

THE COALITION FOR
HEMOPHILIA



HEMOB.ORG

WE MEET YOU WHERE YOU ARE

**ANNUAL SYMPOSIUM
APRIL 9-13, 2025**

RENAISSANCE ORLANDO AT SEAWORLD
ORLANDO, FLORIDA

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Hi! How do I join the wifi?

It's' easy! Login to **Renaissance_CONFERENCE** using password: **NovoNordisk**

Thank you!!

Alhemo[®]
concizumab-mtci
Injection 60 mg | 150 mg | 300 mg pens

WELCOME

2025 ANNUAL SYMPOSIUM

35 YEARS OF COMMUNITY, CARE, AND CONNECTION

Dear Friends,

Welcome to this very special gathering. This year marks 35 years of standing together as a community rooted in love, strength, and purpose and we're honored to celebrate this milestone with you.

This weekend is more than an event, it's a celebration of shared journeys. Whether it's your first symposium or your nineteenth, you are part of something extraordinary. Families, caregivers, and individuals facing challenges with courage continue to connect, grow, and move forward together.

We're deeply grateful to have served this community for more than three decades. From humble beginnings to this exciting moment, we've seen remarkable progress driven by your stories, your strength, and your determination. A heartfelt thank you to our sponsors, whose partnership makes this weekend and our year-round programs possible.

Together, we've witnessed treatment breakthroughs once thought out of reach. Challenges remain like insurance barriers and the need for better recognition of women and girls who bleed but this community continues to rise with purpose and unity.

This year, we invite you to lean into your voice and your journey. This weekend is about advocacy, learning, healing, and building deeper connections. Whether you're here to grow as a leader, seek support, or simply find belonging you're in the right place.

We're proud to continue to expand our focus on holistic care, mental health, physical wellness, and career empowerment, all vital to thriving.

No matter where you are on your journey, we meet you where you are -with compassion, community, and care.

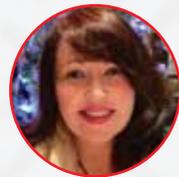
So glad you're here!



David B. Clark
David Clark, PhD
Chairman



Wayne Cook
Wayne Cook
President



Kim Phelan
Kim Phelan
Chief Executive Officer



HEMGENIX[®]
etranacogene dezaparvovec-drlb

"I haven't needed prophylaxis since getting HEMGENIX!"

- Michael, 23-year-old treated with HEMGENIX

Watch Michael's story at [HEMGENIX.com](https://www.hemgenix.com)



Actual HEMGENIX patient. Patient experiences may vary.

IMPORTANT SAFETY INFORMATION

What is HEMGENIX?

HEMGENIX[®], etranacogene dezaparvovec-drlb, is a one-time gene therapy for the treatment of adults with hemophilia B who:

- Currently use Factor IX prophylaxis therapy, or
- Have current or historical life-threatening bleeding, or
- Have repeated, serious spontaneous bleeding episodes.

HEMGENIX is administered as a single intravenous infusion and can be administered only once.

What medical testing can I expect to be given before and after administration of HEMGENIX?

To determine your eligibility to receive HEMGENIX, you will be tested for Factor IX inhibitors. If this test result is positive, a retest will be performed 2 weeks later. If both tests are positive for Factor IX inhibitors, your doctor will not administer HEMGENIX to you. If, after administration of HEMGENIX, increased Factor IX activity is not achieved, or bleeding is not controlled, a post-dose test for Factor IX inhibitors will be performed.

HEMGENIX may lead to elevations of liver enzymes in the blood; therefore, ultrasound and other testing will be performed to check on liver health before HEMGENIX can be administered. Following administration of HEMGENIX, your doctor will monitor your liver enzyme levels weekly for at least 3 months. If you have preexisting risk factors for liver cancer, regular liver health testing will continue for 5 years post-administration. Treatment for elevated liver enzymes could include corticosteroids.

BRIEF SUMMARY OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use HEMGENIX safely and effectively. See full prescribing information for HEMGENIX.

HEMGENIX[®] (etranacogene dezaparvovec-drlb) suspension, for intravenous infusion
Initial U.S. Approval: 2022

INDICATIONS AND USAGE

HEMGENIX is an adeno-associated virus vector-based gene therapy indicated for the treatment of adults with Hemophilia B (congenital Factor IX deficiency) who:

- Currently use Factor IX prophylaxis therapy, or
- Have current or historical life-threatening hemorrhage, or
- Have repeated, serious spontaneous bleeding episodes.

CONTRAINDICATIONS

None.

WARNINGS AND PRECAUTIONS

- Infusion reactions: Monitor during administration and for at least 3 hours after end of infusion. If symptoms occur, slow or interrupt administration. Re-start administration at a slower infusion once resolved.
- Hepatotoxicity: Closely monitor transaminase levels once per week for 3 months after HEMGENIX administration to mitigate the risk of potential hepatotoxicity. Continue to monitor transaminases in all patients who developed liver enzyme elevations until liver enzymes return to baseline. Consider corticosteroid treatment should elevations occur.

What were the most common side effects of HEMGENIX in clinical trials?

In clinical trials for HEMGENIX, the most common side effects reported in more than 5% of patients were liver enzyme elevations, headache, elevated levels of a certain blood enzyme, flu-like symptoms, infusion-related reactions, fatigue, nausea, and feeling unwell. These are not the only side effects possible. Tell your healthcare provider about any side effect you may experience.

What should I watch for during infusion with HEMGENIX?

Your doctor will monitor you for infusion-related reactions during administration of HEMGENIX, as well as for at least 3 hours after the infusion is complete. Symptoms may include chest tightness, headaches, abdominal pain, lightheadedness, flu-like symptoms, shivering, flushing, rash, and elevated blood pressure. If an infusion-related reaction occurs, the doctor may slow or stop the HEMGENIX infusion, resuming at a lower infusion rate once symptoms resolve.

What should I avoid after receiving HEMGENIX?

Small amounts of HEMGENIX may be present in your blood, semen, and other excreted/secreted materials, and it is not known how long this continues. You should not donate blood, organs, tissues, or cells for transplantation after receiving HEMGENIX.

Please see full prescribing information for HEMGENIX at HEMGENIX.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.

- Hepatocellular carcinogenicity: For patients with preexisting risk factors (e.g., cirrhosis, advanced hepatic fibrosis, hepatitis B or C, non-alcoholic fatty liver disease (NAFLD), chronic alcohol consumption, non-alcoholic steatohepatitis (NASH), and advanced age), perform regular (e.g., annual) liver ultrasound and alpha-fetoprotein testing following administration.
- Monitoring Laboratory tests: Monitor for Factor IX activity and Factor IX inhibitors.

ADVERSE REACTIONS

The most common adverse reactions (incidence ≥5%) were elevated ALT, headache, blood creatine kinase elevations, flu-like symptoms, infusion-related reactions, fatigue, malaise and elevated AST.

To report SUSPECTED ADVERSE REACTIONS, contact CSL Behring at 1-866-915-6958 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

USE IN SPECIFIC POPULATIONS

No dose adjustment is required in geriatric, hepatic, or renal impaired patients.

Based on November 2022 version

HEMGENIX is manufactured by uniQure Inc. and distributed by CSL Behring LLC. HEMGENIX[®] is a registered trademark of CSL Behring LLC.

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www.CSLBehring.com www.HEMGENIX.com USA-HGX-0856-SEP24

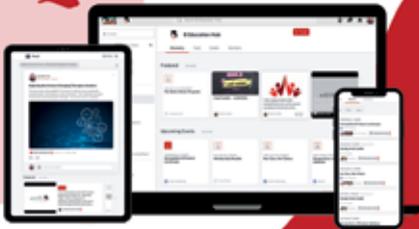
CSL Behring

B EDUCATION HUB

DISCOVER MORE ON THE MIGHTY APP!

It's a dynamic platform packed with exclusive resources, all designed to enrich, support, and facilitate collective growth within our vibrant community. It is all that and it is also our virtual home for the 2025 Annual Symposium.

JOIN THE GROWING
COMMUNITY



- Explore the feed, member posts, and bonus speaker content
- Connect with community
- Search and register for sessions using the interactive agenda
- Explore the speaker directory
- Share photo memories
- And so much more!

- **Download the app:** Mighty Networks
- **Click:** Discover Networks
- **Search:** Hemophilia B
- **Select:** The B Education Community Hub
- **Choose Your Plan:**
 - Full Access - CHB Members
 - Industry Access - Symposium 25
- **Submit:** Screening question answers
- *Set up your profile and explore!*

Download the App



REGISTRATION

REGISTRATION

Location - Oceans Ballroom Foyer

Wednesday, April 9... 5:00 pm – 8:00 pm

Thursday, April 10... 10:00 am – 10:00 pm

Friday, April 11... 10:00 am – 8:00 pm

Saturday, April 12... 10:00 am – 6:00 pm

CHILDCARE, YOUTH CAMP, TEEN TRACK

Location - Unicorn Foyer

Thursday, April 10... 11:00 am – 10:00 pm

Friday, April 11... 8:30 am – 10:00 pm

Saturday, April 12... 8:30 am – 10:00 pm

Teens and Tweens will join GutMonkey for *The Leading Edge* made possible through the exclusive support of Pfizer.

Weekend activities for all ages will be fun and enriching, supervised by staff with regulated ratios to ensure the well-being of all participants.

Pick up the camp packet at youth registration for more information!

MOBILITY SCOOTERS

Scoters are available to sign out at the Registration Desk located in the Ocean's foyer.



For routine prophylaxis in patients 12 years and older with hemophilia A or B without inhibitors

Prefilled pen. Fixed dose.* Once weekly.

Learn more at HYMPAVZI.com and booth 15

*Your first dose (loading dose) of HYMPAVZI is 300 mg (two 150 mg injections). Then you will inject a weekly (maintenance) dose consisting of 1 or 2 injections as prescribed by your healthcare provider. If more than one injection is required to deliver a complete dose, administer each injection at a different injection site.

What is HYMPAVZI?

HYMPAVZI is a prescription medicine used to prevent or reduce the frequency of bleeding episodes in adults and children 12 years of age and older with hemophilia A without factor VIII inhibitors or hemophilia B without factor IX inhibitors.

It is not known if HYMPAVZI is safe and effective in children younger than 12 years old.

Not actual size.

IMPORTANT SAFETY INFORMATION

Important: Before you start using HYMPAVZI, it is very important to talk to your healthcare provider about using factor VIII and factor IX products

(products that help blood clot but work in a different way than HYMPAVZI). You may need to use factor VIII or factor IX medicines to treat episodes of breakthrough bleeding during treatment with HYMPAVZI. Carefully follow your healthcare provider's instructions regarding when to use factor VIII or factor IX medicines and the prescribed dose during your treatment with HYMPAVZI.

Before using HYMPAVZI, tell your healthcare provider about all of your medical conditions, including if you:

- have a planned surgery. Your healthcare provider may stop treatment with HYMPAVZI before your surgery. Talk to your healthcare provider about when to stop using HYMPAVZI and when to start it again if you have a planned surgery.
- have a severe short-term (acute) illness such as an infection or injury.
- are pregnant or plan to become pregnant. HYMPAVZI may harm your unborn baby.

Females who are able to become pregnant:

- Your healthcare provider will do a pregnancy test before you start your treatment with HYMPAVZI.
- You should use effective birth control (contraception) during treatment with HYMPAVZI and for at least 2 months after the last dose of HYMPAVZI.
- Tell your healthcare provider right away if you become pregnant or think that you may be pregnant during treatment with HYMPAVZI.
- are breastfeeding or plan to breastfeed. It is not known if HYMPAVZI passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, and herbal supplements.

What are the possible side effects of HYMPAVZI? HYMPAVZI may cause serious side effects, including:

blood clots (thromboembolic events). HYMPAVZI may increase the risk for your blood to clot. Blood clots may form in blood vessels in your arm, leg, lung, or head and can be life-threatening. Get medical help right away if you develop any of these signs or symptoms of blood clots: swelling or pain in arms or legs; redness or discoloration in your arms or legs; shortness of breath; pain in chest or upper back; fast heart rate; cough up blood; feel faint; headache; numbness in your face; eye pain or swelling; trouble seeing

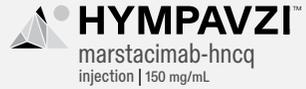
allergic reactions. Allergic reactions, including rash and itching have happened in people treated with HYMPAVZI. Stop using HYMPAVZI and get medical help right away if you develop any of the following symptoms of a severe allergic reaction: swelling of your face, lips, mouth, or tongue; trouble breathing; wheezing; dizziness or fainting; fast heartbeat or pounding in your chest; sweating

The most common side effects of HYMPAVZI are injection site reactions, headache, and itching.

These are not all the possible side effects of HYMPAVZI. Call your doctor for medical advice about side effects. You may report side effects to the FDA at 1-800-FDA-1088.

Please see Important Facts about HYMPAVZI on the next page or at HYMPAVZI.com

IMPORTANT FACTS



Important information: Before you start using HYMPAVZI, it is very important to talk to your healthcare provider about using factor VIII and factor IX products (products that help blood clot but work in a different way than HYMPAVZI). You may need to use factor VIII or factor IX medicines to treat episodes of breakthrough bleeding during treatment with HYMPAVZI. Carefully follow your healthcare provider's instructions regarding when to use factor VIII or factor IX medicines and the prescribed dose during your treatment with HYMPAVZI.

What is HYMPAVZI used for?

HYMPAVZI is a prescription medicine used to prevent or reduce the frequency of bleeding episodes in adults and children 12 years of age and older with hemophilia A without factor VIII inhibitors or hemophilia B without factor IX inhibitors.

It is not known if HYMPAVZI is safe and effective in children younger than 12 years old.

What should I tell my healthcare provider before using HYMPAVZI?

Tell your healthcare provider about all your medical conditions, including if you:

- have a planned surgery. Talk to your healthcare provider about when to stop using HYMPAVZI and when to start it again if you have a planned surgery.
- have a severe short-term (acute) illness such as an infection or injury.
- are pregnant or plan to become pregnant. HYMPAVZI may harm your unborn baby.

Females who are able to become pregnant:

- Your healthcare provider will do a pregnancy test before you start your treatment with HYMPAVZI.
- You should use effective birth control (contraception) during treatment with HYMPAVZI and for 2 months after the last dose of HYMPAVZI.
- Tell your healthcare provider right away if you become pregnant or think that you may be pregnant during treatment with HYMPAVZI.
- are breastfeeding or plan to breastfeed. It is not known if HYMPAVZI passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, and herbal supplements.

How should I use HYMPAVZI?

See the detailed "Instructions for Use" that comes with your HYMPAVZI for information on how to inject a dose of HYMPAVZI, and how to properly throw away (dispose of) used HYMPAVZI prefilled syringe or HYMPAVZI prefilled pen.

- Use HYMPAVZI exactly as prescribed by your healthcare provider.
- Your healthcare provider will provide information on the treatment of breakthrough bleeding during your treatment with HYMPAVZI. **Do not** use HYMPAVZI to treat breakthrough bleeding.

What warnings should I know about HYMPAVZI?

HYMPAVZI may cause serious side effects, including:

- **blood clots (thromboembolic events).** HYMPAVZI may increase the risk for your blood to clot in blood vessels in your arm, leg, lung, or head and can be life-threatening. Get medical help right away if you develop any of these signs or symptoms of blood clots:
 - swelling or pain in arms or legs
 - redness or discoloration in your arms or legs
 - shortness of breath
 - pain in chest or upper back
 - fast heart rate
 - cough up blood
 - feel faint
 - headache
 - numbness in your face
 - eye pain or swelling
 - trouble seeing
- **allergic reactions.** Allergic reactions, including rash and itching have happened in people treated with HYMPAVZI. Stop using HYMPAVZI and get medical help right away if you develop any of the following symptoms of a severe allergic reaction:
 - swelling of your face, lips, mouth, or tongue
 - trouble breathing
 - wheezing
 - dizziness or fainting
 - fast heartbeat or pounding in your chest
 - sweating

The most common side effects of HYMPAVZI are injection site reactions, including:

- itching
- swelling
- hardening
- redness
- bruising
- pain

Headache and itching were also common side effects. A serious side effect of swelling in the legs happened in one patient in the clinical trial.

These are not all of the possible side effects of HYMPAVZI. Call your doctor for medical advice about side effects. For more information, ask your doctor.

This information is not comprehensive. How to get more information:

- Talk to your health care provider or pharmacist
- Visit www.HYMPAVZI.com to obtain the FDA-approved product labeling
- Call 1-888-HYMPAV-Z

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.



Pfizer Inc., 66 Hudson Blvd East, New York, NY 10001

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SYMPOSIUM RAFFLE

HOW TO ENTER

Get a new Exhibitor BINGO Card at the Family Registration Desk every day. Visit each exhibitor booth on Thursday, Friday, and Saturday to get your card stamped. Turn in your cards at the Family Registration Desk at the times below for each day.

RULES

- One entry per person per day.
- Winners must be present to win.
- Friday and Saturday drawings will be in the Exhibit Hall.
- *Winners do not need to be present during Sunday's Breakfast drawing.

EXHIBIT HOURS

- Thursday, April 10 6:30 – 9:30 pm
- Friday, April 11 2:00 – 4:00 pm
- Saturday, April 12 2:00 – 4:30 pm

DRAWING SCHEDULE

- Thursday Cards due by 10:00 pm; Drawing on Friday, at 2:30–3:30 pm
- Friday Cards due by 5:00 pm; Drawing on Saturday, at 2:30–3:30 pm
- Saturday Cards due by 5:30 pm; Drawing on Sunday, at 7:30–8:30 am

PRIZES

- 1st APPLE IPAD
- 2nd \$200 GIFT CARD
- 3rd \$100 GIFT CARD

TEEN EXHIBIT MANIA

\$100 GIFT CARD

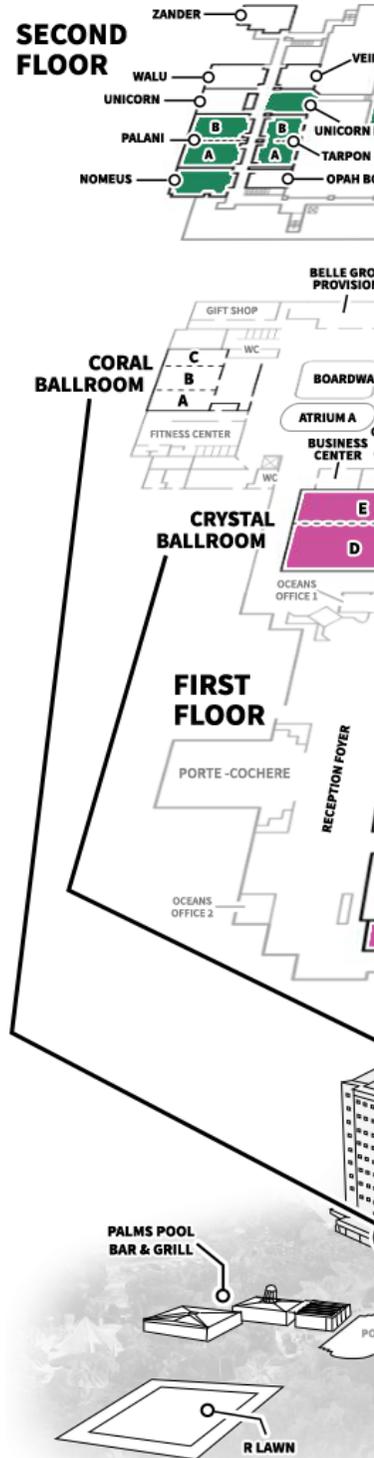


MEETING ROOMS

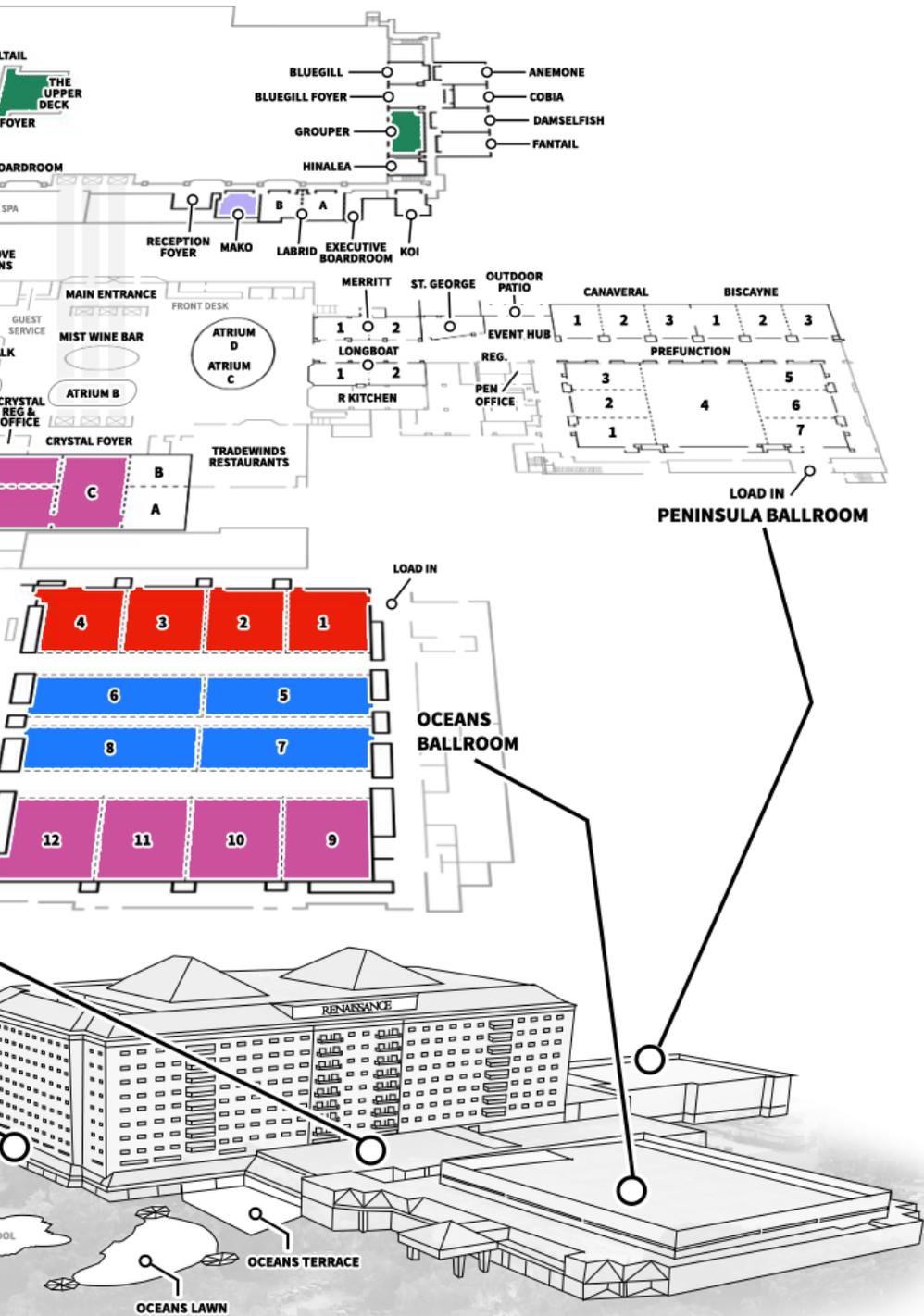
-  General Session
-  Exhibit Hall
-  Break-Out Rooms
-  Nurses Station
-  Youth & Teen Program

Note:

Children will be escorted by the nanny staff to and from all programs held in rooms outside the designated childcare rooms.



MEETING ROOMS



10+

**YEARS
TRUSTED**

ALPROLIX[®]
[Coagulation Factor IX
(Recombinant), Fc Fusion Protein]

CONTINUING

10+ YEARS OF ALPROLIX[®]

**DEDICATION AND
COMMITMENT TO OUR
COMMUNITY**

As it has for the past decade and beyond, our community continues to motivate and inspire us. That's why we look forward to a future filled with possibility, supported by the unity and encouragement that raises us all.

**STOP BY AND
SAY HELLO AT**

**SANOFI
BOOTH 16**

The Coalition for Hemophilia B is a nonprofit organization that does not recommend, endorse, or make any representation about the efficacy, appropriateness, or suitability of any specific products, procedures, treatments, services, opinions, health care providers, or other information that may be contained in or available through this ad.

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sanofi

EXHIBIT HALL

EXHIBIT HOURS

Thursday, April 10

6:30 – 9:30 pm

Friday, April 11

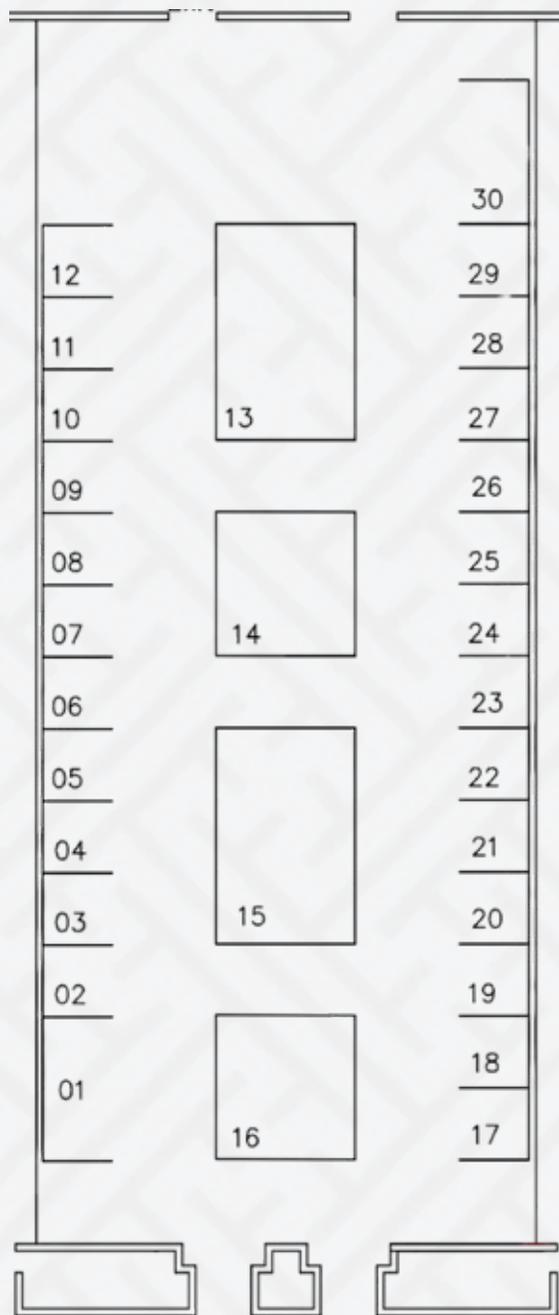
2:00 – 4:00 pm

Saturday, April 12

2:00 – 4:30 pm

EXHIBITORS

1. Medexus Pharma
 2. Accredo by Evernorth
 3. Regeneron
 4. Paragon Healthcare
 5. Promptcare
 6. SandsRx Pharmacy
 7. George King Bio-Medical, Inc.
 8. Soleo Health
 9. Santa Rosa Pharmacy
 10. Cottrill's Specialty Pharmacy
 11. CHB – Women Bleed Too
 12. InfuCare Rx
 13. CSL Behring
 14. Novo Nordisk
 15. Pfizer, Inc.
 16. Sanofi
 17. CVS Specialty
 18. Be Biopharma
 19. Hemophilia Alliance
 20. BioMatrix Specialty Infusion Pharmacy
 21. Superior Biologics
 22. Optum Infusion Pharmacy
 23. Ethical Factor Rx
 24. ASAP Specialty Pharmacy
 25. Profusion Specialty Pharmacy
 26. Specialty Care Rx
 27. Danny's Dose Alliance
 28. Microhealth
 29. The Coalition for Hemophilia B
 30. Wellness Station
- * Visit the Infusion Booth in the Oceans Foyer



ENTRANCE

WEDNESDAY, APRIL 9

6:00 – 7:30 pm
Atrium CD

DINNER GAME NIGHT! **Sponsored by Novo Nordisk**

Let's come together for an evening of games and fun for the whole family!



KEY CARD SPONSOR

THE COALITION FOR HEMOPHILIA B GRATEFULLY
ACKNOWLEDGES NOVO NORDISK FOR THEIR GENEROUS
SPONSORSHIP OF OUR SYMPOSIUM'S KEY CARDS.



NOVO NORDISK WELCOMES YOU TO ORLANDO



novo nordisk®

KEEPING OUR COMMUNITY CONNECTED THROUGHOUT THE EVENT!

THURSDAY, APRIL 10

PRE-CONFERENCE FAMILY DAY

All Programs For Patients And Families Only

These meeting hours are reserved exclusively for attendees diagnosed with hemophilia B, their spouses, partners, and family members.

Thank you for respecting the needs of our community.

7:30 – 9:00 am

Oceans 1 – 4

BREAKFAST PRESENTATION

*Breakthroughs and Breakfast:
A Hemophilia B Gene Therapy Conversation*

Sponsored by CSL Behring

Moderator: Kim Phelan

**Panel: Amber Campbell, CJ Hansen,
Michael Joshua, Domenic Stills, Dr. Doris Quon**

Could one treatment change everything? Discover the transformative potential of gene therapy for hemophilia B. Join a panel led by Kim Phelan, featuring patients and experts who will share insights, experiences, and answer your questions. Come curious and leave inspired!

Session #1

9:15 – 10:00 am

AHA HANDS-ONLY CPR TRAINING

When the time comes to save someone's life, will you BE READY?

Session #2

10:15 – 11:00 am

**Presented by Danny's Dose and AdventHealth
Douglas Becknell, BSHS, RRT**

Oceans 12

Cardiac arrest can happen anywhere, anytime. When it does, every second counts. Join us for this hands-on American Heart Association (AHA) Hands-Only CPR training. This interactive session will provide participants with lifesaving skills, practical experience performing chest compressions, and an AED demonstration. This session will be offered twice, with a maximum of 40 participants per session. Don't miss this chance to learn simple yet powerful techniques that could help save a life!

THURSDAY, APRIL 10

11:00 – 11:45 am
Labrid AB

The Wellness Podcast Live: Giving the World All of You!

Kevin Harris, Rick Starks

What would life look like if you stopped editing yourself — if you stopped hiding the parts that feel messy, complicated, or too heavy for others? In this raw and empowering session, we'll explore what it means to live with radical authenticity: no masks, no apologies, no shame. Because the world doesn't need the watered-down version of you. It needs your full self!

12:00 – 1:00 pm
Oceans 1 – 4

LUNCH PRESENTATION ***Empowering choices for hemophilia B:***

Sponsored by Sanofi

Maissaa Janbain, MD

What matters most when choosing a treatment? Explore new therapeutic options for hemophilia B and dive into what really matters – your individual needs and treatment goals. This interactive session invites you to engage in hands-on activities and thoughtful discussions. We will highlight key considerations to help you work with your care team and make informed decisions that support your treatment journey.

¡HOLA!

¡BIENVENIDOS!

¡SALUDOS!

CSL Behring

TRANSLATION SPONSOR

WE GRATEFULLY ACKNOWLEDGE CSL BEHRING FOR MAKING TRANSLATION SERVICES AVAILABLE TO OUR ATTENDEES. THANK YOU FOR HELPING US BUILD A MORE INCLUSIVE AND ACCESSIBLE EVENT.

Visit the Registration Desk for more details.

PATROCINADOR DE LA TRADUCCIÓN

AGRADECEMOS A CSL BEHRING QUE HAYA PUESTO SERVICIOS DE TRADUCCIÓN A DISPOSICIÓN DE NUESTROS ASISTENTES. GRACIAS POR AYUDARNOS A CONSTRUIR UN EVENTO MÁS INCLUSIVO Y ACCESIBLE.

Visite el mostrador de inscripción para más información.

THURSDAY, APRIL 10

WELCOME, GATHER & CONNECT

Find your community and connect with peers who share similar experiences in welcoming spaces designed for support, conversation, and belonging. Enjoy light refreshments and build connections that last.

1:00 – 1:45 pm
Oceans 9

CAREGIVERS & FAMILY WELCOME

Sponsored by Sanofi

Ashley Smith, Milinda DiGiovanni, Ashley Zebley

1:00 – 1:45 pm
Oceans 10

INHIBITORS COMMUNITY WELCOME

Sponsored by Novo Nordisk

Bri McLaughlin, Deena Lipinski

1:00 – 1:45 pm
Oceans 11

BIENVENIDA PARA FAMILIAS LATINAS

Patrocinado por Sanofi

Giraldo Gonzalez, Laura Echandi, Fel Echandi, Fiach Echandi

1:00 – 1:45 pm
Oceans 12

TEENS & YOUNG ADULTS WELCOME

Sponsored by Sanofi

Jessica Steed, Collin Johnson, Nick Marlatt

2:00 – 3:30 pm
Pool Lawn

WOMEN'S GATHERING

Sponsored by Medexus Pharma

Meredith Paige, Jacqui "Lady J" Maddix, Jennifer DeGlopper

2:00 – 3:30 pm
Pool Terrace

MEN'S GATHERING

Sponsored by Sanofi

Nick Cady, Bill Patsakos, Carl Weixler

Alhemo® is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children 12 years of age and older with hemophilia A with Factor 8 inhibitors or hemophilia B with Factor 9 inhibitors. It is not known if Alhemo® is safe and effective in people using Alhemo® while receiving ongoing immune tolerance induction. It is not known if Alhemo is safe and effective for hemophilia A and B with and without inhibitors in children younger than 12 years of age.

NOW APPROVED

Alhemo®
concizumab-mtci
injection (60 mg | 150 mg | 300 mg pens)

Reimagined bleed protection is now within your reach

First and only prophylaxis treatment in a prefilled, subcutaneous pen for people who have hemophilia B with inhibitors or hemophilia A with inhibitors

Royal lives with hemophilia B with inhibitors, uses Alhemo®, and is an employee of Novo Nordisk.



NO
IV infusions



NO
mixing



NO
vials



NO
refrigeration required*
(up to 4 weeks after first use)

Needles provided separately and may require a prescription in some states.

*Store in refrigerator before first use. After first use, Alhemo® can be stored at room temperature below 86 °F (30 °C) or in a refrigerator at 36 °F to 46 °F (2 °C to 8 °C) for up to 4 weeks. IV=intravenous.

Important Safety Information

What is the most important information I should know about Alhemo®?

- **It is important to follow the daily dosing schedule of Alhemo® to stay protected against bleeding.** This is especially important during the first 4 weeks of treatment to make sure a correct maintenance dose is established. Use Alhemo® exactly as prescribed by your healthcare provider (HCP). **Do not** stop using Alhemo® without talking to your HCP. If you miss doses or stop using Alhemo®, you may no longer be protected against bleeding
- **Your HCP may prescribe bypassing agents during treatment with Alhemo®.** Carefully follow your HCP's instructions regarding when to use on-demand bypassing agents, and the recommended dose and schedule for breakthrough bleeds

Do not use Alhemo® if you are allergic to concizumab-mtci or any of the ingredients in Alhemo®.

Before using Alhemo®, tell your HCP about all of your medical conditions, including if you:

- Have a planned surgery. Your HCP may stop treatment with Alhemo® before your surgery. Talk to your HCP about when to stop using Alhemo® and when to start it again if you have a planned surgery
- Are pregnant or plan to become pregnant. It is not known if Alhemo® may harm your unborn baby

Females who are able to become pregnant

- Your HCP may do a pregnancy test before you start treatment with Alhemo®.
- You should use an effective birth control (contraception) method during treatment with Alhemo® and for 7 weeks after ending treatment. Talk to your HCP about birth control methods that you can use during this time
- Are breastfeeding or plan to breastfeed. It is not known if Alhemo® passes into your breast milk. Talk to your HCP about the best way to feed your baby during treatment with Alhemo®

Tell your HCP about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Know the medicines you take. Keep a list of them to show your HCP and pharmacist when you get a new medicine.

How should I use Alhemo®?

- Change (rotate) your injection site with each injection. **Do not** use the same site for each injection
- To determine the right maintenance dose for you, your HCP will do a blood test to check the amount of Alhemo® in your blood. Your HCP may do additional blood tests during treatment with Alhemo®
- Do not share your Alhemo® pens and needles with another person, even if the needle has been changed. You may give another person an infection or get an infection from them
- **If you miss a dose of Alhemo® during the first 4 weeks of treatment,** contact your HCP right away. Your HCP will tell you how much Alhemo® to inject

What are the possible side effects of Alhemo®?

Alhemo® may cause serious side effects, including:

- **Blood clots (thromboembolic events).** Alhemo® may cause blood clots to form in blood vessels, such as in your arms, legs, heart, lung, brain, eyes, kidneys, or stomach. You may be at risk for getting blood clots during treatment with Alhemo® if you use high or frequent doses of factor products or bypassing agents to treat breakthrough bleeds, or if you have certain conditions. Get medical help right away if you have any signs and symptoms of blood clots, including: swelling, warmth, pain, or redness of the skin; headache; trouble speaking or moving; eye pain or swelling; sudden pain in your stomach or lower back area; feeling short of breath or severe chest pain; confusion; numbness in your face; and problems with your vision
- **Allergic reactions.** Alhemo® can cause allergic reactions, including redness of the skin, rash, hives, itching, and stomach-area (abdominal) pain. Stop using Alhemo® and get emergency medical help right away if you develop any signs or symptoms of a severe allergic reaction, including: itching on large areas of skin; trouble swallowing; wheezing; pale and cold skin; dizziness due to low blood pressure; redness or swelling of lips, tongue, face, or hands; shortness of breath; tightness of the chest; and fast heartbeat

The most common side effects of Alhemo® include: bruising, redness, bleeding, or itching at the site of injection, and hives.

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



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Ready to discover more?

Ask your doctor about Alhemo® or visit [Alhemo.com](https://www.alhemo.com) by scanning the QR Code





Brief Summary of information about Alhemo® (concizumab-mtci) injection

Rx Only

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/alhemo.pdf to obtain FDA-approved product labeling
- Call 1-888-668-6732

What is the most important information I should know about Alhemo®?

- **It is important to follow the daily dosing schedule of Alhemo® to stay protected against bleeding.** This is especially important during the first 4 weeks of treatment to make sure a correct maintenance dose is established. Use Alhemo® exactly as prescribed by your healthcare provider. **Do not** stop using Alhemo® without talking to your healthcare provider. If you miss doses, or stop using Alhemo®, you may no longer be protected against bleeding.
- **Your healthcare provider may prescribe bypassing agents during treatment with Alhemo®.** Carefully follow your healthcare provider's instructions regarding when to use on-demand bypassing agents, and the recommended dose and schedule for breakthrough bleeds.

See "**How should I use Alhemo®?**" for more information on how to use Alhemo®.

What is Alhemo®?

Alhemo® is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children 12 years of age and older with hemophilia A with factor VIII inhibitors or hemophilia B with factor IX inhibitors.

It is not known if Alhemo® is safe and effective in people using Alhemo® while receiving ongoing Immune Tolerance Induction (ITI).

It is not known if Alhemo® is safe and effective for hemophilia A and B with and without inhibitors in children younger than 12 years of age.

Do not use Alhemo® if you are allergic to concizumab-mtci or any of the ingredients in Alhemo®.

Before using Alhemo®, tell your healthcare provider about all of your medical conditions, including if you:

- have a planned surgery. Your healthcare provider may stop treatment with Alhemo® before your surgery. Talk to your healthcare provider about when to stop using Alhemo® and when to start it again if you have a planned surgery.
- are pregnant or plan to become pregnant. It is not known if Alhemo® may harm your unborn baby. **Females who are able to become pregnant**
 - Your healthcare provider may do a pregnancy test before you start treatment with Alhemo®.
 - You should use an effective birth control (contraception) during treatment with Alhemo® and for 7 weeks after ending treatment. Talk to your healthcare provider about birth control methods that you can use during this time.
- are breastfeeding or plan to breastfeed. It is not known if Alhemo® passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby during treatment with Alhemo®.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Know the medicines you take. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use Alhemo®?

- Use Alhemo® exactly as prescribed by your healthcare provider.
- Your healthcare provider will provide instructions for stopping (discontinuing) your current treatment when switching to Alhemo®.
- Inject Alhemo® 1 time a day.
- **Your healthcare provider should show you or your caregiver how to use Alhemo® before you use it for the first time.**
- Alhemo® is given as an injection under the skin (subcutaneous injection) by you or a caregiver.
- Ask your healthcare provider if you need to use a different injection technique. For example, children and people who are lean may need to inject into a pinched fold of skin to avoid injecting too deep (into the muscle).
- Change (rotate) your injection site with each injection. **Do not** use the same site for each injection.
- You will inject a larger dose (a loading dose) of Alhemo® on your first day of treatment. Then your healthcare provider will prescribe a dose to inject 1 time a day until your maintenance dose is established.
- To determine the right maintenance dose for you, your healthcare provider will do a blood test to check the amount of Alhemo® in your blood. Your healthcare provider may do additional blood tests during treatment with Alhemo®.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.

How should I use Alhemo®? (cont'd)

- Your healthcare provider will provide information on the treatment of breakthrough bleeding during your treatment with Alhemo®.
- Do not share your Alhemo® pens and needles with another person, even if the needle has been changed. You may give another person an infection or get an infection from them.
- **If you miss a dose of Alhemo® during the first 4 weeks of treatment**, contact your healthcare provider right away. Your healthcare provider will tell you how much Alhemo® to inject.
- **If you miss a dose of Alhemo® after your daily maintenance dose is established:**
 - For 1 missed dose, continue your normal daily dose.
 - For 2 to 6 missed doses, give 2 doses as soon as you remember. Then continue your normal daily dose the next day.
 - For 7 or more missed doses, contact your healthcare provider right away as you will need to receive a new loading dose before continuing your normal daily dose.
 - If you are unsure about how much to Alhemo® to inject, contact your healthcare provider.

What are the possible side effects of Alhemo®?

Alhemo® may cause serious side effects, including:

- **Blood clots (thromboembolic events).** Alhemo® may cause blood clots to form in blood vessels, such as in your arms, legs, heart, lung, brain, eyes, kidneys, or stomach. You may be at risk for getting blood clots during treatment with Alhemo® if you use high or frequent doses of factor products or bypassing agents to treat breakthrough bleeds, or if you have certain conditions. Get medical help right away if you have any signs and symptoms of blood clots, including:
 - swelling, warmth, pain, or redness of the skin
 - headache
 - trouble speaking or moving
 - eye pain or swelling
 - sudden pain in your stomach or lower back area
 - feeling short of breath or severe chest pain
 - confusion
 - numbness in your face
 - problems with your vision
- **Allergic reactions.** Alhemo® can cause allergic reactions, including redness of the skin, rash, hives, itching, and stomach-area (abdominal) pain. Stop using Alhemo® and get emergency medical help right away if you develop any signs or symptoms of a severe allergic reaction, including:
 - itching on large areas of skin
 - trouble swallowing
 - wheezing
 - pale and cold skin
 - dizziness due to low blood pressure
 - redness or swelling of lips, tongue, face, or hands
 - shortness of breath
 - tightness of the chest
 - fast heartbeat

The most common side effects of Alhemo® include:

- bruising, redness, bleeding, or itching at the site of injection
- hives

These are not all the possible side effects of Alhemo®.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store Alhemo®?

- **Before first use:**
 - Store unused Alhemo® pens in the refrigerator between 36°F to 46°F (2°C to 8°C).
- **After first use:**
 - Store the Alhemo® pen in the refrigerator between 36°F to 46°F (2° to 8°C) or at room temperature below 86°F (30°C) for up to 28 days.
 - Write the date of first use in the space provided on the carton.
 - Throw away (discard) the Alhemo® pen 28 days after first opening even if some medicine is left in the pen.
- Store Alhemo® with the cap on and keep it in the original carton to protect from light.
- Do not store Alhemo® in direct sunlight and keep away from direct heat.
- When stored in the refrigerator, do not store the pen directly next to the cooling element (the part that cools the refrigerator).
- Do not freeze Alhemo®.
- Do not use Alhemo® if it has been frozen or if it has been stored above 86°F (30°C).

Keep Alhemo® and all medicine out of the reach of children.

More detailed information is available upon request.

Available by prescription only.

For information contact: Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536, USA, 1-888-668-6444

Manufactured by: Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, NJ 08536 U.S. License No. 1261

At: Novo Nordisk A/S, Novo Allé 1, 2880 Bagsværd, Denmark

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THURSDAY, APRIL 10

4:30 – 5:00 pm
Ocean's Foyer

ANNUAL GROUP PHOTO

Gather with friends and family, wear your Coalition t-shirts, and show your B Spirit!

5:00 – 6:30 pm
Oceans 1 – 4

DINNER PRESENTATION

Join us for an educational and interactive event

Sponsored by Sanofi

Nick Cady

Sanofi Community Relations and Education, or CoRe, Managers are your connection to hemophilia-related education and resources. They're a team of passionate individuals with diverse professional skills, personal backgrounds, and interests from across the U.S. Working with organizations and directly with the hemophilia community, their mission is to help redefine what's possible for people living with hemophilia.

6:30 – 9:30 pm
Oceans 5 – 8

EXHIBIT HALL OPEN

Explore the booths and get your Bingo Card stamped! Hand in your completed cards at Registration by 10:00 pm to enter the raffle. The first drawing will take place at tomorrow's Exhibit Hall. Indulge in a chair massage at the wellness station, and don't miss out on the opportunity to win a *Big Stick* at the CHB Infusion booth!



FRIDAY, APRIL 11

7:00 – 7:30 am
R Lawn

TAI CHI & QI GUNG

Rick Starks

Come join in for invigorating Tai Chi and Qi Gung movement to power start your day. Also known as moving meditation, gentle on the joints and open to everyone!

7:00 – 7:30 am
Pool Lawn

FAMILY FITNESS

Kevin Harris

Get ready to move! Join in on an interactive exercise demo to start your day off with energy. Together we'll learn a fun routine you can add to your daily life and can enjoy with the entire family!

7:30 – 9:00 am
Oceans 1 – 4

BREAKFAST PRESENTATION

Hear directly from someone who has received gene therapy and learn more!

Sponsored by CSL Behring

Richard Lemons, MD, PhD

Explore gene therapy for hemophilia B through the eyes of both a leading physician and a patient who's received treatment. This is a rare opportunity to learn more about the evolving patient-doctor relationship in the context of cutting-edge treatment, and to ask the questions that matter most to you.

9:00 – 9:45 am
Oceans 1 – 4

KICKOFF & AWARDS CEREMONY

35 years of B community, Honoring the Past, and Celebrating the Future

Sponsored by Medexus Pharma

MC Elec Simon, DJ Chase Williams, Grant Belsham, and the CHB Team

Get ready for an electrifying welcome with MC Elec Simon, whose inspiring music and message will uplift and energize! Celebrate the incredible contributions of dedicated volunteers as we launch into our day with appreciation, recognition, and excitement for the journey ahead.

COME VISIT US AT BOOTH #13



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FRIDAY, APRIL 11

9:45 – 10:30 am
Oceans 1 – 4

KEYNOTE PRESENTATION

Perspectives from Lived Experience – The Future of Hemophilia

Mark W. Skinner, JD

Improving the lives of those who live with hemophilia (PWH) has long been an overarching goal of hemophilia treatment and care. As we consider the future in a rapidly evolving treatment landscape it is vital to acknowledge that PWH have a unique perspective and will consider issues differently than regulators, manufacturers, scientists, clinicians and payers. Through each treatment, individual goals, life ambitions, and aspirations are evolving to achieve what was once thought to be unimaginable. The presentation will explore where we have been, where we need to go and how we can work together to ensure treatment is accessible to all.

10:30 – 11:15 am
Oceans 1 – 4

KEYNOTE PRESENTATION

The Path to Wellness: Embracing Life's Cracks with Strength and Meaning

Wendy Wollner

In today's fast-paced world, finding true wellbeing can feel just out of reach. But what if the key lies not in avoiding life's cracks but in filling them with purpose? Inspired by the art of Kintsugi – the Japanese tradition of repairing broken pottery with gold – this interactive keynote explores how we can embrace our challenges, mend what feels fractured, and create a life that is not just whole, but even more meaningful. Join us for a dynamic and thought-provoking conversation on resilience, mental health, and the beauty of imperfection!

FRIDAY, APRIL 11

MORNING BREAKOUT SESSIONS

11:30 – 12:30 pm
Oceans 9

***BVoice in Action:
Navigating Advocacy from Congress to
Community***

Moderator: James Romano

**Panel: Congressman Erik Paulsen,
Dane Christiansen**

Join this dynamic panel discussion featuring a former Congressman and a health policy expert as they break down the impact of advocacy from Capitol Hill to local communities. Gain insider insights on how Congress shapes healthcare policy, what legislative issues matter most to patients, and how individuals can effectively engage with policymakers. Whether you're new to advocacy or looking to strengthen your voice, this session will equip you with the knowledge and confidence to take action.



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SANOFI FOR THEIR GENEROUS SPONSORSHIP OF OUR
SYMPOSIUM'S WATER STATIONS AND
REUSABLE WATER BOTTLES.**

FRIDAY, APRIL 11

11:30 – 12:15 pm
Oceans 10

Aging with a Bleeding Disorder **Sponsored by CVS Specialty** **Brenda Aldrich, RN ANCC**

As advancements in bleeding disorder treatment lead to improved outcomes, more individuals are living longer, creating a growing aging population. Let's explore the evolving needs of adults with bleeding disorders, highlighting key health considerations and the management of age-related conditions. This session provides insights into new treatment approaches and strategies for comprehensive, long-term care.

11:30 – 12:15 pm
Oceans 11

Communicate with Empathy to Build Stronger Relationships **Lee Kim**

Do you remember the last time you felt truly connected to another person? We go through life with many connections, yet few stand out as joyful and special. One key ingredient in building stronger relationships is the way we communicate with empathy. You will learn to explore your communication styles, discover your preferred style, and experiment with communicating with empathy. Join the session to start building beautiful relationships with your partner, your family, and yourself!



FRIDAY, APRIL 11

11:30 – 12:15 pm
Oceans 12

Descubra una Nueva Opción de Profilaxis para adultos y adolescentes que tienen Hemofilia con Inhibidores

Sponsored by Novo Nordisk
Martha Boria Negrón

Asista a esta presentación de Novo Nordisk para conocer una nueva opción de tratamiento profiláctico subcutáneo en una pluma de inyección precargada para adultos y adolescentes que padecen hemofilia B o A con inhibidores. Esta fascinante presentación ofrecerá una visión general de éste nuevo producto. Hablaremos de los estudios clínicos, la seguridad, la eficacia y el mecanismo de acción. También exploraremos el innovador diseño de la pluma de este producto. ¡Estamos encantados de que se una a nosotros!

12:30 – 2:00 pm
Oceans 1 – 4

LUNCH PRESENTATION

Discover a New Prophylaxis Option for adults & adolescents who have Hemophilia with Inhibitors

Sponsored by Novo Nordisk

Shveta Gupta, MD, FAAP, Royal Smith

Come join to learn about a new subcutaneous prophylactic treatment option in a prefilled injection pen for adults and adolescents who have hemophilia B or A with inhibitors! This engaging presentation will provide an overview of a new product. We'll discuss its clinical studies, safety, efficacy, and mechanism of action. We'll also explore this product's innovative pen design. We are excited for you to join us!

2:00 – 4:00 pm
Oceans 5 – 8

EXHIBIT HALL OPEN

Explore the booths and get your Bingo Card stamped! Hand in your completed card at Registration by 10:00 pm to enter the raffle. The first drawing will take place at tomorrow's Exhibit Hall. Indulge in a chair massage at the wellness station, and don't miss out on the opportunity to win a *Big Stick* at the CHB Infusion booth!

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Ricardo

Mandy, Ryan & Family

FRIDAY, APRIL 11

AFTERNOON BREAKOUT SESSIONS

4:15 – 5:00 pm
Oceans 1 – 4

Carriers DO Count: Understanding Bleeding Symptoms and Advocacy

Joanna Davis, MD

Many women with hemophilia B have expressed feeling invisible — dismissed as “just carriers” and told they do not require medical attention. We will explore the biology of genetic carriers of hemophilia B, shedding light on the bleeding manifestations that can and do occur. Dr. Davis will discuss evolving nomenclature surrounding genetic carriers, emphasizing the importance of recognizing bleeding symptoms beyond factor levels. This session will address the ongoing challenges women face in seeking care, offering insights into the reasons behind these barriers and potential solutions for advocacy and improved medical recognition.

4:15 – 5:00 pm
Oceans 9

***Learn about Charles' Journey Back2Benefix* Sponsored by Pfizer**

Charles Runion

Come hear from a real Benefix (Coagulation Factor IX [Recombinant]) patient sharing why he chose to come Back2Benefix.

4:15 – 5:00 pm
Oceans 10

***Brave is in Our Blood* Sponsored by Medexus Pharma**

Jeron Hill, Dave Todd

Bravery is more than just facing challenges – it's about speaking up, taking charge of your health, and advocating for yourself and others. Join Jeron, a passionate and inspiring member of the bleeding disorders community, as he shares his personal journey of resilience and self-advocacy. Bravery isn't just a choice — it's in our blood!

FRIDAY, APRIL 11

4:15 – 5:00 pm
Oceans 11

***Dream It, Build It:
Entrepreneurship Without Limits***
Parker Feagins

Living with hemophilia comes with unique challenges, but it doesn't have to stop you from pursuing your dreams, especially in business. In this interactive session, we'll explore how to start and grow your own business, from finding the right idea to managing risks and finances with your health in mind. Whether you're looking for flexible income or aiming to build something big, this session will equip you with the tools to take that first step.

4:15 – 5:00 pm
Oceans 12

***Working Together to Address Barriers and Gaps
Across Hemophilia B***

**Moderator: Kimberly Haugsted,
Panel: Fel Echandi, Nelly Miranda, James Romano**

Join and participate in this all-hands meeting regarding the 2024 health equity research that Coalition B and RareRising conducted focused on rural community members, people of color, and women in our community. We will discuss recommendations for change that came from the report and build plans together as a community to address important gaps and needs.

EVENING BREAKOUT SESSIONS

5:15 – 6:00 pm
Oceans 9

***Let's Talk Gene Therapy Rap Session:
Data, Access, & Decision-Making***

Moderator: Brian O'Mahony, FACSLM

What questions do you have about gene therapy? This interactive session is your chance to explore the latest data, share perspectives on real-world access, and unpack the complexities of decision-making together. Come ready for open conversation about benefits, risks, unknowns, and how to make informed choices that reflect your values and goals.

FRIDAY, APRIL 11

5:15 – 6:00 pm
Oceans 10

Finding Light in the Forest: Navigating Uncertainty

Natalie Sayer, PCC, MSMSE

Have you ever felt lost in life's forest, unsure of your next step? Join us for an interactive journey to navigate uncertainty with courage and resilience. Build on your past experiences, uncover practical tools to manage fear, and solve problems rapidly. Leave with 1–3 actionable strategies to face the future – one step at a time.

5:15 – 6:00 pm
Oceans 11

Embracing Aging: A Positive Approach to Life After 50

Karen Boyd, LMSW, David Rushlow, LMSW

Accepting aging as a natural and beautiful part of life can indeed be transformative! Together we will embrace this process with a positive mindset. Being old is a state of mind. We will explore ways of thinking about this life cycle change as we embrace confidence and emotional depth while sharing life experiences. Our community has faced many unique challenges, and it is now time to look forward with enthusiasm to the next chapter - honoring yourself and your community with creative ways to embrace ways to enrich this cycle of our life.

5:15 – 6:00 pm
Oceans 12

Trabajar Juntos para Abordar los Obstáculos y las Lagunas en la Hemofilia B

Moderador: Fel Echandi,

**Panel: Kimberly Haugsted, Nelly Miranda,
James Romano**

Únase y participe en esta reunión de todos en relación con la investigación sobre equidad sanitaria 2024 que Coalition B y RareRising llevaron a cabo centrada en los miembros de la comunidad rural, las personas de color y las mujeres de nuestra comunidad. Discutiremos las recomendaciones para el cambio que surgieron del informe y crearemos planes juntos como comunidad para abordar las brechas y necesidades importantes.

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www.altuviiiio.com

 **ALPROLIX**[®]
[Coagulation Factor IX
(Recombinant), Fc Fusion Protein]



www.alprolix.com

FRIDAY, APRIL 11

6:00 – 7:30 pm
Oceans 1 – 4

DINNER PRESENTATION

*Your Stories, Your Songs:
A Hem Sessions Songwriting Experience*

Sponsored by Sanofi

Shelby Smoak & Ben Hale

Music is a powerful tool for self-expression, able to convey emotions and experiences in a way that words alone cannot. At *Your Stories, Your Songs*, attendees will discover how to tell their own stories through song, learning from two artists and community members who have been putting their own experiences to music for decades. Through live musical performances and hands-on songwriting activities, attendees will get the tools they need to write their own songs inspired by their hemophilia experiences and leave empowered to keep telling their stories and advocating for themselves in any medium.

8:00 – 9:00 pm
Oceans 1 – 4

FRIDAY NIGHT HANGOUT

*Amplified & Unfiltered:
A Night with The Bleeders Band*

Sponsored by Medexus Pharma

The Bleeders Band, with special guests Elec Simon and Chase Williams

Settle in for a laid-back evening of live music and good company! The Bleeders Band will set the tone with their signature sound, creating an intimate atmosphere where the music takes center stage. A handful of experienced musicians from our community will have the chance to share a song, making this a night of unique performances and shared talent. If you're interested in playing, sign up at the registration desk, and we'll do our best to fit in as many performers as time allows.

Whether you're here to listen, play, or just soak in the music over a drink and a bite, this is your chance to connect, unwind, and enjoy the sounds of our incredible community!

SATURDAY, APRIL 12

7:00 – 7:30 am
R Lawn

TAI CHI & QI GUNG

Rick Starks

Come join in for invigorating Tai Chi and Qi Gung movement to power start your day. Also known as moving meditation, gentle on the joints and open to everyone!

7:00 – 7:30 am
Pool Lawn

FAMILY FITNESS

Kevin Harris

Get ready to move! Join in on an interactive exercise demo to start your day off with energy. Together we'll learn a fun routine you can add to your daily life and can enjoy with the entire family!

7:30 – 9:00 am
Oceans 1 – 4

BREAKFAST PRESENTATION

Learn about a rebalancing agent from Pfizer

Sponsored by Pfizer

Akshat Jain, MD, MPH

This presentation will explore a rebalancing treatment option for eligible patients with hemophilia A or B without inhibitors. It will cover various aspects of the treatment, including its usage, safety information, and clinical trial results. It will also provide information on how the product works, its administration, and the case study of a real patient.

9:00 – 9:15 am
Oceans 1 – 4

SATURDAY KICKOFF

Elec Simon, Brad Schoenfeld

Kickstart our final day with an electrifying welcome, sparking energy, inspiration, and a call to community action. Let's ignite the day with rhythm, movement, and motivation, fueling your spirit and setting the tone for a powerful day ahead!

SATURDAY, APRIL 12

9:15 – 10:15 am
Oceans 1 – 4

KEYNOTE PRESENTATION

Let's Talk about Hemophilia B in 2025!

Christopher Walsh, PhD

Time for an in-depth look at the current state of hemophilia B, where we are now and what's ahead. This session will provide the essential information you need to make well-informed decisions about your care and future.

10:30 – 11:30 am
Oceans 1 – 4

KEYNOTE PRESENTATION

Product and Treatments Landscape Panel

Moderator: David Clark, PhD

Panel: Nancy Epp, PharmD, BCACP,

Chad Richardson, PharmD, Michael Wang, MD

Just a few years ago, therapies for hemophilia B were limited to only a handful of options. There are now more options than ever, longer-acting clotting factors, subcutaneous injections, gene therapy, and more. Join us for a panel featuring medical and scientific experts from Be Bio, Pfizer, and Sanofi for the latest advancements in hemophilia B current and upcoming therapies.

MORNING BREAKOUT SESSIONS

11:45 – 12:30 pm
Oceans 9

Gut Brain Axis = Your Food is Your Mood

Catherine Canadeo

As it turns out, food truly does make us happy — biochemically. Growing evidence shows that a nutritious diet can significantly improve long-term mental health. Let's explore how eating nutrient-rich foods instead of processed, unhealthy options triggers the release of neurotransmitters like dopamine, serotonin, and GABA, all of which play a role in mood regulation, sleep, cravings, weight management, inflammation, anxiety, fatigue, and depression. While we often think of mental health as solely brain-based, the gut and brain are in constant, two-way communication, meaning your diet could be a key factor in how you feel, think, and function every day.



We move science to medicine because our world is

MEANT FOR MORE

Regeneron is driven by a relentless pursuit to use science to benefit patients.

We use our scientific knowledge and cutting-edge technologies to make significant advancements for people with serious diseases.

Learn more at [Regeneron.com](https://www.regeneron.com)

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SATURDAY, APRIL 12

11:45 – 12:30 pm
Oceans 10

How to be an Educated Advocate

Deena Lipinski

In this session, a lived experience expert will share tools and tips for effectively communicating health concerns. We will explore shared decision-making and self-advocacy to empower you to start up vital conversations with your healthcare providers. Ultimately, the goal is to feel seen, heard, and to get the best care - so let's work together to get you there!

11:45 – 12:30 pm
Oceans 11

Building Relationships and Expanding Your Career Horizons Through the Power of Networking

April Willis, EdD, MBA, MEd

Unlock new career opportunities by mastering the art of strategic networking and relationship-building! This session will provide actionable insights on cultivating meaningful connections that open doors to professional growth, mentorship, and business success

11:45 – 12:30 pm
Oceans 12

Construyendo Vínculos Fuertes con sus Hijos a lo Largo de sus Etapas de Desarrollo

Carolina Castillo, LPC, LMHC, BC-CMHC

Aprendamos sobre las diferentes etapas de desarrollo humano y cómo relacionarnos con nuestros hijos durante cada una de ellas para fortalecer el vínculo y construir relaciones sanas.

12:30 – 2:00 pm
Oceans 1 – 4

LUNCH PRESENTATION

When Factor IX Matters Most

Sponsored by CSL Behring

Elliot Goldrick

Join us for a Q&A lunch symposium to learn about Patient Advocate Elliot's perspective living with hemophilia B and treating with IDELVION.

SATURDAY, APRIL 12

2:00 – 4:30 pm
Oceans 5– 8

EXHIBIT HALL OPEN

Explore the booths and get your Bingo Card stamped! Hand in your completed cards at Registration by 10:00 pm to enter the raffle. The first drawing will take place at tomorrow's Exhibit Hall. Indulge in a chair massage at the wellness station, and don't miss out on the opportunity to win a *Big Stick* at the CHB Infusion booth!

2:30 – 3:30 pm
Oceans 5– 8

ICE CREAM SOCIAL

Cool off with an afternoon tasty treat!

AFTERNOON BREAKOUT SESSIONS

4:30 – 5:45 pm
Oceans 1– 4

Infuse With Hope & The Power Of Kinesiology

**Hope WoodcockRoss, RN, BSN, and
Douglas Stringham, MS, LAT, ATC**

Get hands-on experience with infusing in a live instruction session and discover the power of kinesiology taping for pain reduction and muscle support in joints from hips to neck. Join our interactive double workshop to learn proper techniques, and take home samples!

4:30 – 5:45 pm
Oceans 9

Drowning in Debt

Donnie Akers, Jr., JD

In this session, we'll explore common financial pitfalls and practical strategies to protect yourself from making costly mistakes. Learn how to navigate creditor negotiations, hospital bills, and debt collection while gaining insight into the Fair Debt Collection Practices Act and bankruptcy tools that can help you take control of your financial future.

4:30 – 5:30 pm
Oceans 10

Las Perdidas no Dichas de la Maternidad

Carolina Castillo, LPC, LMHC, BC-CMHC

Exploremos las numerosas perdidas que se viven a lo largo de las diferentes etapas de la maternidad y aprendamos como vivir esos duelos.

SATURDAY, APRIL 12

4:30 – 5:30 pm
Oceans 11

Voices of Resilience: Navigating Uncertainty Together

Karen Boyd, LMSW, David Rushlow, LMSW

Let's come together to explore the emotions surrounding today's uncertainties – access to care, diminishing support programs, and the state of our country. Through an interactive discussion, we'll reflect on the challenges we face, their impact on daily life and mental health, and the support we need. The bleeding disorder community is resilient; you've mastered tools to navigate health and personal challenges. Let's discover how to apply those strengths to manage uncertainty and fear!

4:30 – 5:30 pm
Oceans 12

Wilderness Survival & First Aid

Kevin Harris

This fun, hands-on session teaches real-life first aid through wilderness-inspired scenarios the whole family can enjoy! Using SFX blood and putty, you'll create mock injuries, learn how to treat them, and gain skills to stay calm in emergencies. We'll cover everything from wound care and sanitation to team-based carries and creative challenges. It's all designed to build confidence, spark curiosity, and help families feel prepared for adventure, without fear getting in the way.

7:00 – 10:00 pm
R Lawn

FINAL NIGHT EVENT ***Totally 80s Dance Party***

Break out your neon, tease up your hair, and get ready to dance the night away at our ultimate 80s-themed party! This high-energy evening will feature iconic hits, epic karaoke, and a dance floor made for moonwalking and voguing. Enjoy a delicious dinner, strike a pose with some legendary lookalikes, and relive the magic of the decade that defined pop culture. It's the perfect way to wrap up our time together – big hair, big beats, and even bigger memories!

FINAL NIGHT



Totally

80'S

PARTY



Saturday, April 12
7pm-10pm R LAWN

THE COALITION FOR
HEMOPHILIA



35
ANNIVERSARY

HEMOB.ORG

Don't forget to wear your 80s best!



WE WORK FOR YOU!

Our Mission:

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



HEMOPHILIA ALLIANCE



**Connect
With Us!**

Since 2009, Hemophilia Alliance has granted over \$30,000,000 to the community and funds the Hemophilia Alliance Foundation (HAF), an independent nonprofit organization. In 2024 HAF awarded \$870,000 to various community projects.

SUNDAY, APRIL 13

7:30 – 8:30 am
Oceans 1 – 4

COALITION B BREAKFAST

Fuel up for your journey home with a simple meal, great company, and tune in for one last chance to win at our final Exhibit Winner Drawing before heading home!



Nurses on Call



LEAD NURSE:

Hope Woodcock-Ross,
RN, BSN
(607) 222-8412

Heidi Lynch, RN, RNC-NIC
(901) 288-8447

Jackie Macauley, FNP
(860) 384-5661

Tiffani Pokrajac, RN
(419) 461-8113

THE COALITION TEAM



David Clark, PhD
Chairman



Wayne Cook
President



Kim Phelan
Chief Executive Officer



Erica Garber, MEd
Executive Director



Glenn Mones
Dir of Advocacy &
Public Policy



Jim Romano
Advocacy & Public Policy



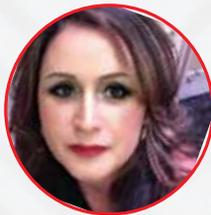
Donnie Akers, Jr, JD
Legal Consultant



**April Willis, EdD,
MBA, MEd**
Dir of Development



Rocky Williams
Community Relations Dir



Farrah Muratovic
Office & Community
Relations Mgr



Jennifer DeGlopper
Communications Dir



Yalda Kasaeen
Event Coordinator



Chris Villareal
Program and
Community Liaison



Nathy De La Cruz
Event Coordinator



Melinda Cobovic
Admin Assistant



Samantha Gregory
Admin Assistant



Marta Thomas
Admin Assistant

NEARBY MEDICAL SERVICES

HOSPITAL EMERGENCY ROOM

AdventHealth Palm Parkway Emergency Room

2 miles – 7 minute drive

Open 24 hours

Address: 7823 Palm Pkwy
Orlando, FL 32836

Phone: (407) 550-0500

HEMOPHILIA TREATMENT CENTER | PEDIATRIC

Arnold Palmer Hospital Haley Center for Children's Cancer and Blood Disorders

13 miles – 20 minute drive

Address: 92 W. Miller St, MP318
Orlando, FL 32806

Phone: (321) 841-8588

Fax: (321) 841-8560

Pediatric After hours:
(321) 841-8588 ext. 2

Urgent Triage RN:
(321) 841-8588, ext. 2

Primary Contact: Stephanie Sharon
Phone: (321) 841-7744
Email: Stephanie.Sharon@orlandohealth.com

HTC Director: Dr. Zhongbo Hu
Phone: (321)841-8588
Email: zhongbo.hu@orlandohealth.com

EMERGENCY SERVICES

HCA Florida Hunter's Creek Emergency

4.5 miles – 11 minute drive

Open 24 hours

Address: 12100 S John Young Pkwy
Orlando, FL 32837

Phone: (407) 903-7033

HEMOPHILIA TREATMENT CENTER | ADULT

University of South Florida Hematology and Medical Oncology Hemophilia Treatment Center

73 miles – 1 hour, 24 minute drive

Address: 13220 Laurel Drive, 4th Fl
Tampa, FL 33612

Phone: (813) 974-3725

Fax: (813) 974-9476

After hours: (813) 974-2201

Primary Contact: Antonio Brown
Phone: (813) 974-3725
Email: abrown134@usf.edu

HTC Director: Dr. Bradley Fletcher
Phone: (813) 974-9452
Email: bsfletcher@usf.edu

CONTACT INFORMATION

SHARE WITH US AT #CHB25

ON-SITE EXHIBIT SETUP SUPPORT

Stephanie Placeres
(321) 296-5080

EXHIBITOR SUPPORT

Erica Garber
(973) 534-3157

B HUB & MEDIA

Jennifer DeGlopper
(941) 204-0473

SCOOTER RENTAL

Rocky Williams
(618) 593-0643

NURSE ON CALL

Hope Woodcock
Ross, RN BSN
(607) 222-8412

YOUTH CAMP

Ricky Muratovic
(718) 536-6962

MEMBER SUPPORT

Farrah Muratovic
(718) 915-6897

Rocky Williams
(618) 593-0643

Erica Garber
(973) 534-3157

Kim Phelan
(917) 582-9077

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EthicalFactorRX

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BIO-MEDICAL, INC.

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ALLIANCE

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Microhealth
Digital Hematology

Optum



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SRRX
SANTA ROSA PHARMACY

SOLEO
HEALTH

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