



**IDAHO CHAPTER  
NATIONAL HEMOPHILIA FOUNDATION**

# 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.

## FROM THE DIRECTOR

*It is with sadness but excitement that I must say goodbye to all of you.*

I am retiring at the end of the year. With 57 years in the nonprofit business, I felt it was time to turn the reins over to a new set of eyes and a younger energy-level! After five years at the NHF Idaho Chapter, I have made good friends and been impressed with the concern you show to each other. Hemophilia was new to me and I have learned about the hardships and the joys each victory brings to families.

We are pleased to introduce Michael Krieger, our new Chapter Executive Director for NHF Idaho. Michael has moved to Idaho with his wife, Kyla, and 1½ years old son, Huxley—who has Hemophilia A severe. Michael comes to the National Hemophilia Foundation from the Higher Education sector. Most recently, he spent over 7 year at the University of the Pacific in Stockton, California. While there, he held roles that created programming, both social and educational; policies and procedures; fundraising; and volunteer efforts for the University and its students. Michael was also involved with his local hemophilia chapter, Central California Hemophilia Foundation, where he was the Board of Director's Vice President. He holds a Bachelor of Science from University of the Pacific in Business Administration and a Master of Science from Indiana State University in Student Affairs & Higher Education. Michael enjoys spending time with his family and friends, watching and playing soccer, and trying local restaurants. He is looking forward to exploring and learning more about his new community with his wife, son, and family that lives in the area, and says, "I look forward to connecting with all families in the Idaho community soon!"

*Barbara Fawcett, Executive Director*

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## 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*  
Jacki Lamb  
Joe Rex  
Michelle Weickum  
Greg Myers

### 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, 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 the Chapter office.

**208-344-4476**

## WELCOME TO OUR CHAPTER

*NHF Idaho Chapter's new Executive Director, Michael Krieger with his wife, Kyla and son, Huxley.*



## Two Educational Dinners

Both Takeda and Genentech provided dinners at Outback. Each held the audiences' attention with educational material that could be put to immediate use. We thank both companies for their generosity and learning experience.

Foundation's Annual Conference in Anaheim, California. With thousands of people there from all over the world, it was two days of education, camaraderie and comparing Chapter programs, challenges and solutions.

On the final day of the Conference, the Idaho Chapter was presented with a *Chapter of Excellence* award.

## Giving Tuesday

As you know, Giving Tuesday was December 3rd but you can continue giving throughout the month. Make this your year-end, Holiday donation.

Go to [Idahoblood.org](http://Idahoblood.org) and click on the DONATE button. Thank you.

## National Conference

Rebecca Guy, our Board President, and Marlyn Walker, our Chapter Development Manager, represented Idaho at the National Hemophilia





This Partnership Award recognizes chapters who have made particular effort in shared initiatives, trainings and programs of NHF while contributing to the relevance and vitality of the national network. Chapter Partnership awardees have gone above and beyond in their support and application of our mission.

*Rebecca Guy (far right) and other NHF Chapter representatives receiving the Partnership Chapter of Excellence Award from NHF CEO, Val Bias.*



*The hemophilia treatments of today were once  
the dreams of yesterday. Proof that when*

## SCIENCE AND THE COMMUNITY

*come together, great things happen.*

**Genentech** | Hemophilia A  
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*Let's put science to work*

**GenentechHemophilia.com**

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## HEALTH INSURANCE

M HEALTH LAB (Michigan) *July 18, 2019*

### Health Insurance Rule Change Could Help Millions of Chronic Disease Sufferers Spend Less for the Care They Need Most

Millions of Americans with chronic conditions could save money on the drugs and medical services they need the most if their health insurance plans decide to take advantage of a new federal rule.

The idea behind the rule was born at the University of Michigan.

This week, the U.S. Department of the Treasury gave health insurers more flexibility to cover the cost of certain medications and tests for people with common chronic conditions who are enrolled in many high-deductible health plans.

The rule change came about in part because of research and over a decade of health policy engagement by U-M professor A. Mark Fendrick, M.D., and his colleagues at the U-M Center for Value-Based Insurance Design.

About 43 percent of adults who get health insurance through their jobs have a high-deductible plan, which requires them to spend at least \$1,300 out of their own pockets before their insurance starts covering their care, or \$2,600 if they cover dependent family members.

People with high-deductible health plans typically have to pay the entire cost for services used to manage chronic conditions – such as inhalers for asthma, blood sugar testing and insulin for diabetes, and medicines to treat depression and high cholesterol – until they have reached their plan deductible.

More than half of them have access to a special kind of tax-advantaged health savings account to save money for their healthcare costs, and some employers contribute to those accounts.

But until today, the federal tax code specifically barred high-deductible plans with health savings accounts, or HSA-HDHPs, from covering drugs and services for common chronic conditions until enrollees met their deductibles. Such coverage could reduce the chance that people with chronic conditions will skip preventive care visits because of cost, and improve their longer-term outcomes.

Meanwhile, the bipartisan Chronic Disease

Management Act of 2019 was introduced in the Senate and House of Representatives last month with the same goal of lowering out-of-pocket costs for Americans with chronic conditions confronting high plan deductibles.

"As more and more Americans are facing high deductibles, they are struggling to pay for their essential medical care," says Fendrick, a professor at the U-M Medical School and School of Public Health and an internal medicine physician at Michigan Medicine.

"Our research has shown that this policy has the potential to lower out-of-pocket costs, reduce federal health care spending, and ultimately improve the health of millions diagnosed with chronic medical conditions. We have actively advocated for this policy change for over a decade."

### Specific Coverage for Specific Enrollees

The new rule designates 14 services for people with certain conditions that high-deductible health plans can now cover on a pre-deductible basis.

The list closely aligns with the one laid out by the V-BID Center in a 2014 analysis. That report, based on clinical evidence available at the time, shows that these tests and treatments could help people with chronic diseases manage their health and detect or prevent the worsening of their conditions at a lower cost.

#### The list includes:

- ♦ ACE inhibitor drugs for people with heart failure, diabetes and/or coronary artery disease
- ♦ Bone-strengthening medications for people with osteoporosis or osteopenia
- ♦ Beta-blocker drugs for people with heart failure and/or coronary artery disease
- ♦ Blood pressure monitors for people with hypertension
- ♦ Inhalers and peak flow meters for people with asthma
- ♦ Insulin and other medicines to lower the blood sugar of people with diabetes
- ♦ Eye screening, blood sugar monitors and long-term blood sugar testing for people with diabetes
- ♦ Tests for blood clotting ability in people with liver disease or **bleeding disorders**
- ♦ Tests of LDL cholesterol levels in people with heart disease

- ♦ Antidepressants (SSRIs) for people with depression
- ♦ Statin medications for people with heart disease and/or diabetes

The new Treasury guidance also leaves the door open to allow high-deductible plans more flexibility in the future for coverage of other preventive services for people with these and other chronic conditions. Fendrick and Harvard University professor Michael Chernew, Ph.D., articulated the need for regulatory changes to level the playing field for people with chronic conditions in high-deductible health plans in the

Journal of General Internal Medicine article in 2007.

V-BID principles – based on the idea that the highest-value clinical services should cost the least to people who need them most – have also made their way into other kinds of health insurance plans. For instance, Medicare Advantage plans, offered by private insurers to people over age 65 and with disabilities, are now able to offer plans with value-based co-pays. So are plans offered under TRICARE, the insurance program for military families, and private employer-sponsored plans without high deductibles.



## HEMOPHILIA THREE TIMES MORE PREVALENT THAN THOUGHT

NEWSWISE (Hamilton, On) Sept. 10, 2019

More than 1,125,000 men around the world have the inherited bleeding disorder of hemophilia, and 418,000 of those have a severe version of the mostly undiagnosed disease, says a new study led by McMaster University researchers.

This is three times what was previously known. Only 400,000 people globally were estimated to have the disorder which is caused by a defect in the F8 or F9 gene which encodes instructions for making the factor proteins that helps blood clot. For those with hemophilia, lack of treatment leads to chronic and disabling joint disease, while bleeding into organs and brain hemorrhages can lead to disability and death.

The international research team was also able to calculate, for the first time, the prevalence of hemophilia among babies at birth, which enabled them to estimate that the life expectancy of those with hemophilia is significantly less than other people, particularly in lower-income countries where there is lack of treatment.

They found that, per 100,000 males, 21 will have hemophilia A or B, seven of whom severely; among newborns, per 100,000 males, 29 will have hemophilia A or B, of whom 12 will have the severe form of disease.

Putting the numbers together, the 'life expectancy disadvantage' associated with hemophilia may be estimated and varies depending with the availability of care. For those born with hemophilia, the chances of living a life of normal duration and quality will be

reduced by 64% in upper-middle income countries, 77% in middle income and up to 93% in low income countries. The study will be published in the Annals of Internal Medicine on Sept. 10.

"This paper is a milestone in our journey to providing care for hemophilia patients worldwide," said Dr. Alfonso Iorio, lead author of the paper, professor health research methods, evidence, and impact at McMaster University and director of the Hamilton-Niagara hemophilia program at Hamilton Health Sciences.

"Knowing how many patients are expected in each country given its population is an important measure of the efficiency of the health care system. Knowing how many patients should be there, and how many less instead are reported to national and international registries is a measure of the work left to be done," he said.

"Knowing how many patients are out there will enable health care systems to estimate the resources needed to treat the disease, and enable drug manufacturers to increase the investment in research to match the demand of a patient population three times larger than we previously thought."

For the World Federation of Hemophilia, Iorio assembled an international team of researchers from France, U.S. and U.K. to perform a meta-analysis of the registry data in countries with the most comprehensive registries of hemophilia, which were Australia, Canada, France, Italy, New Zealand and the U.K.





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#### 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](http://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 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

## UNITE FOR BLEEDING DISORDERS

We tried something new this year and it worked!! Not only did we hold a Walk in Boise at Hillsdale Park in Meridian, but we also held the first Walk in Idaho Falls in McCowin Park.

The Eastern Community members really came through, bringing in almost as much money as the Boise group!

Together over \$18,000 was raised. We want to thank Kim Poling for all her help in Idaho Falls.

Next year we will hold a contest between the two Idaho "Coasts" to see which raises the most money for Camp Red Sunrise! Below are pictures from each Walk.

### Boise Walk, Hillsdale Park







Idaho Falls Walk, McCowin Park







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# HAPPY HOLIDAYS



WE LOOK FORWARD TO WORKING WITH YOU IN THE NEW YEAR

## Diplomat Specialty Infusion Group

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Visit [diplomatpharmacy.com/specialtyinfusion](http://diplomatpharmacy.com/specialtyinfusion)

  



## 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**

## 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](http://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.*

## 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**

**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 3½" 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](mailto:mwalker@hemophilia.org).

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