



AUGUST 1-8, 2020

VIRTUAL CONFERENCE PROGRAM



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

NHF WOULD LIKE TO THANK THE GENEROSITY OF OUR 2020 SPONSORS
WITHOUT THEIR SUPPORT THIS EVENT WOULD NOT BE POSSIBLE.

PLATINUM



SILVER



BRONZE



Table of Contents

Welcome 4

Registration and General Information..... 6

Games/Social Events 8

Childcare Program..... 9

Teen Track 9

Industry-Sponsored Symposia 11

Provider and Pharmacist Symposia.....12

Conference Sessions15

Exhibitor Listing40

Speaker Listing..... 47

NHF Staff.....50

Welcome

Welcome to NHF's first Virtual Bleeding Disorders Conference. This year's conference, while not the one we had originally planned, will still be an experience full of education, opportunities for networking, and chances to make connections to people with bleeding disorders from around the world and the healthcare professionals who provide care.

I hope you will take advantage of all that the conference has to offer. We have a wide range of sessions that cover many topics, so you will be sure to find something that interests you. For families who are new to the bleeding disorders community, be sure to mark Basics: Hemophilia or Basics: VWD on your calendar; these sessions will give you an overview of what you need to know to understand these bleeding disorders. If you are interested in new and novel therapies, be sure to look for Advancements in Treatment for Hemophilia: What You Need to Know and Gene Therapy: Getting Up to Speed. If your family is affected by von Willebrand disease (VWD) our VWD pre con is a can't-miss session, covering medical updates and an exploration of ways to connect as a community.

Our sessions for healthcare providers are of equal interest. Forging A New Path – Gene Therapy Readiness and HTC Implementation will discuss how gene therapy will affect the future of bleeding disorders care. Nurses, social workers, and physical therapists will also have full tracks of sessions covering pain management, disorders of fibrinogen, poverty and barriers to healthcare, and caring for an aging population, among others. Be sure to check the NHF Daily, the NHF BDC website, or the NHF BDC app for information about these sessions and more.

Our virtual Exhibit Hall will give you the opportunity to meet with our sponsors and exhibitors to learn more about the latest products and services they offer. While in the hall, be sure to stop by the NHF booth to learn about NHF's new programs and initiatives. And on Saturday, August 8th, be sure to tune in to NHF's Final Night Event, featuring a live DJ, family-friendly activities, and more.

I hope you will make the most of this virtual Bleeding Disorders Conference. Please participate in the chats, ask questions of the speakers, and connect with each other. Even while we are unable to be together in person, we are still a community, and NHF is – and always will be – here for you.

I look forward to hearing from you!

Len Valentino, MD
President and CEO

Conference Organizer

NHF Conference & Travel Services Department

Maria M. Salas-Pilla, HMCC, LLM

Senior Director of Conference & Travel Services

Ciarra De Leon

Conference & Travel Services Assistant

Karina Lopez

Operations Specialist

Johanna Ong, CMP, HMCC

Conference & Travel Services Specialist

Kathy Tsandilas, HMCC

Senior Exhibitor Manager

Alla Vaynshteyn, MBA

Conference & Travel Services Manager

Registration

To access the Conference, you will need the e-mail address used to complete registration as well as your registration number. This number can be found in your confirmation e-mail, as well as the final e-mail containing log in instructions.

General Information (A-Z)

APP - NHF'S 72ND BLEEDING DISORDERS CONFERENCE APP

Don't miss a minute of the conference! Download our conference mobile app from your app store by searching for "National Hemophilia Foundation" and have all sessions and events right at your fingertips. Create your own personalized schedule, get the latest information, ask questions about the sessions or speakers and a lot more. It also has some exclusive conference features that is only exclusive in the app, like a chance to request for your favorite song to be played during the Final Night Event and play the Scavenger Hunt to win Visa gift cards. The app works on iOS and Android smartphones and tablets.

EBADGES

Sponsored by Takeda

CONTINUING EDUCATION FOR HEALTHCARE PROFESSIONALS

FEE INFORMATION

There are no registration fees charged for the medical, nursing, social work, and physical therapy tracks. However, all eligible healthcare professionals need to pre-register as a provider (i.e. physician, physician assistant, researcher, nurse, nurse practitioner, pharmacist, social worker, physical therapist) to be able to obtain CME/CE credits for specific provider track sessions at NHF's 72nd Virtual Bleeding Disorders Conference.

For complete accreditation and program information, please visit the NHF website and click on the CME/CE tab. For any additional questions about provider education at NHF's 72nd Bleeding Disorders Conference, please check the NHF website for updates or contact Angelina Wang, NHF Director of Medical Programs and Information at awang@hemophilia.org.

EXHIBIT HALL

NHF's Virtual BDC Exhibit hall is a resource that brings together manufacturers, pharmaceutical companies, not-for profit organizations and specialty pharmacy companies in one place to offer solutions and perspectives for patients, and medical practitioners. Here, each company has the opportunity to explain their products and services just like they would if you attended a conference Exhibit Hall in person. The goal of NHF's Virtual BDC Exhibit Hall is to keep you informed of all the options and treatments available that can improve the lives of those living with bleeding disorders.

Visit 28 customized virtual booths from top suppliers and learn more about their products/services through videos and downloadable files. Plus, connect through an open chat, one-on-one meetings with exhibit personnel, participate in raffles and play games while visiting their booths.

EXHIBIT CHAT HOURS

The virtual Exhibit Hall is available 24/7 from Saturday August 1 to Saturday August 8. To chat with Exhibitor representatives, please visit their booth during the following schedule:

Saturday, August 1	12:00 p.m.	1:00 p.m.
Sunday, August 2	1:00 p.m.	2:00 p.m.
Monday, August 3 to Friday, August 7	4:30 p.m.	5:30 p.m.
Saturday, August 8	10:30 a.m.	11:30 a.m.

Please note: Exhibitors are solely responsible for the content of their exhibits and any information distributed within their booths. The information presented on products and services as well as promotions or advertisements occurring during the 72nd Bleeding Disorders Conference do not reflect the opinion of or endorsement by the National Hemophilia Foundation.

GAMES – MOBILE APP

APP SCAVENGER HUNT GAME

Bleeding Disorders Conference attendees who download the Bleeding Disorders Conference mobile app can participate in the BDC Scavenger Hunt app game.

Once you have the mobile app installed and have logged in, explore the virtual Exhibit Hall on your computer, tablet or another smart phone.

Winners will be announced Saturday, August 8 at the NHF Final Night Event. You must be present to claim your prize. *Some restrictions apply*.*.

TWO WAYS TO WIN!

1. All Exhibitors App Challenge

- Look for the Exhibitors' QR codes in their respective pages.
- As you see the QR code, use the barcode scanner found in the app's Scavenger Hunt module to scan.
- You must scan all 28 QR codes by August 8th, 11:00 AM (EDT) to qualify for the raffle.
- How to know if you scanned all QR codes?
- A check mark will replace the trophy icon on each of the Exhibitors listed in the Scavenger Hunt module.
- Prize: 3 winners will each receive one \$100 Visa gift card

2. Platinum Sponsors App Challenge

- Extra chances of winning prizes by visiting Platinum Sponsors' booths daily during the conference week
- Every day, beginning August 1st until August 8th at 11:00AM (EDT), look for the daily QR codes on each of the Platinum Sponsors' booth pages (CSL Behring, Novo Nordisk, Sanofi Genzyme, and Takeda).
- These daily QR codes are labeled with sponsor's name and date.
- Remember to scan the daily QR codes by 6:00PM (EDT) on August 1-7, and by 11:00AM (EDT) for the August 8 codes.
- You must scan all 32 codes to qualify for the raffle.
- How to know if you scanned all QR codes?
- A check mark will replace the trophy icon on each of the Exhibitors listed in the Scavenger Hunt module.
- Prize: 1 winner of a \$200 Visa gift card

Fine print: 1. No purchase necessary. 2. Only one entry per person. 3. Only consumers and providers are eligible. 4. Only those who have scanned all QR codes will be entered in the raffle. 5. Must live in US and 18 years old or older to be eligible to win. 6. QR codes must be scanned by 11:00 am on Saturday, August 8, 2020. 7. Winners will be selected at random and announced during the NHF BDC Final Night Event on August 8, 2020 and will be notified via email. Must be present during the Final Night Event to win. 8. Employees of sponsoring companies and their immediate families and household members are not eligible to win. 9. Employees, national chapter staff, national board directors and consultants of the National Hemophilia Foundation and their immediate families and household members are not eligible to win.

VIRTUAL BDC CAMP: CAMP UNITE - KIDS AND TEENS

This year, we're bringing camp to you! NHF's first ever virtual Bleeding Disorders Conference youth camp: Camp Unite will be held at the same time as NHF'S Virtual Bleeding Disorders Conference, from August 1st through 8th. This camp is open to youth aged 6-12, as well as teens aged 13-17 years. Camp Unite is completely free to attend! Registration for Camp Unite is now closed.

For more information [click here](#)

NHF BOOTH

Stop by the NHF booth, where you can pick up our publications, and chat with a staff member about our programs and services. We have a lot to offer you, so come by and find out what we are working on. We look forward to meeting you!

NHF DISCLAIMER

All information that is disseminated in the Exhibit Hall, as well the content that is presented in the satellite symposia, and at companies' events are funded by and are the sole responsibility of the exhibitors, sponsors and satellite symposia organizers. The National Hemophilia Foundation (NHF) does not endorse particular treatment products or manufacturers; any reference to a product name is not an endorsement by NHF. NHF is not a regulatory agency and cannot make recommendations relating to safety of manufacturing of specific treatment products. For recommendation relating to a particular product, the regulatory authority in a particular country must make these judgements based on domestic legislation and national health policies.

SOCIAL MEDIA

Use the hashtag #NHF2020 to connect with NHF and other attendees on Twitter and Instagram. We will also be live tweeting sessions and sharing photos.

Follow us on Twitter and Instagram at: @NHF_Hemophilia.

NHF'S 72ND BLEEDING DISORDERS CONFERENCE NETWORKING HRS.

Session name	Session Date	Start Time
Chapter Leadership Networking Hour - Sponsored by Pfizer	8/5/2020	6:00 PM
LGBTQI Networking Hour - Sponsored by Takeda	8/6/2020	4:30 PM
VWD Networking Hour - Sponsored by Takeda	8/7/2020	4:30 PM

NHF'S 72ND BLEEDING DISORDERS CONFERENCE FINAL NIGHT EVENT

SATURDAY, AUGUST 8, 2020

This year's Final Night Event will be a virtual party in celebration of all that we have achieved together as a community and the milestones leading to a new era of treatment which will transform the lives of people with bleeding disorders. Please join us for a mixology class, photo booth, music, interactive games and the chance to win amazing prizes! Arrive early as the first 500 attendees to participate and stay for the hour will receive a Grubhub gift card for a future meal order.

Sponsored by Takeda

Industry Sponsored Symposia - Consumer

There are several educational symposia held during NHF's 72th Bleeding Disorders Conference that are not coordinated by NHF. Please note that the companies or groups holding these symposia are solely responsible for their content, including any information presented or distributed during the symposium.

Session name	Session Date	Start Time	End Time
Industry Symposium: Give it a Shot: A Different Type of Hemophilia A Therapy, Sponsored by Genentech	8/1/2020	5:45 PM	7:15 PM
Industry Symposium, Hello Factor! - Sponsored by Takeda	8/2/2020	5:00 PM	6:30 PM
Industry Symposium, Staying Active with Hemophilia A - Sponsored by Takeda	8/3/2020	5:30 PM	7:00 PM
Industry Symposium, How often do you use your joints? - Sponsored by Sanofi	8/4/2020	5:30 PM	7:00 PM
Industry Symposium, The path forward: Importance of healthy lifestyles -Sponsored by Novo Nordisk	8/5/2020	5:30 PM	7:00 PM
Industry Symposium, Beyond Trough Levels: Taking a Closer Look at Hemophilia B - Sponsored by Sanofi	8/6/2020	5:30 PM	7:00 PM
Industry Symposium, Gene Therapy Research: Understanding the Science- Sponsored by Biomarin	8/8/2020	11:30 AM	12:45 PM

Industry Sponsored Symposia - Provider

Session name	Session Date	Start Time	End Time
Industry Symposium - Hemophilia Gene Therapy - Learning from Clinical Trials and Preparing for Clinical Practice - Sponsored by ISTH and The France Foundation (Providers)	8/5/2020	7:00 PM	8:30 PM
Payers and HTC's: How the Comprehensive Care Sustainability Collaborative (CCSC) is Forging New Ground to Meet the Evolving Needs of Patients	8/6/2020	12:00 PM	1:30 PM

When it comes to your hemophilia A treatment

Move beyond the threshold^a

Esperoct[®] can give you high factor levels for longer.^b

Extend half-life beyond the standard 22-hour average half-life in adults^c

FOR ADULTS AND ADOLESCENTS

Switching made easy

with a standard 50 IU/kg dose every 4 days

-50% fewer infusions if you previously infused every other day

-40% fewer infusions if you previously infused 3x a week

High factor levels

At or above 3%
for 100% of the time^{d,e}

At or above 5%
for 90% of the time^{d,f}

Flexible on the go

The ONLY extended half-life product that can be stored up to 104°F^g

Please see Brief Summary for complete storage instructions.

Safety Proven across 5 studies, the largest and longest EHL clinical trial program

^aOf 1% trough factor levels for standard half-life (SHL) products in adults and adolescents.

^bCompared with SHL products.

^cData shown are from 42 adults who received a pharmacokinetic (PK) assessment around the first Esperoct[®] 50 IU/kg dose.

^dTrough level goal is 1% for prophylaxis.

^eData shown are from a study where 175 previously treated adolescents and adults received routine prophylaxis with Esperoct[®] 50 IU/kg every 4 days.

Pre-dose factor activity (trough) levels were evaluated at follow-up visits. Mean trough levels for adolescents (12- <18 years) were 2.7 IU/dL.

^fSteady-state FVIII activity levels were estimated in 143 adults and adolescents using pharmacokinetic modeling.

^gFor up to 3 months.

What is Esperoct[®]?

Esperoct[®] [antihemophilic factor (recombinant), glycopegylated-exei] is an injectable medicine to treat and prevent or reduce the number of bleeding episodes in people with hemophilia A. Your healthcare provider may give you Esperoct[®] when you have surgery

- Esperoct[®] is not used to treat von Willebrand Disease

IMPORTANT SAFETY INFORMATION

Who should not use Esperoct[®]?

- You should not use Esperoct[®] if you are allergic to factor VIII or any of the other ingredients of Esperoct[®] or if you are allergic to hamster proteins

What is the most important information I need to know about Esperoct[®]?

- Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center
- Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as: hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face

What should I tell my healthcare provider before using Esperoct[®]?

- Before taking Esperoct[®], you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII

- Your body can make antibodies called "inhibitors" against Esperoct[®], which may stop Esperoct[®] from working properly.

Call your healthcare provider right away if your bleeding does not stop after taking Esperoct[®]

What are the possible side effects of Esperoct[®]?

- Common side effects of Esperoct[®] include rash or itching, and swelling, pain, rash or redness at the location of infusion

Please see Brief Summary of Prescribing Information on the following page.

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



Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

Esperoct[®] is a registered trademark of Novo Nordisk Health Care AG.

Novo Nordisk is a registered trademark of Novo Nordisk A/S.

© 2020 Novo Nordisk Printed in the USA. US20ESP00014 February 2020

esperoct[®]

*antihemophilic factor (recombinant),
glycopegylated-exei*

esperoct®

antihemophilic factor (recombinant),
glycopegylated-exei

Brief Summary information about ESPEROCT® [antihemophilic factor (recombinant), glycopegylated-exei]

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/esperoct.pdf to obtain FDA-approved product labeling
- Call 1-800-727-6500

Patient Information

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

Read the Patient Information and the Instructions For Use that come with ESPEROCT® before you start taking this medicine and each time you get a refill. There may be new information.

This Patient Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about ESPEROCT® after reading this information, ask your healthcare provider.

What is the most important information I need to know about ESPEROCT®?

Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ESPEROCT® so that your treatment will work best for you.

What is ESPEROCT®?

ESPEROCT® is an injectable medicine used to replace clotting Factor VIII that is missing in patients with hemophilia A. Hemophilia A is an inherited bleeding disorder in all age groups that prevents blood from clotting normally.

ESPEROCT® is used to treat and prevent or reduce the number of bleeding episodes in people with hemophilia A.

Your healthcare provider may give you ESPEROCT® when you have surgery.

Who should not use ESPEROCT®?

You should not use ESPEROCT® if you

- are allergic to Factor VIII or any of the other ingredients of ESPEROCT®
- if you are allergic to hamster proteins

If you are not sure, talk to your healthcare provider before using this medicine.

Tell your healthcare provider if you are pregnant or nursing because ESPEROCT® might not be right for you.

What should I tell my healthcare provider before I use ESPEROCT®?

You should tell your healthcare provider if you:

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing.
- Are pregnant or planning to become pregnant.
- Have been told that you have inhibitors to Factor VIII.

How should I use ESPEROCT®?

Treatment with ESPEROCT® should be started by a healthcare provider who is experienced in the care of patients with hemophilia A.

ESPEROCT® is given as an infusion into the vein.

You may infuse ESPEROCT® at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your hemophilia treatment center or healthcare provider. Many people with hemophilia A learn to infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much ESPEROCT® to use based on your weight, the severity of your hemophilia A, and where you are bleeding. Your dose will be calculated in international units, IU.

Call your healthcare provider right away if your bleeding does not stop after taking ESPEROCT®.

If your bleeding is not adequately controlled, it could be due to the development of Factor VIII inhibitors. This should be checked by your healthcare provider. You might need a higher dose of ESPEROCT® or even a different product to control bleeding. Do not increase the total dose of ESPEROCT® to control your bleeding without consulting your healthcare provider.

Use in children

ESPEROCT® can be used in children. Your healthcare provider will decide the dose of ESPEROCT® you will receive.

If you forget to use ESPEROCT®

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and continue as advised by your healthcare provider.

If you stop using ESPEROCT®

Do not stop using ESPEROCT® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

What if I take too much ESPEROCT®?

Always take ESPEROCT® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you infuse more ESPEROCT® than recommended, tell your healthcare provider as soon as possible.

What are the possible side effects of ESPEROCT®?

Common Side Effects Include:

- rash or itching
- swelling, pain, rash or redness at the location of infusion

Other Possible Side Effects:

You could have an allergic reaction to coagulation Factor VIII products. **Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as:** hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face.

Your body can also make antibodies called "inhibitors" against ESPEROCT®, which may stop ESPEROCT® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

These are not all of the possible side effects from ESPEROCT®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

Tell your healthcare provider about any side effect that bothers you or that does not go away.

What are the ESPEROCT® dosage strengths?

ESPEROCT® comes in five different dosage strengths. The actual number of international units (IU) of Factor VIII in the vial will be imprinted on the label and on the box. The five different strengths are as follows:

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Gray	1500 IU per vial
Yellow	2000 IU per vial
Black	3000 IU per vial

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

How should I store ESPEROCT®?

Prior to Reconstitution (mixing the dry powder in the vial with the diluent):

Protect from light. Do not freeze ESPEROCT®.

ESPEROCT® can be stored in refrigeration at 36°F to 46°F (2°C to 8°C) for up to 30 months until the expiration date stated on the label. During the 30 month shelf life, ESPEROCT® may be kept at room temperature (not to exceed 86°F/30°C) for up to 12 months, **or** up to 104°F (40°C) for no longer than 3 months.

If you choose to store ESPEROCT® at room temperature:

- Record the date when the product was removed from the refrigerator.
- Do not return the product to the refrigerator.
- Do not use after 12 months if stored up to 86°F (30°C) **or** after 3 months if stored up to 104°F (40°C) **or** the expiration date listed on the vial, whichever is earlier.

Do not use this medicine after the expiration date which is on the outer carton and the vial. The expiration date refers to the last day of that month.

After Reconstitution:

The reconstituted (the final product once the powder is mixed with the diluent) ESPEROCT® should appear clear and colorless without visible particles.

The reconstituted ESPEROCT® should be used immediately.

If you cannot use the reconstituted ESPEROCT® immediately, it must be used within 4 hours when stored at or below 86°F (30°C) or within 24 hours when stored in a refrigerator at 36°F to 46°F (2°C to 8°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

What else should I know about ESPEROCT® and hemophilia A?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ESPEROCT® for a condition for which it is not prescribed. Do not share ESPEROCT® with other people, even if they have the same symptoms that you have.

Revised: 10/2019

ESPEROCT® is a trademark of
Novo Nordisk Health Care AG.

For Patent Information, refer to: <http://novonordisk-us.com/patients/products/product-patents.html>

More detailed information is available upon request. Available by prescription only.

Manufactured by:
Novo Nordisk A/S
Novo Allé
DK-2880 Bagsværd, Denmark

For information about ESPEROCT® contact:
Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA
1-800-727-6500

© 2019 Novo Nordisk

US19ESP00168 December 2019



Virtual Conference Sessions

August 1 - 8, 2020

Saturday August 1

V - EXHIBIT HALL - CHAT WITH OUR EXHIBITORS

12:00 PM - 1:00 PM | Track: Nursing, Social Work, Physical Therapy, Physician, For All

PUBLIC HEALTH PRE CON: FUTURE THERAPIES AND SURVEILLANCE FOR BLOOD DISORDERS

12:00 PM - 3:00 PM | Track: Chapters, For All

Moderator: Neil Frick, MS

Speakers: Michelle Witkop, DNP, FNP-BC; Diane Nugent, MD; Rachel Rosovsky, MD; Brendan Hayes; Jessical Klass; Jeanne Boudreaux, MD; Raj Kasthuri, MD; Vanessa Byams, DrPH, MPH

After a successful public health offering at NHF's 2019 BDC, NHF decided to collaborate with several national blood disorder advocacy organizations to deliver two public health sessions for chapters and consumers. This session will address the public health implications of future therapies and surveillance and was created by the Sickle Cell Community Consortium, National Blood Clot Alliance, Center for Inherited Bleeding Disorders, Cooley's Anemia Foundation, Cure HHT, CDC, and NHF.

EVALUATING CHOICES IN A CHANGING INSURANCE MARKET

1:00 PM - 1:45 PM | Track: For All

Speakers: Marla Feinstein

Changes in federal healthcare policy over the past three and a half years have led to a more complicated insurance marketplace for people with chronic diseases. In this session, you'll learn how to evaluate your insurance options and avoid insurance products that won't serve your needs.

INTRODUCING THE YOUNG HOPE SOCIETY: DEDICATED SPACE FOR YOUNG PROFESSIONALS IN THE BLEEDING DISORDERS COMMUNITY

1:00 PM - 1:45 PM | Track: Teens and Young Adults

Moderator: Marlee Whetten

Speakers: Elizabeth Molnar; Maureen Parsons

The Young Hope Society (YHS) is a space for young professionals and supporters in the bleeding disorders community. Created in 2019 by the NHF in collaboration with our 52-chapter network, the society aims to inspire the next generation of philanthropic leaders in the bleeding disorders community. Membership is open to individuals between the ages of 21-40 who want to make a difference. Through the Young Hope Society, individuals can expand their social and professional networks, develop outreach and leadership skills, and help raise awareness and support for our cause in their local communities and nationally.

VWD PRE-CON - SPONSORED BY CSL BEHRING

1:00 PM - 2:35 PM | Track: Von Willebrand Disease

Speakers: Veronica Flood, MD; Bridget Tyrey; Lisa Vertrees; Jill McCray; Madonna McGuire Smith; Jason Walsh; Jeanette Cesta

The von Willebrand disease (VWD) pre-conference brings together the VWD community to connect in a lively, engaging and supportive educational environment. This year, we will focus on the elements of reconnecting, rebuilding and refocusing as a community. We will explore the many

ways that we as a community can help raise awareness of VWD and help those who are unaware of their status. We'll also discuss new medical updates and NHF's course of action with VWD. Sponsored by CSL Behring.

BASICS: HEMOPHILIA

1:50 PM - 2:35 PM | Track: For All

Speaker: Sue Geraghty, RN, MBA

Whether you or someone in your family has been recently diagnosed with hemophilia, or you've lived with hemophilia your entire life and want a refresher on the fundamentals, this session is for you. We will explain what hemophilia is, how it's treated, and what issues may arise at different life stages.

BATTLE OF THE SEXES: SEX AND RELATIONSHIPS

1:50 PM - 2:35 PM | Track: Spouses and Partners

Speaker: Ed Kuebler, MSW

Join us for an informative and enlightening session about sex, intimacy and relationship issues for couples living with a bleeding disorder. With this information you may learn some strategies for coping with issues that arise in your day to day lives.

PAIN MANAGEMENT: TOOL BOX NOT A PILL BOX

2:00 PM - 5:00 PM | Track: Physical Therapy

Moderator: Cindy Bailey, DPT

Speakers: James Luck, Jr., MD; Lena Volland, PT, DPT; Annette Von Drygalski, MD, PharmD; Marc Gilgannon, PT

The session will discuss pain related to bleeding disorders in the developmental stages and how infants, children and adolescents with bleeding episodes experience, express and cope with pain. It will review the latest research on management and assessment of pain in children and provide guidance on pain education for families and caregivers. Treatment and intervention strategies for physical therapists will be reviewed and followed by a group discussion.

MANAGEMENT OF PATIENTS ON NOVEL THERAPIES (ANCC)**

2:00 PM - 5:00 PM | Track: Nursing

Moderator: Moderators: Penny Kumpf, RN-BC, BSN; Kelly Tickle, MSN, APN, PPCNP-BC; Emily Bisson, APRN, CPNP

Speaker: Lydia Johnson, RN, BSN; Robert Sidonio, Jr., MD, MSc; Kathaleen Schnur, LSW; Leigh Carpenter, RPh Susan Knight, PT, PCS Becky Garcia, RN, BSN, CPN

Novel therapies for hemophilia have dramatically changed our management of patients with hemophilia A with and without inhibitors. However, the presence of inhibitors remains a major determinant of therapeutic options for bleeding and surgical management. This session will review therapies commercially available for patients with hemophilia A and inhibitors and discuss the role of immune tolerance induction in the era of non-factor replacement therapies.

PREGNANCY AND CHILDBIRTH IN WOMEN WITH BLEEDING DISORDERS**2:40 PM - 3:25 PM | Track: Women with Bleeding Disorders****Speakers: Charletta Ayers, MD, MPH; Michelle Ryzak**

Pregnancy and childbirth for women with bleeding disorders takes extra planning and care. Come learn from an expert and community member about issues women with bleeding disorders face when pregnant and giving birth, and how to advocate for the care you need.

WASHINGTON INSIDER: A FEDERAL POLICY UPDATE**2:40 PM - 3:25 PM | Track: Chapters, For All****Speakers: Johanna Gray; Ellen Riker**

What are the latest healthcare policy issues in Washington, DC, demanding NHF's attention? How is our skilled nursing facility (SNF) bill being affected by Congress' attention on the COVID-19 pandemic and the upcoming presidential election?

NHF'S SECOND ANNUAL VICTOR GRIFOLS ROURA MEDICAL SYMPOSIUM - GENETIC ANALYSIS AND OTHER DIAGNOSTIC TOOLS FOR RARE INHERITED BLEEDING AND PLATELET DISORDERS (NOT FOR CME/CE)**3:00 PM - 5:00 PM | Track: Physician****Moderator: Meera Chitlur, MD****Speakers: Amy Shapiro, MD; Diane Nugent, MD; Jorge DiPaola, MD; Joe Zuraw, Sr. Director-Corporate Affairs, Grifols Shared Services North America, Inc.; Brett Spitale, Vice President for Advancement, NHF;**

Thanks to a generous donation from Grifols, this year's NHF Victor Grifols Roura Medical Symposium will focus on rare inherited bleeding and platelet disorders. Targeted to physicians, researchers, pharmacists, nurses and other allied health professionals, NHF has brought together some of the leading experts in the field to share the latest updates in diagnosis and clinical management of rare bleeding disorders. We will review the currently available treatments used to manage bleeding in these rare patients, share some of the advances being made to improve genetic diagnosis of rare bleeding and platelet disorders, and also provide insights on how to interpret rare platelet gene panels. This will be an incredible opportunity to hear the advances being made nationally to address patients with these very rare conditions.

BASICS: VWD**3:30 PM - 4:15 PM | Track: Von Willebrand Disease****Speaker: Daisy Cortes, MD**

This session will review the signs and symptoms of von Willebrand disease, discuss genetics and inheritance patterns, and define and compare the three types of VWD. The presentation will also cover laboratory diagnosis and its challenges, and the therapeutic options available for people with VWD. In addition, you will learn important skills to advocate for yourself and loved ones.

FAITH AND BLEEDING DISORDERS

3:30 PM - 4:15 PM | Track: For All

Moderator: Christi Humphrey, LCSW

Speakers: Anthony Haugabrook; Aamina Iftikhar

Faith can provide many things to a person: comfort, love, and a community of support. But sometimes living with the realities of a chronic illness can result in a struggle between one's beliefs and one's day-to-day situation. In this session, we'll discuss ways that faith can affect your perception of your bleeding disorder, how your bleeding disorder can affect your faith, and how to navigate the complexities and find a balance while still upholding your own beliefs. This session welcomes people of all faiths and beliefs.

MEDICINAS CASERAS

4:15 PM - 5:00 PM | Track: En Español

Speaker: Maria Tovar-Herrera, RN-BC, BSN

Muchas familias y culturas tienen sus propios remedios caseros "especializados" para tratamientos y curas. Esta sesión explorará cuántos de estos remedios caseros a veces pueden causar daño y entrar en conflicto con el tratamiento. Many families and cultures have their own "specialized" home remedies and so-called cures. This session will explore how many of these home remedies can sometimes cause harm and interfere with treatment.

MOVEMENT AND MOBILITY

4:15 PM - 5:00 PM | Track: Adult Men

Speaker: Jhon Velasco, MA, RYT300

Throughout the different stages of living with a bleeding disorder, we can be or become immobile at one point or another. During this session you will learn movement and meditation techniques that alleviate stress and anxiety that come along with a bleeding disorder.

NHF'S VIRTUAL BDC OPENING SESSION

5:00 PM - 5:45 PM | Track: For All

Join us as NHF President and CEO Leonard Valentino, MD welcomes you to NHF's virtual Bleeding Disorders Conference and outlines the future direction for the National Hemophilia Foundation, and how you can play a part in shaping that future.

INDUSTRY SYMPOSIUM: GIVE IT A SHOT: A DIFFERENT TYPE OF HEMOPHILIA A THERAPY, SPONSORED BY GENENTECH

5:45 PM - 7:15 PM | Track: Industry Symposium

Please join us for an engaging symposium led by, and made for, members of the hemophilia A community! Learn from our panelists as they share their personal experiences with treating and living with hemophilia A. This presentation will also include information about a subcutaneous treatment option for hemophilia A, including important clinical trial data, its half-life and dosing options. Our panelists will provide useful resources for the hemophilia A community and answer your questions in a live Q&A. We hope to see you there!

Sunday August 2

MAKE THE MOST OF NHF - SPONSORED BY TAKEDA

12:30 PM - 1:30 PM | Track: For All, BDC Networking/Social Events

Speakers: Mosi Williams, PsyD.; Eric Iglewski, LMSW

This introduction to NHF's 2020 Virtual Bleeding Disorders Conference will provide tips on how to get the most out of this year's conference. It will highlight key sessions, the Exhibit Hall's vast offerings, and social gatherings and events not to be missed.

V-EXHIBIT HALL - CHAT WITH OUR EXHIBITORS

1:00 PM - 2:00 PM

ASIAN & PACIFIC ISLANDER CULTURES & BLEEDING DISORDERS

2:00 PM - 2:45 PM

Speakers: Michelle Kim, Esq; Kyra Calbero

This session will examine the intersection between Asian and Pacific Islander (API) culture and life with a bleeding disorder. We will discuss successes, challenges, and cultural nuances. The session will close with a group discussion on how to continue to engage various API communities.

WESTERN ASIA/MUSLIM CULTURE & BLEEDING DISORDERS

2:00 PM - 2:45 PM | Track: For All

Speakers: Burak Ozturk; Ali Haidar; Laila Jafri

This session will examine the intersection between Western Asian/Muslim culture and life with a bleeding disorder. We will discuss challenges and successes confronting generational issues, acceptance, and cultural nuances. The session will close with audience discussion on how to enhance engagement within this community. No industry representatives will be allowed in this session.

FORGING A NEW PATH - GENE THERAPY READINESS AND HTC IMPLEMENTATION *CME/ACPE

2:00 PM - 5:00 PM | Track: Physician

Moderator: Steven Pipe, MD; Christopher Walsh, MD, PhD

Speakers: Steven Pipe, MD; Radek Kaczmarek, PhD; Kayla Douglas, PharmD, CSP; Kollet Koulianos, MBA; Michael Wang, MD; Rebecca Kruse-Jarres, MD, MPH

See the Medical Track program handout for further details about this session. It can be accessed by clicking the 'CME/CE' tab on the main NHF Virtual BDC72 Conference website.

COVID-19: ASK THE EXPERTS

2:50 PM - 3:35 PM | Track: For All

Speakers: Tammueella Singleton, MD; Leonard Valentino, MD; Peter Kouides, MD

Join us for the latest updates and get expert answers to your questions about how COVID-19 affects our community of people with bleeding disorders, healthcare providers, manufacturers, and others.

GENE THERAPY: GETTING UP TO SPEED

2:50 PM - 3:35 PM | Track: For All

Speaker: Mark Reding, MD

Advancements in gene therapy are happening at a fast clip. Having a solid understanding of this technology is important to patients, caregivers and families. Join us for an in-depth discussion of gene therapy including historical aspects, key terms, various approaches to the technology, and how it may revolutionize hemophilia treatment.

HEMO 201: WHAT TO DO WHEN YOU HAVE NO CLUE

3:00 PM - 4:00 PM | Track: Physical Therapy

Moderator: Kori Williams, PT, DPT

Speaker: Ruth Mulvany, PT, DPT, MS

Hemophilia is a uniquely challenging and sometimes perplexing condition for physical therapists to manage and treat. Physical therapists who see patients across the lifespan may manage conditions that range from athletic injuries to frailty. Clinicians often rely on reviewing limited evidence, consulting colleagues, and ultimately critical thinking and best clinical judgment to develop a management plan. This session will outline a framework for different scenarios seen in the clinic and look at six broad management schemes.

WALKING A NEW PATHWAY: COAGULATION & MEASURES OF HEMOSTASIS *ANCC

3:00 PM - 4:00 PM | Track: Nursing

Moderator: Kerry Hansen, RN

Speaker: Jim Munn, MS, BS BSN, RN-BC

This session will review the cell-based theory of hemostasis and how it relates to the “coagulation cascade”. Specific laboratory assays will be reviewed in light of this understanding, examining the strength and weakness of each. Evaluation of how these assays help guide individualized treatment options in hemophilia will be explored. Laboratory considerations in evaluation of EHL concentrates and non-replacement therapies will be emphasized.

ETHICS: BLURRED BOUNDARIES *ASWB

3:00 PM - 5:00 PM | Track: Social Work

Moderators: Lucy Ramirez, MSW, LCSW

Speaker: Alana Brunner, LCPC, NCC, CCMHC

This two hour closed session provides information on ethics and professional boundaries for social workers in the bleeding disorders community. Updated to reflect the most current professional codes of ethics, the course explores common ethical dilemmas as well as provide a decision making model aimed at helping practitioners work through these challenges. Special attention is paid to the importance of professional boundaries and how to distinguish between a boundary extension and boundary violation. Case studies throughout the learning materials highlight key learning points unique to the bleeding disorders community.

NAVEGANDO POR LA ESCUELA VIRTUAL EN CASA**3:35 PM - 4:20 PM | Track: Parenting/Caregiver, En Español****Speakers: Octavio Zalva; Alfredo A. Narvaez, Jr., MSW, LMSW**

Durante COVID-19 muchos niños están ahora averiguando cómo aprender en línea a través de la escuela virtual. Muchos padres y cuidadores ahora tienen la tarea de trabajar, la escuela en línea y el cuidado de niños. En esta sesión se discutirán estrategias, consejos e historias sobre cómo navegar por la escuela en línea y el aprendizaje virtual con un niño que tiene un trastorno hemorrágico. Navegando por la escuela virtual en casa.

NAVIGATING VIRTUAL SCHOOL AT HOME**3:35 PM - 4:20 PM | Track: Parenting/Caregiver****Speakers: Kelly Baker; Alayna Sipple, LCSW**

During COVID-19, many children are now figuring out how to learn online through virtual schooling. Many parents and caregivers are now tasked with balancing work, online school, and child care. This session will discuss strategies, tips, and stories of how to navigate the online school and virtual learning with a child who has a bleeding disorder.

DEMYSTIFYING THE ILIOPSOAS: THE BOOGEYMAN OF ALL MUSCLE BLEEDS**4:00 PM - 5:00 PM | Track: Physical Therapy****Moderators: Bruno Steiner, PT, DPT, LMT, RMSK; Anita Wood, PT**

This session will take a deep dive into identification and management of acute to chronic iliopsoas bleeds. Is the psoas to blame for all hip pain?

DISORDERS OF FIBRINOGEN *ANCC**4:00 PM - 5:00 PM | Track: Nursing****Moderator: Kimberly Hurdstrom, RN, BSN****Speaker: Marilyn Manco-Johnson, MD**

This session will look at fibrinogen disorders: their prevalence, range of presentations, types of treatment, and outcomes. We will discuss treatment of acute bleeding, acute clotting, surgery, pregnancy and delivery, genetic testing, as well as prophylaxis. The discussion will include relevant case presentations. We will also describe the differences in phenotypes between hypo and dysfibrinogenemia.

DE LO QUE TODOS LOS QUE TRATAN CON FACTOR DEBEN SABER SOBRE LOS INHIBIDORES

4:20 PM - 5:00 PM | Track: En Español

Speaker: Maria Tovar-Herrera, RN-BC, BSN

Si trata con factor de coagulación, puede estar en riesgo de desarrollar un inhibidor. Este taller es para personas que no tienen un inhibidor pero desean aprender más sobre el riesgo. Explicaremos los conceptos básicos de los inhibidores, cómo se desarrollan y cómo y por qué debería conversar con su proveedor de atención médica sobre la detección de un inhibidor. If you treat with clotting factor, you may be at risk of developing an inhibitor. This workshop is for people who do not have an inhibitor but want to learn more about risk. We will explain the basics of inhibitors, how they are developed, and how and why you should have a conversation with your healthcare provider about detecting an inhibitor.

WHAT EVERYONE WHO TREATS WITH FACTOR NEEDS TO KNOW ABOUT INHIBITORS

4:20 PM - 5:00 PM | Track: For All

Speaker: Maria Tovar-Herrera, RN-BC, BSN

If you treat with clotting factor, you may be at risk of developing an inhibitor. This session is for people who do not have an inhibitor but want to learn more about risk. We will explain the basics of inhibitors, how they develop, and how and why you should have a conversation with your healthcare provider about screening and monitoring for an inhibitor.

INDUSTRY SYMPOSIUM: HELLO FACTOR! - SPONSORED BY TAKEDA

5:00 PM - 6:30 PM | Track: Industry Symposium

Speaker: Grace Hernandez, PT

Join Takeda for an educational discussion and hear from a real-life patient as they discuss their hemophilia A experience with physical therapist Grace Hernandez. You'll also experience an educational presentation to learn more about how you can become a greater advocate for your hemophilia A.

TEEN IMPACT AWARDS - PRODUCED BY BELIEVE

6:30 PM - 8:00 PM | Track: Teens and Young Adults, BDC Networking/Social Events

The 6th Annual Teen Impact Awards honors teens affected by bleeding disorders making a positive impact in their homes, schools, and communities. The show features community presenters, documentaries on selected honorees, and community teen honorees sharing their experiences and wisdom. Founding Sponsor: Takeda



BE AMAZING

At the CSL Behring Virtual Booth

**Join us to learn how we
can help you manage your
bleeding disorder.**

**There will be a raffle for
an Amazon Echo Show 8.**

**CSL Behring 3D, Interactive Virtual Booth
Saturday August 1st-Saturday August 8th.**



Biotherapies for Life® is a registered trademark of CSL Behring LLC.

©2020 CSL Behring LLC 1020 First Avenue, PO Box 61501, King of Prussia, PA 19406-0901 USA
www.CSLBehring.com COA-0466-JUN20

CSL Behring
Biotherapies for Life®

Monday August 3

MEETING WITH NHF'S PRESIDENT AND CEO

2:00 PM - 3:00 PM | Track: Chapters

Speaker: Leonard Valentino, MD

Please join NHF President & CEO Dr. Len Valentino to hear his vision for the future of NHF, discuss NHF's strategic planning process, and learn how NHF's chapter network and stakeholders will play a role in helping shape NHF's vision and strategy.

EMBRACING OUR STRENGTHS IN THE WORKPLACE

3:30 PM - 4:30 PM | Track: Chapters

Speaker: Taylor Shanklin

A happy work environment is a productive work environment. But how to achieve one? Changing workplace culture starts from within. When we focus on bringing strengths-based intention, mindfulness, and gratitude into our workplace, the culture thrives and this leads to better performance and happier work environments. Through this thought-provoking conversation, attendees will learn about a strengths-based approach to professional development and the benefits it can bring into our work.

V-EXHIBIT HALL - CHAT WITH OUR EXHIBITORS

4:30 PM - 5:30 PM

INDUSTRY SYMPOSIUM: STAYING ACTIVE WITH HEMOPHILIA A - SPONSORED BY TAKEDA

5:30 PM - 7:00 PM | Track: Industry Symposium

Speaker: Tammuella Singleton, MD

Hear the real-life stories of two hemophilia A patients and how each manage and maintain their active lifestyles. You'll also learn from Dr. Singleton as she discusses the importance of staying physically active and how you can personalize your treatment regimen to help meet your lifestyle and treatment needs.

COVID-19 AND PROVIDER MENTAL HEALTH *ASWB

6:00 PM - 7:00 PM | Track: Social Work

Moderators: Lucy Ramirez, MSW, LCSW

Speaker: Jeannie Aschkenasy, PhD

During the COVID-19 pandemic, social workers have been "essential" in responding to the needs of individuals and families faced with real-life stressors – from handling unemployment, accessing insurance coverage and finding financial assistance, to dealing with anxiety and grief. This session will focus on the need for social workers to also attend to their own stress and well-being. We will cover effective ways and good self-care practices for social workers to cope with the challenges of their work in these demanding times.

TODAY'S TECHNOLOGY *ANCC**6:00 PM - 7:00 PM | Track: Nursing****Moderator: Tamara Bullock, RN-BC, BSN****Speakers: Michael DeGrandpre; Penny Kumpf, RN-BC, BSN**

Today's nurses and medical professionals have a real challenge when it comes to all of the available information accessible online and on social media. This session will discuss some of the ethical challenges and related guidelines under the nurse practice acts. We will explore some expert-vetted online tools available to nurses and HTC staff to enhance patient education and communications. This session will inspire you to rethink ways of engaging and working with patients, towards delivering the best care possible.

TOTAL JOINT REPLACEMENT: FULL DISCLOSURE**6:00 PM - 7:00 PM | Track: Physical Therapy****Moderator: Kimberly Baumann, PT, MPT****Speaker: Cindy Bailey, DPT**

Total joint replacements can be performed safely in people with bleeding disorders. In this session, we will address realistic expectations, possible complications, and potential outcomes of total joint replacement surgery in patients with bleeding disorders.

ADVANCEMENTS IN TREATMENT FOR HEMOPHILIA: WHAT YOU NEED TO KNOW**7:00 PM - 8:00 PM | Track: For All****Speaker: Guy Young, MD**

These are exciting times in hemophilia research, with many new treatment options on the horizon. Come learn about the latest results of various phases of clinical trials on gene therapy and other new treatment options to see what the future holds for the treatment of hemophilia.

Tuesday August 4

CHAPTER LUNCHEON - SPONSORED BY TAKEDA

1:00 PM - 2:00 PM | Track: Chapters

Speakers: Alison Clifford, Rodney Dickson, Joanna Stevens, Jorge Caicedo

Join Takeda Hematology executive leadership for an engaging presentation and discussion exploring Takeda's plans to meet the bleeding disorders community's needs in the years to come through evolved educational offerings. We look forward to engaging with the NHF chapter leaders.

FROM THE GROUND UP: HOW THE USA HELPS THE WFH CHANGE COMMUNITIES AROUND THE WORLD

2:30 PM - 3:30 PM | Track: Chapters

Speakers: Madonna McGuire Smith; Eric Stolte; Jennifer Laliberte; Andreina Tovar; Antonietta Colavita; Salome Mekhuzla; Firaoli Kumbi; Chimwemwe Chande

The World Federation of Hemophilia believes that where people with bleeding disorders are born or live should not determine their level of care, and the US bleeding disorders community is among our staunchest allies in working to ensure that no one gets left behind. The WFH works to help establish comprehensive care for people with bleeding disorders in communities across the world. Our US partners provide us with invaluable expertise and support that transforms the lives of patients. Come hear how we are changing the world together today and how you can help us tomorrow.

V-EXHIBIT HALL - CHAT WITH OUR EXHIBITORS

4:30 PM - 5:30 PM

INDUSTRY SYMPOSIUM: HOW OFTEN DO YOU USE YOUR JOINTS? - SPONSORED BY SANOFI

5:30 PM - 7:00 PM | Track: Industry Symposium

Speaker: Kimberly Baumann, PT, MPT

Whether you're going about your day, or doing the things you love, you may not realize how much you rely on your joints. Taking care of yourself and your joints plays an essential role in your ability to pursue what you're truly passionate about in your life, especially if you're living with hemophilia A. Join Community Relations and Education Manager Shelley Gerson and physical therapist Kim Baumann as they share their experiences, and professional insights in to what it takes to care for your joints - you use them more than you may think.

MILD PHENOTYPES: THE STRUGGLE IS REAL *ANCC

6:00 PM - 7:00 PM | Track: Nursing

Moderator: Jennifer Donkin, DNP, CPNP, CFNP

Speakers: Sharon L. Littig, RN; Penni Smith, MPA, BSN, RN-BC; Brooke Towns, RN, BSN

Nurses often lack knowledge regarding methods for identifying patients with mild phenotypes of bleeding disorders and addressing their needs in the clinic setting. We will recognize barriers to care for patients with mild phenotypes of bleeding disorders and describe nursing care management strategies for patients with mild phenotypes of bleeding disorders.

NIPPING PAIN IN THE BUD: THE SCIENCE BEHIND MEDICAL MARIJUANA**6:00 PM - 7:00 PM | Track: Physical Therapy****Moderator: Bruno Steiner, PT, DPT, LMT, RMSK****Speaker: Khalid Namoos**

Patients are increasingly turning to cannabis-related pharmaceuticals for pain relief and management. This session will address the available evidence, and the negative or positive hype from the facts, and discuss the need for more research. Dispensation, delivery and dose control will be discussed as well as implications for the bleeding disorders community, ranging from pain management to fall risk in our aging hemophilia population.

PREVALENCE OF DEPRESSION AND/OR ANXIETY IN CHILDREN SEEN AT THE ARIZONA HEMOPHILIA AND THROMBOSIS CENTER *ASWB**6:00 PM - 7:00 PM | Track: Social Work****Moderators: Amy Schadewald, MSW, LICSW, ACM; Connie Thibodeaux, MSW, LCSW, BAC****Speaker: Maria Ianonne, MA, LPC**

Many social workers are not familiar with validated instruments to support a clinical diagnosis of anxiety and/or depression and hence lack competence in addressing the ethical implications of such screenings. We will define the clinical diagnosis of depression and/or anxiety, including the use of validated instruments, and discuss the ethical implications associated with screening for depression and anxiety.

BLOOD AND PRODUCT SAFETY**7:00 PM - 8:00 PM | Track: For All****Speakers: Johanna Gray; Nathan Schaefer; Mark Skinner, JD**

An update on safety and supply issues relating to blood and therapeutic products used by people with bleeding disorders. This will include discussion of product recalls the past two years, the January 2020 NHF/HFA Safety Summit convened by the National Hemophilia Foundation and Hemophilia Federation of America, emerging pathogens (e.g., COVID-19), and the latest safety surveillance information.

Wednesday August 5

DIAMONDS IN THE ROUGH: FINDING THE BEST DONOR PROSPECTS HIDDEN IN YOUR DATABASE

2:00 PM - 3:00 PM | Track: Chapters

Speaker: Steven Shattuck

Let's face it: prospect research is difficult, and not every chapter has access to a dedicated fundraising professional. For many chapter leaders, wealth screening tools, social media, and good old-fashioned Google searches can only get you so far. In this session, we'll explore prospect research strategies that build deeper, more meaningful relationships with donors. Participants will learn engagement strategies that enhance existing relationships, as well as how to find and engage new donors.

CAPTURING ATTENTION WITH OUR AUTHENTIC VOICE

3:30 PM - 4:30 PM | Track: Chapters

Speaker: Taylor Shanklin

Authenticity in branding, messaging and the case for support is critical to capture and keep the attention of today's supporters. To maximize fundraising efforts and build a thriving community, it is critical to bring our authentic voices to the forefront. Join us for a thought-provoking conversation, learn how to tap into your authentic voice, and help bring forward an authentic brand for the bleeding disorders community and its supporters.

V-EXHIBIT HALL - CHAT WITH OUR EXHIBITORS

4:30 PM - 5:30 PM

INDUSTRY SYMPOSIUM: THE PATH FORWARD: IMPORTANCE OF HEALTHY LIFESTYLES -SPONSORED BY NOVO NORDISK

5:30 PM - 7:00 PM | Track: Industry Symposium, For All

During this symposium, we will discuss the importance of healthy living in people with hemophilia, including weight management. We will explain how small changes, such as managing portion sizes and engaging in the right physical activities, can improve the overall health of people with hemophilia. Information on a new treatment option for hemophilia A will also be presented.

CANNABIS APPLICATIONS & IMPLICATIONS *ANCC

6:00 PM - 7:00 PM | Track: Nursing

Speaker: Khalid Namooos

As legalization and deregulation become more widespread, nurses may lack knowledge regarding appropriate use of cannabis for pain management in patients with bleeding disorders. We will compare cannabis formulations, identify clinical indications for cannabis use, and describe its pharmacokinetics and physiologic effects.

CHAPTER LEADERSHIP NETWORKING HR. - SPONSORED BY PFIZER

6:00 PM - 7:00 PM | Track: Chapters, BDC Networking/Social Events

Chapter Leaders, please join us at the Old-Fashioned Watering Hole for a fun and engaging networking hour to connect with your peers from across the country. Expect some special guests, great music and a sneak peek into the endless opportunities of the virtual world.

JUST DO IT . . . OR DON'T

6:00 PM - 7:00 PM | Track: Physical Therapy

Moderator: Tiffany Kaltenmark, PT, DPT

Speaker: Stacie Akins, PT, MHS

Given relatively limited literature specifically on return to physical activity after injury for people with bleeding disorders, many physical therapists may lack competence in developing tailored recovery plans and providing prudent guidance to patients and their families. We will consider and apply recommended guidelines for return to activity and sport, critically appraise existing return to activity evaluation tools and applications, and compare and contrast return-to-work evaluation tools and applications for people with bleeding disorders.

POVERTY AND BARRIERS IN HEALTHCARE *ASWB

6:00 PM - 7:00 PM | Track: Social Work

Moderator: Christi Humphrey, LCSW

Speakers: Diane Bartlett, LCSW, OSW-C; Bob Loudon, MSW, LCSW

Join this session for an in-depth understanding of how poverty can negatively affect the treatment and health outcomes of a patient with a bleeding disorder. This session will enable you to identify poverty and socio-economic issues that can often dictate a patient's treatment outcomes. From a social work perspective, you will gain strategies on how to manage and guide individuals or families living with such challenges to help achieve the best and most successful medical outcomes. There will be ample time for Q&A.

OUCH! TACKLING PAIN TOGETHER

7:00 PM - 8:00 PM | Track: For All

Moderator: Michelle Witkop, DNP, FNP-BC

Speakers: Tyler Buckner, MD, Msc; Emily Wheat, PhD; Sean Jeffrey

NHF's Medical and Scientific Advisory Council (MASAC) recently approved new treatment guidelines for providers who administer opioids to treat pain in people with bleeding disorders. Come learn about the new guidelines from expert providers and consumers and what they might mean to you.

INDUSTRY SYMPOSIUM: HEMOPHILIA GENE THERAPY - LEARNING FROM CLINICAL TRIALS AND PREPARING FOR CLINICAL PRACTICE - SPONSORED BY ISTH AND THE FRANCE FOUNDATION (PROVIDERS)

7:00 PM - 8:30 PM | Track: Providers - Industry Symposium, Nursing, Social Work, Physical Therapy, Physician

Speakers: Guy Young, MD; Steven Pipe, MD

With the expected approval of the first gene therapy for hemophilia in the next few months, it is important that clinicians are prepared for implementation in their respective hemophilia treatment centers (HTCs). During this 90-minute session, Drs. Steven Pipe and Guy Young will provide an overview of gene therapy for treatment of hemophilia along with an update on clinical trials in hemophilia A and B. They will also discuss what success looks like and how HTCs should be preparing for the advent of gene therapy. The presentation will conclude with a live question and answer session between attendees and Drs. Pipe and Young.



You are why.

At Sanofi Genzyme, we are deeply connected to the rare blood disorders community. From innovative research to personal support, you inspire our efforts to make more possible for you and the people you love.

[Visit our virtual booth to learn more.](#)

SANOFI GENZYME 

© 2020 Genzyme Corporation. All rights reserved.
MAT-US-2012740 06/2020

Thursday August 6

PAYERS AND HTCS: HOW THE COMPREHENSIVE CARE SUSTAINABILITY COLLABORATIVE (CCSC) IS FORGING NEW GROUND TO MEET THE EVOLVING NEEDS OF PATIENTS

12:00 PM - 1:30 PM | Track: Nursing, Social Work, Physical Therapy

CHAPTER LUNCHEON - SPONSORED BY GENENTECH. GENENTECH'S COMMITMENT TO HEMOPHILIA A: CREATING WHAT'S NEXT TOGETHER

1:00 PM - 2:00 PM | Track: Chapters

Speakers: Sonali Chopra; Adam Pryor; Gina Truslow

Get yourself ready, from the waist up at least, for some conversation and a little TV magic. Sonali Chopra from Advocacy Relations and Adam Pryor from Corporate Relations at Genentech will share upcoming Genentech projects that support the hemophilia community. This includes a new professional development resource and an episode of CHALLENGE ACCEPTED, an original TV series inspired by and made for the hemophilia community that challenges the meaning of life with a bleeding disorder. We want to hear how Genentech can continue to support the Hemophilia A community. You won't want to miss this magic! (You'll see what we mean.)

THE GOOD, THE BAD & THE UGLY: SUPERVISION AND COACHING OF STAFF AND VOLUNTEERS

2:30 PM - 3:30 PM | Track: Chapters

Speaker: Michael Craciunoiu, Ed.M, PCC; Erika Gill; Kevin Bernier

It takes a village to run a successful chapter. Gain the tools to motivate, inspire, and get the best results from your village of staff and volunteers while maintaining your sanity.

V-EXHIBIT HALL - CHAT WITH OUR EXHIBITORS

4:30 pm - 5:30 pm

LGBTQI NETWORKING HOUR - SPONSORED BY TAKEDA

4:30 PM - 5:30 PM | Track: BDC Networking/Social Events

NHF hosts a reception to bring together lesbian, gay, bisexual, transgender and queer (LGBTQI) members and allies of the bleeding disorders community. Join us for this informal networking and social hour.

INDUSTRY SYMPOSIUM: BEYOND TROUGH LEVELS: TAKING A CLOSER LOOK AT HEMOPHILIA B - SPONSORED BY SANOFI

5:30 PM - 7:00 PM | Track: Industry Symposium

You know that hemophilia B is different from hemophilia A in many ways, but when it comes to factor IX there's more to explore. Unlike factor VIII, which stays in the bloodstream, factor IX also travels outside the bloodstream and into other areas of the body. This means that trough levels, which only measure factor in the bloodstream, may not tell the full story. Join Dr. Malec and Community Relations and Education Manager Rachel Kroouze to learn more about factor IX and other PK measurements you should consider as part of your treatment.

THE NEXT WAVE: CLINICAL UPDATES ON NEW AND EMERGING TREATMENT OPTIONS IN HEMOPHILIA (PART 1) *CME/ACPE

5:30 PM - 7:00 PM | Track: Physician

Moderator: Stacy Croteau, MD, MMS

Speakers: Robert Sidonio, Jr, MD, MSc; Mark Reding, MD

See the Medical Track program handout for further details about this session. It can be accessed by clicking the 'CME/CE' tab on the main NHF Virtual BDC website.

GYNECOLOGIC MANAGEMENT FOR FEMALES WITH BLEEDING DISORDERS *ANCC

6:00 PM - 7:00 PM | Track: Nursing

Moderator: Kelly Tickle, MSN, APN, PPCNP-BC

Speaker: Kalinda Woods, MD

This session will review common gynecologic concerns for women with bleeding disorders. We will review the differential diagnoses, workup and treatment options for various causes of abnormal uterine bleeding. Best practices in treatment based on current and emerging evidence will be discussed.

MARIJUANA: BREAKING IT DOWN, THE GOOD, THE BAD, AND THE CONSUMPTION *ASWB

6:00 PM - 7:00 PM | Track: Social Work

Moderators: Kathaleen Schnur, LSW; Alfredo A. Narvaez, Jr., MSW, LMSW

Speaker: Khalid Namooos

Cannabis continues to be a topic of discussion. In this session we will learn about the pharmacokinetics of administration and how CBD and THC cannabinoids are processed by the body. Attendees will learn about the potential medical benefits, indications and management of cannabis, and how to navigate the legal implications that it often raises in work and school environments. Additionally, the session will cover potential toxicities and adverse effects that healthcare providers should be attuned to.

MEN? I FEEL LIKE A WOMAN . . . WITH A BLEEDING DISORDER

6:00 PM - 7:00 PM | Track: Physical Therapy

Moderator: Makenzie Sledd, MPT

Speakers: Sherry Herman-Hilker, PT, MS; Angela C. Weyand, MD

Expanding your PT evaluation skills to include the unique considerations for women with bleeding disorders.

30TH ANNIVERSARY OF THE RYAN WHITE CARE ACT

7:00 PM - 8:00 PM | Track: For All

Moderator: Nathan Schaefer

Speakers: Jeanne White-Ginder; Dana Francis, MSW; Craig Kessler, MD

This session will commemorate and reflect on the landmark legislation on HIV/AIDS care with a renewed call to action for the bleeding disorders community to be vigilant and engaged healthcare policy advocates.

Friday August 7

V-EXHIBIT HALL - CHAT WITH OUR EXHIBITORS

4:30 PM - 5:30 PM

VWD NETWORKING HOUR - SPONSORED BY TAKEDA

4:30 PM - 5:30 PM | Track: Von Willebrand Disease, BDC Networking/Social Events

THE NEXT WAVE: CLINICAL UPDATES ON NEW AND EMERGING TREATMENT OPTIONS IN HEMOPHILIA (PART 2) *CME/ACPE

5:30 PM - 7:00 PM | Track: Physician

Moderator: Christopher Walsh, MD, PhD

Speakers: Guy Young, MD; Margaret Ragni, MD, MPH

See the Medical Track program handout for further details about this session. It can be accessed by clicking the 'CME/CE' tab on the main NHF Virtual BDC website.

CARE COORDINATION FOR THE AGING BLEEDING DISORDERS POPULATION *ANCC

6:00 PM - 7:00 PM | Track: Nursing

Moderator: Tamara Bullock, RN-BC, BSN; Sharon L. Littig, RN

Speakers: Jeff Cornett, MSN, RN; Shanna Mattis, MPH

A coordinated nursing approach is fundamentally important to addressing the multitude of diverse changes and health conditions that may affect people with bleeding disorders in the later stages of life. We will focus attention on challenges in obtaining health services specifically for the aging population and identify two key strategies for providing care to those aging with bleeding disorders.

HOW TO SURVIVE 3-5: DEVELOPMENTALLY APPROPRIATE CARE FOR PWBD AGES 3-5

6:00 PM - 7:00 PM | Track: Physical Therapy

Moderator: Makenzie Sledd, MPT

Speaker: Lora Joyner, MS, PT, PCS

In this session, we will evaluate bleed presentation in children with bleeding disorders at 3 to 5 years of age, discuss educational tools and safety guidelines for caregivers, and analyze developmentally appropriate activities for children with bleeding disorders in this age group.

I'M NOT OKAY: OPENING UP ABOUT MENTAL HEALTH

7:00 PM - 8:00 PM | Track: For All

Moderator: Patrick James Lynch

Speakers: Mosi Williams, PsyD.; Sandra Valdovinos-Heredia, MSW, ACSW; Debbie de la Riva, LPC

NHF invites you to join us in kicking off this year's mental health sessions with a screening of a new film by Believe Limited (the team behind the Bombardier Blood documentary). Come hear community stories of navigating both physical and emotional aspects of life with a bleeding disorder. By coming together to listen and understand, we can begin to de-stigmatize mental health challenges and better support each other and our loved ones.

Saturday August 8

MASAC MEETING

10:00 AM - 4:00 PM | Track: Nursing, Social Work, Physical Therapy, Physician

The Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation will hold its meeting on Saturday, August 8, 2020. All physicians, researchers, and other interested guests are invited to attend.

INDUSTRY SYMPOSIUM: GENE THERAPY RESEARCH: UNDERSTANDING THE SCIENCE- SPONSORED BY BIOMARIN

11:30 AM - 12:45 PM | Track: Industry Symposium

Speaker: Guy Young, MD

Have questions about gene therapy research? Learn about the goals of gene therapy research, possible risks and eligibility criteria from a leading expert. This interactive program will answer questions about gene therapy research, including: How gene therapy research is designed to work. What different types of gene therapies are being researched? Why are some people eligible for gene therapy trials while others are not? No gene therapies have been approved for hemophilia A or B or been determined to be safe or effective.

DESAFÍO LEGAL E INMIGRACIÓN

1:00 PM - 1:45 PM | Track: En Español

Speaker: Alejandro Barajas

En esta sesión abordaremos sus derechos como inmigrante, así como los retos que afronta cada grupo familiar con el tema de inmigración; incluyendo a los niños que están indocumentados o tienen padres indocumentados que temen deportación y no saben si deben buscar atención médica para su trastorno hemorrágico. Le ayudaremos a aclarar cualquier duda que pueda tener sobre cómo navegar estos sistemas complejos. In this session we will address your rights as an immigrant, as well as challenges that families may face related to immigration; including undocumented children and/or undocumented parents who fear deportation and don't know if and how they should seek medical attention for their bleeding disorder. We will help you clarify any questions you may have about how to navigate these complex systems.

PARENT PARTNERSHIP & MENTAL HEALTH

1:00 PM - 1:45 PM | Track: Parenting/Caregiver

Speaker: Theresa Schaffer, LCSW; Kelly Baker

As a parent or primary caregiver of a child with a bleeding disorder, it's easy to put all of your focus into managing your child's care. Especially during this time, it is important to nurture your relationship with your partner - and to make your mental and emotional health a priority. This session will impart some personal experiences, as well as strategies and tips on how to balance your roles in your partnership and designate time to nurture your mental health and well-being.

INSIGHTS FROM AFRICAN AMERICAN COMMUNITIES WITH BLEEDING DISORDERS**1:50 PM - 2:35 PM | Track: For All****Speaker: Kelly Macias, PHD**

This session will present findings from a national needs assessment conducted by NHF in partnership with the CDC about the experiences and needs of people with bleeding disorders within African American communities. The group will discuss implications for individuals, chapters, and partners to serve African American communities.

PTSD IN CHRONIC CONDITIONS**1:50 PM - 2:35 PM | Track: Adult Men****Speaker: Amanda Stahl, MSW, LICSW**

During this session you will gain a deeper understanding of post-traumatic stress disorder (PTSD) and how it can manifest for a person with a bleeding disorder or a family member. We will discuss how PTSD can affect your personal and professional relationships and ways you can seek both medical and non-medical help.

PUBLIC HEALTH FOR WOMEN & GIRLS**2:00 PM - 5:00 PM | Track: Chapters, For All****Moderator: Kate Nammacher****Speakers: Jhon Velasco, DO; Kristina Haley, MD; Rachel Rosovsky, MD; Sylvia Singer, MD; Janet Chupka; Judith Baker, DrPH, MHSA; Kay Strawder, JD, MSW**

A session presented by the regional coordinators of the HTC network. After a successful public health offering at NHF's 2019 BDC, NHF decided to collaborate with several national blood disorder advocacy organizations to deliver two public health sessions for chapters and consumers. This session will address women's issues in public health and was created by the National Blood Clot Alliance, Center for Inherited Bleeding Disorders, Cooley's Anemia Foundation, Foundation for Women and Girls with Blood Disorders, NHF, and HFA.

MEET NYLI**2:40 PM - 3:25 PM | Track: Teens and Young Adults****Speakers: Kenny Thach; Rieley Schneider; Maria Gonzalez**

What does it mean to be a future leader of the bleeding disorders community? Is it possible to make a difference at my chapter while I'm still a teen? If you're looking to get involved these questions are probably on your mind. Come meet members of NHF's National Youth Leadership Institute (NYLI), who will share how they've been able to make a difference through education, advocacy, and chapter work training. Not only are they making a difference - they're leveling up in the real world as a result.

RUNNING ON EMPTY: COUPLES COMPASSION FATIGUE

2:40 PM - 3:25 PM | Track: Spouses and Partners

Speakers: Cathy Tiggs, MSSA, LISW; Heather Britton

There is no “clocking out” of providing care for a loved one with a bleeding disorder or any other chronic illness that requires complex treatment or management. But sometimes labor of love can lead to physical and mental exhaustion as well as emotional withdrawal. This session will discuss how to prevent and overcome compassion fatigue through self-full living and self-care strategies.

CHALLENGING CASES *ANCC

3:00 PM - 5:00 PM | Track: Nursing

Moderators: Sharon L. Littig, RN; Jessica Pindilli, BSN, RN

Speakers: Maria Tovar-Herrera, RN-BC, BSN; Elisabeth Ambrose, BSN, RN; Courtney Carr, RN-BC, MSN, CPNP; Shelia O'Donnell, FNP-C; Charmaine Biega, RN; Pamela Widener, BSN, RN

This year's session will look at two challenging cases related to bleeding disorders therapy and medication management, and describe the nursing and psychosocial considerations involved in managing complex cases.

OUR RESILIENT MINDS, BODIES AND SOULS: EMPOWERMENT THROUGH STORYTELLING *ASWB

3:30 PM - 5:00 PM | Track: Social Work

Moderators: Damia Dillard, LCSW; Denise Lowery, LCSW

Speaker: Caroline Giroux, MD, FRCPC

This session will focus on ways to identify signs and symptoms of trauma and the long-term impacts of early childhood trauma. We will discover the importance of becoming trauma informed, ways to avoid re-traumatization, and the key elements of resilience.

PRACTICAL PLANNING FOR AGING

3:30 PM - 4:15 PM | Track: Adult Men

Moderator: Marla Feinstein

Speakers: Christi Humphrey, LCSW; Ayana Woods, MPH

Whether you are currently experiencing some of the challenges of aging, or want to get ahead and plan for yourself or an aging family member, this session will provide practical tips on how to navigate through important considerations and available resources, from knowing your options for care at home or assisted living, to lining up power of attorney or living wills, and having well-informed conversations with loved ones.

WOMEN BLEED TOO**3:30 PM - 4:15 PM | Track: Women with Bleeding Disorders****Speakers: Paula James, MD, FRCPC; Nabila Husseni**

Women and girls with bleeding disorders often deal with particular issues and taboos related to diagnosis, symptoms, access to care. In this session, an expert who works to improve quality of life for women and girls with bleeding disorders will discuss essential information on the challenges of getting a diagnosis and accessing care and treatment. In addition, an affected individual will share their experience as a woman with a bleeding disorder.

GENE THERAPY: A CANDID CONVERSATION**4:15 PM - 5:00 PM | Track: For All****Moderator: Tammueella Singleton, MD****Speakers: Michael Joshua, Donna LeBrun, Jim Rippy**

The realization that gene therapy could be just around the corner is both daunting and exciting. Join us for a balanced, patient-centric discussion on gene therapy from multiple perspectives: a provider, a patient in a gene therapy clinical trial, a patient on a newer therapy, and a patient who is satisfied with conventional factor replacement therapy.

THE NEW VWD GUIDELINES**4:15 PM - 5:00 PM | Track: Von Willebrand Disease****Speaker: Veronica Flood, MD**

2020 is the year that VWD guidelines will be announced. This will be an opportunity to learn, explore and understand the new measures for treatment, diagnosis and protocols.

NHF'S VIRTUAL BDC AWARDS CEREMONY - SPONSORED BY TAKEDA**5:00 PM - 6:00 PM | Track: Nursing, Social Work, Physical Therapy, Physician, For All****Speakers: Mosi Williams, PsyD.; Eric Iglewski, LMSW; Leonard Valentino, MD****BDC 2020 FINAL NIGHT EVENT, SPONSORED BY TAKEDA****6:00 PM - 7:00 PM | Track: BDC Networking/Social Events****Speakers: Dawn Rotellini; Leonard Valentino, MD; Nikole Scappe**

This year's Final Night Event will be a virtual party in celebration of all that we have achieved together as a community and the milestones leading to a new era of treatment which will transform the lives of people with bleeding disorders. Please join us for live music, interactive games and a last chance to mingle with friends and peers. Arrive early as the first 500 attendees to participate and stay for the hour will receive a Grubhub gift card for a future meal order. Sponsored by Takeda.

No matter where you are on your bleeding disorder journey, we're there for you.

EVERY MILE OF THE JOURNEY.



THREE GREAT WAYS TO CONNECT AT NHF!

Join us at our virtual booth!

Learn about new product information and learn how Takeda can support you throughout your Bleeding Disorders Journey.

Hello Factor!

Becoming a Better Advocate with Hemophilia A Symposium

Sunday, August 2nd

5pm - 6:30pm ET

Hear from a patient like you as they discuss their experience with Hemophilia A.

Staying Active with Hemophilia A

A Takeda Patient Symposium

Monday, August 3rd

5:30pm - 7pm ET

The inspiring real-life stories of two Hemophilia A patients.

SIGN UP. STAY INFORMED. FIND YOUR DRIVE.

Go to www.hematologyoptin.com and sign up to receive the latest Takeda Bleeding Disorders Community News.



Copyright ©2020 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-XMP-0365v1.0 06/20



Booth Directory

ACCREDITO

8455 University Place Drive, St. Louis, MO 63121 | 314-684-6922 | www.hemophilia.com

Specialty Pharmacy. Experienced Care.

At Accredo, we understand it can be difficult to live with a chronic or complex illness and subsequent care. As one of the nation's leading and largest providers of specialty pharmaceuticals, our dedicated therapy teams work diligently to coordinate solutions for the challenges of 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.

Patients call: 866.712.5200

Physician offices call: 866.712.5007

BAYER

100 Bayer Blvd, Whippany, NJ 07981 | 862-404-3000
www.pharma.bayer.com/hemophilia

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

THE SCIENCE FAIR

2426 Cazaux Pl., Los Angeles, CA 90068 | 434-258-7222 | www.thesciencefair.org

Put on your lab coat, approach the microscope, and enter Believe Limited's Science Fair! Guided by virtual host Dr. Morales, the Science Fair is a family-friendly (and fun!) way to learn the fundamental science of today, the breakthrough science that brought us here, and the cutting-edge science guiding where we go next. The Science Fair explores the treatments for and science behind hemophilia, vWD, rare factor deficiencies, women with bleeding disorders, and so much more—including the exciting science behind gene transfer! Click the "Enter the Science Fair" link below to start your adventure in blood! Founding sponsor: Spark Therapeutics.

BIOMARIN PHARMACEUTICAL

105 Digital Drive, Novato, CA 94949 | 415-506-6700 | www.biomarin.com

Let's HemDifferently!

There's so much information available about gene therapy research, you might be wondering where to start. HemDifferently is a great place! We'll answer your questions—openly and accurately. Our events and resources connect members of the community with healthcare professionals as they share their knowledge of the science behind gene therapy research.

Have questions?

Join us—Gene Therapy Research: Understanding the Science

Saturday, August 8, 2020 | 8:30 AM - 9:45 AM PT/11:30 AM - 12:45 PM ET

Stay informed!

Sign up to receive the latest information and connect with a BioMarin Representative

BIOMARIN MEDICAL AFFAIRS

105 Digital Drive, Novato, CA 94949 | 415-506-6700 | www.biomarin.com

BioMarin focuses on developing first-in-class and best-in-class therapeutics that provide meaningful advances to patients who live with serious and life-threatening rare genetic diseases. BioMarin remains steadfast to its original mission to bring new treatments to market that will make a big impact on small patient populations.

BioMarin is currently investigating valoctocogene roxaparvovec, an investigational gene therapy treatment for severe hemophilia A. Valoctocogene roxaparvovec is under investigation and has not been approved for use outside of a clinical trial.

Find out about educational events, resources, and the latest in gene therapy research at HemDifferently.com.

NHF'S COMPREHENSIVE CARE SUSTAINABILITY COLLABORATIVE (CCSC)

7 Penn Plaza, Suite 1204, New York, NY 10001 | 309-397-8431 | www.ccschemo.com

The Comprehensive Care Sustainability Collaborative (CCSC) is an ongoing quality improvement and cost management initiative sponsored by NHF. CCSC provides a unique forum for Hemophilia Treatment Center (HTC) clinicians to collaborate with payers to facilitate the sustainability of the HTC comprehensive care model. Visit CCSchemo.com to become a CCSC member and have access to useful tools and resources that will help your HTC thrive in this ever-changing health care landscape. Use the chat box to ask NHF experts how CCSC can support your practice.

COALITION FOR HEMOPHILIA B

757 Third Avenue, 20th Floor, New York, NY 10017 | 212-520-8272 | www.hemob.org

Now celebrating 30 years of service to the community, the Coalition for Hemophilia B empowers individuals and their families affected by Hemophilia B, allowing them to achieve better health outcomes and the highest quality of life. We've been working tirelessly to help countless patients through connectivity and caring. We offer a diverse range of engaging virtual and in-person programs and services throughout the year. These programs and services address the needs of our community members from all walks of life. Be a part of our Hemophilia B family!

CSL BEHRING

1020 First Ave, King of Prussia, PA, 19406 | 610-878-4000 | cslbehring.com

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 biotherapies that are used to treat serious and rare conditions such as coagulation disorders, primary immune deficiencies, hereditary angioedema and respiratory disease. Although we will miss seeing you live in Atlanta this year, we are happy to see you at our virtual booth!

CVS SPECIALTY

1 CVS Dr., Woonsocket, RI 02895 | 847-224-0671 | cvsspecialty.com

Our commitment to helping patients and their physicians manage complex drug therapies by delivering expert individualized care and unmatched, multi-channel access has made us one of the leading specialty pharmacies in the country. We provide a full-range of pharmaceutical care, dispensing the latest FDA-approved medications.

GRIFOLS

2410 LILLYVALE AVE, Los Angeles, CA 90032 | 323-227-7630 | www.grifols.com/en/usa

For more than 75 years, Grifols has worked to improve the health and well-being of people around the world. We are a global healthcare company that produces essential plasma medicines for patients and provides hospitals, pharmacies, and healthcare professionals with the tools, information, and services they need to help them deliver expert medical care.

HEMOPHILIA ALLIANCE

20 Vine Street #1227, Lansdale, PA 19446 | 215-439-7173 | hemoalliance.org

The Hemophilia Alliance is a not-for-profit organization that comprises federally supported hemophilia treatment centers (HTCs) that either have, or are seeking to have, pharmacy programs under Section 340B of the Public Health Service Act.

The purpose of “the Alliance” is to promote the common interests of our member HTCs. In addition to providing support through advocacy, we provide consultant expertise and organizational support:

- Operations
- Regulatory compliance
- Payer relations
- Legal updates affecting practices
- Contract pharmacy

We work on our members’ behalf to make sure they are not disadvantaged, and to promote policies and procedures that lead to successful patient outcomes.”

HEMOPHILIA FEDERATION OF AMERICA

999 N. Capitol Street NE, Suite 201, Washington, DC 20002 | 202-675-6984
www.hemophiliafed.org

HFA is a patient education, services, and advocacy organization serving the rare bleeding disorders community. We exclusively focus on the bleeding disorders patient and caregiver community. Our member organizations across the country utilize HFA’s collaborative federation to strengthen community support and awareness, develop effective local organizations, and implement valuable programs.

JUNE FOR JOINT HEALTH

50 Binney Street, Cambridge, MA 02142 | www.juneforjointhealth.org

The National Hemophilia Foundation and Sanofi Genzyme are committed to building awareness about the important role activity plays in improving joint health in the hemophilia community. That’s why we created June For Joint Health.

Join community members for a fun activity session and walk away with healthy tips on stretching and the benefits it has on your joints. Together, you and your family can develop lifelong habits that promote safe, joint-building physical activities through June and beyond.

We’re excited to be moving with you.

MEDEXUS PHARMA

29 N Wacker, Suite 704, Chicago, IL 60606 | 215-370-9818 | www.signthe9.com

Medexus Pharma is the company behind IXINITY [coagulation factor IX (recombinant)] – we are excited to join NHF's virtual event. Show your support for the community by taking part in Sign the 9. Visit signthe9.com to see how easy it is to help people who may not have access to factor. Every time you "sign the 9", we'll donate 9 IU of IXINITY to people living in the United States who can't afford to be without it. Build your own one-of-a-kind 9 graphic that's as unique as you. Sign the 9 at signthe9.com! Important Safety Information/Prescribing Information at <http://bit.ly/IXINITY-ISI>.

NATIONAL HEMOPHILIA FOUNDATION

7 Penn Plaza, Suite 1204, New York, NY 10001 | 212-328-3700 | www.hemophilia.org

The National Hemophilia Foundation (NHF) is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy and research. Established in 1948, the National Hemophilia Foundation has chapters throughout the country. Its programs and initiatives are made possible through the generosity of individuals, corporations and foundations as well as through a cooperative agreement with the Centers for Disease Control and Prevention (CDC).

NOVO NORDISK

800 Scudders Mill Road, Plainsboro, NJ 8536 | 609-578-9985 | www.novonordisk-us.com

Novo Nordisk is dedicated to supporting you from MANY ANGLES

Novo Nordisk has supported our community for over 30 years with our products, including NovoSeven® RT (Coagulation Factor VIIa [Recombinant]), Novoeight® (Antihemophilic Factor [Recombinant]), Rebinyn® (Coagulation Factor IX (Recombinant), GlycoPEGylated), Tretten® (Coagulation Factor XIII A-Subunit [Recombinant]), and the most recently added product, Esperoct® (antihemophilic factor (recombinant), glycopegylated-exei). Our Community Liaisons are available to provide you with educational resources. We believe in supporting the community with educational programs and product assistance and continue to cultivate our relationships as we move forward.

[Click here for NovoSeven® RT Prescribing Information.](#)

OPTUM

15529 College Blvd, Lenexa, KS 66219 | 913-217-9766 | www.specialty.optumrx.com

About Optum Specialty

Optum Specialty is a leading specialty pharmacy services company dedicated to helping administer and deliver high-quality, cost-effective specialty pharmacy care. Optum Specialty Pharmacy combines technology, data and expertise to provide educational resources, 24/7 pharmacy support and trusted advice to the individuals, caregivers and care teams we serve.

For Questions or More Information please reach out to one of our reps below

West | Ally Remigio, 707.317.0704, aremigio@optum.com

Southeast | Joey Privat, 337.501.0554, jprivat@optum.com

Northeast | Jennifer Laughlin, 319.930.2911, jlaughlin@optum.com

Midwest | Bill Laughlin, 319.325.5080, blaughlin@optum.com

PAN FOUNDATION

805 15th St NW #500, Washington, DC 20005 | 800-394-0161 | www.panfoundation.org

The PAN Foundation is an independent, national 501 (c)(3) organization dedicated to helping federally and commercially insured people living with life-threatening, chronic and rare diseases with the out-of-pocket costs for their prescribed medications. Partnering with generous donors, healthcare providers and pharmacies, we provide the underinsured population access to the healthcare treatments they need to best manage their conditions and focus on improving their quality of life.

PFIZER, INC.

500 Arcola Rd., Collegeville, PA 19426 | 484-865-3267 | www.pfizer.com

Pfizer Inc.: Breakthroughs that change patients' lives

At Pfizer, we apply science and our global resources to bring therapies to people that extend and significantly improve their lives. We strive to set the standard for quality, safety and value in the discovery, development and manufacture of health care products. Every day, Pfizer colleagues work across developed and emerging markets to advance wellness, prevention, treatments and cures that challenge the most feared diseases of our time.

SANOFI GENZYME

**50 Binney Street, Cambridge, MA 02142 | 800-745-4447
www.sanofigenzymehemophilia.com**

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 strive 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 potential to truly transform. To shift the trajectory. To change lives.

SIGILON THERAPEUTICS, INC

100 Binney St, STE 600, Cambridge, MA 02142 | 617-678-5083 | www.sigilon.com

Sigilon Therapeutics™ is a biotech company based in Cambridge, MA. At Sigilon, our goal is to liberate patients from chronic diseases with our Shielded Living Therapeutics™ platform. Our engineered cell therapies are designed to restore cell function in a person living with a chronic disease or disorder such as rare blood, lysosomal storage or endocrine disorders. We care deeply about patients and caregivers and we are working to create therapies with the potential to deliver functional cures. We envision a future with less fear of "what ifs." We, together, can deliver on hope.

SOLEO HEALTH

2801 Network Boulevard, Suite 505, Frisco, TX 75034 | 833.765.3648
www.soleohealth.com

Soleo Health is a provider of complex specialty pharmacy and infusion services dedicated to the bleeding disorder community and the patients we serve.

Our Bleeding Disorder Therapy Management Program is led by specialized care teams with extensive experience in Hemophilia A, B, Factor X Deficiency, Von Willebrand, and other factor deficiencies. The bleeding disorders team provides individualized services and education, which encourages your independence and enhances your care experience.

Hablamos Español

www.soleohealth.com

Our Locations

Soleo Health Factor X Deficiency Program

Meet Our Team

Enter our raffle for an Amazon Fire Tablet

SPARK THERAPEUTICS

3737 Market Street, Philadelphia, PA 19104 | 1-855-SPARKTX / +1 215-220-9300
www.sparktx.com

Spark Therapeutics is creating a path for advancements in hemophilia gene therapy research.

We are committed to discovering, developing and delivering gene therapies, we challenge the inevitability of genetic diseases, including blindness, hemophilia, lysosomal storage disorders and neurodegenerative diseases. Learn more at www.sparktx.com.

Be Informed. Feel Empowered

Advance your knowledge of gene therapy research at HemophiliaForward.com

To connect with a representative from Spark Patient Advocacy email us at: patients@sparktx.com or contact a member our team at the conference:

Guillermo Campillo | (720) 364-6214, guillermo.campillo@sparktx.com

Tessa Field | (267) 595-9868, tessa.field@sparktx.com

Laureen Temple | (267) 250-2532, laureen.temple@sparktx.com

N-HEM-US-420086

TAKEDA

125 Binney Street, Cambridge, MA 02142 | 617-795-6155 | www.EveryMileoftheJourney.com

For over 70 years, Takeda has been committed to the Bleeding Disorders Community. You have trusted us to continue to provide support and education through conferences like NHF, community walks and talks, and all engagements in between. Our patients are always at the forefront of what we do. No matter where you are on your bleeding disorder journey, we're there for you.

Every Mile of the Journey.

Explore our virtual booth below or visit EveryMileoftheJourney.com to learn how Takeda can support you along your unique path.

The contents of this booth are intended for US audiences only.

THE ALLIANCE PHARMACY

44 Bond Street, Westbury, NY 11590 | 866-767-4883 | www.TheAlliancePharmacy.org

The Alliance Pharmacy, founded in 2000 (Positudes, Inc.) is a 501(c)(3) nonprofit pharmacy organization focused on collaborative patient care. We provide pharmacy and wholesale distribution services nationally, as well as trial programs and patient assistance support to the bleeding disorders community and their caregivers.

TREMEAU PHARMACEUTICALS

53 Main St, Suite 202, Concord, MA, 01742 | 617-812-0123 | www.tremeaux.com

Tremeau is focused on developing non-opioid pain therapies for people with significant unmet need. Our lead clinical stage product, TRM-201 (rofecoxib), is a COX-2 selective NSAID and a non-opioid analgesic. We plan to initiate a Phase III trial for TRM-201 for the treatment of hemophilic arthropathy later this year.

UNIQUE

Paasheuvelweg 25a, Amsterdam, 1105 BP | +31 20 240 6000 | www.unique.com

uniQure is delivering on the promise of gene therapy – single treatments with potentially curative results. We are leveraging our modular and validated technology platform to rapidly advance a pipeline of proprietary and partnered gene therapies to treat patients with hemophilia, Huntington's disease and other severe genetic diseases. We are currently conducting a pivotal phase 3 trial in our lead indication, hemophilia B, and have initiated a phase 1/2 trial in Huntington's disease.

WORLD FEDERATION OF HEMOPHILIA

1425 René- Lévesque West, Montreal, QC, Canada H3G 1T7 | +1 (514) 875-7944
www.wfh.org/en/home

The World Federation of Hemophilia (WFH) deeply believes that where you live should not determine your access to care and treatment for an inherited bleeding disorder.

We work to ensure every person— including those living with hemophilia and von Willebrand disease (VWD), those with rare factor deficiencies, and women with bleeding disorders— have access to world-class care and recognition of their condition.

Our vision of is that one day, all people with a bleeding disorder will enjoy a more certain future filled with promise, no matter where they live.

Treatment for All.

Speakers

Stacie	Akins	PT, MHS	Indiana Hemophilia and Thrombosis Center
Elisabeth	Ambrose	BSN, RN	Mary M. Gooley Hemophilia Center
Jeannie	Aschkenasy	PhD	Rush Hemophilia and Thrombophilia Center
Charletta	Ayers	MD, MPH	Rutgers - Robert Wood Johnson Medical School
Cindy	Bailey	PT, DPT, OCS, SCS, ATC	Los Angeles Orthopaedic Hemophilia Treatment Center
Kelly	Baker		
Judith	Baker	DrPH, MHSA	Center for Inherited Blood Disorders
Alejandro	Barajas		Loyola Immigrant Justice Clinic, Loyola Law School
Kaitlin	Barnett	LCSW	Mount Sinai Hospital Hemophilia Treatment Center
Diane	Bartlett	LCSW	St. Luke's Hemophilia Center
Kimberly	Baumann	PT, MPT M	Health, Fairview
Kristen	Benya	DPT	
Charmaine	Biega	RN	Nationwide Children's Hospital
Emily	Bisson	APRN, CPNP	Connecticut Children's Medical Center
Jeanne	Boudreaux	MD	Emory Univ/CHOA
Heather	Britton	NBC-HWC	
Alana	Brunner	LCPC, NCC, CCMHC	St. Luke's Health System
Tyler	Buckner	MD, MSc	University of Colorado School of Medicine
Tami	Bullock	RN-BC, BSN	UIHC/SFCH HTC
Craig	Butler		Cooley's Anemia Foundation
Vanessa	Byams	DrPH, MPH	CDC/NCBDDD/Division of Blood Disorders
Leigh	Carpenter	RPh	Hemophilia of Georgia
Courtney	Carr	RN-BC, MSN, CPNP	St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital
Jeanette	Cesta		VWD Connect Foundation
Chimwewe	Chande		Society of Haemophilia and Allied Disorders
Deniece	Chevannes	MPH, MCHES	Hemophilia of Georgia
Meera	Chitlur	MD	Children's Hospital of Michigan
Janet	Chupka	RN, BSN	Hemophilia Federation of America
Marianne	Clancy	RDH MPA	Cure HHT
Annie	Colavita		World Federation of Hemophilia
Jeff	Cornett	RN MSN	Hemophilia of Georgia
Stacy	Croteau	MD, MMS	Boston Hemophilia Center / Boston Children's Hospital
Debbie	De la Riva	LPC	Mental Health Matters Too
Michael	DeGrandpre		Hemophilia Federation of America
Jorge	Di Paola		Washington University School of Medicine in St. Louis
Damia	Dillard	LCSW	UC Davis
Jennifer	Donkin	DNP, FNP, PNP	Children's Hospital Los Angeles
Roddy	Doucet	WFH	
Kayla	Douglas	PharmD, CSP	Mississippi Center for Advanced Medicine
Luisa	Durante		World Federation of Hemophilia
Marla	Feinstein		National Hemophilia Foundation
Veronica	Flood	MD	Medical College of Wisconsin
Angela	Forsyth	PT, DPT	Diplomet Specialty Infusion Group: An affiliate of Optum
Neil	Frick	MS	National Hemophilia Foundation
Becky	Garcia	RN-BC MSN, CPN	Hemophilia and Thrombosis Center at Phoenix Childrens Hospital
Sue	Geraghty	RN	
Marc	Gilgannon	PT	University of Virginia HTC
Caroline	Giroux	MD	UC Davis
Johanna	Gray	MPA	Artemis Policy Group

Kristina Kerry	Haley Hansen	D.O., MCR RN, BSN	Oregon Health & Science University University of Minnesota National Hemophilia Foundation
Kristi Anthony	Harvey-Simi Haugabrook		
Sherry	Herman-Hilker	PT, MS	University of Michigan Hemophilia and Coagulation Disorders Program
Christi	Humphrey	LCSW	Hemophilia of Georgia
Kimberly	Hurdstrom	RN	
Nabila	Husseni		Hemophilia Federation (India)
Maria	Iannone		AzHTC
Aamina	Iftikhar		
Eric	Iglewski	LMSW	Mary M. Gooley Hemophilia Center
Paula	James	MD, FRCPC	Queen's University
Sean	Jeffrey		
Lydia	Johnson	RN, BSN	Cardinal Glennon Children's Hospital
Lora	Joyner	MS, PT, PCS	East Carolina University Hemophilia Treatment Center
Radek	Kaczmarek	PhD	Indiana University School of Medicine
Tiffany	Kaltenmark	PT, DPT	Indiana Hemophilia and Thrombosis Center
Raj	Kasthuri	MD	University of North Carolina at Chapel Hill
Craig	Kessler	MD	Georgetown University Medical Center
Michelle	Kim	JD	Hemophilia Foundation of Southern California
Jessica	Klass		BioMarin Pharmaceutical
Susan	Knight	PT, PCS	
Peter	Kouides		Mary M. Gooley Hemophilia Center
Rebecca	Kruse-Jarres	MD, MPH	Washington Center for Bleeding Disorders
Edward	Kuebler	MSW, LLC	Global Blood Disorder Foundation
Firaoli	Kumbi		
Penny	Kumpf	BSN, RN-BC	Hemophilia of Georgia
Kollet	Koulianos	MBA	National Hemophilia Foundation
Jennifer	Laliberté		World Federation of Hemophilia USA
Sharon	Littig	RN	Cardeza Foundation, Thomas Jefferson University
Robert	Louden	MSW, LCSW	Indiana Hemophilia & Thrombosis Center
Denise	Lowery	LCSW	UC Davis HTC
James	Luck	MD	Orthopaedic Institute for Children
Patrick	Lynch	Believe Limited	
Kelly	Macías	PhD	Kelly Macias Consulting
Marilyn	Manco-Johnson	MD	Hemophilia & Thrombosis Center
Shanna	Mattis	MPH	HoG Center for Bleeding & Clotting Disorders of Emory University
Jill	McCary		
Madonna	McGuire Smith	MPA	Pacific Northwest Bleeding Disorders
Salome	Mekhuzla		World Federation of Hemophilia
Ruth	Mulvany	PT, DPT, MS	University of Tennessee Hemophilia Treatment Center
Jim	Munn	MS, BN, RN-BC	Michigan Medicine HTC
Kate	Nammacher	MPH	National Hemophilia Foundation
Khalid	Namoos		
Alfredo	Narvaez	MSW, LMSW	LA Center for Bleeding & Clotting Disord
Diane	Nugent		CHOC Children's Hospital/UC - Irvine
Sheila	O'Donnell	APRN, FNP-C	Maine Hemophilia and Thrombosis Center
Laurel	Pennick	MSSW, LCSW	Arizona Hemophilia and Thrombosis Center
Jessie	Pindilli	BSN, RN	University of Wisconsin Health
Steven	Pipe	MD	University of Michigan
Margaret	Ragni		University of Pittsburgh and Hemophilia Center of Western PA
Lucy	Ramirez	MSW, LCSW	Rush
Mark	Reding	MD	University of Minnesota Medical Center
Ellen	Riker	MHA	National Hemophilia Foundation
Dawn	Rotellini		National Hemophilia Foundation
Michelle Ryzak			

Brittany	Savage	MSW, LICSW, ACM	M Health Fairview, University of Minnesota
Nathan	Schaefer	MSW	National Hemophilia Foundation
Theresa	Schaffer	LCSW	Hemophilia of Georgia
Kathaleen	Schnur	LSW	HCWP
Taylor	Shanklin		Firefly Partners
Amy	Shapiro	MD	Indiana Hemophilia & Thrombosis Center
Steven	Shattuck		Bloomerang
Robert	Sidonio	MD, MSc	Emory University and Aflac Cancer and Blood Disorders
Sylvia	Singer	MD	UCSF Benioff Children's Hospital Oakland
Tammueella	Singleton	MD	
Alayna	Sipple	LMSW	Hemophilia of Georgia
Mark	Skinner	JD	Institute for Policy Advancement Ltd.
Makenzie	Sledd	MPT	St. Louis Children's Hospital
Penni	Smith	MPA, RN-BC	Intermountain Healthcare -- Primary Children's Hospital
Brett	Spitale	NHF	
Amanda	Stahl	LICSW	Boston Hemophilia Center
Bruno	Steiner	PT, DPT, LMT, RMSK	Washington Center for Bleeding Disorders
Eric	Stolte	WFH USA	
Kay	Strawder	JD, MSW	U.S. HHS, Office of the Assistant Secretary for Health, Region 9
Constance	Thibodeaux	MSW, LCSW, BACS	Louisiana Center for Bleeding and Clotting Disorders
Kelly	Tickle	MSN, APN, CWON, PCNS-BC, PPCNP-BC	
Cathy	Tiggs	MSSA, LISW	Children's Healthcare of Atlanta
Oly-Andreina	Tovar		UH Hospitals of Cleveland Hemostasis & Thrombosis Center
Maria	Tovar-Herrera	RN-BC, BSN	World Federation of Hemophilia
Brooke	Towns	RN, BSN	
Sandra	Valdovinos-Heredia		Indiana Hemophilia and Thrombosis Center
Leonard	Valentino	LCSW	
Jhon	Velasco	MD	National Hemophilia Foundation
Lena	Volland	MA, RYT 300	National Hemophilia Foundation
Annette	Von Drygalski	PT, DPT	University of St. Augustine
Christopher	Walsh	MD, PharmD, RMSK	University of California San Diego
Jason	Walsh	MD, PhD	Icahn School of Medicine at Mount Sinai
Michael	Wang		
Lisa	Webb		University of Colorado Hemophilia & Thrombosis Center
Angela	Weyand	MD	
Emily	Wheat	PhD	University of Michigan Medical School
Marlee	Whetten		
Jeanne	White Ginder		National Hemophilia Foundation
Pamela	Widener	RN, BSN, NC	
Mosi	Williams		Nationwide Children's Hospital
Kori	Williams	PT, DPT	
Michelle	Witkop	DNP, FNP-BC	Emory University
Anita	Wood	PT	National Hemophilia Foundation
Ayana	Woods	MPH	Louisiana Center for Bleeding and Clotting Disorders
Kalinda	Woods	MD, FACOG	End of Life Choices New York
Guy	Young	MD	Emory University School of Medicine
Octavio	Zavala	BS	Children's Hospital Los Angeles
Michael	Zolotnitsky	PT, DPT	Children's Hospital Los Angeles

NHF Staff

Leonard Valentino, MD

President and Chief Executive Officer

Jonathan Angarola

Senior Manager of Medical Programs and Information

Saliena Balos

Assistant to Chief External Affairs Officer

Timothy Brent, MBA

Senior Director of Business Development

Amy Burns

Senior Manager of Grants Administration

Maya Cernotova

Manager of Accounting

Candice Comisi

Development Coordinator

Kathleen Cooper

Director of Chapter Development

Michael Craciunoiu, Ed.M

VP of Chapter Services

Frenil Dand

Director of Information Technology

Ciarra de Leon

Conference & Travel Services Assistant

Tracy Earll

Director of Chapter Development

Marla Feinstein

Senior Public Policy Analyst

Neil Frick, MS

SVP of Medical Programs and Information

Chelsea Frimpong, MPH

Manager of Education

Elvira Goody

Executive Assistant to the CEO

Mariana Halova, MS

Database Specialist

Dillon Harp

Government Relations Specialist

Peter Havey

CBO

Kristi Harvey-Simi

Director of Chapter Development

Brendan Hayes

Director of Education, Innovative Therapies

Hasan Inal

Manager of Accounting

Morgan Johnson, MPA, CAE

Manager of Healthcare Provider Programs

Nick Kallinicou

Medical Information Coordinator

Kollet Koulianos, MBA

Senior Director of Payer Relations

Peter Lieuw

Assistant Controller

Adeli Lopez

Director of Human Resources

Karina Lopez

Operations Coordinator

Beth Marshall

Director of Communications

Kenneth McElderry

Director of Chapter Development

Abby Miller

Productions and Creative Services Specialist

Elizabeth Molnar

Manager of Chapter Development

Kate Nammacher, MPH

VP of Education

Emma Neely

Development Specialist

Johanna Ong

Conference & Travel Services Specialist

Maureen Parsons

Annual Giving Manager

Jay Patel, MS

Director of Online Marketing and Data Systems

Jasmine Pauldurai

Education Specialist

Diana Perrault, MA

Manager of Peer to Peer Fundraising & National Events

Lauryn Polo

Social Media Specialist

Vincent Price

Web Marketing Specialist

Michelle Rice

Chief External Affairs Officer

Bill Robie

Government Relations Specialist

Sonia Roger

Education Department Coordinator

Dawn Rotellini

Chief Operating Officer

Maria Salas-Pilla, HMCC, LLM

Senior Director of Conference & Travel Services

Maria Santaella, RN-BC, MSN

Research Nurse Specialist

Nikole Scappe

Education Specialist

Nathan Schaefer

VP of Public Policy

Dennis Shpits

Senior Accountant

Brett Spitale

VP of Advancement

Anna Sprovskaya, MS

Controller

Jenny Tran

Staff Accountant

James Uyeda

Director of Development

Alla Vaynshteyn, MBA

Manager of Conference & Travel Services

Jhon Velasco, MA

Manager of Education

Rosaura Vidal, MPH

Clinical Research Education Specialist

Angelina Wang

Director of Medical Programs and Information

Marlee Whetten

Education Specialist

Michelle Witkop, DNP, FNP-BC

Head of Research

Annie Wong

Senior Accountant

Jordana Zeger, MBA

Chief Financial Officer



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

Would like to thank Platinum Sponsor:



VISIT TAKEDA'S VIRTUAL BOOTH

JOIN TAKEDA AT:

SUNDAY, AUGUST 2, 2020 | 5:00 PM-6:30 PM EDT

Industry Symposium, Hello Factor! - Sponsored by Takeda

Join Takeda for an educational discussion and hear from a real-life patient as they discuss their Hemophilia A experience with physical therapist Grace Hernandez

MONDAY, AUGUST 3, 2020 | 5:30 PM 7:00 PM EDT

Industry Symposium, Staying Active with Hemophilia A - Sponsored by Takeda

Hear the real-life stories of two hemophilia A patients and how each manage and maintain their active lifestyles



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

Would like to thank Platinum Sponsor:

Genentech
A Member of the Roche Group

JOIN GENENTECH AT:

SATURDAY, AUGUST 1, 2020 | 5:45 PM-7:15 PM EDT

Industry Symposium - Breakfast: All of You - Prioritizing Your Self Over Your Diagnosis



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

Would like to thank Platinum Sponsor:



SANOFI GENZYME

VISIT SANOFI GENZYME'S VIRTUAL BOOTH

JOIN SANOFI AT:

TUESDAY, AUGUST 4, 2020 | 5:30 PM-7:00 PM EDT

Industry Symposium, How often do you use your joints? - Sponsored by Sanofi

THURSDAY, AUGUST 6, 2020 | 5:30 PM-7:00 PM EDT

Industry Symposium, Beyond Trough Levels: Taking a Closer Look at Hemophilia B -
Sponsored by Sanofi



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

Would like to thank Platinum Sponsor:

CSL Behring

Biotherapies for LifeTM

VISIT CSL BEHRING'S VIRTUAL BOOTH



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

Would like to thank Platinum Sponsor:



VISIT NOVO NORDISK'S VIRTUAL BOOTH

JOIN NOVO NORDISK AT:

WEDNESDAY, AUGUST 5, 2020 | 5:30 PM-7:00 PM EDT

Industry Symposium, The path forward: Importance of healthy lifestyles -
Sponsored by Novo Nordisk



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

Would like to thank Silver Sponsor:



VISIT BAYER'S VIRTUAL BOOTH

Would like to thank Bronze Sponsors:



VISIT BIOMARIN'S 2 VIRTUAL BOOTHS