



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

Our summer months and experiences were not ones of typical years. We had expectations of gathering together in the Sawtooth Mountains for our annual family camp, Camp Red Sunrise, gathering in the Boise-area for an educational weekend capped off with some fun, and other community gathering opportunities. Even though these events were not offered as originally planned, I hope you all had a great time with our adjusted virtual experiences. As we are all adjusting to how to learn, connect, and collaborate virtually, I hope everyone had an opportunity to connect with our community.

As we round out the rest of the 2020 year, we plan to have a few more virtual events. One of those events to note is our Holiday Party. Yes, we are bringing our annual Holiday party back! Save the date, Saturday, December 12, and RSVP on our web site now. We plan to send the kids in attendance a special gift, make sure you sign up early so we can ensure we can get the gifts to you in time.

Marlyn and I have been working on our programming for 2021—we hope to bring you new programs and experiences.

I hope you all are enjoying your fall months and I look forward to seeing you on a Zoom event soon!

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

Walter Justus, *Acting President*
Joe Rex
Michelle Weickum

Office Staff

Executive Director
Michael Krieger
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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



Zach Walker, Camp Director



This year was Camp Red Sunrise's ninth annual family camp. Every year Camp provides new experiences for our campers and our staff, and this year was no exception. We were not able to meet together in the beautiful mountains of Idaho this year, but we were able to "virtually" gather and still have a lot of fun together.

The theme for Camp this year was "Around the World-One Community". Each day of camp we "flew" to another location on our planet and learned a little about that location. Kids and parents were able to participate in Camp through activities delivered to their homes, video conferencing and a private social media group. Thanks to the generous supporters of Camp Red Sunrise, we were also able to have a couple of meals delivered to camp families' homes during camp week.

No, it wasn't the same as being at a camp facility together, but we were able to do some things together that have meant a lot to our campers and staff in the past. For instance, the Squirrely song was still sung, and we still all had S'mores. Our camp nurse taught all of us how to better care for ourselves. We

held classes with different age groups using video conferencing. Our awards ceremony was a little different this year, but a tradition we didn't want to miss out on. So, we asked parents to hold a ceremony for their own kids, record the ceremony, then share it with our private social media group.

Our Camp Planning Committee and Staff would like to thank the parents and grandparents who helped make Camp Red Sunrise a memorable experience this year for the kids. We could not have made it a success without their participation.

Thank you to our sponsors for making out virtual camp for 2020 such a success!



Family Education Weekend

Our Annual Meeting, or Family Education Weekend, looked a little bit different this year. Instead of traveling to Boise and spending time in a hotel going to education sessions and reconnecting with friends, we stayed home and connected over Zoom. Thank you to all those who attended: we had 22 families join us, which accounted for 81 community members! Since we were virtual, we had community members from four states attend: Idaho, Oregon, Utah, and California.

Even with being apart, we were able to still learn from our educational speakers and peers and connect with new and familiar friends. We had 6 education sessions, ranging from hearing personal experiences from those with bleeding disorders to learning concepts and tools that can be used in every-day life.

Thank you to our sponsors for supporting our Family Education Weekend!



*Join us for our
Holiday Party!*

*Saturday, December 12,
starting at 12:30 PM MT*

*RSVP on our website's
event calendar.*

*Please RSVP early so we can
ensure your children can fully
enjoy the event with a gift to open*



GO SEEK. GO EXPLORE. GO AHEAD.

PEOPLE LIKE YOU. STORIES LIKE YOURS.
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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
Revised: 10/2018



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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 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

Women's Group

At the end of September, our women's group was able to meet and connect over a Zoom call. Thank you to DrugCo Health and Stephanie Shea for leading an important conversation on the emotional and stressful components of blood clotting conditions. We had 12 ladies join us for this education and community connections opportunity.

We look forward to our next Women's event.

Thanks for reading the Autumn 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 December 1, 2020.



In July, there was a voluntary recall of **Stimate**. For more information, contact us or the HTC.



COMMUNITY ASSISTANCE FUNDS AVAILABLE

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

208-344-4476

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.

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 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.



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WE NEED YOUR PHOTOS!

*We are putting together a 2021 Calendar again, but need your help with photos!
Do you have family or group photos of community members from this year to share?
Please send them to Idaho@hemophilia.org to be featured in our calendar.*

