UPCOMING EVENTS AND PROGRAMS

BDCF Advocacy Days
Tallahassee, FL
February 18-19

NHF Washington Days
Washington, DC
February 26-28

Coalition for Hemophilia B Annual Symposium
Orlando, FL
March 19-22

FHA/UM Educational Dinner
Miami, FL
March 25

World Hemophilia Day
April 17

Lighten Up!
Johnson & Wales, North Miami, FL
April 19

HFA Annual Symposium
Baltimore, MD
April 23-26

Unite for Bleeding Disorders Walk
Coconut Creek, FL
May 3

Let’s Make a Difference!

March is Bleeding Disorders Awareness Month

This is the time to remember those we’ve lost and to honor those living with a bleeding disorder. Help raise awareness by sharing your personal story.

Bleeding Disorders Awareness Month is a great time to invite your friends, family, and coworkers to join you at the

10th Annual Unite for Bleeding Disorders Walk
on May 3rd at Tradewinds Park in Coconut Creek

Let’s rally together to continue to raise awareness and crucial funds for our important programs and services
Happy 2020!
We are off to a great year and we’re looking forward to providing you with some new and exciting programming for 2020!

This year commemorates our 10th Annual Walk! It’s hard to believe that it’s been a decade since our inaugural walk on March 5, 2011! We look forward to celebrating 10 YEARS on May 3rd with you and your loved ones at our new walk location at Tradewinds Park, Coconut Creek, FL. Our walk is one of the biggest fund-raisers throughout the country that UNITES the bleeding disorders community. Funds raised will be used to assist our overall mission of finding better treatments and cures and prevent complications of bleeding disorders by providing education, emotional support, advocacy, research and services. With your help this year, we can reach our goal. Please contact the FHA office if we can assist you with registering for the walk, creating a team, providing you with fund-raising ideas or with letters of requests for sponsorships, in-kind donations, etc.

Please be on the lookout for Save the Dates and some of the upcoming events.

Finally, I want to express my deepest gratitude to everyone who continues to support FHA! You make it possible for us to continue our mission of serving the bleeding disorders community year after year!

THANK YOU!

Debbi Adamkin
FHA Executive Director

¡Feliz 2020!
¡Estamos empezando un gran año y estamos entusiasmados en proveerles nueva y excitante programación en este 2020!

Este año, celebramos nuestra decima caminata. ¡Que difícil es creer que esta caminata es la edición diez desde la primera caminata del 5 de Marzo del 2011! Esperamos celebrar diez años este 3 de Mayo con ustedes y sus seres queridos en nuestro nuevo lugar, el parque Tradewinds Park en Coconut Creek, FL. Nuestra caminata es uno de los más grandes recaudatorios de fondos que toma acabo por todo el país y que une a la comunidad de desórdenes sanguíneos.

Fondos recaudados serán usados para continuar nuestra misión de encontrar mejores tratamientos y curas. Por medio de la educación, apoyo emocional, abogacía, estudios y servicios, buscamos prevenir complicaciones en los que padecen/padecemos de estas enfermedades. Con su ayuda este año, podemos alcanzar nuestra meta. Por favor comuníquese con la oficina del FHA para que le ayudemos en la registración para la caminata, creando un equipo, con ideas para recaudar fondos, con pedidos a patrocinadores, o con donaciones.

Por favor este pendiente de la sección “Save the Dates” y de nuestros eventos que se avcean.

Para concluir, quiero expresar mi más profundo agradecimiento a todos que continúan apoyando FHA. Ustedes hacen posible que nosotros continuemos nuestra misión de servir a nuestra comunidad año tras año.

¡MUCHAS GRACIAS!

Debbi Adamkin
Directora Ejecutiva de FHA
This year, we celebrate our 10th Annual UNITE Walk. The walk is not just a fundraiser, but an opportunity to support those in the bleeding disorders community. While we look proudly at our past programs and services, this is no time to rest on our laurels. This year and into the future, we look forward to continuing our mission of serving the bleeding disorders community and celebrating many more milestones. You in?
CELEBRATING a Decade OF WALKING continued...
Women’s Retreat

This program was made possible by a grant from CSL Behring

END OF THE YEAR EVENT

Thank You Sponsors

In Memory of Donald Emory

Sadly, we lost Donald, an active community member and a dedicated and valued volunteer at FHA Events. He generously donated his time and contributed to the Florida bleeding disorders community. He was a loving husband and father and is survived by his wife Heather and daughters Victoria and Amanda...
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-kwxh) 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 or during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen)
  - 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:
  - cough up blood
  - feel faint
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - pain or redness in your arms or legs
  - 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 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 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-kwxh

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 94080-6993
U.S. License No. 1048
HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan ©2018 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 Revised: 10/2018

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Let’s All Lighten Up!

Sunday, April 19, 2020, 10:00 a.m.

The Lighten Up Program is back! On April 19, 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 March 20th and it may be one of the recipes that the Chefs at Johnson and Wales recreate into a healthier version. Even if you’re not a Cook you will have an opportunity to be a “Chef for the Day” preparing food in a state of the art kitchen. Afterwards we’ll all enjoy our delicious creations.

SPACE IS LIMITED, PLEASE RSVP BEFORE APRIL 8
to: admin@floridahemophilia.org
Program is intended for Adults, Teens (13 & up)

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

¡Todos aligeran!

Domingo, 19 de abril de 2020, 10:00

¡El Aligerar para Arriba programa está de vuelta! En 19 de Abril de 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, llegará este divertido programa de cocina y nutrición informativa.

¿Tiene una receta favorita que podría usar algún rayo? Envíela a nosotros antes del 20 de marzo y puede ser una de las recetas que los Chefs de Johnson y Wales se recrean en una versión más saludable. Incluso si no eres cocinero tienes la oportunidad de ser un "Chef para el Día" preparación de alimentos en una cocina de vanguardia. Luego todos disfrutaremos de nuestras deliciosas creaciones.

EL ESPACIO ES LIMITADO, por favor confirme su asistencia antes del 8 de Abril a:
admin@floridahemophilia.org
Programa está destinado a Adultos, Adolescentes (13 y hacia arriba)

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

FHA will be awarding up to FIVE (5) $500-1,500 scholarships for the 2019-2020 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 by May 8, 2020 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

APPLICATIONS ARE NOW BEING ACCEPTED!
We are excited to announce the
6th Annual Camp (B)LEAD:
Action League of Bleeders

For more information, please contact us by email admin@floridahemophilia.org or call 305-235-0717.

Date: TBD Keep an eye out for date announcement

37th Annual Florida Bleeding Disorders Conference
NEW LOCATION: Marriott Palm Beach Gardens
REGISTRATION OPENS IN APRIL

We’re preparing a great program, with informative sessions, exciting activities for kids and teens, and fun for the whole family! You don’t want to miss out!
FHA ResourceCenter

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.

CENTERS FOR BLEEDING DISORDERS
*Hemophilia Treatment Center (HTC)

Johns Hopkins All Children’s Outpatient Care Clinic
Pediatric Cancer and Blood Disorders Center
601 5th Street South, Third Floor
St. Petersburg, FL 33701
Phone: (727) 767-4931
www.allkids.org

Arnold Palmer Hospital for Children
The Haley Center for Children’s Cancer and Blood Disorders
92 West Miller St., MP 318
Orlando, FL 32806
Phone: (321) 841-8588
www.orlandohealth.com

Joe DiMaggio Children’s Hospital
Pediatric Specialty Center
1150 N. 35th Ave.
Suite 520
Hollywood, FL 33021
Phone: (954) 986-2234

Lee Memorial Hospital
Department of Pediatric Hematology & Oncology
9981 So. Healthpark Dr.
Suite 156
Ft. Myers, FL 33908
Phone: (239) 332-1111

Nemours Children’s Clinic, Jacksonville
Department of Pediatric Hematology/Oncology
807 Children’s Way
Jacksonville, FL 32207
Phone: (904) 697-3789
(904) 697-3600
www.nemours.com

Nicklaus Children’s Hospital
Kidz Medical Services Division of Hematology/Oncology
3100 SW 62 Ave
Suite 121
Miami, Florida 33155
Phone: (305) 662-8360

University of Florida
Hemophilia Treatment Center Division of Pediatric Hematology/Oncology
1600 SW Archer Road
Gainesville, FL 32610
Phone: (352) 273-9120
www.peds.ufl.edu/divisions/hemonc/

Nemours Children’s Clinic, Orlando
Department of Pediatric Hematology/Oncology
13535 Nemours Parkway
Orlando, FL 32827
Phone: (904) 697-3789,
(904) 697-3600

Sacred Heart Pediatric Hemophilia Program, Pensacola
Phone: (850) 416-7712

St. Joseph’s Children’s Hospital
Pediatric Hematology Oncology Out-patient Clinic
3001 W. Dr. Martin Luther King Jr. Blvd.
Tampa, FL 33607
Phone: (813) 554-8294
or (813) 321-6820

The University of Miami Hemophilia Treatment Center Pediatrics and Adults
University of Miami Miller School of Medicine
Department of Pediatrics Div of Hematology/Oncology
Locator Code D820
1601 NW 12th Ave., Room 5019
Miami, FL 33136
Phone: (305) 243-0834
www.htcextras.org

USF Adult Hemophilia Center
Hematology 4th Floor
13220 Laurel Drive
Tampa, FL 33612
Phone: (813) 974-3725

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

LIFE LINE is the official Newsletter of the Florida Hemophilia Association. It is produced quarterly and distributed free of charge to requesting members of the bleeding disorder community.

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WINTER 2020 • LIFELINE
Florida Hemophilia Association (Formerly known as Florida Chapter, NHF)
915 Middle River Drive, Suite 501
Ft. Lauderdale, FL 33304

Florida Hemophilia Association
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Amazon donates a percentage to the Florida Hemophilia Association

HOW DOES IT WORK?!
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"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!