



NEWSLETTER

VISION STATEMENT

The Idaho Chapter of NHF 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.

INSIDE

- 2 Chapter Staff Unite Walk
- 3 Golf Tournament Annual Conference
- 6 Camp Red Sunrise
- 9 Your HTC
- 10 Men's Group Event Coming Events

FROM THE DIRECTOR

What a Summer!!

We have been chucked full of activities and events all summer long.

June saw Camp Red Sunrise full again with enthusiastic kids, parents and caretakers. However, for the first time in 8 years, we had snow! The weather was cold but that didn't stop the kids from having great fun and exploring their world. Luckily, the Camp had extra blankets and sleeping bags for those who only thought of our usual warm times on the mountain!

July started with an excellent educational dinner from Genentech and, later in the month, the Men's Group pulled out their guns at the indoor shooting range in Meridian. After an hour of gun safety, the group shot for two hours to see how good they were. It was followed by dinner and camaraderie sponsored by Octapharma.

August was full from start to finish. The Annual Conference at the Riverside Hotel in Boise hosted over 100 people from across the state from Idaho Falls to Post Falls. There were nine educational seminars for adults, a whole day of teen programs, and the smaller kids went to the Idaho Discovery Center for the afternoon. And, then of course, off to Roaring Springs Water Park for an evening of fun in the water.

August 16th saw us making up for the golf tournament that got rained out in May. At Eagle Hills Golf Course, the 24th Annual Blood, Sweat and Cheers was a success with a beautiful day and fourteen teams teeing off.

Barbara Fawcett, Executive Director

208-344-4476

bfawcett@hemophilia.org

OUR CHAPTER

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

Board of Directors

Rebecca Guy, *President*
Jacki Lamb
Joe Rex
Walter Justus
Meghan Levy
Michelle Weickum

Office Staff

Executive Director

Barbara Fawcett
Cell, 208-490-2596
bfawcett@hemophilia.org

Development Manager

Marlyn Walker
Cell, 208-631-9729
mwalker@hemophilia.org

Address

4696 W. Overland Road
Suite 234
Boise, Idaho 83705
208-344-4476
idahoblood.org

BOARD HELP WANTED

The NHF Idaho Chapter is looking for additional members to serve on our Board of Directors. If you, or someone you know, think you might like to serve our bleeding disorders community by being on our board please let us know. To add balance to the board we would be especially interested in talking to folks outside of the bleeding disorders community. To learn more about this opportunity to serve please call Barbara Fawcett at the Chapter office.

208-344-4476

Unite

for Bleeding Disorders

For the first time, the Idaho Chapter will have a Walk in Meridian and one in Idaho Falls. We are very excited to be presenting a Walk in the eastern part of the state.

9:00 Register

10:00 Walk

September 21, 2019
Hillsdale Park, Meridian

September 28, 2019
McCowin Park, Idaho Falls

Unite for Hope
Unite for Community
Unite to Make a Difference

Unite is the event that allows us to present so many educational and fun activities to you free-of-charge: Camp Red Sunrise, educational dinners, Victory for Women, the Annual Meeting, the Teen Group, Community Assistance, National Conference and the Men's Group.

The many important programs for those with hemophilia, von Willebrand disease and other bleeding disorders are possible because of the Walks!

Please Recruit Your Team Today
And Start Raising Money for the Cause
We Are With You Every Step of the Way!

www.uniteforbleedingdisorders.org

From Last Year



GOLF TOURNAMENT

The Delay Was Worth the Wait A Beautiful Day for Golf

Although our May date was rained-out, August 16th was a beautiful day to be out in the sunshine and on the course at Eagle Hills. Fourteen teams got an early start at a Scramble that included poker hands distributed around the holes. At noon, there was lunch and raffle prizes galore. This was the 24th Blood, Sweat and Cheers golf tournament held by the Chapter. We are looking forward to a smashing 25th year!



Winning foursome, Green Services, Inc.

ANNUAL MEETING?

Back at the Riverside Hotel this year. It is a perfect location to hear educational seminars and visit with pharmaceutical representatives. About one hundred community members met to see old friends again and meet new ones.

There were nine seminars lead by experts for the adults. The teens had an all-day program that included an infusion class and an excellent seminar on being a leader. The younger kids spent the day at the Idaho Discovery Center.

The luncheon speaker talked about not letting your

condition become "You." Working beyond it and using outside resources to get around it.

There were ten men who helped plan future Men's Group activities. If you are interested, please let the staff know.

After all the educational seminars were done and all the Reps had been talked to, the younger kids meet up with their parents and headed out to Meridian and the Roaring Springs Water Park.

This free event is one of the biggest activities we do each year.





GO SEEK. GO EXPLORE.
GO AHEAD.

Discover your sense of go. Discover HEMLIBRA®.

HEMLIBRA.com

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. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). 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.

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



HEMLIBRA
emicizumab-kxwh | 150 mg/mL
injection for subcutaneous use

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.

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 ingredients: 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

©2018 Genentech, Inc. All rights reserved.

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: 10/2018



© 2018 Genentech USA, Inc. All rights reserved. EML061818/0106a
HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
The HEMLIBRA logo is a trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
The Genentech logo is a registered trademark of Genentech, Inc.
All other trademarks are the property of their respective owners.

Genentech
A Member of the Roche Group

CAMP RED SUNRISE • 2019

Seventy hardy campers, parents, caretakers and siblings spent three days and two nights in the mountains, where the weather is usually warm during the day and cooler at night. This year was a surprise! Snow, rain and cold temperatures up until the last day.

The theme this year was GO EXPLORE and the kids did just that, although a lot of it had to be inside.

Arts, crafts, science projects, S'mores from the kitchen, movies and bike rides on the last day. Extra blankets and sleeping bags kept everyone toasty at night.

As always, Camp Red Sunrise is a *free*, family camp that welcomes all those with hemophilia or other bleeding disorders.







CAMP RED SUNRISE 2019

GO EXPLORE





YOUR HTC

The Idaho Hemophilia Treatment Center (HTC) is located in the St. Luke's Children's Hospital and Mountain States Tumor Institute (MSTI). A dedicated staff of skilled caregivers provide treatment and extensive support including: annual checkups, counseling, disease specialists, lab tests, and education for patients with hemophilia, von Willebrand's disease, and other blood disorders.

Staff

HTC Coordinator and Pediatric Nurse Practitioner

Kara Gardner, RN, PNP-BC

Hematologists/Oncologists

Eugenia Chang, MD

Nicolas Camilo, MD

Matthew Hansen, MD

Nathan Meeker, MD

Infectious Disease

Thomas Rand, MD, PhD

Family Nurse Practitioner

Marni Allen, FNP-BC

Social Worker

Becky Wiskus

Physical Therapist

Kay Craig

Career Counselor

Colin Car, MSEd

Nutritionist

Amy Mercer

Genetic Counselor

Christina Ikard

Address

100 E. Idaho St.

Boise, ID 83712

For information and appointments

208.381.2782

or Toll Free

1-800-845-4624

MARK YOUR CALENDAR

Coming Chapter Events

September 20

6:30 pm Educational Dinner,
Brickyard, 601 W. Main, Boise.
Sponsored by Takeda/Shire

September 21

10:00 am, NHF Idaho Chapter
Unite Walk, Hillsdale Park,
5155 Howry Lane, Meridian

September 28

10:00 am, NHF Idaho Chapter
Unite Walk, McCowin Park, 3074
Targhee St. Idaho Falls

October 3-5

National Hemophilia Foundation
Annual Conference
Anaheim, California

October 10

6:30 pm, Victory for Women dinner
Venue TBD

October 16

6:15 pm, Board Meeting
Chapter office

November 2

6:30 pm Educational Dinner,
Venue TBD, Boise.

November 12

6:30 pm, Men's Group dinner
Venue TBD, Boise



MEN'S GROUP

The Men's Group met at the new indoor shooting range in Meridian in July for education and camaraderie, and dinner which was sponsored by Octapharma. They spent an hour learning about gun safety and the

rules of the facility, then took to the range. They had great fun finding out who was the best shot and who could hit that center ring.

Any male over 18 with a bleeding disorder or caring for someone affected is welcome to the Men's Group events.



COMMUNITY ASSISTANCE FUNDS AVAILABLE

We are all aware of the huge cost of factor and the care of those with bleeding disorders.

We want to remind you that the Chapter can help with the expense of utilities, doctors' bills, travel and other household bills up to \$500 per year. If you need help with immediate expenses, please call or e-mail Barbara at the Chapter office and ask for a Community Assistance Project form.

208-344-4476
bfawcett@hemophilia.org

TEEN PROGRAM Calling all Teens

We want to hear from you. This year we are working to get a regular schedule of activities. What do you like to do? What activities would you like to try? What outdoor skills do you want to learn? We are looking for ideas and suggestions.

We also need teens to help plan and develop the program. Involvement looks great on a scholarship or college application, or a resume.

Please contact the chapter office with your ideas or your desire to help.

208-344-4476

Find us on our new facebook group and join the group.
Teens With Idaho Chapter of NHF

DID YOU KNOW?

Do you hate: to fund raise, asking everyone for money, don't have money to donate in a big chunk, but still want to help the chapter?

Did you know that NHF Idaho has a great new program that makes it easy to donate a little every month to the Chapter?

Go to idahoblood.org, click on **DONATE NOW**, set up a reoccurring monthly donation account. You can set it up for any amount: \$10 a month is \$120 a year—that helps send a kid to camp.

Share the news. If we all give a little we can help our Chapter to grow.

WE ARE LOOKING FOR INDIVIDUALS TO MAKE A DIFFERENCE in our community and who would like to be on a committee.
Help is needed on the following:

**CAMP
SOCIAL MEDIA
GOLF PROGRAM
VICTORY FOR WOMEN
TEEN PROGRAM
WALK**

If you can help, please call the Chapter office, today!
208-344-4476

OWN A SMALL BUSINESS?

Members of the NHF Idaho Chapter community are invited to submit advertisements for their business to appear in our Newsletter,

 **FREE** 

Ads will be subject to space availability and approval by the staff.

Ads should be submitted in a ready to print digital format.

Acceptable files are JPG (150dpi, minimum) or PDF.

Size of ad must be 3¼" w x 3¾" h. For additional information call the Chapter office,

208-344-4476

The NHF Idaho Chapter NEWSLETTER is published quarterly in Boise, ID. For information, questions, to submit articles or advertising for the Newsletter please contact,

Marlyn Walker at 208-631-9729 or
mwalker@hemophilia.org.

The information contained in the NHF Idaho Chapter Newsletter is provided for your general information only. NHF Idaho does not give medical advice or engage in the practice of medicine. NHF Idaho, under no circumstances, recommends particular treatments or endorses products for specific individuals and in all cases recommends that you consult your physician or Hemophilia Treatment Center before pursuing any course of treatment.



**IDAHO CHAPTER
NATIONAL HEMOPHILIA FOUNDATION**

4696 W. Overland Road
Suite 234
Boise, Idaho 83705-2864

Unite
for Bleeding Disorders



**IDAHO CHAPTER
NATIONAL HEMOPHILIA FOUNDATION**

2019 Walk

UNITE FOR HOPE.

UNITE FOR COMMUNITY.

UNITE TO MAKE A DIFFERENCE.

September 21
Hillsdale Park, Meridian, ID
10:00 am

September 28
McCowin Park, Idaho Falls, ID
10:00 am

REGISTER TODAY AT
www.uniteforbleedingdisorders.org