NEHA
NEW ENGLAND HEMOPHILIA ASSOCIATION

7th Annual CONSUMER MEDICAL SYMPOSIUM

MARCH 25–26, 2023
HARTFORD, CT

www.nehemophilia.org

WELCOME

March 2023

NEHA Community,

Welcome to our 7th Annual Consumer Medical Symposium! We are excited to have you here as we explore current and novel therapies for bleeding disorders and engage in important conversations around caring for our physical and mental health in the midst of change.

The theme of this year's conference is unity. Our conference planning committee has dedicated their time and expertise to create an agenda that combines foundational information with forward-thinking concepts. As a community, we have much in common, including our shared biology. However, what occurs when we have a bleeding episode depends on our diagnosis. Deepening our understanding of what makes each of us unique helps unify our community as we seek answers related to our diagnosis and consider new treatment options. We've also invited speakers from outside of the bleeding disorders community to open and close this year's conference. We hope their presentations will leave you energized for the weekend and beyond.

While you may see some changes to our typical conference agenda, this event remains focused on delivering a mix of medical, scientific, and psychosocial information. Our intention is to create a highly informed space for you to ask questions to local and national health care providers. Whether through research or medical practice, these individuals have spent decades working to improve the lives of patients with a bleeding disorder. We invite you to immerse yourself in the weekend in order to make the most of the sessions, peer support, and networking opportunities, in a safe space.

NEHA's staff, our dedicated committee members, and our board of directors sincerely appreciate your interest and attendance. We welcome your valuable participation, comments, and feedback throughout the weekend.

Sincerely,

The NEHA Staff

Rich Pezzillo, *Executive Director*
Sarah Shinkman, *Program Director*
Jodi Weeks, *Outreach & Engagement Manager*
Brandon Greene, *Marketing & Communications Manager*
Jill DeVirgilio, *Office & Operations Manager*

REMINDERS & QUICK FACTS

• **Check-in begins at 7:30 AM on Saturday, March 25**, and the conference concludes on Sunday, March 26, at 11:45 AM.

• **Breakfast, lunch and dinner are provided on site by NEHA on Saturday.** Breakfast will also be provided on Sunday. We have requested that our industry partners not provide any separate meals during this time. Please attend all meals.

• **There is a teen and youth track, as well as childcare for infants and toddlers.** Please see the program for their respective agendas.

• **Renew your annual memberships at the NEHA Table.** Membership has many benefits, including a NEHA canvas tote bag at the bronze level and above! Most NEHA events are free to members and there are some popular events which open first to members only. Checks, cash and credit cards are accepted. You can also become a 2023 member today at *www.nehamembership.org*!

• **A survey will be sent via email to all attendees after the event.** Please complete the survey and share your input about the event. Your feedback is used to enhance NEHA programming and ensure we are providing dynamic and engaging educational opportunities that meet the needs of the community.

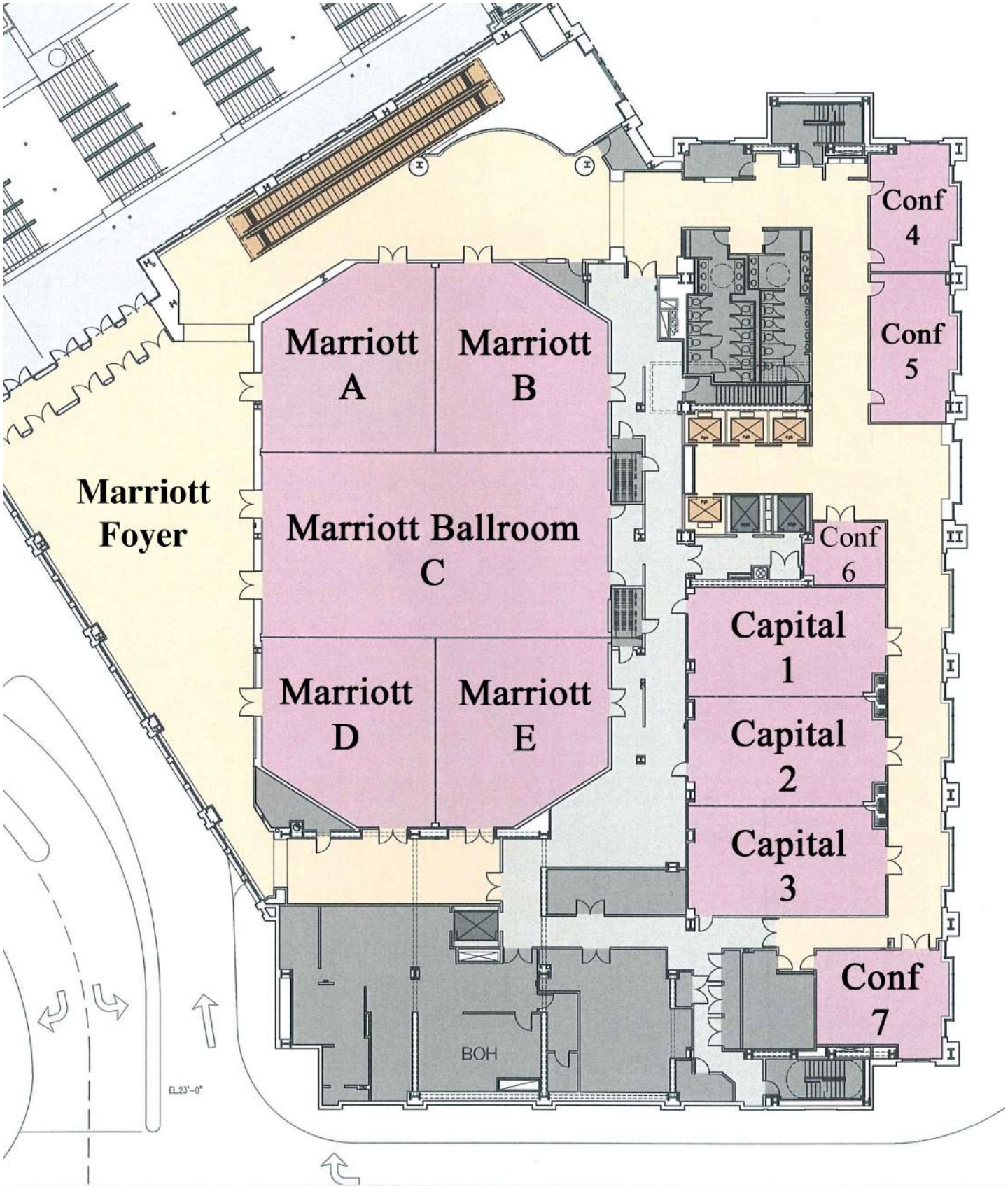
• **All 2023 NEHA Members will be eligible for our "$100 for 100 miles" travel assistance program** if you traveled more than 100 miles, roundtrip to attend this event. More details will be shared via email after the event, with the survey.

• **Register for the Walk!** The NEHA Unite for Bleeding Disorders Walk is **September 30, 2023,** at Prowse Farm in Canton, MA! Learn more about this important event and how you can make a difference at the NEHA Table, or visit *www.nehawalk.org.*

Speaker Disclaimer:

The views expressed in presentations made at NEHA's Consumer Medical Symposium or at other NEHA events are those of the speaker and not necessarily of NEHA. Presentations at NEHA events, or the presence of vendors at NEHA events, does not constitute an endorsement of the vendor or speaker's views, products or services.

HOTEL MAP


Marriott A
Marriott B
Marriott Foyer
Marriott Ballroom C
Marriott D
Marriott E
Conf 4
Conf 5
Conf 6
Capital 1
Capital 2
Capital 3
Conf 7
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PROGRAM AGENDA

Friday, March 24

6:00 – 8:00 PM **Welcome Reception, Sponsored by:** Novo Nordisk — Capital Ballroom

All are welcome to join us for a welcome reception and short presentation. Appetizers and a light dinner will be served and a bar will be available.

The speaker for the presentation is Kim Schafer, Clinical Resource Nurse and Nurse Practitioner from University of California Davis Hemophilia Treatment Center. The presentation will discuss the safety and efficacy of one of Novo Nordisk's extended half-life treatment options for hemophilia and how it provides flexibility for all ages.

Saturday, March 25

7:30 – 8:50 AM **Registration** — Marriott Foyer

7:30 – 8:50 AM **Exhibit Hall Open** — Marriott Foyer

8:00 – 8:50 AM **Breakfast** — Marriott ABC

8:30 – 8:50 AM **Childcare // Youth // Teen Program Drop-Off**
Childcare (0–5): Conference Room 5
Youth (ages 6–12): Capital Rooms 2 & 3
Teens (ages 13–18): Conference Room 7

9:00 AM **Welcome** — Marriott ABC

Speaker: Rich Pezzillo, NEHA Executive Director

9:10 – 10:30 AM **Keynote: Making the Most of What You Have** — Marriott ABC

Speaker: Stephen Maguire

Join us for an engaging, fun, and interactive keynote session as we explore multiple ways to make the most of any situation. Some circumstances in life are well beyond our control, like having a bleeding disorder. How we respond to those circumstances ultimately helps to determine our path to happiness. This session will set the conference tone by giving you some practical methods to explore joy and how to make the most of any situation.

10:30 – 10:45 AM **Coffee Break | Exhibit Hall Open** — Marriott Foyer

10:45 – 11:30 AM **The Magic (Biology) of Blood Clotting (Hemostasis)**

Speaker: Cathy Rosenfield, MD — Marriott ABC

The body is a remarkable machine. Your blood flows through your vessels without a second thought on your part. When injury occurs, whether it is a surgical or dental procedure, a simple bump of the shin, or sometimes no known factor, a multitude of mechanisms come into play to immediately get the flow of blood to stop and prevent hemorrhage at the site of vessel injury. Today, we will discuss how this is supposed to happen and why it does not for individuals with different types of bleeding disorders. When it comes to hemostasis (blood clotting), how are we alike and how are we different?

11:30 AM- 12:15 PM **Biology of Treatment - Educational Breakouts *(Please choose one)***

Session #1: Search for a Cure: Understanding Treatment Options for Hemophilia in the Modern Era — Marriott ABC

Speaker: Stephanie Prozora, MD, Pediatric Medical Director, Yale Hemostasis and Hemophilia Program

While hemophilia was first described in the 2nd century AD, treatment options were severely limited until the late 1900s. Great strides were made from the use of plasma derived factor replacement therapy in the 1970s to the advent of commercially available recombinant factor replacement therapy in the late 1990s. In the last decade, countless new treatment options have either been approved or are in development. We will discuss current and potential upcoming treatment options for hemophilia A and B, including standard and extended half-life factor replacement therapy, non factor therapies, and gene therapy.

Session #2: Treatment of von Willebrand Disease & Rare Bleeding Disorder Treatment — Marriott DE

Speaker: Laura McKay, MD, Director, Hemostasis & Thrombosis Program at CT Children's

This session will review current treatment options and considerations for von Willebrand disease and rare bleeding disorders as well as a look toward the future.

12:15 – 1:00 PM **Exhibit Hall Open** — Marriott Foyer

12:15 – 1:00 PM **Lunch** — Marriott ABC

If you have a child(ren) in childcare (ages 0–5), please pick them up in Conference Room 5 before lunch so you may eat together.

Youth and teens should be picked up in Capital Rooms 2 & 3.

12:50 PM **Childcare // Youth // Teen Program Drop-Off**

Youth and teens will go directly to the Connecticut Science Center after drop-off in the foyer. Please bring any items they may need for the field trip at this time.

Youth (ages 6–12) & Teens: Marriott Foyer
Childcare (ages 0–5): Conference Room 5

1:00 – 2:00 PM **Rap Sessions *(Please choose one)***

Rap sessions are a safe and confidential space to discuss topics specific as a smaller group. All sessions are facilitated by a HTC provider or trained NEHA community member and are meant to provide support, encouragement and a forum to process ongoing stressors or questions regarding life with a bleeding disorder.

Regardless of your bleeding disorder, please pick the session that resonates with you. These topics were selected based on attendee feedback and recurring themes of the conference.

Rap Session #1: Transitioning to Independence Conference Room 7

Join us for a discussion about helping your kids transition to independence with care for their bleeding disorder. This session is geared for parents of pre-teens and teenagers, although anyone who's interested in helping their kids prepare for this important milestone is welcome to attend.

Facilitator: Jen Feldman, MSN, RN, UMass Medical Center and Emily Bisson, APRN, CPNP, Dartmouth-Hitchcock Medical Center

Rap Session #2: Insurance Marriott DE

As treatments continue to evolve, the bleeding disorders community faces new challenges accessing services and care. Learn about what you can do and how we can help you navigate barriers being put in place through accumulator adjusters, understanding your explanation of benefits (EOB) and the insurance plan you are currently enrolled in.

Facilitator: Jennifer Deperry, Pfizer Alliance Development for CT, RI, and MA, and Joe Zamboni, JD, MPH, MPPM, New England Bleeding Disorders Advocacy Coalition Manager

Rap Session #3: Aging Capital 2

In this session, we will discuss issues you encounter as you age (regardless of gender) and expectations around issues. How does having a bleeding disorder change the aging process? How do you navigate your health and healthcare? What should you be thinking about as you get older?

Facilitator: Emily Baker, MSW, LCSW, UConn Health, and Jackie Bottacari, LCSW II, Yale Medicine

Rap Session #4: Caregivers of Younger Kids Capital 1

Caring for a dependent with a bleeding disorder brings a unique skill set. This session is geared towards parents with infants, toddlers and elementary aged children. Share experiences and ask questions to help you navigate this age.

Facilitators: Kristina Selander, BSN, RN, Yale Medicine, and Heather Baribault, PNP, Yale Medicine

Rap Session #5: Other Health Issues / Comorbidities Marriott ABC (left)

This session will serve as an open forum for attendees to share health issues they're dealing with in addition to a bleeding disorder. For example: Hepatitis C, HIV, mental health, and inhibitors (current or past).

Facilitator: Melanie Duclos, LCSW, Connecticut Children's Center and Jen Grande, APRN, Connecticut Children's Center

2:00 - 2:30 PM **Coffee Break | Exhibit Hall Open** Marriott Foyer

2:30 – 3:30 PM **Industry Partner Updates** Marriott ABC

Moderator: Michael DeGrandpre

Companies: Bayer, BioMarin, CSL Behring, Genentech, Octapharma, Sanofi, Spark Therapeutics, and Takeda

During this session, Medical Science Liaisons (MSL's) from the above companies will provide a brief introduction to their pharmaceutical company and their product(s) on the market and emerging treatments in the pipeline. Following the overview, attendees will have an opportunity to ask questions to the MSL's in a fun "speed dating" atmosphere.

3:30 – 4:00 PM **Snack Break | Exhibit Hall Open** Marriott Foyer

4:00 – 5:00 PM **Promoting Positive Coping** Marriott DE

Facilitators: Jackie Bottacari, LCSW II, Melanie Duclos, LCSW, and Emily Baker, MSW, LCSW

Join us for a brief presentation on the utilization of cognitive behavioral therapy with a focus on proactive coping strategies to manage stress and anxiety in our daily lives. This session will then involve a hands-on activity where you will be the creator of your own coping toolkit.

5:00 PM **Pick-Up Childcare / Youth / Teens**

If you have a child(ren) in childcare (0–5 years old) please pick your child up in Conference Room 5. Youth should be picked up in Capital 2 & 3; Teens in Conference Room 7.

5:00 - 6:00 PM **Free Time**

6:00 - 6:45 PM **Dinner, Sponsored by CSL Behring** Marriott ABC

Dinner will be available in the Foyer from 6:00-7:00 PM. We also have a cash bar available in the Foyer from 6:00-10:00 PM (credit cards are also accepted). Attendees with kids are encouraged to come for dinner on the earlier end.

6:45 - 7:30 PM **Evening Programming**

After dinner, we invite our adult attendees to join us in Marriot DE for a presentation on gene therapy and to receive one complimentary drink ticket. Attendees under 18 will stay in Marriott ABC to play arcade games, monitored by our wonderful volunteers. When the adult presentation concludes, adults will return to ABC for our family game night and karaoke!

Kids/Teens: Arcade Games Marriott ABC

Adults: Gene Therapy for Hemophilia, Marriott DE
Sponsored by CSL Behring

Speaker: Dr. Tami Singleton, Director and Chief, Pediatric Hematology at the Mississippi Center for Advanced Medicine and Louisiana Center for Advanced Medicine

The first FDA-approved gene therapy is now here for hemophilia B. Our evening programming will include a presentation about this new therapy, HEMGENIX, and live Q&A.

7:30 PM	**Family Activity: Game Night & Karaoke**	Marriott ABC
10:00 PM	**Games & Bar Close**	

Sunday, March 26

For those staying at the hotel, checkout is at 11:00 AM. Luggage can be stored in Conference Room 4.

7:30 – 9:00 AM	**Exhibit Hall Open**	Marriott Foyer
8:00 – 8:50 AM	**Breakfast**	Marriott ABC
8:50 AM	**Childcare // Youth // Teen Program Drop-Off** Childcare (ages 0–5): Conference Room 5 Youth (ages 6–12): Capital Rooms 2 & 3 Teens (ages 13–18): Conference Room 7	
9:00 – 10:00 AM	**Educational Breakouts (Please choose one)**	
	Session #1: Provider Q&A	Marriott DE

Speakers: Jen Feldman, MSN, RN and Emily Bisson, APRN, CPNP

Before the weekend comes to a close, join us for an opportunity to process the information you've learned with a provider and to ask any final questions that have come up during the conference. This is a safe space to talk about any anxiety, emotions, or concerns you have about the rapidly changing treatment landscape.

Session #2: Artificial Intelligence & Big Data in Healthcare	Marriott ABC

Speakers: Pat Mancini & Kevin Mills, PhD

Are you curious about artificial intelligence, data science and how these are influencing health care in our daily lives? Join us for an interactive and provocative presentation to discuss the continuous developments surrounding us in the world of healthcare technology - what's hot, who's hot and where are we heading next!

10:00 - 10:30 AM	**Coffee Break & Exhibit Hall Open**	Marriott Foyer

During the break we will have therapy dogs joining us! Teens will return to Marriott ABC to join us for the final session of the weekend.

10:30 AM	**New England Organizational Update: NEHA & CT Hemophilia Society (CHS)**

Speakers: Nancy Messina, NEHA Board President, and Saurabh Shweta and Dennis Mackey, Connecticut Hemophilia Society

Join us to hear updates about the future partnerships of the New England bleeding disorders community.

10:45 - 11:45 AM	**Mastering Vocal Confidence In Challenging Conversations**	Marriott ABC

Speaker: Claire Fry, Professional Voice Actor, and Owner, Vocal Confidence

The human voice is an incredible tool for advocacy: it has the power to persuade, inspire and engage. But what happens when emotions are running high and our voices betray us? Without control and intention behind it, our voice can also send the wrong message and lead to miscommunication, frustration and conflict. Learn from a professional voice actor about harnessing the power of the voice, getting heard with clarity, and incorporating this tool into advocacy work for everyone from parents to providers to patients.

11:45 AM	**Pick-Up Childcare & Youth**

If you have a child(ren) in childcare (0–5 years old) please pick your child up in Conference Room 5. Youth should be picked up in Capital 2 & 3.

11:45 AM	**Symposium Concludes**

TEEN TRACK: AGES 13 – 18
CONFERENCE ROOM 7

Conference Room 7 will serve as our "home base" for the teens. Teens will participate in a combination of programming just for their age group, adult general sessions, and help as volunteers with the youth track and field trip.

Teen Track Lead: Nitya Bhattarai

Saturday, March 25

8:30 - 8:50 AM	**Teen Drop-Off**	Conference Room 7
9:15 – 10:15 AM	**Self-Advocacy**	Conference Room 7
10:15 – 10:30 AM	**Break**	Conference Room 7
10:30 AM – 12:15 PM	**STEM & Teambuilding with the Youth**	Capital 3
	Facilitator: Dean Vieira	
12:15 – 12:50 PM	**Lunch (Reunited with parents)**	Marriott ABC
12:50 PM	**Meet in Marriott Foyer to depart for the Connecticut Science Center**	
	See right for a map from the hotel to the Science Center. Participants will walk.	
1:00 - 4:00 PM	**Chaperone Field Trip to the Connecticut Science Center**	

4:00 – 5:00 PM	**Debrief & Snack**	Conference Room 7
5:00 PM	**Return to Parents**	Conference Room 7

Sunday, March 26

8:50 AM	**Meet in Conference Room 7 for sign-in**	
9:00 – 10:00 AM	**Therapy Pets Presentation**	Capital 3
	Facilitator: Kim Fontaine, President and Director, Animal Assisted Therapy Services-MA	
10:00 – 10:30 AM	**Snack Break**	Capital 3
10:30 – 11:45 AM	**Teens will Join Adults for Vocal Confidence Session**	Marriott ABC
	Facilitator: Claire Fry, Professional Voice Actor, and Owner, Vocal Confidence	
11:45 AM	**Symposium Concludes**	

YOUTH TRACK: AGES 6 – 12
CAPITAL ROOMS 2 & 3

The youth sessions will include activities to engage youth in education, imagination, support, and advocacy. Youth will also go to the Connecticut Science Center for a field trip, accompanied by volunteers and the teens.

Youth Track Leads: Bree Vieira & Chris Morse

Saturday, March 25

8:30 - 8:50 AM	**Youth Drop-Off**	Capital 3
9:15 – 10:00 AM	**Leo the Magician**	Capital 3
	Facilitator: Leo Desilets	
10:00 – 10:30 AM	**Snack Break & Balloon Twisting**	Capital 3
10:30 – 11:15 AM	**STEM and Bleeding Disorders**	Capital 3
	Facilitator: Dean Vieira & Teens	
11:15 AM – 12:15 PM	**STEM Challenge**	Capital 3
	Facilitator: Dean Vieira & Teens	

12:15 PM	**Parents Pick Up Child(ren) for Lunch**	Capital 3
	Please note that lunch is with parents. *It is your responsibility to pick up your child after the adult session is over.*	
12:15 – 12:50 PM	**Lunch (Reunited with parents)**	Marriott ABC
12:50 PM	**Meet in Marriott Foyer to depart for the Connecticut Science Center** See right for a map from the hotel to the Science Center. Participants will walk.	
1:00 – 4:00 PM	**Field Trip to the Connecticut Science Center**	
4:00 – 5:00 PM	**Camp Games and Snack**	Capital 3
5:00 PM	**Parents Pick Up Youth**	Capital 3

Sunday, March 26

8:30 - 8:50 AM	**Youth Drop-Off**	Capital 3
9:00 – 10:00 AM	**Therapy Pets Presentation**	Capital 3
	Facilitator: Kim Fontaine, President and Director, Animal Assisted Therapy Services-MA	
10:00 – 10:30 AM	**Snack Break**	Capital 3
10:30 – 11:30 AM	**Deep Play for Kids Yoga**	Capital 3
	Facilitator: Amy K. Valente	
11:45 AM	**Parents Pick Up Youth/Symposium Concludes**	

CHILDCARE: AGES 0 – 5
CONFERENCE ROOM 5

- *Children over the age of 3 may attend some facilitated sessions in the Youth Room. A chaperone will accompany any child switching rooms at all times.*
- *With parental permission, children over 4 are welcome to join the scheduled field trip with a chaperone.*
- *All other children will remain in the room with age appropriate toys and activities such as story-time, sensory play, craft time, and nap/quiet time.*

Saturday, March 25

8:30 - 8:50 AM	**Childcare Drop-off**	Conference Room 5
9:15 – 10:00 AM	**Leo the Magician in the Youth Room**	Capital 3
	Facilitator: Leo Desilets	
10:00 – 10:30 AM	**Snack Break and Balloon Twisting**	Conference Room 5
10:30 – 11:15 AM	**Story Time and a Craft**	Conference Room 5
11:15 AM – 12:15 PM	**Sensory Play**	Conference Room 5
12:15 PM	**Parents Pick Up Child(ren) for Lunch**	Conference Room 5
	Please note that lunch is with parents. *It is your responsibility to pick up your child after the adult session is over.*	
12:15 – 12:50 PM	**Lunch (Reunited with parents)**	Marriott ABC
12:50 PM	**Children (ages 4–5) Meet in Marriott Foyer, Depart for the CT Science Center**	
12:50 PM	**Parents drop-off Children at Childcare Room**	Conference Room 5
1:00 - 4:00 PM	**Children (ages 4–5) - Field Trip to the CT Science Center**	
1:00 – 2:30 PM	**Quiet Time**	Conference Room 5
2:30 – 3:30 PM	**Ribbon Play**	Conference Room 5
3:30 – 4:00 PM	**Snack Break**	Conference Room 5
4:00 – 5:00 PM	**Story Time and a Craft**	Conference Room 5
5:00 PM	**Parents Pick Up Child(ren)**	Conference Room 5

Sunday, March 26

8:30 - 8:50 AM	**Childcare Drop-Off**	Conference Room 5
9:00 – 10:00 AM	**Therapy Pets Presentation OR Sensory Play**	Capital 3
	Facilitator: Kim Fontaine, President and Director, Animal Assisted Therapy Services-MA	
10:00 – 10:30 AM	**Snack Break**	Conference Room 5
10:30 – 11:30 AM	**Deep Play for Kids Yoga OR Dance Party**	Capital 3
	Facilitator: Amy K. Valente	
11:45 AM	**Parents Pick Up Children/Symposium Concludes**	

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Saturday Dinner & Entertainment

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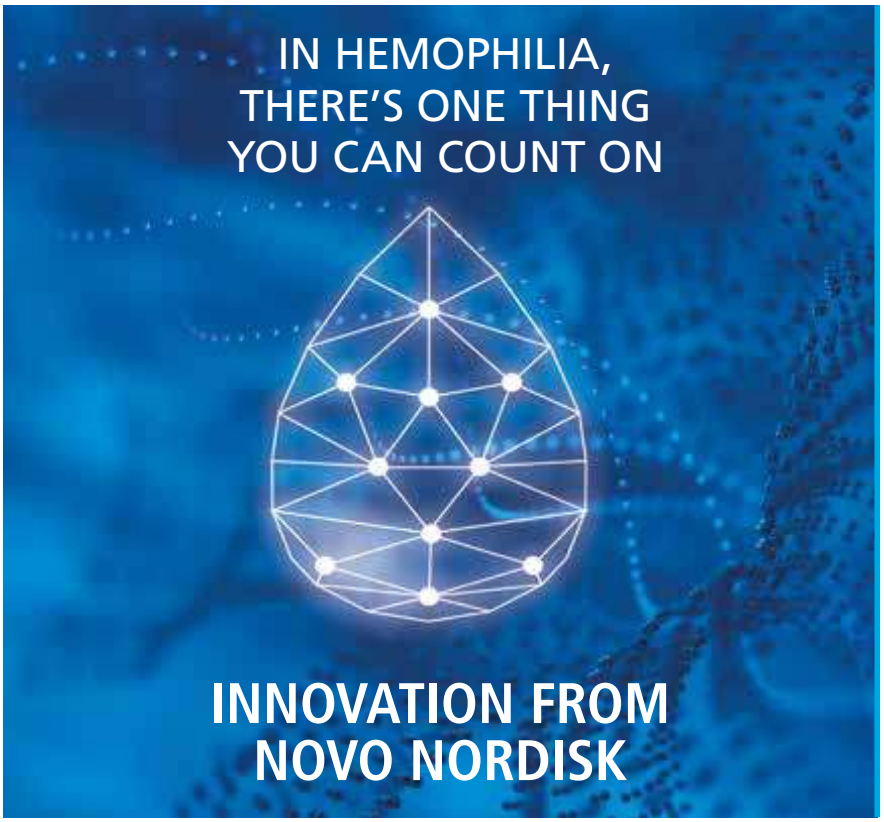

We strive to help improve the lives of people with hemophilia

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

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

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

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

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Date of preparation: 2/2021. NUW-0342-CAD

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* Hemophilia FIX Market Assessment. Third-Party Market Research.

‡ The average AsBR for people who started and stayed on 7- or 14-day prophylaxis was 0. For people who switched to prophylaxis from on-demand, the average AsBR was 0.7. AsBR-annualized spontaneous bleed rate.

‡ Once well-controlled (1 month without spontaneous bleeding or requiring dose adjustments on a weekly dose of ≤40 IU/kg), people 12 years and older can be transitioned to 14-day dosing.

IMPORTANT SAFETY INFORMATION

IDELVION®, Coagulation Factor IX (Recombinant), Albumin Fusion Protein (rFIX-FP), is used to control and prevent bleeding episodes in people with hemophilia B. Your doctor might also give you IDELVION before surgical procedures. Used regularly as prophylaxis, IDELVION can reduce the number of bleeding episodes.

IDELVION is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Do not inject IDELVION without training and approval from your healthcare provider or hemophilia treatment center.

Tell your healthcare provider of any medical condition you might have, including allergies and pregnancy, as well as all medications you are taking. Do not use IDELVION if you know you are allergic to any of its ingredients, including hamster proteins. Tell your doctor if you previously had an allergic reaction to any FIX product.

Please see additional Important Safety Information and brief summary of prescribing information on adjacent page and full prescribing information including patient product information at IDELVION.com.

You are encouraged to report negative side effects of prescription drugs to the FDA. **Visit www.fda.gov/medwatch, or call 1-800-FDA-1088**.

You can also report side effects to CSL Behring's Pharmacovigilance Department at **1-866-915-6958**.

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Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information in a way you can understand.

Let's explore gene therapy together at **HemDifferently.com**

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

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SAMPLE QUESTIONS TO ASK WHEN VISITING EXHIBITS

When you visit each booth, be sure to ask for a signature from each representative on your scavenger hunt card. Be sure to turn in your completed scavenger hunt to the NEHA Table by Saturday, March 25 at 5 PM. Winners will be announced during dinner.

Pharmaceutical Companies

1. What types of bleeding disorders are your products intended/indicated for?
2. At what temperature am I able to store your product in my house?
3. What is your product's half-life? How often do you need to infuse your product?
4. How many mL are each vial?
5. What are the different doses your product is available in?
6. Does your company offer co-pay assistance? How much?
7. What other programs does your company offer?

Specialty Pharmacy Companies

1. Will I have a consistent representative and pharmacists each time I call?
2. Where will my medication be shipped from?
3. Do you arrange home-nursing if I need it?
4. Do you work with my treatment's co-pay assistance program?
5. How do I know if I can use your company?
6. Can I receive my favorite brand of supplies?
7. Do you have a mail-back Sharps container program?
8. What other programs or services do you provide?
9. Do you handle all my insurance issues involving my bleeding disorders medication?
10. Is a pharmacist available 24/7?
11. Do you deliver to my home?
12. Do you remind me when it's time to order?

CONSUMER MEDICAL SYMPOSUM COMMITTEE

A huge thanks to our planning committee for their time and expertise over the past three months, as well as their volunteer service during the conference!

Heather Hoiseth, Rachel Katzman, Pat Mancini, Carolyn Miazga, Kevin Mills,
Mike Reutershan, Cathy Rosenfield, Mark Zatyrka

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THANK YOU TO OUR VOLUNTEERS

Special thanks to Diane Bruno, NEHA's Program Consultant, for all of her work on planning programming for our Consumer Medical Symposium, especially childcare and the tracks for youth and teens.

A heartfelt thanks for all our volunteers. Everyone involved in our Consumer Medical Symposium is invaluable to NEHA and a simple "thank you" hardly seems enough. If we have forgotten anyone, please accept our apologies. We appreciate everyone's help!

Nitya Bhattarai
Ines Castillo
Ismael Castillo
Michael DeGrandpre
Chris Morse
Rebecca Smith
Karen Thibeault
Bree Vieira
Dean Vieira
Autumn Wagner
Sandy Williams

SPEAKER BIOGRAPHIES

NEHA thanks all of the speakers who have presented during the conference. You can read more about our speakers by scanning the QR code and clicking on the speaker bio button on our conference webpage.

GLOSSARY OF HELPFUL MEDICAL TERMS

This glossary was created to help you understand key terms used during our Consumer Medical Symposium. This list was created by the Consumer Medical Symposium Committee and edited by Hemophilia Treatment Center (HTC) providers.

Common Bleeding Disorder-Related Terms

Adeno-Associated Virus (AAV): A non-pathogenic virus that is commonly used as a vector in gene therapy that can be engineered to deliver a gene (e.g. for factor VIII or IX) to target cells of interest (e.g. liver cells) for various therapeutic applications.

Antibody: A protein secreted into the bloodstream to neutralize pathogens, including bacteria, viruses, or foreign proteins. Antibodies may be designed to interact with specific proteins for therapeutic purposes such as the response to a vaccine. Sometimes, the immune system recognizes a protein as foreign, such as infused factor VIII, and produces an antibody (inhibitor) against that.

Antigen: A type of molecule that can initiate an immune response.

Antithrombin: A protein that regulates clotting and helps to prevent over-clotting by inhibiting thrombin (activated Factor II) as well as several other clotting factors, which are necessary for the formation of fibrin in the clotting process.

Biologics: A drug that is made from or by a living organism and is used to treat certain chronic conditions. Biologics are often referred to as "reference products" or "innovator drugs." Factor products are biologics.

Biosimilars: Medicine that is highly similar, but not identical, to a biologic medicine. They are also known as "follow-on biologics." Biosimilars cost less than their biologic counterparts. This is because, while both biologics and biosimilars are made from living organisms, biosimilars are likely to have a less expensive and burdensome FDA approval process than the biologic on which a biosimilar is based.

Bispecific Antibody: An antibody that can simultaneously bind to two different antigens (example: emicizumab, which binds both factor IXa and X).

Bone-Mineral Density (BMD): A bone mineral density test measures how much calcium and other minerals are in an area of bone. This test helps your health care provider detect osteoporosis and predict your risk for bone fractures.

Chromogenic Assay: In general, a chromogenic assay is one that uses color or fluorescence to quantify enzymatic activity. In bleeding disorders, chromogenic assays are used to determine the factor activity in a patient's plasma.

Clotting Cascade: The chain or sequence of biochemical reactions in which the various blood clotting proteins become activated to ultimately generate fibrin (activated Factor I), the protein from which clots are formed.

Clustered Regularly Interspaced Short Palindromic Repeats (CRISPR): A genetic engineering tool that is used to edit genes. Studies using this tool to attempt to treat genetic diseases in animals are ongoing.

Comorbidity: The simultaneous presence of two or more diseases or medical conditions in a patient

DNA: Deoxyribonucleic acid; the molecules inside cells that carry genetic information and pass it from one generation to the next.

Diversity, Equity and Inclusion (DEI): DEI encompasses the symbiotic relationship, philosophy and culture of acknowledging, embracing, supporting, and accepting those of all racial, sexual, gender, religious and socioeconomic backgrounds, among other differentiators.

Factor Deficiencies: Bleeding disorders identified by the missing clotting factor. They include factors I, II, V, VII, VIII, IX, X, XI, XII and XIII. (See below for disorder definitions.)

Factor I Deficiency: A rare bleeding disorder caused by deficient or defective fibrinogen.

Factor II Deficiency: An extremely rare bleeding disorder caused by a deficiency of prothrombin.

Factor V Deficiency: A rare bleeding disorder caused by a deficiency of factor V protein.

Factor VII Deficiency: Also called Alexander's disease, which is caused by a deficiency of factor VII protein. This is the most common rare bleeding disorder and it can be mild to severe.

Factor VIII Deficiency: Also called hemophilia A, caused by a deficiency of factor VIII protein.

Factor IX Deficiency: Also called hemophilia B, caused by a deficiency of factor IX protein.

Factor X Deficiency: A rare bleeding disorder caused by a deficiency of factor X protein, which activates enzymes that help form a clot.

Factor XI Deficiency: Also called hemophilia C, caused by a deficiency of factor XI protein.

Factor XII Deficiency: A rare factor deficiency. People do not bleed, even if their levels are 0%.

Factor XIII Deficiency: The rarest bleeding disorder caused by a deficiency of factor XIII protein which is needed to stabilize a clot.

Fc Fusion: Fusion of an active protein (for example, clotting factor) to a protein with a long half-life (for example, the Fc, or "fragment crystallizable," portion of an antibody) to extend the half-life of the active protein.

Fibrinogen: Also known as Factor I, it is a soluble protein made by the liver and present in blood plasma. It is converted during tissue injury to fibrin and subsequently to a fibrin-based blood clot.

Gene: The functional and physical part of DNA that is passed from parent to offspring. Genes are pieces of DNA, and most genes contain the information for making a specific protein.

Gene Therapy or Editing: Inserting a functional copy of a gene or DNA segment into a patient to treat a disease.

Genome: All the genetic information of a cell or organism. In humans, almost every cell in the body contains a complete copy of the genome. The genome contains all of the information needed for a person to develop and grow.

Genotype: This refers to the particular variants of genes in your DNA. It is often contrasted with "phenotype," which refers to the particular physical characteristics (for example, height, lactose intolerance, or extended bleeding time) that results from the genotype. See "Phenotype" below.

Hemostasis: Stoppage of bleeding through clot formation.

Hemostatic Agent: A drug or other agent designed to promote rapid blood clotting.

Immune Tolerance Therapy (ITT): A treatment of repeated infusions of factor concentrate over a period of time. The goal is to train the body to tolerate the factor concentrate and not react to the protein by creating antibodies. This treatment is often used with inhibitor patients.

Immunogenic: The tendency of a foreign substance to provoke an immune response.

Intravenous (IV): Administration of a drug directly into a vein.

Lyophilization: Also known as freeze-drying, a water removal process where a mixture is frozen and placed under reduced pressure to allow ice removal by sublimation. This process is used to preserve perishable materials and extend their shelf-life.

Medical Science Liaison (MSL): A specific role within a pharmaceutical or biotechnology company where experts focus on a specific therapeutic area (e.g. hematology) and disease state (e.g. bleeding disorders). Their role as scientific experts includes ensuring that products are used effectively, serving as scientific peers and resources within the medical community and internally at companies, and establishing relationships with leading physicians.

Microbleeds: Also known as "subclinical" or "silent" bleeds, these are chronic, small bleeds which can occur even during ongoing prophylaxis treatment for bleeding disorders.

Mimetic: A synthesized molecule that mimics the function of a naturally occurring protein. For example, emicizumab is a mimetic for factor VIII.

Off-Label Usage: Use of an FDA-approved drug for an indication, or in a group, not approved on the prescription label.

Osteopenia: A condition where a person's bone density is lower than normal for a given age group. Often considered the first step toward osteoporosis, osteopenia isn't as serious as osteoporosis because the bones aren't as porous.

Osteoporosis: A disease that causes bones to become weak and brittle, resulting in an increased risk of fracture. Osteoporosis is a more serious progression of osteopenia.

Phenotype: A description of your actual physical characteristics resulting from both your environment and your genotype.

Pegylation: Attachment of polyethylene glycol (PEG), a non-toxic and non-immunogenic polymer, to a biomolecule in order to prolong the biomolecule's half-life.

Plasma: The liquid part of blood. It has water, sugar, fat, protein, and salts. Plasma is the yellow-colored, protein-rich portion of the blood that transports red and white blood cells, and platelets, nutrients, waste products, antibodies, clotting factors and other clotting proteins, and chemical messengers (like hormones) throughout your body.

Plasma Derived Factor: Factor products produced from blood donors' plasma.

Platelets: Tiny disc shaped components (blood cells) of blood that help seal injured blood vessels and stop bleeding.
Platelet-Rich Plasma (PRP): A type of therapy that uses injections of a concentration of a patient's own platelets to accelerate the healing of injured tendons, ligaments, muscles and joints.
Prophylaxis: Measures taken to preserve health or prevent disease.

Recombinant Factor: Clotting factor that is produced in a lab rather than derived from plasma.

Red Blood Cells (RBCs): RBCs are also called erythrocytes. They are red and make up about 45% of your blood's volume, which is why blood is red. RBCs are red because of a special protein called hemoglobin, which carries oxygen from your lungs to your body and returns carbon dioxide to your lungs to be exhaled.

RNA Interference (RNAi): A process in which the production of a specific protein is decreased by an RNA molecule. RNA (or ribonucleic acid) is a chemical "cousin" of DNA.

Subcutaneous (Sub-Q): Administration of a drug under the skin.

Therapeutic Dataset: de-identified real-world data for researchers to translate into actionable insights about topics like the patient journey, provider prescribing patterns, disease progression, procedure volumes, and the overall delivery of care.

Thrombosis: Formation or presence of a blood clot in the body.

Titer: A measurement of the amount (concentration) of something in a solution. It commonly refers to the amount of antibodies found in a person's blood.

Tolerize: To induce immunologic tolerance, for example when the patient's inhibitors are reduced or eradicated with treatment.

Vector: The term refers to the transport system used to deliver a product, such as DNA, into cells. A product could be a virus (often an adeno-associated virus, or AAV), as well as synthetic, or natural compounds, which are used in gene therapy to deliver a functional gene to cells in the body in order for those cells to begin manufacturing copies of the gene.

von Willebrand Disease (VWD): A bleeding disorder in which von Willebrand factor (VWF), a blood protein, is either deficient or defective.

von Willebrand Factor (VWF): A blood protein that helps platelets plug injured blood vessel walls by causing them to stick together. It is also a carrier for factor VIII.

White Blood Cells (WBCs): WBCs are also called leukocytes. Their primary job is to protect your body from infection. They only make up about 1% of your blood volume. There are three types of WBCs: granulocytes (which include neutrophils, your immediate response cells which live less than a day), monocytes, and lymphocytes (which can live in tissue indefinitely). The two main types of lymphocytes are T lymphocytes, which help regulate immune cell function and attack infected cells and tumors, and B lymphocytes, which make antibodies (proteins that attach to bacteria, viruses, and other foreign materials).

Drug Metabolism Terminology

Drug Metabolism: Describes the biotransformation of a drug in the body to facilitate its elimination from the body.

Half-Life: The amount of time it takes for the concentration of a drug (or factor activity levels) to decrease by half.

Peak Level: Maximum concentration of a drug in the bloodstream of a patient after administration of one dose.

Pharmacodynamics (PD): The study of the biochemical and physiologic effects of a drug on organisms, that is, how a drug affects the organism.

Pharmacokinetics (PK): The study of what happens to a drug or compound once it is administered to a living organism, that is, how an organism affects a drug. PK refers to the absorption, distribution, metabolism, and excretion of a drug. A Pharmacokinetics Study (or PK Study) can be used, for example, to determine the half-life of a drug or clotting factor in the blood and can be used by a physician to help optimize and/or personalize treatment.

Other common terms associated with pharmacokinetics and their definitions:

> **Area Under the Curve (AUC):** The variation of drug concentration in blood plasma over time. AUC represents the total exposure of drug over time.
>
> **Clearance:** The parameter that describes the efficiency of elimination of a drug from the body. It's essential to know a drug's clearance to determine the dosing of a medication.
>
> **Drug Disposition:** A broad term that covers all of the processes by which the body handles drugs. The processes include absorption, distribution, metabolism, and excretion (often abbreviated ADME).
>
> > *Absorption:* The movement of drug into the bloodstream following administration.
> > *Distribution:* The disbursement of unmetabolized drug as it moves through the body's blood and tissues.
> > *Metabolism:* The chemical alteration of a drug by the body.
> > *Excretion:* The removal of drugs from the body either as metabolites or unchanged drug.
>
> **Elimination:** The removal of drugs from the body. Drugs may be eliminated after being chemically altered (metabolized), or they may be eliminated intact. Most drugs and their metabolites are eliminated by the kidneys in urine.
>
> **Exposure:** Refers to drug levels achieved in the body for a given dose, and is typically represented as AUC. Understanding the relationship between drug exposure and response is critical to finding a dose that optimally strikes a balance between drug efficacy and adverse events.
>
> **Metabolism:** The chemical alteration of a drug by the body. The primary site for drug metabolism is the liver, where special enzymes convert drugs to metabolites to allow the body to more easily eliminate them. The study of drug metabolism is called pharmacokinetics.

Toxicity: Damage or harmful side effects of a drug on animals or humans.

Trough Level: Minimum concentration of a drug in a patient's blood stream prior to the next planned dose.

Clinical Trial Terminology

Adverse Event (AE): Any negative change in the health of a clinical trial participant that occurs during a clinical trial or for a specified period after the trial.

Clinical Trial: A systematically designed and implemented experiment for testing the safety and efficacy of a new drug in humans. Trials are categorized into three or four sequenced "phases" that differ in their purpose and size. See "Phase I Trial," "Phase II Trial," "Phase III Trial," and "Phase IV Testing" below.

Cohort: A group of clinical trial research participants who share a characteristic of interest.

Control: Standard treatment that is given in a clinical trial and compared against the investigational treatment in order to determine whether the investigational treatment makes a statistically significant difference.

Double-Blind: This describes clinical trials in which, by design, neither the research participants nor the investigators know whether the participants are receiving the experimental intervention that is being studied (for example, an investigational drug) or a non-experimental intervention (for example, a placebo or already approved medication). A third party reveals which group received which intervention after the outcome of the trial has been assessed. The purpose of "double-blinding" a clinical trial is to prevent bias from affecting how the study is carried out or how the results are recorded or interpreted.

Efficacy: The property that enables drugs to produce a beneficial response. Efficacy refers to whether a drug demonstrates a health benefit compared to a placebo or other intervention.

Inclusion/Exclusion Criteria: Clinical and laboratory data that define who is appropriate (eligible) to participate in a specific clinical trial or study, for example, diagnosis, prior treatment history, inhibitor status, organ dysfunction, etc.

Investigational New Drug (IND): A substance under development for potential use as a medication. The term "IND" is often also used as shorthand for the application that must be submitted to the FDA for permission to begin testing a drug in human clinical trials. Such an application contains results of toxicity studies and protocols for manufacturing the drug and carrying out clinical trials.

Institutional Review Board (IRB): A panel or body composed of individuals with relevant scientific, legal, ethical, lay community, and other expertise responsible for reviewing proposed studies involving human subjects before the studies can be undertaken. IRBs can be
internal bodies established by the medical center (or other study site) or external commercial bodies under contract to the study site.

Label: The FDA-approved written materials that come with a drug (also called "package insert" or "prescribing information"). The label contains extensive information about the drug, including its approved uses, possible side effects, contraindications, general
pharmacokinetic data, results of clinical trials in which the drug was tested, instructions for drug administration, etc.

Maximum Tolerated Dose (MTD): The highest dose of a drug or treatment that does not cause unacceptable side effects. The maximum tolerated dose is determined in clinical trials by testing increasing doses on different groups of people until the highest dose with acceptable side effects are found.

New Drug Application (NDA): The vehicle through which a drug manufacturer submits data about a new drug to the FDA for review and approval for sale and marketing in the U.S. The data gathered during the animal studies and human clinical trials of an investigational new drug (IND) become part of the NDA.

Open-Label: Both research participants and investigators know the drug or intervention being administered to a patient participating in a clinical trial. (Compare with "Double-Blind" above.)

Phase I Trial: A clinical trial in which a drug is tested on a small group of research participants to determine safety and often the maximum tolerated dose of a drug.

Phase II Trial: A clinical trial in which a drug is tested on a small group of patients to establish whether a drug has any potential efficacy and further test the safety of the drug. This phase can only begin after a phase I trial has been completed successfully, although trials are sometimes carried out jointly as phase I/II trials.

Phase III Trial: The phase of testing before a drug can be approved. In a phase III trial a drug is tested on a large group of patients to further establish the efficacy of a drug in treating a disease. The data from this trial is reviewed by the FDA in hopes of approval. This phase can only begin after a phase I/II or phase II trial has been completed successfully.

Phase IV Testing: A clinical study to evaluate a drug for safety or efficacy after it has been approved by the FDA. It is also known as post-marketing surveillance. It does NOT evaluate the drug for new indications.

Previously Untreated Patients (PUPs): An individual or group of individuals that have not been exposed to a certain drug.

Primary Endpoint: The outcome that a study is designed to investigate; this is determined before the trial begins. For example, an endpoint of a study of a new clotting product might be the average number of bleeds experienced by study participants.

Real-World Evidence (RWE): Real-world evidence in medicine is the clinical evidence regarding the usage and potential benefits or risks of a medical product derived from analysis of real-world data.

Serious Adverse Effect (SAE): Reportable events by medical professionals and researchers during the conduct of studies and medical care which include: death, life threatening events, hospitalization, disability or permanent damage or any event requiring intervention to prevent permanent damage or impairment.

Single Blind: This describes clinical trials in which, by design, the research participants do not know whether they are receiving a study drug or device or a placebo intervention, whereas the study investigators do.

Study Arm: A group of research participants that receives a specific type of treatment or has specific characteristics while being studied in the same clinical trial. Clinical trials usually have two or more arms (for example, one arm of patients who receive a high dose of the study drug, one arm of low-dosed patients, and one arm of patients who receive a placebo).

Top Line Results: The results of statistical analysis indicate if the primary endpoints have been met for the clinical trial. Topline data is the highest quality data with respect to a clinical trial as it includes statistically analyzed summaries of all demographic, safety and endpoint data and not just portions of it. Examples may include showing an experimental drug is statistically superior to another already approved drug or that an experimental drug shows no statistical difference with a placebo.

Trial Sponsor: The person or organization who initiates a clinical trial and holds the investigational new drug application. This is usually but not always the entity that pays the costs of the clinical trial. It may be a governmental organization, a corporation, or an individual investigator.

Artificial Intelligence (AI) Terminology

Artificial Intelligence: The ability to everage computers and machines to mimic the problem-solving and decision-making capabilities of the human mind.

Data Science: The study of data to extract meaningful insights for business. It is a multidisciplinary approach that combines principles and practices from the fields of mathematics, statistics, artificial intelligence, and computer engineering to analyze large amounts of data.

Deep Learning: A type of machine learning based on artificial neural networks in which multiple layers of processing are used to extract progressively higher level features from data.

Machine Learning: The use and development of computer systems that are able to learn and adapt without following explicit instructions, by using algorithms and statistical models to analyze and draw inferences from patterns in data.

Mental Health Terminology

Anxiety: A feeling of worry caused by perceived threats in the environment.

Bipolar Disorder: An illness characterized by extreme swings in mood, energy and activity level.
Cognitive Behavioral Therapy: a type of psychotherapy in which negative patterns of thought about the self and the world are challenged in order to alter unwanted behavior patterns or treat mood disorders.

Coping Skill: A strategy to help you deal with difficult situations and lessen unpleasant emotions, thoughts, or behaviors

Depression: Sad or low mood which persists for at least two weeks.

Eating Disorders: Serious illnesses in which people have severe disturbances in their eating behaviors and distorted thoughts and emotions about how their body looks or feels.

Mental Health: Mental health includes our emotional, psychological, and social well-being. It affects how we think, feel, and act. It also helps determine how we handle stress, relate to others, and make choices.

Mental Health Challenge: A mental health challenge is a major change in a person's thinking, feeling or behavior which interferes with a person's ability to live their life and to relate to others and to their surroundings.

Post Traumatic Stress Disorder (PTSD): A disorder that can occur after a person has experienced a traumatic event. Psychiatrist: a licensed medical doctor who has completed additional psychiatric training; can diagnose mental health conditions, prescribe and manage medication, and provide therapy

Psychotherapy: The treatment of mental conditions by verbal communication and interaction.

Psychotic Disorders: Psychosis is a condition in which a person has lost contact with reality.

Social Worker: Provides mental health services for the prevention, diagnosis, and treatment of mental, emotional, and behavioral disorders in individuals, families, and groups.

Stigma: Negative, judgmental, and/or discriminatory attitudes toward mental health challenges and those who live with them

Substance Use Disorder (SUD): A pattern of using alcohol or another substance that results in impairment in daily life or noticeable distress.

Therapist: A mental health professional trained to help individuals understand and cope with their thoughts, feelings, and behaviors; may assess and/or diagnose mental health conditions

COVID-19 and Vaccination Terminology

Coronavirus: A large family of viruses that cause respiratory illness. Some produce mild, cold-like symptoms while others can produce severe symptoms (i.e. SARS-CoV-2).

COVID-19: The respiratory disease caused by a novel coronavirus known as SARS-CoV-2. COVID-19 stands for coronavirus disease 2019.

mRNA (messenger RNA): A single-stranded molecule that is complementary to one of the DNA strands of a gene. mRNA is 'read' by a ribosome inside a cell in the process of protein synthesis. mRNA can be thought of as instructions for the cell on how to make a protein.

mRNA Vaccine: A vaccine that uses mRNA to produce an immune response. For COVID-19, the mRNA in the vaccine provides instructions to make COVID-19's spike protein. Once absorbed, the body makes the harmless protein and displays it on the cell surface. The spike protein is then recognized as foreign, eliciting the immune system to produce antibodies to fight off this perceived infection. The immune system is then primed to protect against future infection.

SARS-CoV-2: The scientific name of the new strain of coronavirus that causes the respiratory disease COVID-19. SARS stands for severe acute respiratory syndrome.

Vaccine: A product that stimulates a person's immune system to produce protection from an infectious disease without inducing the disease.

Sources:
Hemophilia Federation of America: www.hemophiliafed.org
National Hemophilia Foundation: www.hemophilia.org

NEHA
NEW ENGLAND HEMOPHILIA ASSOCIATION

2023 COMMUNITY DATES

Men's Retreat Stratton Mountain, VT	Friday, April 21 – Sunday, April 23
vWD Retreat Providence, RI	Saturday, May 6
Family Camp Moultonborough, NH	Wednesday, June 28 – Saturday, July 1
Women's Retreat Stratton Mountain, VT	Friday, August 11 – Sunday, August 13
Golf Tournament Boylston, MA	Monday, August 21
14th Annual Unite For Bleeding Disorders Walk Canton, MA	Saturday, September 30
Hispanic Heritage Symposium Rocky Hill, CT	Saturday, October 7
FallFest Portland, ME	Saturday, November 4 – Sunday, November 5
Holiday Party Boylston, MA	Sunday, December 3

Visit *nehaevents.org* to see all our events & register!

NOTES

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NEHA
NEW ENGLAND HEMOPHILIA ASSOCIATION

NEHA'S Mental Health Resource Page

We are here to support the mental health of our bleeding disorders community. In 2021, we established a Mental Health Task Force made up of patients, caregivers, and mental health professionals, to create resources and education. Thanks to their efforts, we are pleased to announce the creation of this important tool!

Scan this QR code to access the webpage for mental health information by state, as well as links to national organizations, and past webinars. You can also visit our website to learn more.

www.newenglandhemophilia.org/mental-health