenge of learning something new, and joined the team at the Henry Ford Hemophilia Treatment Center and the Hematology Division at Henry Ford. She really enjoys when she gets to combine her two career interests, women's care and bleeding disorders!

Rebecca Hauke, University of Michigan Hemophilia and Coagulation Disorders Program, Ann Arbor, MI

Becky has been at the HTC for more than 24 years serving as the HTC's Research/Clinical Trial Coordinator and Database Administrator. She currently serves on the Community of Practice Advisory Committee as a representative of the Great Lakes Region and has served on the ATHN-Clinical Manager Technology Committee since 2006.

Anne Henningfeld, MA, CTRS, Managing Partner, Beyond Recreation, NC

Anne has over ten years' experience directing summer resident, day, and travel camps for a variety of populations, including hemophilia, traumatic brain injury, and at-risk youth. Since 2014, she has spent her summers executing her favorite part of summer camp: staff training. Anne completed her master's degree in therapeutic recreation from the University of Toledo in 2011 and is a Certified Therapeutic Recreation Specialist. A two-time recipient of the Health Education Award of Distinction from the National Hemophilia Foundation, and the 2009 Michigan Hemophilia Professional of the year, Anne is in demand as a speaker and presenter. She was the 1998 Central Florida Yo-Yo Champion and toured the United States doing motivational school

IN HEMOPHILIA,
THERE'S ONE THING
YOU CAN COUNT ON

INNOVATION FROM
NOVO NORDISK

We strive to help improve the lives of people with hemophilia

For 30 years, Novo Nordisk has been a driving force for people living with rare bleeding disorders. We take pride in striving for innovative solutions to help improve patients' lives. This motivates us to uphold the highest standards in our product research and development. This vital research is just the beginning of our commitment in hemophilia.

We will continue our research and connect with people with hemophilia and health care professionals to ensure we understand and respond to the specific needs of the hemophilia community.

With a rich history, Novo Nordisk remains at the forefront of discovery. We are poised to continue to develop innovative solutions that can help improve the lives of people with hemophilia in the future.

Please visit www.rarebleedingdisorders.com
or find us on Facebook at
www.facebook.com/cpih.us.



Herman-Hilker



Inverso



Kachalsky



Klein

I choose to
make the rest
of my life the
best of my life.
~ Louise Hay

assembly programs. Prior to Covid-19, Anne spent the off-season researching and improving her staff training modules while accompanying her husband Michael as he performed in the global tour of Cirque du Soleil's Kooza. Currently, Anne develops virtual programming and produces virtual events and camps for non-profit organizations.

Sherry Herman-Hilker, PT, MS, Physical Therapist, Hemophilia Treatment Center, University of Michigan, Ann Arbor, MI

Sherry is a physical therapist at the University of Michigan Hemophilia and Coagulation Disorders Program where she has worked with both the adult and pediatric bleeding disorders teams since 1996. She provides consultation and education regarding activity, mobility, and bleed recognition and management to patients with bleeding disorders of all ages and their families. Sherry is also actively involved in the greater hemophilia community locally, regionally, and nationally.

Nancy Inverso, RN, Hemophilia Program Manager, Bronson Hemophilia Treatment Center, Kalamazoo, MI

Nancy had over 30 years of experience in pediatric hematology and oncology prior to joining the bleeding disorders community in 2015. She is the current representative from the Great Lakes Region V-E on the National Hemophilia Foundation Nursing Working Group.

Ellen Kachalsky, LMSW, Social Worker, Henry Ford Health System, Detroit, MI

Ellen has her Master of Social Work degree from Adelphi University in New York, but moved to Michigan after obtaining her degree. After working in several hospital systems, Ellen came to Henry Ford Hospital in 1997 to work in Bone Marrow Transplant and Hematology-Oncology, and

covered several clinics, including the Multi-Disciplinary Clinics for Breast Cancer, and the Head and Neck Clinic. She has worked in hemophilia since 1999, but prior to that, she worked in hematology & oncology, family practice, and the ICU and Step-Down units at Harper Hospital, Sinai Hospital, Providence Hospital and St. Mary Hospital. She also worked for 3 years at HUD-subsidized senior congregate living, where she helped residents maintain their independence by linking them with community resources and providing support, counseling and programs. Ellen has 2 adult children, a son who keeps her on her toes with puns and trivia contests, and a daughter who is in film and production. She enjoys teaching clients about coping with conditions, and also teaching about the ins and outs of insurance so that they can get the maximum benefit from their insurance plans, and also helps clients realize their full potential in education and employment so that they may lead happier and productive lives, while dealing with pain and other issues related to bleeding disorders.

Kayla Klein, Manager, Patient Advocacy, Sigilon Therapeutics, Inc., Cambridge, MA

Kayla has her BA from Saint Mary's College of Notre Dame and her master's degree in teaching from Simmons College and has worked in both education and patient advocacy before joining Sigilon. Kayla has been featured on NPR regarding children on Medicaid, and has spoken alongside Massachusetts State Senator Ed Markey about CHIP funding. She serves on the Board of Directors for Save One Life, an international non-profit serving the bleeding disorders community. She lives in Boston, MA with her husband Joel, sons Robbie and Eddie, and dog Atticus.



Kulkarni

The real voyage of discovery consists not in seeking new landscapes, but in having new eyes.

~ Marcel Proust

Roshni Kulkarni, MD, Professor Emerita of Pediatrics and Human Development, and former Director Michigan State University Center for Bleeding and Clotting Disorders, Lansing, MI

Dr. Kulkarni is currently Professor Emerita of Pediatrics and Human Development and former director of the Michigan State University (MSU) Center for Bleeding and Clotting Disorders, and Pediatric and Adolescent Hematology/Oncology (PHO). She was the director and distinguished Hematology Consultant, Division of Blood Disorders, at the Centers for Disease Control and Prevention (CDC), Atlanta GA. She is a founding member of the Foundation for Women and Girls with Blood Disorders. She is a member of various professional societies and committees, including the

World Federation of Hemophilia Women with Inherited Bleeding Disorder Committee, CDC Joint Outcomes Committee and Inhibitor Committee. She has been a past member of the Medical and Scientific Advisory Committee of the National Hemophilia Foundation (NHF), American Thrombosis and Hemostasis Network leadership committee, American Society of Pediatric Hematology/Oncology and the Hemophilia and Thrombosis Research Society. She is a founding member of the MSU Women and Girls Blood Disorder clinic, a collaborative comprehensive care clinic of the MSU Departments of Pediatrics and Human Development, Ob-Gyn and Reproductive Biology and Internal Medicine. She has received numerous awards that include NHF's "Physician of the Year," the MSU

DEDICATION AND PERSONAL SUPPORT



Introducing your **Pfizer Patient Affairs Liaison**, a professional dedicated to serving the rare disease community by connecting patients, caregivers, and patient advocacy organizations with Pfizer Rare Disease tools and resources. A Patient Affairs Liaison's work is guided by the principles of **compassion, commitment, and connection.**

Chris Liddell

Southern OH, MI, KY, IN

I'm here to:



Provide compassion by understanding the needs of patients, caregivers, and patient advocacy organizations and serving as a point of contact for questions they may have



Maintain commitment by educating patients and caregivers about Pfizer Rare Disease patient support resources



Facilitate connection by providing educational programs that bring patients, caregivers, and patient advocacy organizations together to share experiences and support advocacy for their communities

“
I've worked in rare disease for 15 years, and I have experience collaborating with and advocating for different members of this community.
”



To get in touch with Chris:

248-660-7384

chris.liddell@pfizer.com

Rare Disease



Kuriakose



Laliberté

It is good to have an end to
journey toward; but it is the
journey that matters, in the end.

~Ursula K. Le Guin

“Distinguished Faculty” award, and distinguished service award from the Federal Drug Administration and CDC and named to the Best Doctors in America since 2007.

Philip Kuriakose, MD, Senior Staff Physician, Hematology, Henry Ford Cancer Institute, Detroit, MI

Dr. Philip Kuriakose attended medical school at Christian Medical College in Ludhiana, India. He completed his post-graduate training at Christian Medical College, Brown Memorial Hospital, and Henry Ford Hospital. Dr. Kuriakose went to the Mayo Graduate School of Medicine in Florida for his fellowship in hematology/oncology. He is a senior

staff physician at the Henry Ford Cancer Institute and an assistant professor at Wayne State University Medical School. Dr. Kuriakose specializes in hematology, hemophilia, leukemias, thrombosis, and general cancer care. He is the principal investigator in multiple clinical trials and has published numerous articles on a variety of topics.

Jennifer Laliberté, National Director, World Federation of Hemophilia (WFH), USA, Montreal, Quebec, Canada

Jennifer has been working with the global bleeding disorders community for over 10 years in education, research, and public



Connected.

We're here to help patients and caregivers
living with rare blood disorders embrace the
moments that matter.



Let's connect.
rareblooddisorders.com
1-855-SGZHEME

© 2020 Genzyme Corporation. All rights reserved.
MAT-US-2019876-v1.0-09/2020

SANOFI GENZYME 



Lerch



Maahs



Mohnach



Mullins

policy. She currently serves as National Director of WFH USA, working to raise awareness and support for the WFH's mission of Treatment for All within the US.

Susan Fenters Lerch, HFM Executive Director, Federal Great Lakes Region V-E Network HTC Director, Ypsilanti, MI

Sue is an accomplished leader who has served in the non-profit sector for more than three decades. Sue joined HFM as the Executive Director in June 2014; however she came to this role having previously served as the HFM associate director from 1983-1996. In 1997 Sue joined Make-A-Wish Foundation of Michigan as president and CEO until 2010 when she launched Autism Alliance of Michigan. Additionally, Sue has served as the lead consultant in implementing World AIDS Day Detroit, initiated the Hospice of Michigan Foundation and created Bring Joy consulting services. Currently, as the executive director at HFM, Susan is responsible for state-wide patient educational programming and advocacy services and also serves as the Great Lakes and Region V-East Hemophilia Treatment Centers' regional director.

Jennifer Maahs, MSN, PNP, RN-BC, Director of Bleeding Disorder Care and Coordination, Indiana Hemophilia and Thrombosis Center, Indianapolis, IN

Jen is a Pediatric Nurse Practitioner and the Director of Bleeding Disorders Care and Coordination at the Indiana Hemophilia and Thrombosis Center (IHTC) in Indianapolis, Indiana. She has over 25 years' experience working with patients with bleeding disorders. She was a recipient of NHF's Nurse of the Year award and is a very well-respected and requested presenter. Ms. Maahs is looking forward to meeting you during this virtual presentation.

Jim Mohnach, Marketing Lead, Ford Motor Company, Detroit, MI

Jim serves as the President of the Board of Directors for the Hemophilia Foundation of Michigan. Jim is also an Executive Committee Member of the Cascade Board of Directors. In his professional life Jim is a marketing lead at Ford Motor Company where he has worked since 2018. Prior to that he held various leadership positions at GTB/Team Detroit, the advertising agency for Ford Motor Company. Jim has been involved in the hemophilia community for almost 10 years. He's so appreciative of the community and the people he's been fortunate enough to meet within the bleeding disorders community. He loves seeing so many old friends at events like Spring-Fest and the Walk at the Detroit Zoo. In his free time, Jim loves spending time with his family, which includes his wife Lauren, son Aiden, and daughters Emma and Isla.

Eric Mullins, MD, Hemophilia Treatment Center, Cincinnati Children's Hospital Medical Center, Cincinnati, OH

Dr. Mullins is an associate professor of pediatrics at Cincinnati Children's Hospital Medical Center and the University of Cincinnati - College of Medicine. He has focused his career on the care of children with coagulation disorders, both bleeding disorders and thrombosis. Dr. Mullins, along with the Department of Pediatric Gynecology, founded the Young Women with Bleeding Disorders Clinic at Cincinnati Children's in 2008 and has had active collaborations with gynecology since that time. More recently, he has enjoyed collaborating with the Transgender Health Clinic in Adolescent Medicine for care of transgender adolescents and young adults. He enjoys making barbeque (North Carolina and Memphis styles are the best y'all!) and hiking in the National Parks.



Phillips



Raymond



Robinson



Rushlow



Stolte

Annie Phillips, LMSW, PMH-C, Licensed Therapist, Healing Home Counseling Group, Bloomfield Hills, MI

Annie Phillips is a licensed clinical social worker and the co-owner of Healing Home Counseling Group. She spent the beginning of her career working at Children's Hospital of Michigan Hemophilia Treatment Center, and recently left that position to open her own therapy practice. As a therapist certified in perinatal mental health, she can better understand and assist families who are struggling with fertility issues, difficult pregnancies, perinatal mood disorders and postpartum struggles. Annie has devoted her career to individual people as well as her community, most recently developing a swim program in Detroit for children, adolescents, and teens diagnosed with a bleeding disorder and their siblings. These experiences have helped her develop strong therapeutic relationships and techniques with adolescents, teenagers, young adults, and parents.

Stephanie Raymond, Executive Director, Cascade Hemophilia Consortium, Ann Arbor, MI

Stephanie has been with Cascade since 1996, including 17 years serving as Associate Director. As Executive Director, she guides the daily operations of 17 full- and part-time staff. She has extensive knowledge of the 340B Federal Drug Discount Program. Stephanie also manages Cascade's multi-million-dollar funding award program to 18 hemophilia treatment centers (HTCs) and seven hemophilia foundations located in Michigan, Ohio, and Indiana. Stephanie holds a bachelor's degree in health care administration from Concordia University. Stephanie and her husband live with their Boston

Terrier, Winston, just outside of Ann Arbor. Stephanie feels very fortunate and thankful for the many long-time friendships made throughout her years at Cascade. "We have an exceptional region filled with many wonderful and dedicated people."

Dave Robinson, PhD, LMFT, Director of the Marriage and Family Therapy Program at Utah State University, Logan, UT

Dr. Dave Robinson is a licensed and practicing marriage and family therapist and director of the Marriage and Family Therapy Program at Utah State University. He and his wife, Jamie, have 5 children (three sons and two daughters). The oldest and youngest sons both have moderate Factor IX hemophilia. Dave travels the country sharing his experience and expertise with families on behalf of HFA's outreach programs.

Dave Rushlow, LMSW, Program Manager, Bleeding Disorder Center, Munson Medical Center Traverse City, MI

Dave has over 30 years of experience as a licensed social worker and graduated from the University of Michigan with a Master of Social Work degree. He has worked in a medical setting for many years and has unique experience working with chronic health conditions, grief, loss, and end of life issues.

Eric Stolte, President, World Federation of Hemophilia (WFH) USA, London, Ontario, Canada

Originally born in the USA, Eric and his family immigrated to Canada in 1987. During their time in Canada, Eric and Marion have been active volunteers with the Canadian Hemophilia Society (CHS). Marion's dad had hemophilia A and their son was born with FVIII deficiency. Eric was a National Board



Tate



Tussing



Wicks

A good traveler has
no fixed plans and is
not intent on arriving.
~Lao Tzu

member of the CHS from 1994 until 2011 and served as president/chair from 2004 to 2007. In 2008 he was co-opted to serve as a volunteer on the Board of the World Federation of Hemophilia and 2012 was elected to serve as VP of finance and administration and served until 2018. After serving on the WFH USA Board for a number of years, Eric was elected as president (chair) and is currently in that role.

Dezarae Tate, Nurse Coordinator,
South Texas Comprehensive Hemophilia
Treatment Center, San Antonio, TX

Travis Tussing, JD, Regional Coordinator,
Federal Grants Director, Hemophilia
Foundation of Michigan, Ypsilanti, MI

Travis has been involved with HFM programming since attending Camp Bold Eagle as a child. Following completion of law school Travis worked in private practice locally, which lent itself to considering a position with HFM more than six years ago. He serves as the Regional Coordinator for the Great Lakes Regional Hemophilia Network. In this role, he works with the federally funded Hemophilia Treatment Centers in Michigan, Indiana, and

Ohio to provide guidance and assistance to ensure that federal grant goals and objectives are met, including, providing quality multidisciplinary comprehensive care for our patients. Travis and Kristy have an adorable daughter who keeps them busy along with their dog, Marley, and Piggy the cat.

Tim Wicks, Camp Director and Youth
Services Manager, Hemophilia Foundation
of Michigan, Ypsilanti, MI

Tim is responsible for the year round components of Camp Bold Eagle, Eagle Outpost, Eagle Expedition, and the Counselor-In-Training (CIT) program. He coordinates other youth programs including Teen Retreat, and the SpringFest youth programming. Tim also co-manages HFM's media requirements for educational programs and events.

Tim was raised outside of Deshler, Ohio and holds a BS from Grace Bible College in Grand Rapids, Michigan. Prior to HFM, he was employed as the Outdoor Education Instructor at Michindoh Camp and Conference Center. Tim has worked with HFM as a camp staff member since 2000. He also has severe hemophilia A.

Please **fill out** session & speaker **evaluatons**

Thank you!



Eagle Journeys Camping Programs

Register by May 28, 2021

Go to: www.hfmich.org/camp



CAMP BOLD EAGLE AT HOME: JULY 5-30, M-F, AGES 6-17

Due to the continued impact of the COVID pandemic, all 2021 HFM camping programs will be virtual.

The safety of our campers and staff is HFM's number one priority. We understand the desire to return to our traditional camp experience and

appreciate your understanding and support of this decision. We are thankful for the opportunity to continue offering Eagle Journeys' experiences virtually and hope to see you this summer!

Register today: www.hfmich.org/camp