



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.

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FROM THE DIRECTOR

As I wrap up my third month with the organization, I want to thank all that have reached out and I have met in person or talked to on the phone for the warm welcome. I am very impressed with the community support and connection that I see amongst us.

The beginning of 2020, programmatically, has been very successful. We had a group of community volunteers travel to Arizona for the annual NACCHO conference and volunteers and myself traveled to Washington DC to attend Washington Days. Our local events included effective advocacy education and trainings and successful Men's Group and Women's Group events. More details about the events can be found later in the newsletter.

We are now in the midst of the international health crises – COVID-19 (coronavirus). In the best interest of our community members and supporters, we will need to be nimble and make adjustments to the community calendar. We have already postponed or re-imagined events through the beginning of May – but that may not be enough. Most notably, we have postponed the Bloody Mary Mix-off, originally scheduled for middle of April. The staff is working closely with the national office and following local and national guidelines to make decisions on events moving forward. We will continue to provide updates via email and social media. If you need updates in a different way, please let me know.

Through all of this, we are still committed to the mission of our organizing and our main focus is on the health of our community members. If you need anything, please know our organization is here for you – please feel free to reach out. I look forward to seeing you at our next in-person or virtual event!

Michael Krieger, Executive Director

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*
Walter Justus, *Vice President*
Joe Rex
Michelle Weickum

Office Staff

Executive Director

Michael Krieger
Cell; 208-490-2596
mkrieger@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, 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 the Chapter office.

208-344-4476

Advocacy Educational Series

To start off the year, we had a 5-session Advocacy Training Series. Each session built upon the previous and was well received by the attendees. Thank you to Takeda for supporting this program and to our presenters: Zach Walker, Debbie Field, Walter Justus, and Michael Krieger. The conversations allowed the attendees to develop their advocacy platform, understanding the importance of telling their story, and made plans for continuing the advocacy program at our state capitol.

Communication and Social Media

Please connect with us via electronic communication. We will still be sending out hard copies of this newsletter, but we are increasing our email and social media presence. The office is working on our communication plan. We have introduced a few new generic email addresses that we want you to save. Our general communication will be sent through a third-party email service from idaho@hemophilia.org. Please make sure you save this to your contacts so emails do not end up in spam folders. On that note, if you have not been receiving emails over the last

month, please check your spam folder, we have been sending emails out. If you cannot find any emails, contact our office so we can make sure your personal contact information is up to date. For our walk programs, we have introduced a new email address:

idahowalk@hemophilia.org.

This email address will support both walk events.

We are also increasing our social media usage. Please follow us on Facebook:

facebook.com/NHFIIdaho

and on Instagram:

Instagram.com/NHFIIdaho

Please interact with our page, tag/mention us. If you do not use Social Media not to worry, we are making an effort to keep our web site up-to-date:

www.idahoblood.org

When communicating via email with our office, you can contact Michael or Marlyn directly, or you can send an email to our generic accounts:

idaho@hemophilia.org

or

idahowalk@hemophilia.org.

If you have any questions, ideas, thoughts, or interest helping with communication or social media, please contact Michael:

mkrieger@hemophilia.org

Volunteers Needed

Interested in getting more involved in our community? We are always looking for community members to volunteer and assist with our programming efforts. If you have any interest in event planning and outreach, please contact us.

Comprehensive Clinics

Coming to Boise for a comprehensive clinic or any schedule appointment at St. Luke's HTC? Call or email us to let us know! We would love to have you stop by the office while you are in town.



Explore HEAD-TO-HEAD Pharmacokinetic (PK) Study Data

See half-life, clearance and other
PK data from the crossover study
comparing **Jivi®** and **Eloctate®**

Visit **PKStudies.com** to find out more.

► **Pharmacokinetics** is the study of the activity
of drugs in the body over a period of time.


antihemophilic factor
(recombinant) PEGylated-sulfate
LET'S GO



February Educational Dinner

We had an impressive turnout for a middle of the week educational dinner. We had a great conversation on self-advocacy and its importance. The community members in attendance were fully engaged and gained confidence in being their best self-advocate. Thank you to our sponsor Pfizer for leading the conversation.

Victory for Women

This year's third Annual Victory for Women retreat was unforgettable! A record number of ladies joined us on March 6th and 7th at the Oxford Suites in Boise, Idaho. We were taught and inspired by some wonderful ladies. They shared stories, facts and thoughts to uplift us in knowing we are not alone in our journey. This year's theme, "Find your Word," helped us all to find purpose and determination through picking a word that meant something to us. We found that one word can set us on a path to change us, our family, and the world if we choose to.

Friday night started off with a wonderful presentation by Takeda on being prepared. The advice given has helped us all find peace in the craziness of the world. Dinner was at Tucanos where we enjoyed great food and even better company. Saturday was filled with wonderful classes from the Hemophilia Treatment Center, Novo Nordisk,

CSL Behring, Octapharma, Bayer, and Genentech. We also had time for crafts and visits with friends.

We are very thankful to our many wonderful sponsors that made this event possible! Thank you all who helped prepare, plan, sponsor and carry out the Victory for Women retreat. We cannot wait for another great event next year!



NACCHO

The North American Camping Conference for Hemophilia Organizations (NACCHO) was held this past January 17–19 in Phoenix, Arizona. The annual event is hosted by the Arizona Bleeding Disorders. This year 180 camp directors and counselors from around the world attended. The conference is designed to learn from experts and to exchange ideas and information about creating safe and meaningful camps for people with bleeding disorders. The theme this year was, *Camp–Home Away From Home*.



Representing the Idaho Chapter this year were; Zach Walker, Walter Justus, Joe and Tanna Rex. Joe and Tanna, our Camp Red Sunrise co-director were there to attend various sessions, networking with other camp staff on creating better camp activities, and dealing with safety and social issues. Zach and Walter were there as speakers. Zach and Walter directed a session, “What Would Adults Want?” The session was about creating camp style programs to engage and impact adult patients, the largest and fastest growing segment of the bleeding disorders community. The sessions included some very thought provoking discussions from camp-experienced adult patients about designing programs specifically for adults.

Zach presented at two other sessions: “Let It Snow–In June,” which was about what to do when not everything goes as planned because of things you have no control over, like the weather. The session included ideas for planning ahead and having alternative plans for unexpected events that impact your camp. Zach’s other session was, “Get Everyone Involved.” This session was about engaging

everyone at a family camp especially at camp wide activities when there are campers of widely different ages and abilities.

NACCHO Bowl—The Best Of The Best. Each year camps are invited to submit a two-minute video sharing their best ideas. Amazon gift cards are awarded to the top three to fund their camp program. This year our Camp Red Sunrise captured first place and a \$1,000 gift card. Thanks to camp staff member, Bob Graham, for putting the video together.



Upcoming Events

BLOODY MARY MIX OFF
Postponed

CAMP RED SUNRISE
June 25–27

ANNUAL MEETING
August 14–15

**25th Annual
BLOOD, SWEAT & CHEERS
GOLF TOURNAMENT**
Spread the word
August 21

UNITE WALK - IDAHO FALLS
September 12

UNITE WALK - MERIDIAN
September 19

We also have educational dinners, evening and daytime events. Please check our website frequently for information about dates and times.

www.idahoblood.org

GO SEEK. GO EXPLORE.
GO AHEAD.

PEOPLE LIKE YOU. STORIES LIKE YOURS.
Explore more at HEMLIBRAjourney.com



Discover your sense of go. Discover HEMLIBRA®.

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**.



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 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.

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Genentech
A Member of the Roche Group

YOUR HTC

The Idaho Hemophilia Treatment Center (HTC) is part of the St. Luke's Health System, located in Boise. 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

Nicolas Camilo, MD

Eugenia Chang, MD

Matthew Hansen, MD

Nathan Meeker, MD

Infectious Disease

Thomas Rand, MD, PhD

Family Nurse Practitioner

Marni Allen, FNP-BC

Social Worker

Diane Bartlett

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

Men's Group

Our first men's group event of the year turned out quite the crowd. We had 13 community members attend, plus members of our partners who helped us host the event – Bayer and Diplomat. We enjoyed a great conversation around

joint health over dinner before cheering on the Idaho Steelheads. Thank you to those who attended the event; we are looking forward to seeing you and more members of the community at our next event!



Washington Days

we took in the sights and history, but most importantly advocated on behalf of the state of Idaho to four of our state representatives. We were able to talk to the following offices:

Congressman Mike Simpson, Senator Jim Risch, Congressman Russ Fulcher, and Senator Mike Crapo. Overall, we had great conversations with each of the offices. Each family was able to share their story which was very impactful and left a lasting impression on the staff members that we met with; in addition to speaking to them on behalf of the active bill looking to provide our community access to Skilled Nursing Facilities at an appropriate care level.

The Shaw family was really grateful for this experience – they were able to advocate and take in some museums and monuments. Reflecting on the experience, both Whitney and Ashley



At the end of February, Washington, D.C. welcomed over 400 bleeding disorder advocates from around the country. This year, we were fortunate enough to send 6 members of our community: The Shaw Family: Kymm, Milo, Ashley, Whitney, and Carter; Walter Justus; and Michael Krieger. It was the Shaw Family and Michael's first time at the event, so we took our cues from event-veteran Walter. In addition to the NHF training, Walter helped coach us through the conversations. During our time in Washington, D.C.,



identified that this was a valuable experience in advocacy but also in showing the legislative staff how hemophilia impacts the entire family, not just the affected person. Carter appreciated the ability to tell his story directly to the team that is able to make a difference. Let's also not forget to commend Carter

for providing his coat to someone less fortunate he met while touring the monuments. GREAT JOB CARTER – WE ARE PROUD OF YOUR GENEROSITY. Kymm added, while reflecting, that she realized the importance of advocacy — every story, every voice is important and should be heard! Milo was proud to be able to educate the government staff on bleeding disorders and provide real-life situations where decisions made could impact our community drastically. Michael was proud of the efforts put forth by our team in Washington, D.C. He believes a real impact was made on those we were able to meet with and tell our stories.

Until next year...

Washington Days

March 3-5, 2021

If you are interested in participating in this experience, please be on the lookout for a communication from the Chapter later this year.



JUNE 25-27, 2020
FAMILY CAMP

REGISTER TODAY AT
IDAHO-blood.org



AROUND
THE
WORLD

CAMP RED SUNRISE
IS OPEN TO ALL FAMILIES
IN THE IDAHO AREA THAT
ARE AFFECTED BY A
BLEEDING DISORDER

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 Michael at the Chapter office and ask for a Community Assistance Project form.

208-344-4476
mkrieger@hemophilia.org

Thanks for reading the Spring Newsletter, email Michael, mkrieger@hemophilia.org, to be entered in a drawing for your chance to win some NEW NHF Idaho Swag! Drawing will happen on May 1, 2020.

DID YOU KNOW?

Did you know that NHF Idaho has a 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 child to camp.

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

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 you desire to help.

208-344-4476

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

**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 contact the
Chapter office, today!**

**208-344-4476
or idaho@hemophilia.org**

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 3⅜" 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,

Michael Krieger 208-490-2596 or
mkrieger@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.



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