



8th Annual
**CONSUMER
MEDICAL
SYMPOSIUM**

MARCH 16-17, 2024
NASHUA, NH

www.nehemophilia.org

WELCOME

March 2024

NEHA Community,

Welcome to our 8th 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.

Our 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 so 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 healthcare 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.

We sincerely appreciate your interest and attendance. Together we welcome your valuable participation, comments, and feedback throughout the weekend.

Warm Regards,

THE NEHA STAFF

Rich, Tracey, Sarah, Diane, Jodi, Brandon and Jill



REMINDERS & QUICK FACTS

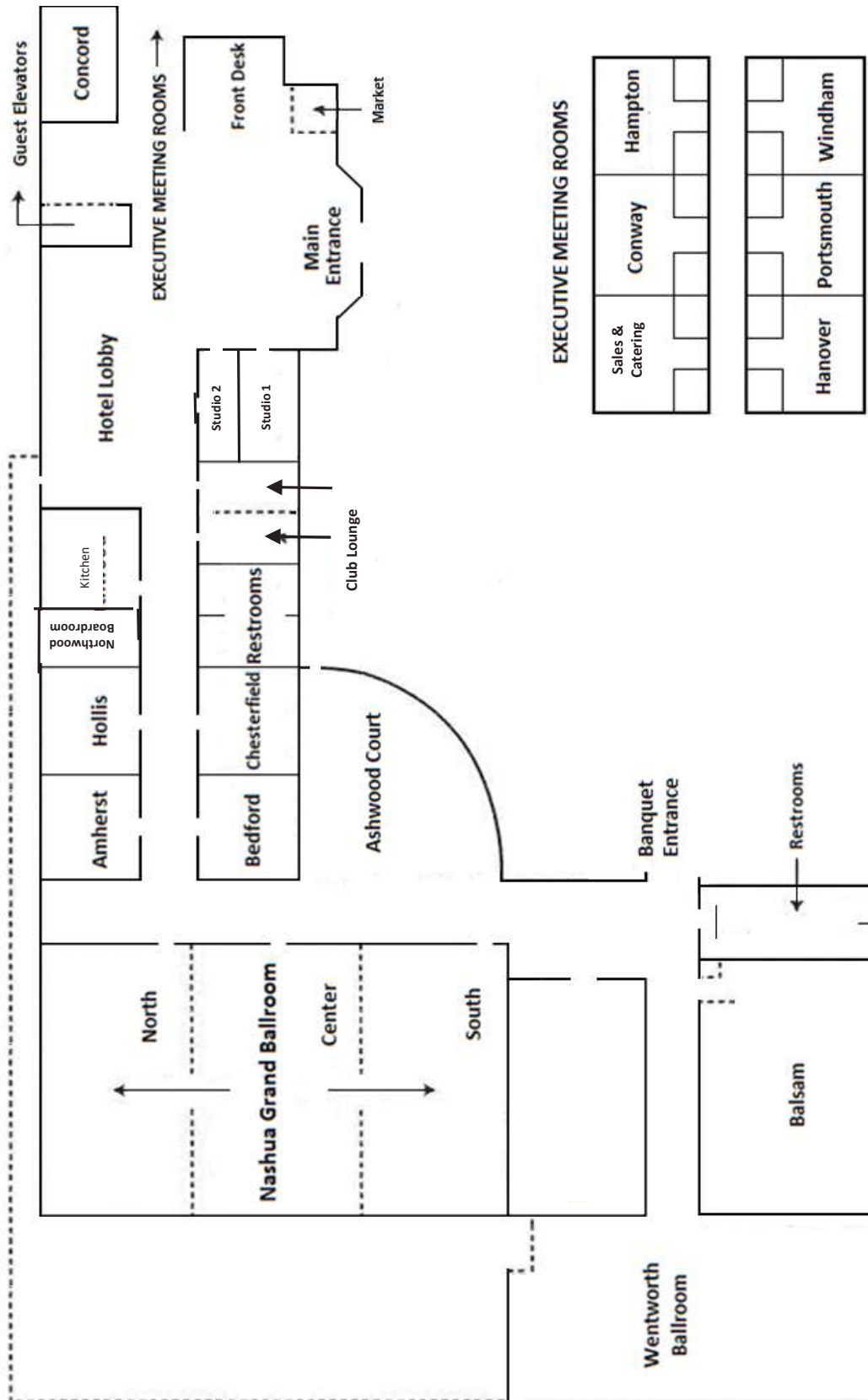
- Check-in will begin at 7:30 AM on Saturday morning outside of the Nashua Grand Ballroom. Breakfast will be available beginning at 8 AM.
- Our conference will conclude on Sunday at 11:30 AM.
- Breakfast, lunch and dinner will be provided on site by NEHA on Saturday. Breakfast will be provided on Sunday. You are expected to attend all meals. We have requested that our industry partners not provide any separate meals during this time.
- There is a teen and youth track, as well as childcare for infants and toddlers. Please explore the following pages for their respective agendas.
- 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 future NEHA programming and ensures we are providing dynamic and engaging educational opportunities that meet the needs of the community.
- Put your dancing shoes on and join us at the Red Tie Soiree on Saturday, April 20! Learn more about this important event and how you can make a difference at the NEHA Table, or visit www.nehaevents.org.
- Register for our Walk! The NEHA Unite for Bleeding Disorders Walk is Saturday, September 28 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



EXECUTIVE MEETING ROOMS

| | | |
|------------------|--------|---------|
| Sales & Catering | Conway | Hampton |
| | | |
| | | |

| | | |
|---------|------------|---------|
| Hanover | Portsmouth | Windham |
| | | |
| | | |

PROGRAM AGENDA

Friday, March 15

6:00 – 8:00 PM **Welcome Reception, Sponsored by:** Sanofi Wentworth Ballroom

Join us to kick-off the weekend and celebrate Bleeding Disorders Awareness Month together as a community! All are welcome for passed hors d'oeuvres, dinner for the entire family, and a cash bar.

The reception is sponsored by Sanofi and will feature a presentation where you will learn about ALTUVIIIIO: their new replacement therapy for hemophilia A. This will be given by Shevta Gupta, MD, and will also include first-hand experience from a patient.

Dr. Shevta Gupta, MD, is the HTC Director at Arnold Palmer Hospital for Children-The Haley Center for Children's Cancer and Blood Disorders in Orlando, Florida.

Saturday, March 16

7:30 – 8:50 AM **Registration** Nashua Grand Ballroom Foyer

7:30 – 8:50 AM **Exhibit Hall Open** Ashwood Court

8:00 – 8:50 AM **Breakfast** Nashua Grand Ballroom

Quiet Space Open
Lobby Office Space
8:30 AM – 6:15 PM

- The Lobby Office Space will be open throughout the day for quiet reflection and
- space. We've set-up coloring books and other mindfulness activities for you to do
- at your leisure. This space is intended for adult use only. Special thanks to our
- Mental Health Task Force for helping organize this space.

8:40 – 8:50 AM **Childcare // Youth // Teen Program Drop-off**
Childcare (0-4): Bedford/Chesterfield Rooms
Youth (5-12): Balsam Room
Teens (13-17): Hollis Room

8:50 – 9:00 AM **Welcome** Nashua Grand Ballroom

Speaker: Rich Pezzillo, NEHA Executive Director

9:00 – 10:00 AM **Keynote: Benefits of Hypnosis** Nashua Grand Ballroom

Speaker: Roderick Russell, CHt, CPH, CMH

In this workshop designed for both those with bleeding disorders as well as caregivers, Roderick Russell will demystify hypnosis, teach you how it can be applied in your unique situation, and equip you with the tools and techniques to practice self-hypnosis on your own to manage the many challenges bleeding disorders may present.

Hypnosis can be deployed to address a number of concerns, be it stress, anxiety, pre- and post-operative management, fears and phobias, treatment adherence, pain management, circulatory control, dental procedures, behavior modification and more. Join us to uncover what hypnosis really is, understand how it can serve your needs, and leave you equipped with valuable knowledge and practical resources that you can seamlessly and immediately integrate into your daily life.

1:15 – 2:15 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: Young Adult Challenges

Amherst Room

Facilitators: Elie Naous and Lissa Blanchard, LICSW, NEHA Mental Health Consultant

Join this session to participate in a discussion about challenges facing young adults in today's changing environment. Some topics may include employment challenges, psychological burden and mental health, treatment adherence, and more.

Rap Session #2: Insurance

Hollis Room

Facilitator: Joanne Wagner, LICSW, Dartmouth-Hitchcock Medical Center

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.

Rap Session #3: Aging / Comorbidities

Wentworth Ballroom

Facilitator: Amanda Stahl, LICSW, Brigham and Women's Hospital and Boston Hemophilia Center

In this session, we will discuss issues you may encounter as you age (regardless of gender) and expectations around the aging process. Does having a bleeding disorder change the aging process? How do you navigate your health and healthcare while aging? This session will serve as an open forum for attendees to share information if it is helpful.

Rap Session #4: Physical Activity

Nashua Grand Ballroom

Facilitator: Laura Zitnik, PT, Dartmouth-Hitchcock Medical Center

Knowing what physical activity is safe and appropriate while living with a bleeding disorder can be hard. Are you a parent of a young person worried about their participation in sports? Do you struggle to find motivation to exercise? Come, share and listen while we help you navigate this challenge. We can help get you started!

Rap Session #5: Parents of Teens Transitioning to Adults

Balsam Room

Facilitator: Emily Bisson, APRN, CPNP-PC, Dartmouth-Hitchcock Medical Center

Parents often have many unanswered questions and frustrations as teenagers transition into adulthood. Join this session to learn some tried and true tips.

2:15 – 2:30 PM

Coffee Break | Exhibit Hall Open

Ashwood Court

2:30 – 3:30 PM

Industry Partner Updates

Nashua Grand Ballroom

Facilitator: Michael DeGrandpre, NEHA Volunteer

Companies: Biomarin, CSL Behring, Genentech, Kedrion, Octapharma, Sanofi, Spark Therapeutics

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.

Below you will find a description for which bleeding disorders each company has treatments for or is working towards treatments for:

Biomarin

- Hemophilia A

CSL Behring

- Hemophilia A
- Hemophilia B
- VWD
- Congenital Fibrinogen Deficiency
- Congenital Factor 13 Deficiency

Genentech

- Hemophilia A

Kedrion

- Hemophilia A
- Factor 10 Deficiency
- Plasminogen Deficiency Type-1 (PLGD-1)

Octapharma

- Hemophilia A
- VWD
- Congenital Fibrinogen Deficiency

Sanofi

- Hemophilia A
- Hemophilia B

Spark Therapeutics

- Hemophilia A

3:30 – 4:30 PM

Exhibit Hall Hour | Snack Break

Ashwood Court

4:00 – 4:30 PM

Therapy Dogs Visit

Ashwood Court

4:30 – 5:30 PM

**Community Voices in Research:
How the Lived Experience is Paving the Future of Research**

Wentworth Ballroom

Facilitators: Matthew Hartnett, B.S., M.P.H and Maria E Santaella, PhD(c), MSN, RN-BC, CPHON

Want to learn how research is being used to help medical advancements? Join us for a presentation on Community Voices in Research, a community-based registry using the lived experience to further research efforts and a discussion on how community participation in research impacts research on bleeding disorders.

5:30 PM

Childcare // Youth // Teen Program Pick Up

Childcare (0-4): Bedford/Chesterfield Rooms

Youth (5-12): Balsam Room

Teens (13-17): Hollis Room

5:30 - 6:15 PM

Free Time

6:15 - 7:00 PM

Dinner

Nashua Grand Ballroom

Dinner will be available from 6:15 - 7:00 PM. A cash bar will be available from 6:15 - 10:00 PM. Attendees with kids are encouraged to come for dinner on the earlier end.

7:00 - 8:00 PM

Hypnotist Show

Wentworth Ballroom

After dinner, we invite our adult attendees and those 9 and older to join us in the Wentworth Ballroom for a Hypnotist Comedy Show. Attendees under 9 and any children who aren't interested, can stay in the Nashua Grand Ballroom to play arcade games, monitored by our wonderful volunteers. When the Hypnotist Show concludes, adults will return to the main ballroom to join in the fun family games.

7:00 PM

Family Game Night & Music

Nashua Grand Ballroom

Arcade games, board games, and cards will be available for families to play the night away.

10:00 PM

Family Game Night Concludes

Sunday, March 17

| | | |
|------------------|---|-----------------------|
| 8:00 – 8:50 AM | Breakfast | Nashua Grand Ballroom |
| 8:50 AM | Childcare // Youth Program Drop-off Childcare (0-4): Bedford/Chesterfield Rooms Youth (5-12): Balsam Room <i>*Teens are expected to participate in adult programming on Sunday.</i> | |
| 9:00 - 10:00 AM | A Conversation about Mental Health and Bleeding Disorders <i>Speakers: Mark Zatyрка & Lissa Blanchard, LICSW, NEHA Mental Health Consultant</i> From needle phobia to guilt to isolation to body image, we will have an open discussion on the challenges we face in the bleeding disorders community. Attendees will be allowed to share their challenges and what coping mechanisms have worked for them. This session will be informative, personable, and interactive. | Nashua Grand Ballroom |
| 10:00 - 10:30 AM | Coffee Break | |
| 10:30 - 11:30 AM | Educational Breakouts (Select One) #1: Bleeding Disorders Community Perspective Panel <i>Moderator: Michael DeGrandpre, NEHA Volunteer</i> <i>Speakers: Michael Eck, Craig MacDonald, Rachel Miller Kroouze, Ann Marie Minichiello-Charlsen, and Rich Vogel</i> Please join us for a talk with community members who will share their history with bleeding disorders including treatments, challenges, and their outlook for the future. It is important to remember where we have been as we move forward in this ever changing landscape of bleeding disorders treatments. | Nashua Grand Ballroom |
| | #2: Evolutionary Medicine <i>Speaker: Dr. Lara Durgavich</i> This session will include a general introduction to the field of evolutionary medicine. It will include an evolutionary perspective on some blood conditions like sickle-cell anemia and/or hemochromatosis and will also review broader ideas about evolutionary mismatch and constraints & proximate/ultimate perspectives. | Wentworth Ballroom |
| 11:30 AM | Childcare // Youth Program Pick Up Childcare (0-4): Bedford/Chesterfield Rooms Youth (5-12): Balsam Room Teens (13-17): Hollis Room | |
| 11:30 AM | Symposium Concludes <i>*Hotel room checkout is at 12 PM.</i> | |



TEEN TRACK: AGES 13 – 18

HOLLIS ROOM

Hollis Room will serve as our “home base” for teens. They will participate in a combination of programs over the weekend. Some programs will be specific for their age group; on Sunday they will join the adult general sessions, and, at times, they will help as volunteers with the youth track.

Teen Track Lead: Shane Secinaro

Saturday, March 16

| | | |
|---------------------|--|--------------------|
| 8:40 - 8:50 AM | Teen Drop-off | Hollis Room |
| 9:15 – 10:15 AM | Create Scavenger Hunt for Youth | Hollis Room |
| 10:15 – 10:30 AM | Break | Hollis Room |
| 10:30 AM – 12:15 PM | Pool Time | Atlantis Pool |
| 12:15 – 1:00 PM | Teen Lunch with one parent/guardian <i>Teens and one parent/guardian will participate in a BLeader session over lunch.</i> | Wentworth Ballroom |

Please note: One parent/guardian must accompany their teen.

Sponsored by Novo Nordisk, this presentation will discuss powerful tools to make transitions easier, successful, and exciting.

| | | |
|----------------|------------------------------------|-----------------------|
| 1:00 PM | Teen Drop-Off | Hollis Room |
| 1:15 - 1:45 PM | Field Trip Prep | Ashwood Court |
| 1:45 – 4:45 PM | Indoor Skydiving Field Trip | Off Site - SkyVenture |
| 4:45 PM | Return from Field Trip | Hollis Room |
| 4:45 – 5:30 PM | Debrief/Pickup | Hollis Room |

Sunday, March 17

Teens are expected to participate in adult programming on Sunday.



YOUTH TRACK: AGES 5 - 12

BALSAM ROOM

The youth sessions will include activities to engage youth in education, imagination, support, and fun. Ages 9 and over will go to SkyVenture Indoor Skydiving Facility for a field trip, accompanied by volunteers and the teens.

Youth Track Lead: John Bruno

Saturday, March 16

| | | |
|---------------------|---|---------------|
| 8:40 - 8:50 AM | Youth Drop-off | Balsam Room |
| 9:00 - 9:15 AM | Youth Introductions | Balsam Room |
| 9:15 - 10:30 AM | Pool Time | Atlantis Pool |
| 10:30 - 11:00 AM | Snack Break | Balsam Room |
| 11:00 AM - 12:15 PM | Ashwood Court Scavenger Hunt | Ashwood Court |
| 12:15 PM | Parents Pick Up Child(ren) for Lunch | Balsam Room |

Please note that lunch is with parents. It is your responsibility to pick up your child after the adult session is over.

| | | |
|-----------------|--------------------------------------|-----------------------|
| 12:15 - 1:00 PM | Lunch (Reunited with parents) | Nashua Grand Ballroom |
| 1:00 PM | Youth Drop-Off | Balsam Room |
| 1:15 - 1:45 PM | Field Trip Prep | Ashwood Court |
| 1:45 - 4:45 PM | Indoor Skydiving Field Trip | Off Site - SkyVenture |

This is restricted for ages 9 and above. Any children in the youth room who are not old enough will participate in activities with the childcare staff on site.

| | | |
|----------------|-------------------------------|-------------|
| 4:45 PM | Return from Field Trip | Balsam Room |
| 4:45 - 5:30 PM | Debrief/Pickup | Balsam Room |

Sunday, March 17

| | | |
|------------------|--|-------------|
| 8:50 AM | Youth Drop-off | Balsam Room |
| 9:00 - 10:00 AM | Group Art Project | Balsam Room |
| 10:00 - 10:30 AM | Snack Break | Balsam Room |
| 10:30 - 11:30 AM | Bleeding Disorders Bingo | Balsam Room |
| 11:30 AM | Parents Pick Up Youth/Symposium Concludes | Balsam Room |

CHILDCARE: AGES 0 – 4

BEDFORD / CHESTERFIELD

Children 4 and over may attend some facilitated sessions with the Youth if parents allow it. A chaperone will accompany any child switching rooms at all times.

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.

Childcare Lead: Samantha Vail, Daycare Professional

Saturday, March 16

| | | |
|---------------------|--|-----------------------|
| 8:40 - 8:50 AM | Childcare Drop-off | Bedford/Chesterfield |
| 9:00 – 10:00 AM | Sensory Play | Bedford/Chesterfield |
| 10:00 – 10:30 AM | Snack Break | Bedford/Chesterfield |
| 10:30 – 11:45 AM | Story Time and a Craft or Pool | Bedford/Chesterfield |
| 11:45 AM – 12:15 PM | Clean Up | Bedford/Chesterfield |
| 12:15 PM | Parents Pick Up Child(ren) for Lunch <i>Please note that lunch is with parents. It is your responsibility to pick up your child after the adult session is over.</i> | Bedford/Chesterfield |
| 12:15 – 1:00 PM | Lunch (Reunited with parents) | Nashua Grand Ballroom |
| 1:00 PM | Childcare Drop-Off | Bedford/Chesterfield |
| 1:00 – 2:30 PM | Quiet Time & Movie | Bedford/Chesterfield |
| 2:30 – 3:30 PM | Group Art Project | Bedford/Chesterfield |
| 3:30 – 4:00 PM | Therapy Dogs Visit | Bedford/Chesterfield |
| 4:00 – 4:30 PM | Snack Break | Bedford/Chesterfield |
| 4:30 – 5:30 PM | Ribbon Play/Ashwood Court Walk | Bedford/Chesterfield |
| 5:30 PM | Parents Pick Up Child(ren) | Bedford/Chesterfield |

Sunday, March 17

| | | |
|------------------|---|----------------------|
| 8:50 AM | Childcare Drop-off | Bedford/Chesterfield |
| 9:00 – 10:00 AM | Group Art Project | Bedford/Chesterfield |
| 10:00 – 10:30 AM | Snack Break | Bedford/Chesterfield |
| 10:30 – 11:30 AM | Dance Party/Bubbles or Bingo with Youth | Bedford/Chesterfield |
| 11:30 AM | Parents Pick Up Children/Symposium Concludes | Bedford/Chesterfield |

THANK YOU TO OUR SPONSORS

Presenting Sponsors

B:OMARIN

CSL Behring

Biotherapies for Life®

Genentech

A Member of the Roche Group

KEDRION
B I O P H A R M A

octapharma

For the safe and optimal use of human proteins

sanofi

Spark
THERAPEUTICS

Advocate Sponsors

accredo



BIOMATRIX



CENTESSA
PHARMACEUTICALS



CVS specialty

MEDEXUS
PHARMA



Optum



**Friday Welcome
Reception Sponsor**

sanofi

**Family Activity
Sponsor**



**Snack
Sponsor**



**Coffee
Sponsor**

CSL Behring
Biotherapies for Life™

**Friend
Sponsor**



SAMPLE QUESTIONS TO ASK WHEN VISITING EXHIBITS

Pharmaceutical Companies

1. What types of bleeding disorders are your products intended/indicated for? Are there any restrictions based upon age?
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 administer your product? How is it administered? (IV, SQ)
4. How many mL are each vial? How is it mixed?
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 SYMPOSIUM 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,
Mike Reutershan, Cathy Rosenfield, Mark Zatyрка

BOARD MEMBERS

Nancy Messina, MARC, *President* | Neal Picard, *Treasurer* | Carolyn Miazga, PhD, *Secretary*

Matthew Collins
Mike Dowling
Nicholas McRae-Cyr

Mike Reutershan
Cathy Rosenfield, MD
Kenny Thach

Saurabh Shweta
Marleny Vidal
John Wells, JD

THANK YOU TO OUR VOLUNTEERS

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!

Lynne Alley
Lissa Blanchard
Heidi Blanchette
Joe Blanchette
Jim Boutin
John Bruno
Nancy Edwards
Scott Fitzpatrick
Mary Fitzpatrick

Laura Glufing-Tham
Victoria Kuhn
Manny Lopez
Elaine Meyers
Ann Marie Minichiello-Charlsen
Lucas Morse
Elie Naous
Kristina Robinson

Paul Robinson
Kathy Secinaro
Shane Secinaro
Tim Sharpe
Brenda Sharpe
Krystal Tenner
Britnee Vieira
Susi Von Oettingen
Jacob Wagner



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 below 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. Please scan this QR Code for a digital copy of the glossary or if you would like a printed copy you may request one at the registration table.



CONSUMER MEDICAL SYMPOSIUM QUESTION SUBMISSION

If you have a question that can be answered by one of our Consumer Medical Symposium speakers, scan this code and submit! If you have more than one question, once you submit, you will see a link to appear saying “Submit Another Response.”

Take Our Needs Assessment Survey



Our first priority at NEHA is serving you and your family. To do so effectively, our Board and Staff want to hear from you. We are excited to invite you to take our 2024 Needs Assessment Survey!

This short 15-minute survey will allow you to share your feedback and suggestions as to how we can better serve the New England bleeding disorders community.

- Your answers are anonymous and will help us plan and prioritize our programs and services. Your feedback will also help us create our next 5-Year Strategic Plan.
- This survey is open to anyone who is involved with the New England bleeding disorders community, including: patients, family members, friends, volunteers, donors, industry partners, HTC staff, social workers, medical providers, etc.

Since our last Needs Assessment in 2019, much has changed in the world and in our community: a global pandemic, improvements in treatment options, and the uniting of the Hemophilia Alliance of Maine and the Connecticut Hemophilia Society with NEHA.

Your input is an essential tool to ensuring that we meet your needs efficiently and effectively.

Scan this QR Code above to make your voice heard today, or visit newenglandhemophilia.org/needs-assessment



New England Hemophilia Association's Mental Health Resource Page

We are here to support the mental health of our bleeding disorders community. Our Mental Health Task Force is made up of patients, caregivers, and mental health professionals, to create resources and education.

Scan this QR code to access a selection of resources on our Mental Health Resource. You can also visit our website to learn more.





COMMUNITY EVENTS

2024



Maine Mariners Game | Sunday, March 24 | Portland, ME

Educational Dinner | Thursday, March 28 | Bangor, ME

World Hemophilia Day Celebrations | Friday, April 5 | Bangor, ME & Somerville, MA

Red Tie Soiree | Saturday, April 20 | Worcester, MA

Men's Retreat | Friday, May 3 - Sunday, May 5 | Stratton Mountain, VT

Maine Education Day & Unite Walk Kick-Off | Saturday, June 8 | Freeport, ME

Boston's Best Bloody Mary | Sunday, June 9 | Newton Centre, MA

NEHA Family Camp | Wednesday, June 26 - Saturday, June 29 | Moultonborough, NH

Women's Retreat | Friday, July 26 - Sunday, July 28 | Chester, CT

Golf Tournament | Monday, August 5 | Boylston, MA

15th Annual Unite for Bleeding Disorders Walk | Saturday, September 28 | Canton, MA

Hispanic Heritage Symposium | Saturday, October 7 | TBD Location

FallFest | Saturday, November 9 - Sunday, November 10 | Springfield, MA

Holiday Party South | Sunday, December 8 | Boylston, MA

Holiday Party North | Sunday, December 8 | Rockport, ME

**Visit www.nehaevents.org to see
all of our events and register!**





POWERFUL PROPHYLAXIS

LIFE IS TOO GOOD TO MISS OUT BECAUSE OF A BLEED

— IDELVION DELIVERS —

0 SPONTANEOUS BLEEDS*

People who went from 7-day to 14-day dosing in pivotal trials discovered that no matter which schedule they chose, they still had an average of 0 spontaneous and joint bleeds.* That means the powerful bleed protection of IDELVION sticks around while you plan your next adventure.

* 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.

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



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.

IDELVION is manufactured by CSL Behring GmbH and distributed by CSL Behring LLC. IDELVION is a registered trademark of CSL Behring Lengnau AG. Biotherapies for Life is a registered trademark of CSL Behring LLC.

©2022 CSL Behring LLC 1020 First Avenue, PO Box 61501, King of Prussia, PA 19406-0901 USA
www.CSLBehring.com www.IDELVION.com USA-IDL-0315-MAY22

CSL Behring
Biotherapies for Life®

ALTUVIIIIO™
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-ehtl



SWITCH IT UP

like Joey did!

a real ALTUVIIIIO patient

Joey has been compensated for sharing his story.

Sanofi Community Relations and Education (CoRe) Managers are dedicated professionals who can provide personalized education about ALTUVIIIIO, and point you toward helpful support and resources.



CONNECT WITH YOUR CoRe TODAY

sanofi

© 2023 Genzyme Corporation. All rights reserved.
ALTUVIIIIO and Sanofi are trademarks of Sanofi or an affiliate.

MAT-US-2307604-v1.0-09/2023

Supporting our community is the foundation of what we do



That's why Novo Nordisk goes beyond offering a broad range of treatments and is dedicated to providing educational resources and one-on-one support!

We have **resources** for people living with:

- Hemophilia A
- Hemophilia B
- Hemophilia A with inhibitors
- Hemophilia B with inhibitors
- Glanzmann's thrombasthenia when platelets don't work
- Factor VII deficiency
- Factor XIII A-subunit deficiency

Get connected locally with one of our Hemophilia Community Liaisons (HCL) to see how they can help you!

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.
Novo Nordisk and Changing Hemophilia are registered trademarks of Novo Nordisk A/S.
© 2023 Novo Nordisk Printed in the U.S.A. US23PAT00017 July 2023



Scan to
connect

changing
hemophilia®



novo nordisk®

**PFIZER IS WORKING TO UNLOCK
THE POTENTIAL OF GENE THERAPY
FOR PEOPLE LIVING WITH HEMOPHILIA**
Ready to discover what may be on the horizon?

To learn more, scan the code below
or visit hemhorizon.com



PP-FID-USA-0035
©2023 Pfizer Inc.
All rights reserved. March 2023





ROCTAVIAN™
(valoctocogene roxaparvovec-rvox)
Suspension for intravenous infusion

IMAGINE WHAT'S POSSIBLE WITH ROCTAVIAN



Explore more
ROCTAVIAN.com



HEMA
Biologics®



Learn more about our focus on the
rare bleeding disorder community

Visit us online at hemabio.com



HEMA
Biologics®

© 2023 HEMA Biologics, LLC HBCORP-00095

We Hope You Can Join Us!

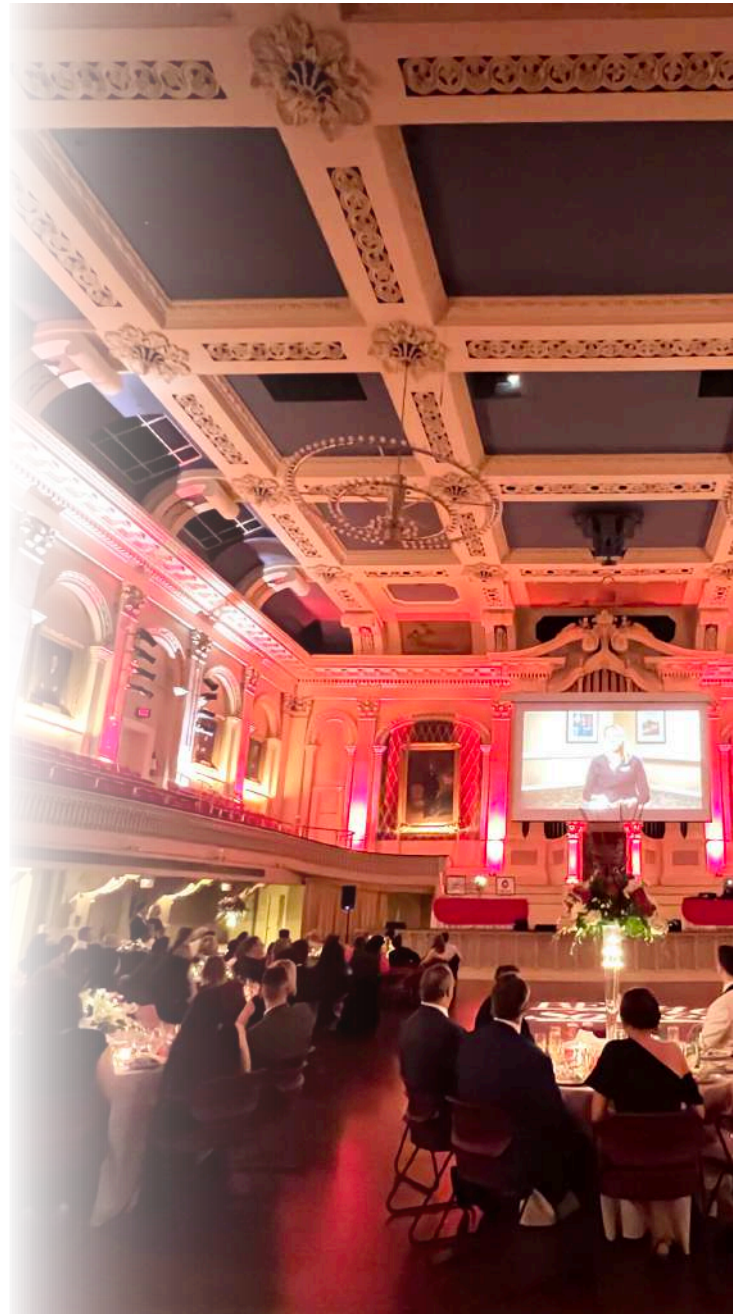
RED *tie* Soiree

.....

April 20
Worcester, MA

.....

Join us for dinner, dessert and dancing to celebrate those who support the New England bleeding disorders community.



www.nehaevents.org