



HEMO-FLO

Newsletter

JANUARY 2021

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TOGETHER!**

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Ana Paredes

HTC BOARD REPRESENTATIVES

Jennifer Borrillo – Tulane HTC
Claudette Vicks – Children's Hospital

3084 Westfork Drive
Suite A
Baton Rouge, LA 70816

Tel: 225.291.1675
Fax: 225.291.1679

E-mail:
outreach@LaHemo.org
contact@lahemo.org

Director:
director@LaHemo.org

Website:
www.LaHemo.org

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Bleeding Disorders Awareness

 Women Bleed Too.

Bleeding Disorders Awareness

LOUISIANA
HEMOPHILIA FOUNDATION

Director's Corner

Dear Friends,

I am thrilled to be introducing myself to you as the new Executive Director of LHF.

A few days after he was born, my youngest son, Max, was diagnosed with Severe Hemophilia A. My husband, Casey, and I knew immediately that we would want to be involved in the community. LHF quickly became a vehicle for us to make connections with other families who were affected by bleeding disorders. Over the last four years, LHF has allowed us to meet amazing people who have offered support and kinship to our entire family, including our oldest son, Leo, who does not have a bleeding disorder, but is affected by his baby brother's diagnosis all the same.

When the opportunity arose to become the Executive Director, it felt like a perfect fit. I come to LHF with a Bachelor's Degree in Elementary Education, a Master's Degree in Counseling, a Specialist License in Prevention Education, and sixteen years of experience working with children and families. I am excited to begin putting my knowledge and skill set to use in growing and improving LHF and actualizing an organization that will serve as a support network for us, the bleeding disorders community, for our children, and for future generations.

As the new Executive Director, my goals are to increase community engagement, develop a strengthened Board of Directors and volunteer base, increase awareness of all bleeding disorders, facilitate education, empowerment, and connectivity within the community, and advocate on state and national levels for access to care.

I am extremely honored to have been chosen for this position, and I am confident that together we can cultivate a shared organization that we are all proud to be a part of. I look forward to working with each and every one of you in service to the bleeding disorders community.

Ashley Castello



Board or Directors



Akesha Allen

President - President@LaHemo.org

Akesha Allen was introduced to the hemophilia community when her son was diagnosed with Von Williebrand 's Disease. This diagnosis is what propelled her to become more involved in research and treatment options not just for her son, but for ALL people who have been and will be impacted with this disease. Akesha has extreme passion for full and complete inclusion for all communities to be represented within Louisiana Hemophilia Foundation. While holding Board of Director positions with other organizations as well as a participant of the Von Williebrand's Disease Therapeutic Policy & Advocacy Advisory Board, Akesha is able to bring an aspect to our community which will allow for greater relationships to be built with underserved communities.



Subodh Pethe

Vice-President - vp@lahemo.org

My Name is Subodh Pethe. Most of you probably know me as Ben's dad. I became involved with the bleeding disorders community the day Ben was born with severe Hemophilia. Over the years I have seen the LHF go through some good times and bad. Throughout it all they have always done what they can to help the bleeding disorders community. I make my living as an IT Pro, what that means is people hire me to fix their problems with technology and related workflows. Now that Ben is in high school, I decided to get actively involved with the LHF. I want to put my experience guided by intelligence to help make LHF the best chapter in the world.



David Reynaud

Secretary - secretary@lahemo.org

My name is David Reynaud and I would like to take this opportunity to introduce myself as one of your new LA Hemophilia Foundation Board members. I have recently been elected the Board's secretary. I am 42-years old and have severe Hemophilia A, which I feel truly qualifies me to serve you as I share a common bond with those with bleeding disorders. Also, by being raised in a "Hemophilia" family, I can relate to family members and I understand the unique challenges that arise while living and caring for someone with a bleeding disorder. Also, I have access to a wealth of knowledge and experience from my Uncle (fellow severe hemophiliac), as well as from my parents, who in the past have been very active in the LHF.

I am married to Nicole Fassbender Reynaud, who many of you already know as she is the nursing coordinator at the Tulane Hemophilia Treatment Center for Bleeding and Clotting Disorders. Nicole and I have been married for nearly 18-years and we have a 7-year old daughter named Watson, a Scottish Terrier named Stewie, 13 chickens, one rabbit and a newly adopted kitten named Gracie. I enjoy cooking, reading, traveling and I am very passionate about the game of golf. Even with a total knee replacement, a fused ankle and a severely arthritic elbow, I can hold my own on the course. Never hesitate to ask me to play should you need to fill a foursome. I would like each and every one of you to know I am available anytime should you need to speak or meet with me. We, the Board of Directors, are here to serve you and we welcome your ideas and visions to make LHF the wonderful organization we all know it should be. Thank you for letting me serve you and please call me if you need anything. I can be reached anytime at 225-623-9287.

Ana Paredes
Trustee-lhfboard1@lahemo.org

Nicole Griffin
Trustee - lhfboard2@lahemo.org

Jennifer Borrillo
HTC Board Representative
tulanehtc@lahemo.org

Claudette Vicks
HTC Board Representative
chnolahtc@lahemo.org



LHF WANTS YOU!

Are you looking for an opportunity for personal and professional growth? Would you like to have the privilege to be of service and gain a greater sense of meaning and purpose?

Join the LHF Board!!

Call (225) 291-1675 for more information or apply at LaHemo.org

LHF

2020



YEAR IN REVIEW

2020 was without a doubt a year for the record books. The Covid-19 pandemic changed the world and all of our lives for the better part of the year, and we have all had to adjust accordingly. Of course, with every gray cloud, there is always a silver lining. The pandemic taught us the value of personal connections and the importance of physical interaction.

Even though we faced the unprecedented challenges presented by a global pandemic, LHF still had a busy and productive year! We kicked off the year in February with our Sweetheart Bowl in New Orleans and Lafayette, and the Lutz and the Robertson families represented us in DC at NHF's Washington Days advocacy event. LHF worked together with Tulane to have our first Women's Educational Retreat in March. In April, we held our very first virtual event, a family game night to celebrate World Hemophilia Day. Ladies affected by bleeding disorders had a virtual Girls' Night In painting party in May, and our campers experienced their first ever virtual Camp Globeclotters in July. In September, the new board members got to meet our industry representatives at the very first Virtual Industry Social. Our annual meeting sessions were also held virtually this year in October, with physically distanced bowling at Rock-N-Bowl to close out the meeting. For Thanksgiving and Christmas, we were able to assist over forty families with our Holiday Gift Giving campaigns. Throughout the year, we had multiple virtual educational seminars brought to us by BioMarin, Genentech, CSL Behring, Grifols, and Sanofi. We also had three new and unique fundraisers this year, a Park Lane Jewelry sale hosted by the Reynaud family, the 225 Gives campaign, and a raffle of a beautiful oyster painting. We are so grateful to all of our sponsors, donors, partners, and families for helping us get through this unusual and difficult year.

Looking ahead to 2021, there is nowhere to go but up! At LHF, we are planning to remain virtual through the first half of the year, and hoping to transition to live and in-person events for the second half. Naturally, we will comply with CDC guidelines, follow the recommendations of the city, state, and national leadership, and adjust our plans as necessary. We are all so excited here at LHF to see what the new year holds in store for us! We look forward to working alongside all of you this year, and we hope to be able to see you soon!

Community Spotlight



My name is Aiden Peterkin and I have Severe Hemophilia A.

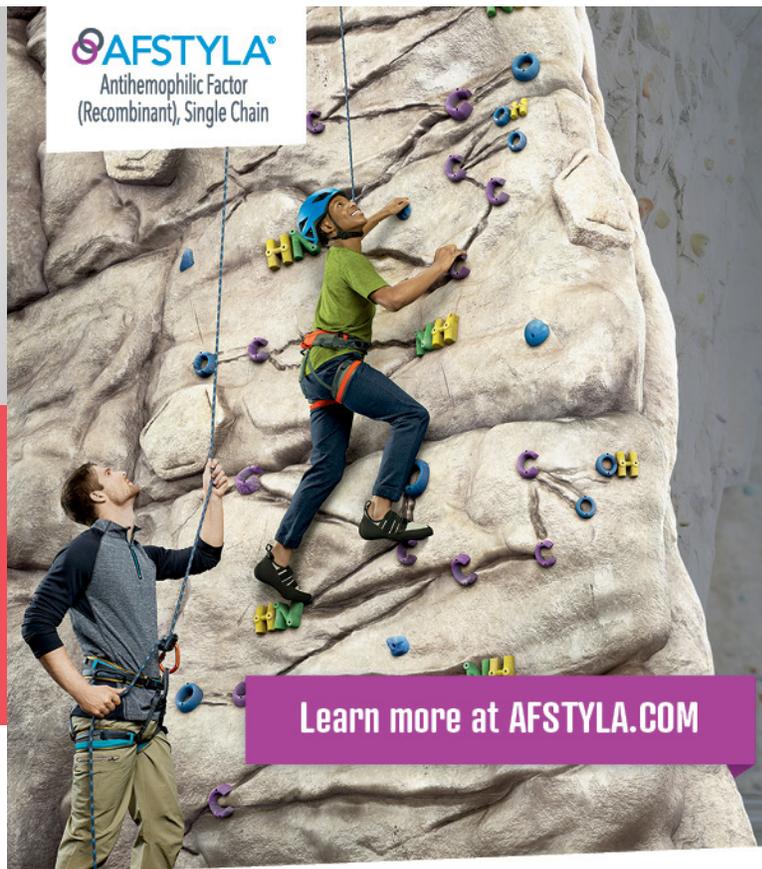
I am currently a Freshman at Centenary College of Louisiana studying pre-medicine so that I can become a Hematologist. My family has been supporting Save One Life for over a decade. Save One Life is a charitable organization that gives out micro-grants to help families start-up businesses to support their families, donates life-saving medication, and give scholarships to people with bleeding disorders in developing countries. Last year, my father had the opportunity to travel to Africa with Save One Life to deliver their generous donations and meet families affected by bleeding disorders. The group would later summit Mt. Kilimanjaro to raise more money. I was so impressed to hear about my dad's experience, that I knew that I wanted to do something to help as well. Over Labor Day weekend, Save One Life held a Wheels for the World virtual cycling event where participants rode their bikes to raise money for the organization. My whole family and I decided to join the cause. We rode a total of 107 miles and raised \$720. Next year, I am hoping to hold a swim marathon with my swim team at Centenary to raise even more money for Save One Life.



***Congratulations to Our
Spring 2021 Scholarship
Recipients!***

- Akeshia Allen**
- Robert Baricev**
- Brooke Bergeron**
- Tristan Conway**
- Benjamin Hicks**
- Brent Hicks**
- Michael Joshua**
- Kylie Kraemer**
- Bailey LeBrun**
- Micah Major**
- Aiden Peterkin**
- Jack Richard**
- Marc Taylor**
- Marilyn Russell**

***Scholarships Provided By:
Louisiana Hemophilia Foundation &
The Wilson's Foundation***



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Opportunity To Give Back

VOLUNTEER WITH US

What would you like to help us out with?

Visit the "donation/volunteer" page on our website (LaHemo.org) to sign up for different opportunities ranging from help with Advocacy to volunteering for Camp Globeclotters.

VOLUNTEER





Our Mission:

To improve the quality of life and assist persons affected by bleeding disorders by providing education, advocacy, support services, and by promoting research.



We here at Louisiana Hemophilia Foundation strive to see every individual with a bleeding disorder have a MedicAlert ID along with membership services in the event of an emergency. LHF will provide this service to you at no cost. Membership services must be renewed annually however, if you previously had a MedicAlert and have let your renewal lapse we can still get that ID and service for you.

Simply go to: www.lahemo.org/medic-alert and click the PDF, fill it out, and email it back to us at Outreach@Lahemo.org.

The ID of your choice will be shipped directly to the you and we cover the cost. Membership services are available once application or renewal is processed. We also accept applications on your behalf from your HTC or Hematologist sent to us at: Outreach@lahemo.org

The importance and benefits of having a MedicAlert ID and membership service!

MedicAlert speaks for it's members in an emergency by providing:

24/7 Emergency Response Team
Personal Profile
Portrait Photo (selfie)
Printable Patient Profile
Emergency Health Profile
24/7 Wandering Support
Emergency Contact Notification

Apply Today by visiting www.lahemo.org



Conciencia de la Hemofilia

Podría tener un trastorno hemorrágico?

¿Que es la hemofilia?

La hemofilia es una condicion muy rara: solo unos 20,000 estadounidenses viven con esta enfermedad.

La hemofilia afecta principalmente a los varones, debido a ser una condicion ligada al cromosoma X. Le hemofilia afecta a 1 de cada 5.000 nacimientos masculinos en los Estados Unidos y aproximadamente 400 bebes nacen con hemofilia cada año. Todas las razas y grupos economicos se ven afectados por igual. Personas con hemofilia que tiene acceso a terapias de reemplazo de factores tienen una esperanza de vivir vidas normales.

Sintomas

Una persona con hemofilia puede sangrar dentro o fuera de su cuerpo aunque no sangran mas que personas sin hemofilia. Simplemente sangran por mas tiempo. Los tipos de sangrado mas comunes estan en las articulaciones y los musculos. Otros sintomas incluyen:

- Sangrados nasales
- Sangrados prolongado por cortes menores
- Sangrado que se detiene y reanuda despues de deternese por un corto tiempo
- Sangre en la orina
- Sangre en los excrementos/heces
- Moretones grandes
- Hematomas
- Hematomas que no tienen explicacion
- Sangrado excesivo con extracciones o procedimientos dentales
- Periodos intensos que duran mas de 7 dias

Adonde voy desde aqui?

Si crees que podrias tener una enfermedad hemorragica, querra consultar con un experto. En este caso, hablar con los hematologos que son los expertos en enfermedades hemorragicas. Un hematology puede diagnosticar que condicion o trastorno tienes, proporcionar orientacion para controlarla y recetar tratamientos y terapias para garantizar el mejor resultado posible.

Los trastornos de sangrado son complejos y a menudo requieren colaboracion entre various profesionales de la salud, como enfermeras, fisioterapeutas, genetistas y trabajadores sociales. Para facilitar la atencion integral a los pacientes con enfermedades hemorragicas, el gobierno federal de los Estados Unidos proporciona algunos de los fondos que apoyan a los centros de tratamiento de la hemofilia (HTC) en todo el pais. Los HTC ayudan a coordinar su tratamiento con otros expertos medicos para tratar todos los aspectos de su condicion hemorragica. Visita www.cdc.gov para encontrar un HTC cerca de ti.

Información proporcionada por:

La Fundación hemofilia de Luisiana: www.LaHemo.org

Contáctenos en: Alcance LaHemo.org o llamando al (225) 291-1675

3084 Westfork Dr. Suite A, Baton Rouge, LA. 70816

LOUISIANA
HEMOPHILIA FOUNDATION
for all bleeding disorders



EXPERIENCE MATTERS

BeneFix is FDA approved for once-weekly prophylaxis and on-demand use to fit your dosing needs—
from the only recombinant factor IX supporting individuals with hemophilia B for more than 20 years.*

Not actual patients.

 **More than 20 years* of experience**—the first recombinant treatment for individuals with hemophilia B

 **Dosing options to meet your needs**—for once-weekly prophylaxis and on-demand use

 Designed with viral safety in mind. More than 150 quality control tests are done on each batch of BeneFix

 The convenience of the BeneFix Rapid Reconstitution (R2) Kit with a range of vial sizes



What Is BeneFix?

BeneFix, Coagulation Factor IX (Recombinant), is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

ASK YOUR DOCTOR WHICH BENEFIX DOSING OPTIONS MAY BE RIGHT FOR YOU

Important Safety Information

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash, or hives.
- Your body can make antibodies, called “inhibitors,” which may stop BeneFix from working properly.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness, and rash.

Please see the Brief Summary for BeneFix on the next page.



BeneFix[®]
Coagulation Factor IX (Recombinant)
Room Temperature Storage

*BeneFix was approved February 11, 1997.

R_x only

Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.Pfizer.com or call our medical communications department toll-free at 1-800-438-1985.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- have any allergies, including allergies to hamsters.
- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take. Your doctor may need to test your blood from time to time. BeneFix should not be administered by continuous infusion.

What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

What are the possible side effects of BeneFix?

Allergic reactions may occur with BeneFix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

| | |
|---|----------------------|
| wheezing | fast heartbeat |
| difficulty breathing | swelling of the face |
| chest tightness | faintness |
| turning blue (look at lips and gums) | rash |
| | hives |

Your body can also make antibodies, called "inhibitors," against BeneFix, which may stop BeneFix from working properly.

Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

Tell your doctor about any side effect that bothers you or that does not go away.

How should I store BeneFix?

DO NOT FREEZE the BeneFix kit. The BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

What else should I know about BeneFix?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use BeneFix for a condition for which it was not prescribed. Do not share BeneFix with other people, even if they have the same symptoms that you have.

If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-12.0, revised June 2020.



*In
Loving
Memory*

*A Heartfelt Thank You to Those
Who Donated in Memory Of:*

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By

Duayne & Dianne Malewicki

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Bryan & Gennifer Kelly

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100%

**of donations received from Individuals
go directly to assist patients.**

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Want to help?

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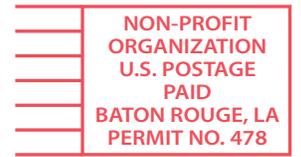
Mail your donation to 3084 Westfork Dr., Suite A, Baton Rouge, LA 70816,
or visit www.LaHemo.org on our "donation/volunteer" page.
You can also give us a call at (225) 291-1675 to give today!

THE LOUISIANA HEMOPHILIA FOUNDATION
was established in 1976 to help Louisiana residents
with hemophilia, von Willebrand's Disease and other
bleeding disorders lead normal and productive lives.

While we support research for a cure to bleeding
disorders and look forward to the cure, our families
continue to need services that we offer to increase
their quality of lives.

Our programs are designed to meet the
needs of the community.

Louisiana Hemophilia Foundation
3084 Westfork Drive
Suite A
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225.291.1675
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Serving the Bleeding Disorders Community Since 1976