

# NBDF IDAHO

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



## From the Director

BY MARLYN WALKER

Can you feel the change in the air? It's pumpkin spice, leaves changing, and sweater weather just around the corner. You don't have to look too far to see the changes we are working on here at the New Idaho Chapter of the National Bleeding Disorder Foundation. You can see a few changes now, such as the start of the updated newsletter with our new colors and logo. What do you all think? I would love to hear your feedback on all these changes. Other changes will continue over the next few months, like website, branded material, and how we address ourselves. It has been hard not to say I'm from the Hemophilia Foundation but to say I am from the Idaho Chapter of the National Bleeding Disorder Foundation, formally The National Hemophilia Foundation. It is a mouth full, but I'm honored to be part of this change that brings everyone together under a united name. As you see the changes coming, be assured that the Idaho Chapter is here for our families, and we have fantastic events in store this fall. You can check out the website for all updated events. Have a happy Fall, and enjoy the changes just around the corner.



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Conference

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# FACTOR UP with ALTUVIIIIO™

**ALTUVIIIIO™**  
Antihemophilic Factor (Recombinant),  
Fc-VWF-XTEN Fusion Protein-eh[tl]

Higher-for-longer Factor VIII levels in the near-normal to normal range (**over 40%**) for most of the week.



**HIGHER FACTOR LEVELS FOR LONGER**  
Above 40% for most of the week (near-normal to normal range).\*†

**48**

**HOUR HALF-LIFE IN ADULTS**  
In a Phase 3 study,† ALTUVIIIIO offered adults the longest half-life of any Factor VIII therapy.

**0.7**

**BLEEDS PER YEAR‡**  
Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.†

In people taking ALTUVIIIIO in the XTEND-1 study, 21% of people had headache, 16% had joint pain, and 6% had back pain

\*Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 10% for children aged 6 years to under 12 years, and 7% for children aged 1 year to under 6 years.

†159 adults and adolescents with severe hemophilia (aged 12 years and older) were enrolled in the XTEND-1 study; 133 people were in Group 1 and switched to ALTUVIIIIO prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients.

Data based on treated bleeds.

## CONNECT WITH YOUR CORE TODAY

Learn more about ALTUVIIIIO, living with hemophilia, and treatment options from your local CoRe.

### INDICATION

ALTUVIIIIO™ [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-eh[tl]] is an injectable medicine that is used to control

and reduce the number of bleeding episodes in people with hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ALTUVIIIIO when you have surgery.

### IMPORTANT SAFETY INFORMATION

#### What is the most important information I need to know about ALTUVIIIIO?

Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center. You must carefully follow your healthcare provider's instructions regarding the dose and schedule for injecting ALTUVIIIIO so that your treatment will work best for you.

#### Who should not use ALTUVIIIIO?

You should not use ALTUVIIIIO if you have had an allergic reaction to it in the past.

#### What should I tell my healthcare provider before using ALTUVIIIIO?

Tell your healthcare provider if you have had any medical problems, take any medications, including prescription and non-prescription medicines, supplements, or herbal medicines, are breastfeeding, or are pregnant or planning to become pregnant.

#### What are the possible side effects of ALTUVIIIIO?

You can have an allergic reaction to ALTUVIIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called "inhibitors" against ALTUVIIIIO. This can stop ALTUVIIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIIIIO are headache, joint pain, and back pain.

These are not the only possible side effects of ALTUVIIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full [Prescribing Information](#).



Cindy Bishop  
cindy.bishop@sanofi.com  
971-940-3044  
Serving Pacific Northwest

## 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.



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

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

Visit [Kovaltry-us.com](https://www.kovaltry-us.com) to find out more.

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Antihemophilic Factor (Recombinant)

# National Bleeding Disorder Conference

WASHINGTON DC

The National Hemophilia Foundation held its 75th annual Educational Weekend in National Harbor, Maryland, August 12-14, 2023. With a fantastic turnout from community members from all over, they announced a massive change to the National Foundation. They changed their name to the National Bleeding Disorder Foundation.

They had beautiful classes on VWD, Rares, Hemophilia, and Caregivers. They held many classes in Spanish as well. We were excited that we had two community members from Idaho attend this year. We look forward to next year and hope more community members can come and enjoy this fantastic event.



## 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](http://Idahoblood.org)

# Jivi<sup>®</sup>, now with up to **7 YEARS OF DATA.**

Talk to your doctor about the study.

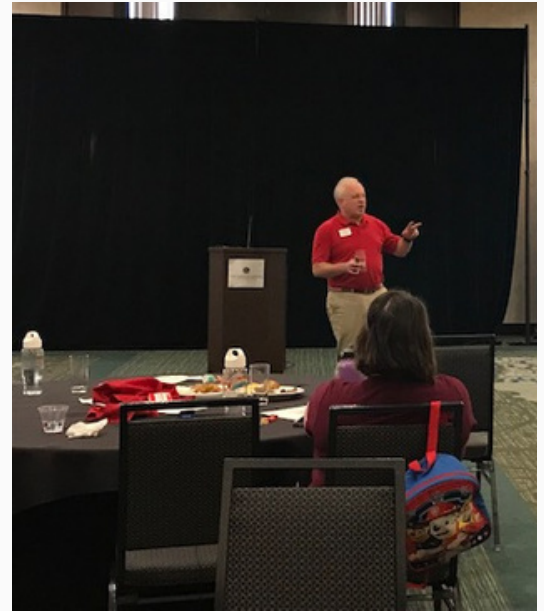


Scan this QR code to learn  
more about the data at  
**JiviExtensionStudy.com**

# Annual Educational Weekend 2023

We had a wonderful time at our Annual Educational Weekend on August 4th and 5th. We started the Friday off with fantastic education hosted by our HTC, which included a how-to-infuse class. The vendor booths opened, and everyone enjoyed getting a chance to talk with them and learn about all the new things many of them had to offer. Other topics on the list were Insurance, Tia Chi, Music Therapy, and more.

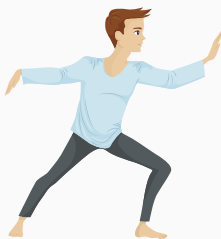
Can't wait until next year. Mark your calendars now for Aug 2 & 3, 2024!



Bill Robie from the National NBDF gave us some great updates on what the National is doing and what we can do here in Idaho to help with our local Government.



We had a great time getting up and moving our bodies and learned a little Tia Chi.



# Annual Educational Weekend 2023

More fun!



The kids had a fun outing at JUMP in Downtown Boise!



Thank you to Dr. Hansen and the staff from St. Luke's!



# Annual Educational Weekend 2023

## TOP SPONSORS

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Thank you!

## BOOTH SPONSORS

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Bio Marin

Medexus

Accredo

BioMatrix

CVS

DrugCo

InfucareRX

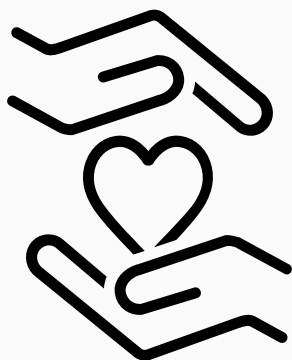
Optum

Paragon Healthcare



# 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](http://Idahoblood.org)

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, Spanish speaking or bilingual, individuals comfortable in the rare disease space, those with 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](mailto:mwalker@hemophilia.org).

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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.





NATIONAL  
**BLEEDING DISORDERS**  
FOUNDATION

Innovate | Educate | Advocate

NHF celebrated its 75th anniversary this year with the exciting news of a new name. NHF is now the National Bleeding Disorder Foundation. This name shows that they are working hard to be an inclusive foundation for all those who live with an inheritable bleeding disorder.

***Things that will change.***

- 1- The Name from NHF to NBDF
- 2- The colors and logos
- 3- The web address will stay the same for now. I will update you when that change becomes official. However, if you ever search for hemophilia, you will still be directed to the national website.

***What will not change?***

- 4- The National commitment to the bleeding disorders community.

**What this means for Idaho**

- 1- We get a new name as well. We are now officially the Idaho Chapter of the National Bleeding Disorder Foundation
- 2- We get a new logo as well.
- 3- We will get a new website and email address, which will happen sometime next year.

**What will not change for Idaho?**

- 1- NBDF Idaho's commitment to bring education and support to all who live with a bleeding disorder.

For more information about the name change, please visit

<https://www.hemophilia.org/who-we-are/our-story/the-national-hemophilia-foundation-has-a-new-name>

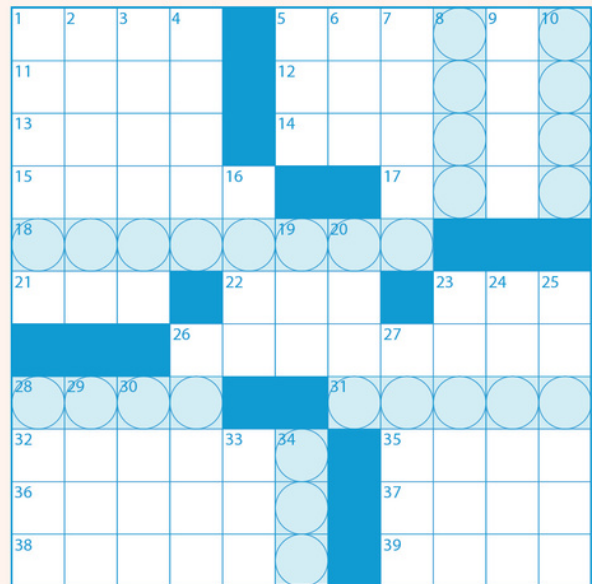
**CAN YOU SOLVE**

**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 April 2020 - May 2021 and accounts for usage in prophylaxis settings in the US.

- 21. Calendar divs.
- 22. Regret
- 23. Banquet hosts (abbr.)
- 26. International travel necessity
- 28. Check out the \_\_\_\_\_ treated bleeds data with HEMLIBRA
- 31. Number of dosing options HEMLIBRA offers

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

- 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. Owns
- 7. Concert venue
- 8. See Medication Guide or talk to your doctor about potential \_\_\_\_\_ effects
- 9. Winter hrs. in Denver and El Paso
- 10. HEMLIBRA is the only prophylactic treatment offered this way under the skin

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

**SOLUTIONS**

**Across:** 1. cask; 5. chasm; 11. Aden; 12. parish; 13. tore; 14. used to; 15. cruel; 17. nest; 18. HEMLIBRA; 21. yrs; 22. rue; 23. M.C.s; 26. passport; 28. zero; 31. three; 32. eyelid; 35. Oreo; 36. anore; 37. tall; 38. lessen; 39. oles  
**Down:** 1. caddy; 2. adorer; 3. serums; 4. kneel; 5. CPU; 6. has; 7. arena; 8. side; 9. M51s; 10. shot; 16. lira; 19. bus; 20. rest; 23. mortal; 24. Creole; 25. steels; 26. pesos; 27. photo; 28. zeal; 29. Eyre; 30. Reis; 33. ESE; 34. ten

Discover more at [HEMLIBRA.com/answers](https://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).** This is a condition 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
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - 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
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - 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).**

See “What are the possible side effects of HEMLIBRA?” for more information about side effects.

**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.

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

HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan  
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For more information, go to [www.HEMLIBRA.com](http://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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A Member of the Roche Group

# UPCOMING EVENTS



FALL 2023

SEPTEMBER  
7, 12, 21, 25

**6:30 PM**  
VWD Awareness Month -  
Virtual

**TUESDAY**  
OCTOBER  
3

**6:30 PM**  
Educational Dinner -Twin Falls  
Red Hawk Restaurant  
330 Canyon Crest Dr

**THURSDAY**  
OCTOBER  
5

**6:30 PM**  
Educational Dinner -Boise

**TUESDAY**  
OCTOBER  
10

**6-9 PM**  
Blood, Sweat, and Cheers Charity  
Golf Tournament - Top Golf in  
Meridian

**SATURDAY**  
OCTOBER  
21

**5:30-8:30 PM**  
Fall Retreat - Boise -  
Wahooz

**THURSDAY**  
NOVEMBER  
9

Educational Dinner - Caldwell -  
Restaurant TBD

REGISTER HERE





# NBDF Idaho Holiday Party


December 2, 2023

5:30 pm

Hilton Garden Inn

7699 W Spectrum St. Boise, ID

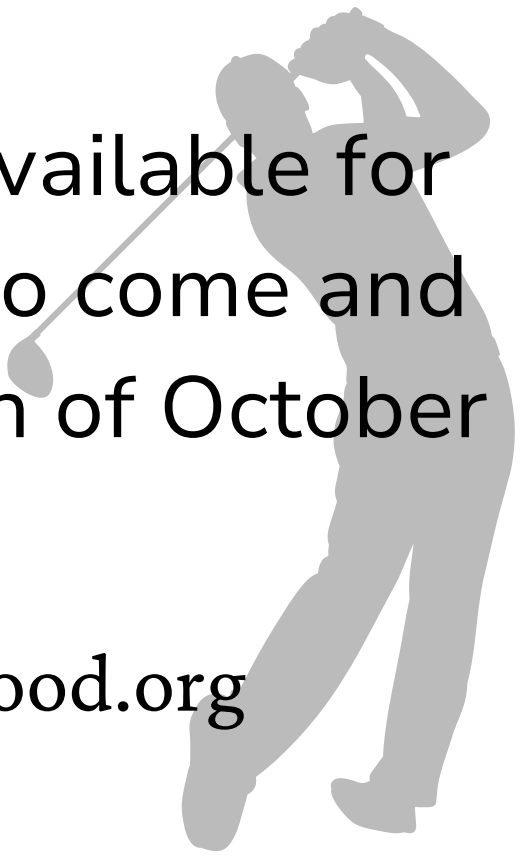
Register at [idahoblood.org](http://idahoblood.org)

- 
- Ugly Sweater Prizes
  - Christmas crafts and games
  - Gifts for kids 18 and under
  - Dinner

We still have tickets available for those who would like to come and golf with us on the 10th of October at Top Golf.



Register at [idahoblood.org](http://idahoblood.org)



**Idaho Chapter**

**NATIONAL BLEEDING DISORDERS FOUNDATION**