

NBDF IDAHO

Official Newsletter of the Idaho Chapter of the
National Bleeding Disorder Foundation



From the Director

BY MARLYN WALKER

Welcome to our mid-year newsletter! I am thrilled to reflect on the amazing first half of the year we've had, filled with unforgettable events and cherished moments. My favorite was our family outing to Topgolf. It was great to bring us together for a day of fun, laughter, and friendly competition. Additionally, our VWD series has been a great success, providing valuable insights and fostering a sense of community among us.

Thank you all for your enthusiastic participation and support. I'm looking forward to many more fantastic experiences in the coming months!



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NBDF IDAHO

Official Newsletter of the Idaho Chapter of the
National Bleeding Disorder Foundation



 **Idaho Chapter**
NATIONAL BLEEDING DISORDERS FOUNDATION

NBDF IDAHO FAMILY

Educational Weekend



GROVE HOTEL
Boise Idaho

AUG 9-10
Starts | 9:30 AM

EDUCATION – WORKSHOPS –
GUEST SPEAKERS –
KIDS’ ACTIVITIES –
ROARING SPRINGS

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Registration closes July 15th


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VISION STATEMENT

THE IDAHO CHAPTER OF NBDF ENVISIONS A UNITED COMMUNITY THAT WILL MAKE A POSITIVE DIFFERENCE IN THE LIVES OF INDIVIDUALS AFFECTED BY A BLEEDING DISORDER. EDUCATION: WITHIN AND OUTSIDE THE BLEEDING DISORDERS COMMUNITY. ADVOCATION: AT LOCAL, STATE, AND NATIONAL LEVELS. INCLUSION: OF FAMILY, FRIENDS, AND ALL THOSE IMPACTED BY THE DISORDERS. DEVELOPMENT: OF A LEGACY FOR A FUTURE OF HOPE.

GETTIN' IN THE GAME™
JUNIOR NATIONAL CHAMPIONSHIP
PRESENTED BY CSL BEHRING

SAVE THE DATE
2024 Gettin' in the GameSM
Junior National Championship (JNC)

September 20 – 22, 2024
Henderson, Nevada

Family Top Golf Night

MERIDIAN, MAY 18



Thank You CSL Behring

We had an incredible time at Topgolf as a group, filled with laughter, friendly competition, and great memories. Each of us took turns swinging for the targets, cheering each other on with every impressive shot. The mix of casual conversation and playful banter added to the enjoyment, making it a perfect blend of relaxation and excitement. The atmosphere was vibrant, the food and drinks were delicious, and the camaraderie among us was undeniable. Overall, our outing to Topgolf was a fantastic experience that brought us all closer together.



Our Chapter

NBDF Idaho is fortunate to be guided by an enthusiastic, talented, and hard-working group of people.

Board of Directors

Joe Rex, Acting
President
Jessica Tulloch
Bob Graham

Office Staff

Executive Director
Marlyn Walker

Address

3989 E 170 N
Rigby, Idaho 83442
208-344-4476
idahoblood.org

Chapter Resources

Financial Assistance



The Financial Assistance program is part of the Idaho Chapter of the National Bleeding Disorder Foundation's continuing effort to improve the quality of life of individuals and families affected by bleeding disorders by providing financial support. The Financial Assistance program is supported by generous contributions from individuals, foundations, and corporations committed to the bleeding disorders community.

Example eligible expenses include, but are not limited to, the following:

- Expenses incurred in the care, treatment, or prevention of a bleeding disorder.
- Transportation services to medical appointments and HTC's
- Medical supplies not covered by insurance.
- Basic living expense emergencies (rent, mortgage, utilities, food, etc.)
- Unexpected home or car repairs
- Medic Alert Bracelets
- Dental expenses
- Health insurance premiums
- Funeral expenses

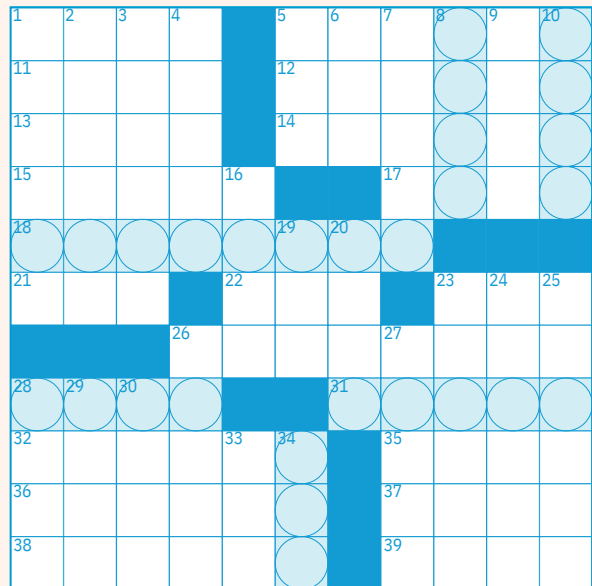
Application can be found at Idahoblood.org

CAN YOU SOLVE

FOR A DIFFERENT HEMOPHILIA A

TREATMENT?

Test your HEMLIBRA knowledge



ACROSS

1. Wine barrel
5. Deep fissures
11. Mideast gulf port
12. District
13. Ripped
14. Familiar with
15. Mean
17. Roost
18. The #1 prescribed prophylaxis for people with hemophilia A without factor VIII inhibitors*

*According to IQVIA claims data from various insurance plan types from a national survey of hemophilia A treatment in the US.

21. Calendar divs.
 - Regret
22. Banquet hosts (abbr.)
 - International travel necessity
23. Check out the _____ treated bleeds data with HEMLIBRA
 - HEMLIBRA offers

26. Number of people with hemophilia A treated as of October 2021.

31.

32. Small hole in lace cloth
35. Central Plains tribe
36. Melodic
37. Towering
38. Reduce
39. Spanish cheers

DOWN

1. Memorable, as an earworm
2. Devotee
3. Medical fluids
4. Prepare to propose, perhaps
5. PC's "brain"
6. _____ settings
7. Concert venue
8. See Medication Guide or talk to your doctor about potential _____ effects
 - Winter hrs. in Denver and El Paso
9. HEMLIBRA is the only prophylactic
10. treatment offered this way under the skin

16. Pre-Euro currency in Italy
 - Subway alternative
19. Relax
 - Human
20. New Orleans cuisine
 - Mentally prepares
23. Collared shirts
 - Instagram post
24. Ardent enthusiasm
 - Brontë heroine Jane
25. Old Portuguese coins
 - Opposite of WNW
26. More than _____ thousand patients have been treated with HEMLIBRA
27. worldwide†

SOLUTIONS

30. Reis, 33. ESE, 34. ten
 25. steels, 26. polos, 27. photo, 28. zeal, 29. Eyo
 16. lira, 19. bus, 20. rest, 23. mortal, 24. Creole
 5. CPU, 6. has, 7. arena, 8. side, 9. MSTs, 10. short
 Down: 1. catchy, 2. adorer, 3. serums, 4. kneel
 35. Oreo, 36. artoise, 37. tall, 38. lessen, 39. oles
 26. passport, 28. zero, 31. three, 32. eyelid
 18. HEMLIBRA, 21. yrs, 22. rue, 23. MCS
 13. tore, 14. used to, 15. oval, 17. nest
 Across: 1. cask, 5. chasms, 11. Aden, 12. parish,

34.

Discover more at HEMLIBRA.com/answers

INDICATION & IMPORTANT SAFETY INFORMATION

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.

These serious side effects include:

- **Thrombotic microangiopathy (TMA)**, a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events)**, which may form in blood vessels in your arm, leg, lung, or head

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.



Medication Guide
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA)**, involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
 - confusion – stomach (abdomen)
 - weakness or back pain
 - swelling of arms and legs – nausea or vomiting
 - yellowing of skin and eyes – feeling sick
 - decreased urination
- **Blood clots (thrombotic events)**. Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
 - swelling in arms or legs – cough up blood
 - pain or redness in your – feel faint arms or legs – headache
 - shortness of breath – numbness in your face
 - chest pain or tightness – eye pain or swelling
 - fast heart rate – trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that

HEMLIBRA has stopped working for you (eg, increase in bleeds).
more information about side effects.
What are the possible side effects of HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

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

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

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

How should I use HEMLIBRA?

See the detailed “Instructions for Use” that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.

- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
 - Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
 - Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
 - You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
 - If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule.
- Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

• See “**What is the most important information I should know about HEMLIBRA?**”

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

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 HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C). After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 12/2021



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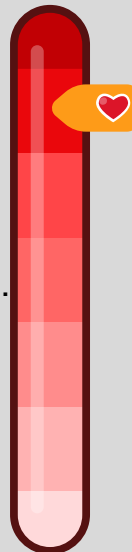
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Unite for Bleeding Disorder Walk

BY MARLYN WALKER



Reflecting on the daily realities of living with a bleeding disorder can quickly become a daunting task. As we recently conveyed our experiences to our State Representative, discussing the financial burdens, emotional strain, and obstacles we face, it struck me just how fortunate we truly are. While our situation isn't flawless, we have access to essential medications. Though attaining them often requires a struggle, they remain available. Our sons are enjoying extended lifespans, and our daughters are being acknowledged as individuals coping with bleeding disorders themselves. Progress may be gradual, but it is undeniably underway. By voicing our concerns and sharing our stories, we catalyze the momentum for necessary change.



We reached
our Goal
\$23,443.00



Team Captains

- *Addies's Angels- Jena Benzel
- *Myers' Tribe - Meredith Myers
- *Lazy Blood Club - Cameron Tullock
- *Bleeding Warriors - Michael Krieger
- *IX Walkers - Zach Walker
- *Pioneer FCU
- *The Rex Factor- Joe Rex
- *Blood Moms - Kyla Krieger
- *Queen Bees - Laura Visoso
- *Sanofi Walks For Blood - Cindy Bishop
- *Team Koda - Stephanie Shea
- *Dickens/Shumway Dream Team- Courtney Dickens



National and Local Sponsors

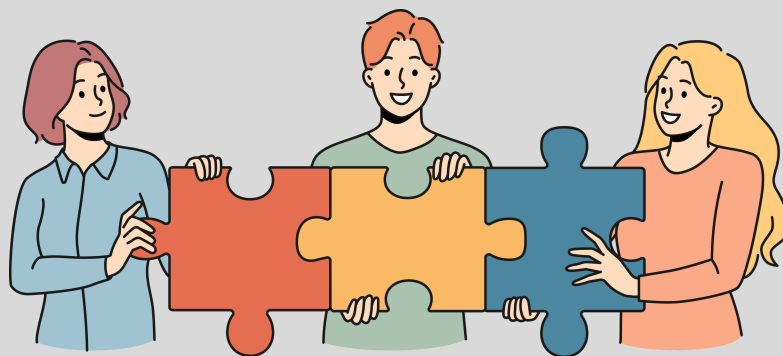


Takeda
Hemophilia Alliance
Sanofi
Genentech
Spark Therapeutics

Novo Nordisk
Octapharma
Bayers
DrugCo
CSL Behring
Genentech
Air Keepers
GoGo Squeeze

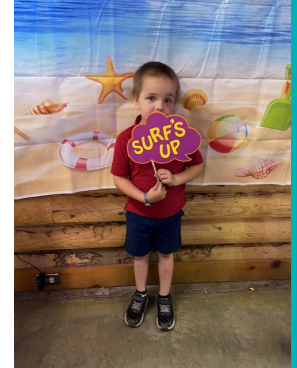
NBDF Idaho is looking to expand our Advisory Board of Directors. We are currently recruiting both affected and unaffected board members. We specifically are looking for members with diverse backgrounds, including those who reside in rural areas, are Spanish-speaking or bilingual, are individuals comfortable in the rare disease space, and have financial or accounting backgrounds, community connections, or a knack for fundraising. If you know someone who would be a good fit for our Board and Chapter, please get in touch with Marlyn at mwalker@hemophilia.org.

Additionally, there's always room on committees for non-board members if you want to get involved and help with Advocacy, Programs, Education, Fundraising and Events, or more. Join us for our community meetings. Watch social media for these dates. If you want to be added to a list, email the chapter today.



catch
t.h.e
wave

Camp Red Sunrise 2024



Aloha, and welcome to Camp Red Sunrise! Nestled in the heart of our tropical paradise, our camp is a place where the sun kisses the waves and adventure awaits at every turn. Here, we embraced the spirit of "riding the wave"—tackling challenges with courage, joy, and an unwavering sense of community. Whether we came to sharpen our skills, make new friends, or bask in the beauty of our island home, we found that every moment at Camp Red Sunrise had the opportunity for us to grow and thrive. Together, we caught the waves of possibility and rode them towards a brighter, stronger future.

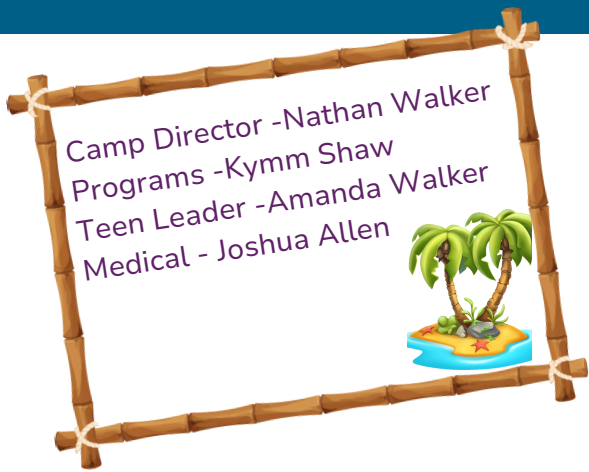
We embarked on this journey, to keep the momentum going and let the spirit of the wave guide us. By supporting each other and embracing the island's vibrant energy, we transform from novices to experts, from friends to family. Each wave we conquered added to our strength and unity, propelling Camp Red Sunrise to new heights. We rode the waves together and made this camp a beacon of growth, learning, and unforgettable memories. Mahalo for being part of our ohana; we made this an adventure to remember!



Adult time



The flamingos were hiding everywhere.



Camp Fun

Directors
Award

In Memory of
Bob Tulloch,
Camper Award



Mckenna Myers



Joe Rex



PARADISE

Teen Program Highlights



What an amazing year!! The teens were absolute superstars this year as they tackled new challenges and learned that things don't always go the way we want them to. Members of the Teen Program this year got the opportunity to build a tipi (which they then slept in for a night!), got to cook their own campfire dinners (which mostly burnt, but thankfully Marlyn brought us pizza), and worked through a challenge course hosted by the amazing staff at Sawtooth!

The teens had a blast at our After Dark party, where we were wrongfully accused of toilet-papering the main lodge while we went on a calm nature walk in glow-in-the-dark accessories.

And finally, with the amazing help of our medical staff, many of the teens overcame a big fear this year and poked themselves for the very first time in our infusion class!!

It was an absolute honor to work with the Teen Program this year and to see their personalities blossom and confidence grow over just a few short days! I can't wait to see what amazing things they all accomplish throughout the next year!

Amanda Walker, TP Director



shenanigans

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We are thrilled to tell you more about the VWD Me Program, where our mission is to empower and support you on your journey to personal and professional development. Get ready for a fantastic experience filled with educational and fun events that will enhance your skills, broaden your horizons, and foster a sense of community.

Meeting Schedule:

Our monthly gatherings will take place on the first Monday of each month, providing you with a regular opportunity to connect, learn, and grow. Mark your calendars, as our first meeting is just around the corner!

Event Highlights:

We understand that a well-rounded development journey involves not only educational but also enjoyable experiences. That's why our events are carefully curated to bring you a mix of insightful discussions, engaging workshops, and entertaining activities. Each session is designed to cater to different aspects of personal and professional growth.

Community Building:

The VWD Me Program is not just about attending events; it's about building a supportive and collaborative community. Share your experiences, learn from others, and forge connections that will last a lifetime. We believe in the strength of a united community, and together, we can achieve great things.

How to Get Involved:

Stay tuned for our monthly newsletters, where we will share details about upcoming events, highlight success stories within the community, and provide resources for your continued growth. Additionally, we encourage you to actively participate in discussions, ask questions, and bring your unique perspectives to the table.

We are excited to embark on this journey with you and can't wait to witness the incredible transformations and achievements that will unfold through the VWD Me Program.

See you on the first Monday of the month for our inaugural event – it's an experience you won't want to miss!

UPCOMING EVENTS



SUMMER
2024

MONDAY
JULY 1 6:30 PM
VWD Me

THURSDAY
JULY 18 5:30 PM
Educational Dinner Hosted by
Bayer- Stampede Rodeo

TUESDAY
JULY 23 6:30 PM
Educational Dinner - Twin Falls

**FRIDAY &
SATURDAY**
AUG 9-10 9:30 AM START
Educational Weekend - Grove
Hotel

**3RD,
19TH,
24TH** SEPTEMBER VWD MONTH
6:30pm

**OCTOBER
1ST** Blood, Sweat & Cheers Charity
Golf Tournament- Top Golf
Meridian



Explore Head-to-Head Pharmacokinetic (PK) Study Data

See half-life, clearance, and other PK data from the crossover study comparing Kovaltry® and Advate®.

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Antihemophilic Factor (Recombinant)



Idaho Chapter

NATIONAL BLEEDING DISORDERS FOUNDATION