Our 10th Anniversary Unite Walk Celebration was postponed due to COVID-19. The NEW date is Sunday, September 13 and it’s going to be AMAZING! Your fund-raising efforts will be more important than ever as we work to support those affected with a bleeding disorder and who have also faced challenging times during these unprecedented times.

Please sign up by creating or joining a walk team today at https://www.uniteforbleedingdisorders.org/event/Florida2020

We can’t wait to UNITE with YOU, once the dust has settled!

Email Walk@floridahemophilia.org or call 305-235-0717 if you have any questions.
I hope everyone is safe and healthy. Our staff and Board of Directors send you good wishes and prayers during this difficult time. Our community is used to dealing with adversity even through unprecedented times. We are an amazing community, let’s continue to stay strong! With that being said, we want you to know that FHA is here for you and your family. Let us know how you’re managing and please reach out if you’re in need of assistance. We’re working remotely so email us at dadamkin@floridahemophilia.org or admin@floridahemophilia.org.

With the current state affairs we are trying to determine the best course of action regarding our upcoming events such as hosting virtual programs and activities. We’ll also consider postponing programs like our (B)LEAD retreat, if possible, to later in the year. We want to do what is in the best interest of our community and will keep you informed as things continue to evolve.

Stay safe and know we will get through this together. We look forward to seeing you all soon.

Debbi Adamkin
FHA Executive Director

Mensaje Ejecutivo

Espero que este mensaje les encuentre bien y con salud. Nuestro personal y directores les tienen en mente y en sus oraciones en este tiempo lleno de retos. Nuestra comunidad ya está acostumbrada a tolerar la adversidad, hasta en tiempos como estos. ¡Somos una comunidad fuerte y maravillosa y vamos a continuar siéndolo!

También les queremos dejar saber que FHA está aquí para continuar a servirles a ustedes y sus familias. Déjen saber cómo andan, y por favor, no tengan pena en dejarnos saber si necesitan ayuda. Estamos trabajando electrónicamente, así que si nos quiere contactar, por favor manden un correo electrónico a dadamkin@floridahemophilia.org o admin@floridahemophilia.org.

Como andan las cosas, estamos tratando de determinar el mejor rumbo con respecto a nuestros eventos y programas que se acercan. Estamos mirando opciones como organizar estos eventos y programas virtualmente. También estamos considerando postergar programas como “(B)LEAD Retreat” a una fecha más distante, si es posible. Queremos hacer lo que está en el interés de nuestra comunidad, y les mantendremos informados en cuanto haya más noticia.

Cuidense y yo sé que vamos a salir adelante juntos. Esperamos verlos pronto.

Debbi Adamkin
Directora Ejecutiva de FHA

DANIEL L. CARLIN MEMORIAL SCHOLARSHIP PROGRAM

APPLICATIONS ARE NOW BEING ACCEPTED!

SCHOLARSHIP FUNDS

FHA will be awarding up to FIVE (5) scholarships for the 2020-2021 academic year.

In order to qualify for this scholarship, the applicant must be diagnosed with Hemophilia, Von Willebrand Disease or related inherited bleeding disorder OR the parent of a child diagnosed with Hemophilia, Von Willebrand disease or other related bleeding disorder. Applicants must be currently enrolled in good academic standing at OR accepted into an accredited college, university or trade school and pursuing a degree, certification or license.

Applications must be received in order to be considered for a scholarship. Applicants must be Florida residents.

For more information or to obtain an application packet, please contact admin@floridahemophilia.org or call 305.235.0717
Submitted by Eric Burgeson, BDCF Advocate Ambassador

After (many hours) of presentations, practicing, and preparation, my small group of south Floridians was ready to ride the elevators, and pound the marble floors of our state’s capital. We represented both the east and west coast of south Florida, but had similar asks for our distinct delegates. We wanted to make sure that the worrying trend of step therapy - making its way around state houses in the country - did not make its way to Florida. We also needed to make clear that a growing issue for people with bleeding disorders (and expensive disorders in general) is the advent of insurance practicing (or not practicing) accumulator adjustors. Overall, I believe we had a successful day, and rarely have I felt more listened to by our elected officials.
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
  - nausea or vomiting
  - or back pain
  - 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

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 all 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 HEMIBRA 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 you weight changes, tell your healthcare provider.

You will receive HEMLIBRA 1 time a week for the first 4 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 HEMIBRA is transferred from the vial to the syringe, HEMIBRA should be used right away.
- Throw away (dispose of) any unused HEMIBRA left in the vial.

Keep HEMIBRA 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 HEMIBRA for a condition for which it was not prescribed. Do not give HEMIBRA 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 HEMIBRA that is written for health professionals.

What are the ingredients in HEMIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, polysorbate 188, and L-aspartic acid.
Health and Wellness Update from
NHF CEO Dr. Valentino

I know many of you are overwhelmed with often-conflicting information on the COVID-19 virus. As a doctor and researcher, the health of the bleeding disorder community is my highest priority. Every Friday, I will be sending you vetted, trusted information about the pandemic and information you can use to keep you and your family safe. This information will also be posted on the NHF website at www.hemophilia.org.

If you have specific questions about the COVID-19 virus, please email them to communications@hemophilia.org and I will try to address them in the next email.

What People With Bleeding Disorders Should Know

We have seen no indication that people with bleeding disorders are at an increased risk for contracting COVID-19, and there is no indication that people with bleeding disorders who have no other underlying conditions are more likely to develop severe symptoms. However, the COVID-19 virus is a respiratory illness that may result in severe coughing, and that can increase risk of head bleeds. It is more important than ever to make sure you are adhering to your prophylaxis regimen to decrease the likelihood of all bleeding. Currently, all of our pharmaceutical partners have assured us their supply of medication is unaffected by the outbreak. Do not ration products at this time. Treat as your healthcare provider has prescribed your medications, contact your HTC or healthcare provider with any questions or concerns and above all, stay healthy.

Health and Exercise

It is important for people with bleeding disorders of all ages to stay active to maintain joint and emotional health. Remember, even during this pandemic it is safe to:

• Let your kids play outside (just no playdates)
• Go for a family bike ride or walk (put those helmets on!)
• Have a family game night
• Exercise as a family

More resources on www.hemophilia.org to help you stay active during this time

• Coronavirus lockdown: How to stay fit, exercise at home
• How We’re Staying Fit Through A Quarantine
• How to Protect Your Mental Health During a Quarantine
• How To Stay Fit While You’re Stuck in Quarantine

Actualización de salud y bienestar del CEO de NHF Dr. Valentino

Entiendo que muchos de ustedes están abrumados con la noticia sobre el virus COVID-19 que muchas veces se contradice. Como doctor e investigador, la salud de la comunidad que sufre de trastornos sanguíneos es mi más alta prioridad. Cada viernes, les mandare información revisada y confiable sobre la pandemia e información para mantener a usted y a su familia saludable. Esta información estará posteada en el sitio web del NHF en www.hemophilia.org.

Si tiene preguntas específicas sobre el virus COVID-19, mándelas a través de correo electrónico a communications@hemophilia.org y tratare de responderlas.

Lo que deben saber los miembros de la comunidad de trastornos sanguíneos

Hemos visto ninguna indicación que los pacientes de trastornos sanguíneos tienen probabilidad más alta de contraer COVID-19, y hemos visto ninguna indicación que los que tienen trastornos sanguíneos y no tienen otra condición subyacente están a riesgo mayor de desarrollar síntomas severos. No obstante, el virus COVID-19 es un mal respiratorio que puede ocasionar tos severa, y eso puede incrementar riesgo de sangramiento en el cráneo. Es más importante que nunca seguir su régimen de profilaxis para reducir el riesgo de sangramiento interno. En este momento, todas nuestras farmacias nos han asegurado que su suministro de medicamento no está afectado por la epidemia. En este momento, no racione sus medicamentos. Continúe su tratamiento como ha indicado su doctor/a, contacte su HTC o doctor/a con cualquier pregunta que tenga, y sobretodo, cuidese.

Salud y Ejercicio

Es importante que los pacientes de trastornos sanguíneos de todas edades se mantengan activos. El ejercicio promueve la salud de sus articulaciones y su bienestar mental. Acuérdense, hasta en esta pandemia es prudente:

• Dejar sus hijos jugar afuera (pero acuérdesel, limite las congregaciones)
• Ir en familia a caminar o montar bicicleta (póngase sus cascos)
• Compartir en juegos de mesa con la familia
• Hacer ejercicio en familia

Más recursos están disponibles en www.hemophilia.org
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.
Florida Bleeding Disorders Conference (FBDC)
July 24 - 26

This year the FBDC will be virtual! We're planning an interactive online event that will bring us all together. It will be similar to our live conference, but will be online rather than in a hotel.

Save the Date and Stay Tuned for More Details!

Este año, la conferencia de los desórdenes sanguíneos se llevará a cabo virtualmente. Estamos planeando un evento interactivo que nos unirá a todos. Será similar a nuestra conferencia usual en persona, pero será por medio de internet en vez de en un hotel.

¡Marque la fecha en su calendario y manténgase al tanto de los nuevos detalles que están por venir!

CONFERENCIA LATINA

SAVE THE DATE
OCTOBER 2 - 4
MARRIOTT HARBOR BEACH RESORT
Let’s make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life’s possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world, is stronger than ever.

bleedingdisorders.com
Let’s All Lighten Up!

Sunday, November 15, 2020, 10:00 a.m.

The Lighten Up Program is back! On November 15, 2020, the Florida Hemophilia Association, together with the University of Miami Hemophilia Treatment Center and Johnson and Wales, will bring you this fun, informative cooking and nutrition program.

Have a favorite recipe that could use some lightening up? Submit it to us before October 15th and it may be one of the recipes that the Chefs at Johnson and Wales recreate into a healthier version.

SPACE IS LIMITED, PLEASE RSVP BEFORE OCTOBER 15
to: admin@floridahemophilia.org
Program is intended for Adults, Teens (12 & up)

Johnson and Wales • 1701 NE 127th Street
North Miami, FL 33181

¡Todos aligeran!

Domingo, 15 de Noviembre del 2020, 10:00 a.m.

¡El programa Todos Aligeremos regresa! En 15 de noviembre del 2020, la Asociación de Hemofilia de la Florida, junto con el Centro de Tratamiento de hemofilia de la Universidad de Miami y Johnson y Wales, les presenta este divertido programa de cocina y nutrición informativa.

¿Tiene una receta favorita que podría usar algún rayo? Envíela a nosotros antes del 15 de octubre y puede ser una de las recetas que los Chefs de Johnson y Wales recrean en una versión más saludable.

Aunque no sea cocinero tiene la oportunidad de ser un "Chef del Día" preparando alimentos en una cocina de vanguardia. Luego todos disfrutaremos de nuestras deliciosas creaciones.

EL ESPACIO ES LIMITADO, por favor confirme su asistencia antes del 15 de Octubre a:
admin@floridahemophilia.org
Programa está destinado a Adultos, Adolescentes (12 y hacia arriba)

Johnson and Wales
1701 NE 127th Street
North Miami, FL 33181
MISSION STATEMENT

The Florida Hemophilia Association, Inc (FHA) is a Not-for-Profit organization that is dedicated to enhancing the quality of life in the bleeding disorders community by creating programs and services that provide education, emotional support and advocacy. We are contributing toward research to ultimately find a cure.

Do the 5

1 Get an annual comprehensive check-up 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

CONTACT NUMBERS

Florida Hemophilia Association Office  
(888) 880-8330

Executive Director  
Debbi Adamkin  
(305) 235-0717  
dadamkin@floridahemophilia.org

National Hemophilia Foundation  
(800) 424-2634

Hemophilia Federation of America  
(800) 230-9797

LA Kelley  
Communications, Inc.  
Free resource material on Hemophilia  
(978) 352-7657

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FLORIDA HEMOPHILIA ASSOCIATION  
for all bleeding disorders
Florida Hemophilia Association
(Formerly known as Florida Chapter, NHF)
915 Middle River Drive, Suite 501
Ft. Lauderdale, FL 33304

Looking for ways to give back?
Shop Amazon Smile! For every purchase
Amazon donates a percentage to the Florida Hemophilia Association

HOW DOES IT WORK?!
On the “Shop Now” link below you’ll be taken to AmazonSmile. Here you will be able to select the charity of your choice.
"Florida Hemophilia Association"
Shop now>

Amazon will donate 0.5% of the price of your eligible AmazonSmile purchases to Florida Hemophilia Association Inc whenever you shop on AmazonSmile. You can select a different charitable organization after signing in. • AmazonSmile is the same Amazon you know. Same products, same prices, same service. • Support your charitable organization by starting your shopping at smile.amazon.com.

Happy Shopping!