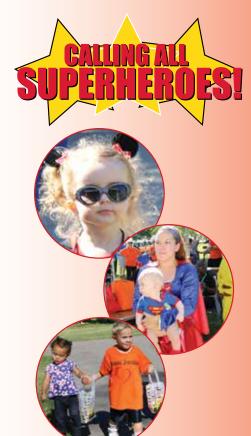
KHFHemospher

Cardiovascular Disease in Hemophilia Patients

Because of their lower factor levels, hemophilia patients are generally thought to be better protected from cardiovascular disease (CVD). To determine whether data would support this long-held assumption, a team of investigators enrolled patients from 19 U.S. hemophilia treatment centers (HTCs) in the "CVD in Hemophilia" study. The lead author of the study was Barbara Konkle, MD, Professor of Medicine in the Division of Hematology at the University of Washington School of Medicine in Seattle, WA. She is also Director of Clinical and Translational Research, Associate Director of the Washington Center for Bleeding Disorders, and Director of the Hemostasis, Platelet Immunology and Genomics Laboratory at Bloodworks Northwest.

In all, 200 moderate and severe hemophilia patients, ranging from 54 to 73 years of age, were enrolled in the study between 2012 and 2015. The purpose was to better understand the prevalence of CVD in these patients. Konkle and her fellow authors collected medical records and patient interviews, then compared the HTC data with unaffected men of comparable age ranges. The comparison data were drawn primarily from the US Atherosclerosis Risk in Communities (ARIC) survey group.

The authors defined CVD in patients who had presented with certain symptoms and procedures including angina, a type of chest pain caused by reduced blood flow to the heart; any myocardial infarction (MI) or heart attack; nonhemorrhagic stroke or transient ischemic attack, often referred to as a "mini stroke"; any history of heart-related procedures such as coronary bypass graft surgery or coronary artery angioplasty. Ultimately, 30 of the hemophilia patients met the established CVD criteria, with the most common events being angina and MI. When compared with the unaffected group, the HTC patients did experience significantly less CVD events and procedures, with an overall rate of 15% vs. 25.8% in the ARIC group.





Walk 2018

Saturday, September 29
Wetherby Park

Special News

NATIONAL HEMOPHILIA FOUNDATION: PENDING INSURANCE MARKET REFORMS — UNDERSTANDING THE POSSIBLE IMPACT



Understanding your health insurance coverage options is challenging in even the best of circumstances. But, when you add in the current uncertainty and dynamics of the health insurance market, these challenges are amplified. As we look to 2019, a lot of attention is being paid to the rising insurance premiums with good reason. Early rate filings from several states show double-digit premium increases for next year for marketplace plans, which are well above increases in previous years. But, that is just part of the story. Many experts believe that changes to marketplace plans and the individual market may impact employer-sponsored insurance. This sheet is designed to help you understand why these projections matter and what you can do to prepare.

Part of the reason for rising premiums is the 2019 Notice of Benefit and Payment Parameters (NBPP). Broadly, the NBPP:

- Lowered protections for people with pre-existing conditions
- · Increased the cost of coverage; and
- Increased barriers to enrollment.

Specifically, NBPP gives states more flexibility to define their essential health benefits (EHBs). As you may recall, EHBs are the ten categories of benefits that all plans must cover such as prescription drugs, hospitalizations, and emergency services. This is important to us because lifetime and annual limits are banned, and out-of-pocket expenses are capped only for services defined as EHBs.

For more information about EHBs: https://www.cms.gov/cciio/resources/data-resources/ehb.html.

The administration is also proposing to expand access to a few different types of plans that don't have to meet the Affordable Care Act (ACA) standards, including:

Short-term, limited duration (STLD) plans: bare bones or skinny plans

- Non-ACA compliant because they do not count as minimum essential coverage.
- Generally, medically underwritten applicants with health conditions can be turned down or charged higher premiums, without limit, based on health status, gender, age, and other factors
- Plans can exclude coverage for people with pre-existing conditions
- Not required to cover EHBs—many have limited or no coverage for prescription drugs
- · Can impose lifetime and annual limits

For more information about STLD plans: https://www.kff.org/health-reform/issue-brief/understanding-short-term-limited-duration-health-insurance/.

Association health plans (AHPs)

- Allows small employers and self-employed people to join together and buy a new type of association health plan coverage (type of multiple employer welfare arrangements, or MEWAs)
- AHPs do not have to meet all requirements applicable to other ACA-compliant plans
 - o Not required to cover EHBs—many have limited or no coverage for prescription drugs
 - o Could vary premiums based on gender, type of job/industry, and other factors

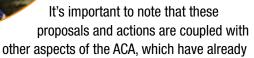
For more information about AHPs:

https://www.kff.org/health-reform/issue-brief/proposals-for-insurance-options-that-dont-comply-with-aca-rules-trade-offs-in-cost-and-regulation/.



UNDERSTANDING THE POSSIBLE IMPACT

continued.



been dismantled, including repeal of the individual mandate in the 2017 tax reform bill.

NHF has submitted comment letters in response to these proposals and previous attempts to compromise access to comprehensive insurance. In addition, we have signed onto numerous patient advocate letters protecting our access to care.

Update on Latest ACA Lawsuit

In February, a group of Republican State Attorneys General filed a case (Texas vs. US), which seeks to invalidate the ACA in its entirety. Their legal argument is that when last year's tax reform law removed the penalty for the individual mandate starting in 2019, this not only essentially invalidates the mandate, but must also invalidate the entire ACA since the mandate is such an integral part of the law. Last week, the Department of Justice said that it would defend most of the ACA in this lawsuit but would not defend the ACA's pre-existing conditions protections, since the guaranteed issue and community ratings provisions are cannot be severed from the individual mandate. Since then, a group of Democratic State Attorneys General, as well as a number of additional health care stakeholders, including patient groups, providers, and insurers,



have filed briefs supporting the ACA in general and pre-existing conditions protections in particular. The legal process for this lawsuit will take several months and there would likely be Congressional and state action if the lawsuit is successful. NHF understands that many community members may have concerns about their access to coverage, and NHF will be closely monitoring the legal and political issues surrounding the lawsuit and will update the community as they progress.

WHY DOES THIS ALL MATTER AND HOW COULD THIS AFFECT ME?

Collectively, these regulations create two separate health insurance markets— one for healthy and the other for people with pre-existing conditions. Moreover, it further destabilizes the health insurance marketplaces.

Plan options for those with pre-existing conditions could be limited and cost more. If you are eligible for a less-costly plan, it may not cover your needs such as prescription drugs, maternity care, and other EHB categories.

WHAT SHOULD I DO?

- Buyer beware we strongly encourage you to shop carefully! Look at all the details and don't buy a plan just because it costs less. Ask questions, like are my prescription drugs covered? Will you have access to the providers you need? Are there limits on services or drugs?
- Only you know your healthcare needs—use caution when considering recommendations for plans.
- Call your HTC social worker or chapter for help in navigating plans!
- Don't wait until the last minute to shop!
- Be prepared for higher premiums and plan accordingly.

NHF will continue to monitor these issues and provide updates. If you have any questions or concerns about your coverage please email us at advocate@hemophilia.org.

Event News

Spring Flowers Fundraiser

Easter Lilies, tulips, hyacinths, and mums were the name of the game for us at the end of March.

We thank all the churches, businesses, and individuals who supported KHF's fundraiser by purchasing spring flowers for the Easter Holiday. Furthermore, we thank our dedicated volunteers in the greater Louisville area, Lebanon Junction, and Owensboro for promoting our fundraiser in their local communities and generating flower orders. Thanks and appreciation to Sharon McMahan, Jenifer Schultz, Sadalia Sturgill, and Nita Wayne-Zehnder! This is one of our long-standing fundraisers that is struggling to survive amidst hefty competition from all sides of the retail sector. We very urgently need more volunteers to help us out and ensure the continuation of this important fundraiser.



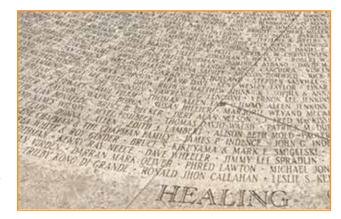
Mini-Marathon

Jerome Stewart proudly represented KHF in this year's Derby City Festival Mini-Marathon featuring the KHF Walk t-shirt for 13.1 miles. His time was 1:57. Congratulations, Jerome!

Leadership Training in San Francisco

During NHF's 2018 Leadership Training in San Francisco, I had the opportunity to visit the AIDS Memorial (shown to the right) and the Hemophilia Memorial (shown above) in a beautiful and serene

section of Golden Gate Park. These compelling memorials and the emotional address by Ryan White's mother, Jeanne White–Ginder, gave me pause to reflect on years past and precious lives lost. The bleeding disorders community has had to pay a heavy price for a brighter future for the next generation. We must always remember those who made the ultimate sacrifice and their loved ones whose hearts will forever ache. Looking ahead, their tears of sadness for their own losses will mix with tears of joy at the news of new and better therapies for subsequent generations that will change so many lives for the better.





Event News



Family Day at the Zoo

The Kentucky Hemophilia Foundation's annual Family Day at the Louisville Zoo was a great event! More than 200 people came from all over Kentucky for information, fun, and meeting other families from Kentucky's bleeding

disorders community. On a hot, sunny day touring the zoo, viewing the many animal exhibits, riding the train and carousel gave a pleasant reprieve.



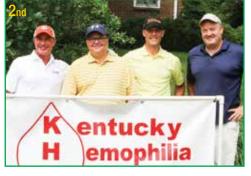


Afterwards, the picnic lunch at the Hillside Gazebo provided a welcome break during which the adults had a chance to chat with our exhibitors and visit with old and new friends. Children meanwhile enjoyed winning cool prizes playing carnival games and the animal presentation shaded by the zoo's large trees. Our Call to Action for Walk participation resulted in several commitments as we recognized last year's Walk Team Captains. The drawing for door prizes concluded the program. We thank our exhibitors who helped support this popular event: Bayer HealthCare, CSL Behring, CVS Caremark, Diplomat Specialty Infusion Group, First Choice Home Infusion, Genentech, Grifols, Matrix Health, Novo Nordisk, Octapharma, Paragon Healthcare, Pfizer, and Shire.

29th Annual Golf Scramble

Cloudy skies and an initial downpour did not dampen our golfers' spirits as we began the day's activities with registration and box lunches on the clubhouse veranda. By the time the shotgun start occurred, a mere drizzle was left that did not hamper play at Oxmoor Country Club's beautiful golf course. Winning teams were CSL Behring in 1st place, HEMA Biologics in 2nd place, and Octapharma in 3rd place. Valerie Waters-Douglas of Team Novo Nordisk won the Putting Contest; Larry Holbrook won Golf Poker with four of a kind; and Chuck Patton from Independence, KY won the \$460 Ball Drop prize. The chicken dinner, awarding of prizes, and silent auction rounded out a great event for a worthy cause. Proceeds from the Golf Scramble help fund our programs and services for Kentucky's bleeding disorders community. We thank our Golf Planning Committee, chaired by William Black; our day-of event volunteers; and our sponsors for supporting this fundraiser. Team Sponsors were Amerimed, Bayer HealthCare, CSL Behring, CVS Caremark, Diplomat Specialty Infusion Group, HEMA Biologics, Novo Nordisk, Octapharma, Republic Bank & Trust Company, and Shire. Tee Sponsor was First Choice Home Infusion.







More News

KHF Membership July 1, 2017 – June 30, 2018

Members, \$20

Barry L. Hatfield James P. Huff

Rickey James

John Noe

Sue Donahue

Marcus E. Omer

Daniel Thies, Manchester Down Home Pharmacy

Supporting Members, \$35

Herbert Devary, Jr.
Judy Hayes, in memory
of Jason Hayes
Shannon & James Hoskins
Donald L. Mattingly
Cory & Whitney Meadows
Mary Ellen Ritchie, in memory
of Michael Steven Mattingly
Clara J. Wheatley

Patron Members, \$50

Dr. David & Leslie Houvenagle Mary E. Marasa Stacey Powell & Family Ian M. & Elaine Thomas Glenn & Laura Webb Sustaining Members, \$100

Brad Comer

Jewel & Cathy Daugherty, in memory

of Gary Bandy

Barbara W. Grayson

D. Spalding Grayson

Glen, Sr. & Deborah Hitt

Keith Peterson

Nita Wayne-Zehnder

Benefactor Members, \$250

Rosemary Johnson-Dean Charles & Ruth Hall Venus & Eric Marcum

Champion/Corporate Members, \$500

Marion & Terry Forcht Ted & Jennifer Forcht Keith & Kristen Urbahn, Benjamin & William

In Memory

April 30, 2018 - June 30, 2018

Gone from our sight but never our memories; gone from our touch but never our hearts...

Judge Ben Barnett Larry Miller

Billie Wayne Hurt Cole Anderson Frances & Boyd Campbell Michael & Vanessa Creek Susan & Jeffrey Hartman Jim, Shirley, Lisa & Bart Napier Leslie & Paul Perlik

Alice Scott

Mr. & Mrs. Henry W. Boyd

Nell Bruce Stewart Mr. & Mrs. Henry W. Boyd, III





Cardiovascular Disease

continued from page 1

The authors cited study strengths including its multicenter structure and the measures that were taken to account for certain variables unique to hemophilia. "If a low baseline factor level is protective against CVD, it would be more likely to be detected in a population with more severe disease, as the protective effect could be diluted or masked in cohorts that include patients with mildly decreased factor levels, explained the authors.

"This is particularly true of rare diseases such as hemophilia, for which subject numbers in studies tend to be low. Our study also used medical records to confirm CVD diagnoses, central laboratory testing for lipids, and hsCRP (high-sensitivity C-reactive protein) and central reading of electrocardiograms."

Study limitations were also noted, including the lack of an active control group and potential selection bias as individuals with more medical complications may visit the HTC more often and thus be more available for study. In addition, the study included HTC patients only, thus excluding the estimated 20%-30% U.S. patients who receive care outside the HTC network. The authors acknowledge that these factors could possibly skew their study group towards patients with more comorbidities, potentially resulting in an "overestimation of CVD in the population."

Strengths and weaknesses notwithstanding, the authors drew important takeaways from the study. While hemophilia may offer some protection from CVD in certain moderate and severe patients, older patients are not completely immune from heart-related complications. Cardiovascular risk factors such as hypertension, are still common in hemophilia and as such prevention measures are still warranted.

"Thus, given the occurrence of CVD in men with hemophilia, and the challenges in its treatment in this population, measures directed at screening for and managing cardiovascular risk factors and optimizing management of CVD in this population are needed," concluded the authors.

The study, "A Cross-Sectional Analysis of Cardiovascular Disease in the Hemophilia Population," was published on June 12, 2018 in the journal *Blood Advances*.



Do The Five

Follow these steps to prevent or reduce complications of bleeding disorders

- 1. Get an annual comprehensive checkup at a hemophilia treatment center.
- 2. Get vaccinated Hepatitis A and B are preventable.
- 3. Treat bleeds early and adequately.
- 4. Exercise to protect your joints.
- 5. Get tested regularly for blood-borne infections.

To find out more about the National Prevention Program developed by the National Hemophilia Foundation in collaboration with the Centers for Disease Control and Prevention (CDC), click on www.hemophilia.org or call toll-free 800-42-HANDI.

KHF does not give medical advice or engage in the practice of medicine. KHF under no circumstances recommends particular treatments for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.



Saturday, September 29 Wetherby Park









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Louisville, KY
Permit No. 883

Meet Carol, your CoRe Manager



Hello! I'm Carol DeMatteis, and I have a lifetime of experience living with hemophilia as an affected carrier and as a mom to a son with severe hemophilia. It is my job to connect you with others in the community, share insights taken from my personal experience, introduce our educational programs, and to support you on your journey. I am here so we can take action together!

Contact me!

Carol.DeMatteis@bioverativ.com | 330.730.1975

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Looking for a new, fresh perspective on living with hemophilia?

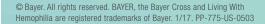
smart

Introducing your all NEW guide to **Living With Hemophilia**

Discover the new online destination for learning about hemophilia, living a healthy life and even leading in the hemophilia community. It's all at the new LivingWithHemophilia.com. Our site has been totally redesigned to give you more of the information you want and less of the stuff you don't want.

See What's New at

www.LivingWithHemophilia.com



A ONCE-WEEKLY SUBCUTANEOUS (GIVEN UNDER THE SKIN) INJECTION FOR PEOPLE WITH HEMOPHILIA A WITH FACTOR VIII INHIBITORS

We extend our appreciation to the individuals, families, and healthcare providers who participated in the clinical trials that led to the approval of HEMLIBRA®. We thank you and celebrate with the community who made it a reality.

Discover **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 with hemophilia A with factor VIII inhibitors.

WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with 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 signs and symptoms of TMA during or after treatment with HEMLIBRA.
- **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 the signs or symptoms of blood clots during or after treatment with HEMLIBRA.

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.



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.

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 OTHER POSSIBLE SIDE EFFECTS OF HEMLIBRA?

The most common side effects of HEMLIBRA include: redness, tenderness, warmth, or itching at the site of injection; headache; and joint pain. These are not all of the possible side effects of HEMLIBRA.

You may report side effects to the FDA at (800) FDA-1088 or www.fda.gov/medwatch. You may also report side effects to Genentech at (888) 835-2555.

Please see Brief Summary of Medication Guide on the following page for more important safety information, including **Serious Side Effects**.

Medication Guide Brief Summary HEMLIBRA® (hem-lee-bruh) (emicizumab-kxwh) injection, for subcutaneous use

NHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with 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
- stomach (abdomen) or back pain
- weakness
- nausea or vomiting
- swelling of arms and legs
- feeling sick
- yellowing of skin and eyes
- 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
- eve pain or swelling
- trouble seeing

f aPCC (FEIBA®) is needed, talk to your healthcare provider in case /ou feel you need more than 100 U/kg of aPCC (FEIBA®) total.

See "What are the possible side effects of HEMLIBRA?" for more nformation about side effects.

NHAT IS HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with 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.

3EFORE 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.

fell your healthcare provider about all the medicines you take. ncluding 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.
- 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.
- 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 before the next scheduled dosing day and then continue with your normal weekly dosing schedule. Do not double your dose 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 7 days at 86°F (30°C) or below.
- 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

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 ©2017 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 Issued: 11/2017



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Meet Carol, your CoRe Manager



Hello! I'm Carol DeMatteis, and I have a lifetime of experience living with hemophilia as an affected carrier and as a mom to a son with severe hemophilia. It is my job to connect you with others in the community, share insights taken from my personal experience, introduce our educational programs, and to support you on your journey. I am here so we can take action together!

Contact me!

Carol.DeMatteis@bioverativ.com | 330.730.1975

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