

# NHF DAILY

## & VIRTUAL CONFERENCE GUIDE

EXTRA

SATURDAY

NHF's 72nd Bleeding Disorders Conference

August 1, 2020

## Welcome to Our Virtual Bleeding Disorders Conference!

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.

Please take advantage of all that the conference has to offer. We have a wide range of sessions covering 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.



At our virtual **Exhibit Hall** you can meet with our sponsors and exhibitors to learn more about the latest products and services they offer. While there, 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.

— Dr. Leonard A. Valentino

NHF Daily will be sent to you every morning during NHF's 72nd Bleeding Disorders Conference. Watch your inbox for full issues tomorrow and Monday, with EXTRA issues August 4-8, followed by a Post-Conference full wrap-up after the meeting.

Sign up for the latest in  
gene therapy research

VISIT HEMDIFFERENTLY



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**TODAY AT BDC**

**Virtually the Best BDC Ever  
 Come on in!**

- 12:00 pm - 1:00 pm EDT  
**V-EXHIBIT HALL -  
 CHAT WITH OUR EXHIBITORS**  
 Chapters • For All • Physician  
 • Nursing • Physical Therapy •  
 Social Work
- 12:00 pm - 3:00 pm EDT  
**PUBLIC HEALTH PRE CON: FUTURE  
 THERAPIES AND SURVEILLANCE FOR  
 BLOOD DISORDERS**  
 Chapters • For All
- 12:00 pm - 7:00 pm EDT  
**CAMP DAY 1**  
 Teens and Young Adults • Kids  
 Program (9-12) • Kids Program  
 (5-8)
- 12:55 pm - 12:58 pm EDT  
**BDC MINI YOGA SERIES -  
 CHAIR ENERGY POSE**  
 Mini Yoga Series For All
- 1:00 pm - 1:45 pm EDT  
**INTRODUCING THE YOUNG HOPE  
 SOCIETY: DEDICATED SPACE FOR  
 YOUNG PROFESSIONALS IN THE  
 BLEEDING DISORDERS  
 COMMUNITY**  
 Teens and Young Adults
- 1:00 pm - 1:45 pm EDT  
**EVALUATING CHOICES IN A  
 CHANGING INSURANCE MARKET**  
 For All
- 1:00 pm - 2:35 pm EDT  
**VWD PRE-CON -  
 SPONSORED BY CSL BEHRING**  
 Von Willebrand Disease
- 1:50 pm - 2:35 pm EDT  
**BATTLE OF THE SEXES:  
 SEX AND RELATIONSHIPS**  
 Spouses and Partners
- 1:50 pm - 2:35 pm EDT  
**BASICS: HEMOPHILIA**  
 For All
- 2:00 pm - 2:30 pm EDT  
**MANAGEMENT OF PATIENTS ON  
 NOVEL THERAPIES PART 1 (\*\*ANCC)**  
 Nursing
- 2:00 pm - 5:00 pm EDT  
**PAIN MANAGEMENT:  
 TOOL BOX NOT A PILL BOX**  
 Physical Therapy

For the first time ever, the National Hemophilia Foundation’s Bleeding Disorders Conference takes place entirely online. Even though things might feel a little different, a lot remains familiar about the event that has gathered members of our community for seven decades. It still offers a front-row seat to targeted learning opportunities, chances to connect, family fun and discussion of the latest research. Even better, you can take it all in from the comfort of your own home – and stay in your comfy clothes.

Let’s take a moment now to find our bearings.

Conference log-in information, sent by email a couple of days prior to the event, allows access to the event platform. The platform was customized specifically for NHF.

After logging in, attendees will find themselves in a virtual conference “lobby.” Hover over

and click on areas such as “sessions,” “e-posters” and “information” to be taken to those areas. There’s also a welcome video, and a number of tabs along the top.

The “lobby” tab is home base.

“Sessions” takes registrants to the various sessions available that day. In addition to the events being presented at specific times, recordings of previous sessions will be available roughly 24 hours after those sessions take place.

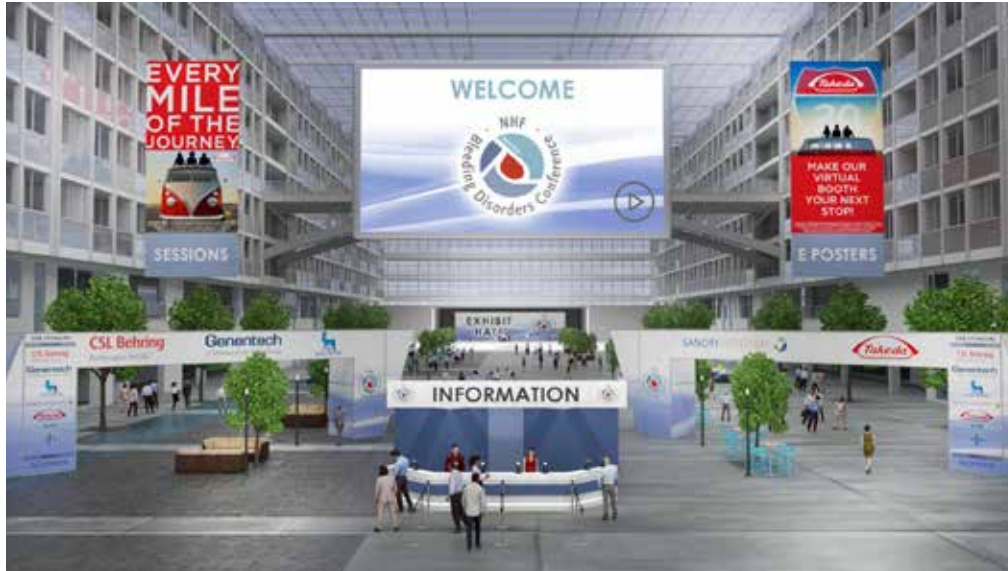
“E-posters” provides the chance to peruse research poster abstracts. Click on an individual poster to view it, and double-click to zoom in.

The “CME/CE” tab leads to requirements for healthcare professionals to receive continuing education credits.

“Exhibit Hall” offers a virtual version of a BDC highlight: the chance to connect with and learn from various exhibitors. For one

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# TODAY AT BDC



hour each day, there's an opportunity for live chat. That takes place from noon-1pm EDT Saturday, August 1; 1pm-2pm Sunday, August 2; 4:30pm-5:30pm Monday-Friday, August 3-7, and 10:30am-11:30am Saturday, August 8.

"Tech support" includes technical info about system requirements, and includes some troubleshooting FAQs.

"Information" features general background about NHF's BDC, as well as how attendees can have the conference branded bags and water bottles sent to their home if they're among the first 500 people to complete a particular number of session evaluations and visit a particular number of booths.

"E-bag" shares companies' flyers and invites.

Finally, "e-badge" provides information related to the attendee's individual badge.

Maria M. Salas-Pilla, LL.M,

HMCC, senior director of conference and travel services for NHF, is excited that a virtual event can draw in attendees who might otherwise not be able to be present due to time, travel or cost considerations. And she hopes that those attendees will take advantage of all it has to offer.

In addition to the sessions and Exhibit Hall, "can't-miss" opportunities include the photo booth open from the start of the event in the information area and on the app; Camp Unite activities for kids; and the final night event complete with cocktails, mocktails, games, giveaways and more.

To get the most out of the event, Salas-Pilla said, be sure to consciously schedule and set aside time to attend the various offerings, take advantage of chat and other interactive opportunities (you won't be on camera) and keep an open mind.

We're all still learning together.

2:30 pm - 4:00 pm EDT  
**MANAGEMENT OF PATIENTS ON NOVEL THERAPIES PART 2 (\*\*ANCC)**  
Nursing

2:40 pm - 3:25 pm EDT  
**WASHINGTON INSIDER: A FEDERAL POLICY UPDATE**  
Chapters • For All

2:40 pm - 3:25 pm EDT  
**PREGNANCY AND CHILDBIRTH IN WOMEN WITH BLEEDING DISORDERS**  
Women with Bleeding Disorders

3:00 pm - 5:00 pm EDT  
**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)**  
Physician

3:30 pm - 4:15 pm EDT  
**BASICS: VWD**  
Von Willebrand Disease

3:30 pm - 4:15 pm EDT  
**FAITH AND BLEEDING DISORDERS**  
For All

4:00 pm - 5:00 pm EDT  
**MANAGEMENT OF PATIENTS ON NOVEL THERAPIES PART 3 (\*\*ANCC)**  
Nursing

4:15 pm - 5:00 pm EDT  
**MEDICINAS CASERAS**  
En Español

4:15 pm - 5:00 pm EDT  
**MOVEMENT AND MOBILITY**  
Adult Men

5:00 pm - 5:45 pm EDT  
**NHF'S VIRTUAL BDC OPENING SESSION**  
For All • Physician • Nursing • Physical Therapy • Social Work

5:45 pm - 7:15 pm EDT  
**GIVE IT A SHOT: A DIFFERENT TYPE OF HEMOPHILIA A THERAPY, SPONSORED BY GENENTECH**  
Chapters • For All • Industry Symposium

## TODAY AT BDC

### A Truce in the Battle of the Sexes?

**D**ifferent doesn't have to be a negative. Consider, for example, the differences between men and women. Stereotypical? Perhaps. Often right anyway? Definitely.

In this most-different-of-years ever, the 2020 Bleeding Disorders Conference will present a fresh take on **Battle of the Sexes: Sex and Relationships**. Inspired by a session originally created by social worker Cathy Tiggs, MSSA, LISW, at UK Cleveland Medical Center, the talk will consider differences in the brain, the emotions, the body, and even how many and women can see the same thing and in dissimilar ways.

It will be led by Edward Kuebler, MSW, LLC, a longtime leader in the bleeding disorders community and recipient of the NHF's Social Worker of the Year Award. He has presented on a great vari-

ety of subjects at NHF events over the past 20 years.

"Give me a topic, and I'll figure out," Kuebler said with a laugh. But this one presented a unique challenge; in the past, a similar session has been highly interactive, with couples working together, and even putting questions into a basket to be answered anonymously.

In a virtual setting, however, the session had to change. So Kuebler dove into research, all the way back to the famed book *Men Are from Mars, Women Are from Venus* from the early 1990s. His biggest learning along the way? "I didn't realize how much research had been done on this," he said. That's particularly so for differences in intimacy, hormones and sexuality. Here, he brings up the disconnect between a man wanting to sleep after sex, while

a woman might choose that time to talk about her feelings.

Kuebler's approach is to encourage the audience to think things through for themselves, rather than force-feed ideas. But he does promise a bit of spark and some fun. He also offers the caveat that the session is meant with no disrespect to same-sex couples.

"What I hope people come away with," he said, "is that men and women really are different. But that's to be celebrated, not fought over. Those differences make us who we are. Differences in the sexes make us unique. And if we're willing to engage in all of that, it could probably make for a really strong relationship."

**BATTLE OF THE SEXES:  
SEX AND RELATIONSHIPS**  
1:50pm-2:35pm EDT  
Saturday, August 1

### Finding Faith, Holding on to Hope

**T**hese days, hope may be hard to come by—but it is as essential as ever.

The Saturday afternoon session **Faith and Bleeding Disorders** explores the role of faith not only in the life of someone with a bleeding disorder overall, but also in this specific season. COVID-19 has proven stressful for many on financial, physical, mental, emo-

The idea is to welcome people of all faiths and beliefs for authentic, open conversation.

tional, relational and other fronts.

Chelsea Frimpong, a manager of education and training at NHF who greatly values and promotes

diversity in perspectives and experiences, has invited panelists Anthony Haugabrook and social worker Aamina Iftikhar, who specializes in supporting those with chronic health conditions. The idea, she said, is to welcome people of all faiths and beliefs for authentic, open conversation. Nobody will be singled out.

"With a session like this, it

# TODAY AT BDC

## The V-Exhibit Hall: No Need for Comfy Shoes – or a Watch

The expansive Bleeding Disorders Conference Exhibit Hall has long been the spot to connect, to learn and to have a bit of fun. This year will be no different. And there's an added bonus: Attendees can peruse the offerings around the clock, whenever most

convenient for their schedules. Simply click on the Exhibit Hall banner in the virtual conference platform lobby, or the Exhibit Hall tab at the top of the page.

NHF's Virtual BDC Exhibit Hall includes 28 customized virtual booths from pharmaceutical companies, manufacturers, not-for-profits, specialty pharmacy companies and others. Each booth will include downloadable infor-



- RESOURCES**
- Questions?
  - Chapter
  - Hemaware
  - Spanish
  - Steps for Living
  - Victory for Women

mation about services and products, but that's not all. There may be videos, interactive elements, creative technology, games, raffles and opportunities to directly schedule a phone call with a representative for another time.

Even though these booths will be "open" 24 hours a day during the Bleeding Disorders Conference, some will also offer live chat with representatives for one

hour daily. That takes place noon-1pm EDT Saturday, August 1; 1pm-2pm Sunday, August 2; 4:30pm-5:30pm Monday-Friday, August 3-7, and 10:30am-11:30am Saturday, Aug. 8.

NHF also has a booth in the Exhibit Hall, and those who visit will find videos

and other resources on programs and offerings such as chapters, *HemAware* magazine, Steps for Living, Victory for Women and Spanish offerings. Attendees can make confidential requests there for additional information, educational publications, and referrals for additional resources.

Please know that personal information shared with exhibitors is not collected by NHF.

would be a disservice to show only one perspective or one faith," Frimpong said. "I don't think faith even has to have a religious component. Belief is belief. Some people believe in the universe, some in a higher power, some just that the world will continue to turn."

In addition to providing hope, Frimpong said, faith can be a source of comfort and support when things get challenging. Panelists, then, may address how faith plays a role in navigating a

bleeding disorder, in conversations with others and in simply living life. "For people that believe, faith can be something to hold onto when times are difficult," she said. "And these are difficult times for everyone in the world."

Faith—regardless of what type—can be seen as a personal issue, and conversations about it can be impacted by the energy in the room, she said. It is possible, however, to create the same sort of positive, honest environment

virtually, and that's exactly what she hopes to see. She encourages attendees of the talk to take part in chat, and expects the session to include a question and answer period, as well.

Faith and Bleeding Disorders will be moderated by Christi Humphrey, LCSW, of Hemophilia of Georgia.

**FAITH AND BLEEDING DISORDERS**  
3:30pm-4:15pm EDT  
Saturday, August 1

## TODAY AT BDC

### En Español: Medicinas Caseras Explores Good, Bad of Home Remedies

Every culture has them: home remedies that have been passed down through the generations, often accepted more for tradition than proof they work.

For those in the bleeding disorders community, however, these remedies may actually interfere with treatment or cause harm.

Medicinas caseras, on the opening day of NHF's 72nd Bleeding Disorders Conference, looks at a number of home remedies specific to the Latino community. The session will be presented in Spanish by Maria Tovar-Herrera, RN-BC, BSN, Rush University, a registered nurse who has worked in the bleeding disorders community for almost nine years.

Jhon Velasco, NHF education

and training manager, said the Latino community is rich with traditions related to health and wellbeing, often incorporating vitamins, herbs, and even candles.

Tovar-Herrera did extensive research on the most popular Latin home remedies, and will help attendees decipher which ones can be beneficial, which ones should be avoided, and which ones should be discussed with a healthcare provider. Often, Velasco said, these remedies are considered family secrets, so they may not have been considered open for discussion. Even if uncomfortable, however, this could be a matter of life and death. "I am taking notes," he said. "And I will be sharing the link with

family and friends."

The information can be especially important for those who do not have health insurance; who do not have legal status in the U.S.; or who avoid going to doctors for fear of the unknown, language barriers or other factors. The idea is to present the information in a way that honors the Latino culture, but still spreads the word about potential threats.

Medicinas Caseras is one of four sessions to be presented in Spanish during the conference. Translation into English will not be available.

#### **MEDICINAS CASERAS**

4:15pm-5pm EDT  
Saturday, August 1

### Rare Inherited Bleeding and Platelet Disorders Get Their Due with Symposium

Back by popular demand, the Victor Grifols Roura Medical Symposium returns to this year's Bleeding Disorders Conference. The second annual event will focus on genetic analysis and other diagnostic tools for rare inherited bleeding and platelet disorders.

Expect to hear the latest updates in diagnosis and clinical management of rare bleeding disorders, and insight from some of the field's top voices. The session is aimed at physicians, research-

ers, pharmacists, nurses and other allied health professionals.

Amy Shapiro, MD, CEO and co-medical director, Indiana Hemophilia and Thrombosis Center, will take part, in addition to Meera Chitlur, MD, director, Hemophilia Treatment Center and Hemostasis Program, Children's Hospital of Michigan; Diane Nugent, MD, medical director, Pediatric Hematology, CHOC Children's Center for Inherited Bleeding Disorders; and Jorge A. Di Paola, MD, division chief, Pediatric Hematology and

Oncology, Washington University School of Medicine at St. Louis.

Last year's groundbreaking symposium highlighted a rare condition called Glanzmann's thrombasthenia, occurring in just one in a million people worldwide.

#### **NHF'S SECOND ANNUAL VICTOR GRIFOLS ROURA MEDICAL SYMPOSIUM – GENETIC ANALYSIS AND OTHER DIAGNOSTIC TOOLS FOR RARE INHERITED BLEEDING AND PLATELET DISORDERS**

3pm-5pm EDT • Saturday, August 1