



HEMO-FLO

APRIL 2021

Newsletter

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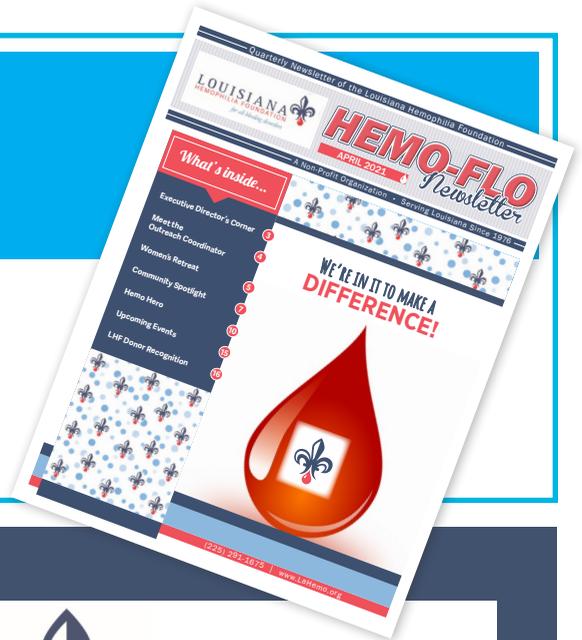
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Bleeding Disorders Awareness

 Women Bleed Too.

Bleeding Disorders Awareness

LOUISIANA
HEMOPHILIA FOUNDATION

Director's Corner

Dear Friends,

My first few months as Executive Director have been productive, exciting, and fun! It has been inspiring to see the renewed energy and enthusiasm amongst our community members and stakeholders.

Much time was spent in my first few weeks on Zoom and conference calls, introducing myself and outlining the goals for LHF to our industry partners and other stakeholders. The overwhelming response has been that these collaborators are thrilled with LHF's recent progression.

In March, we held our 2nd Annual Women's Retreat. Last year, it was held in person right before the pandemic shut most of the world down. This year, the retreat was held virtually, and although we missed seeing each other in person, we were still able to spend quality time together via Zoom and gain valuable knowledge on being a woman with a bleeding disorder. We shared lots of laughter, and the women who participated reported feeling empowered to know they were not alone in their bleeding disorder related struggles.

Also, in March, NHF held its annual Washington Days advocacy event which multiple LHF members participated in, and Octapharma hosted a Taco Tuesday night for our families on Zoom. As we look forward to the rest of the year, we will schedule in person events when it is safe to do so, and in the meantime, we will work on making our virtual offerings as interactive as possible.

Coming up this quarter, we will have our first in-person community get together at Rock-N-Bowl in both the New Orleans and Lafayette locations in May, we will have an in-person Family Field Day to kick off our Virtual Summer Camp in June, and we will have our 2nd Annual Adult Retreat in New Orleans at the end of July.

We are looking forward to seeing everyone both virtually and in person in the upcoming months, and we encourage everyone to get involved in whatever way works best for you, whether that is coming to the events, volunteering, or know that the best way to build this community is to work together.



Meet the Outreach Coordinator



Danielle Rowley

Danielle Rowley, the Outreach Coordinator at LHF since 2019, has been married to her husband, Kevin, for twenty-six years, and they have three children: Mauranda (25), Christopher (21), and Caleb (19). Danielle's daughter, Mauranda, is a pharmacy technician, while both of her sons are members of the military; Christopher is in the Air Force and Caleb is in the Marines. Danielle's husband Kevin is a retired Army veteran, so they now have three branches of the military in their family!

Danielle began her career as a manager for Winn-Dixie until she had her second child and stayed home to raise her family and homeschool her children, all the while running an online business. After homeschooling her children, Danielle became a Pre-K teacher, and remained a teacher and childcare provider until accepting the job at LHF at the end of 2019.

Danielle is a passionate and determined person, and although when she started at LHF, she did not know much about bleeding disorders, her knowledge has increased over the past few years with every event and educational program. In addition to learning more about bleeding disorders, Danielle has also come to know the members of the community and in the process has become a part of our bleeding disorders family. She wants the community to know that she is here to help in any way that she can. Danielle is an incredible asset to the LHF team and her dedication and commitment to LHF and this community can be felt by anyone who has the pleasure to work with her.



2021 Women's Retreat



The 2021 Annual Women's Retreat went virtual this year! Our retreat began interactively, with participants being invited to color a shared document in real time as they logged on and waited for the sessions to begin. We started with an open and honest discussion about being a woman with a bleeding disorder, led by the medical team at Tulane. We shared what that had looked and felt like for each of us throughout our lifetimes. In that very candid discussion, a lot of laughs were shared, as well as support for one another as we realized we were not alone in our journeys as women with bleeding disorders. Our discussion that evening was punctuated by mixology breaks with Lacey Meyers, who taught us how to mix delicious drinks to enjoy during our chat.



On day two, we had three informative and educational sessions from Dr. Rafique, Dr. Janbain, and Dawn Bauer from Tulane, and Martina Willis-McCullough from Octapharma specific to women with bleeding disorders. Then, we closed out the retreat that evening with a guided painting session from Maria Boudreaux at Fleur de Me Designs, who guided participants through painting a bleeding-heart flower with acrylic on canvas.

Participants provided positive feedback on the evaluation survey, and we will use their thoughtful comments and ideas to guide our planning of next year's retreat, which we look forward to holding in person again. Thank you, ladies, for a wonderful retreat!



LHF WANTS YOU!

Are you looking for an opportunity for
personal and professional growth?
Would you like to have the privilege to
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Community Spotlight

Lacey Meyers and Family



Lacey Meyers, the proud mom of three beautiful children, Titus, Taven, and Tanner, has been a member of the bleeding disorders community since 2009 when her youngest son, Tanner, was diagnosed with Severe Hemophilia A as an infant. Only recently was Lacey also properly diagnosed with VonWillebrand Disease 2M and Mild Hemophilia A. Lacey's daughter, Taven, was also recently diagnosed with Von Willebrand Disease 2M and Mild Hemophilia B.

Lacey has been a volunteer in the community for as long as she has been a member. She has volunteered with LHF and with Hope for Hemophilia, being recognized along with her partner, Justin Robinson, as Volunteers of the Year in 2018. As an LHF volunteer, she has helped with the First Steps program, packed boxes for events, delivered poinsettias during the annual poinsettia fundraiser, and assisted as a facilitator for LHF's new support group.

Lacey reports that having three people with a bleeding disorder in one household comes with its challenges. Having two children with bleeding disorders requires extra energy, which is difficult when one of the side effects of your own bleeding disorder is an iron deficiency that effectively eradicates energy. In addition, there is the concern of ensuring that Titus, her only child without a bleeding disorder, receives the same amount of individualized attention as his siblings.

Although these challenges exist, Lacey and her family have found a way to navigate through the difficulties and persevere together. Lacey cites the teamwork and collaboration from her partner, Justin, as well as the assistance and cooperation from all three of the children as the method used to handle the moments of adversity. And when all else fails, she says, coffee and wine help also! Titus has even been able to distinguish himself as a valuable assistant, learning how to assist with his mom's infusions, and offering support to his siblings when needed.

Lacey has utilized the services offered by LHF, such as Medic Alert bracelets, to her family's benefit. She also credits her involvement with LHF as leading to the creation of lifelong friendships with other community members. Lacey experiences a great sense of pride and joy by being able to help other people affected by bleeding disorders, especially girls and women who are seeking a diagnosis and new mothers. Lacey encourages others to get involved by volunteering or simply participating in LHF events and educational offerings. Lacey and her family are proud members of the bleeding disorders community, and they look forward to continuing their involvement with LHF and sharing their experiences to provide a sense of belonging and support to others.



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 enfermedeads 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.

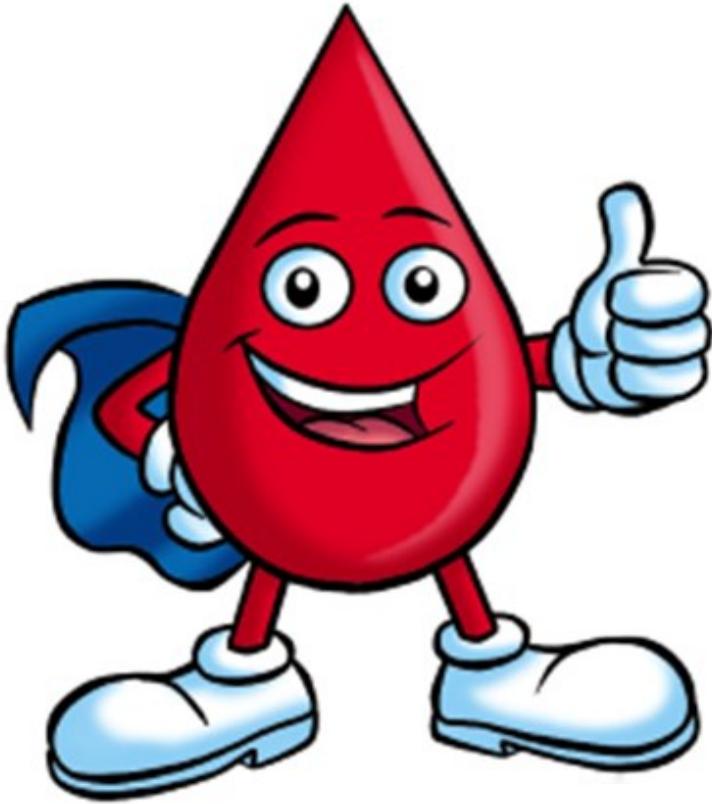
Información proporcionada por:

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

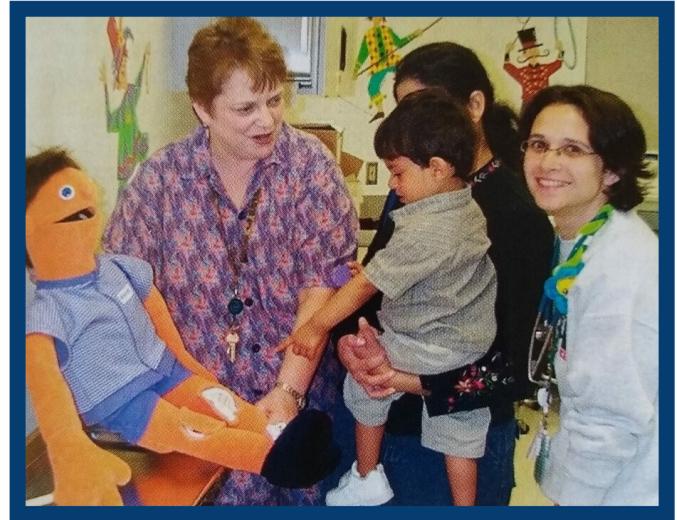
LOUISIANA
HEMOPHILIA FOUNDATION
for all bleeding disorders



LHF

Hemo Hero

Nicole Reynaud



Nicole Reynaud's relationship to the bleeding disorders community is a special one, indeed. Not only is Nicole a hemophilia nurse, but her husband, David, has hemophilia, and their daughter, Watson, is a carrier.

Nicole began her career in nursing in May of 2000 in the pediatric department at Tulane Medical Center after graduating from Southeastern University. Her passion was always pediatric hematology/oncology, and due to her knowledge of administering factor and bleeding disorders by way of her boyfriend (now husband) David, who has Severe Hemophilia A, she was the designated Hemophilia nurse for inpatients. In 2015, Nicole transferred to the Tulane Pediatric Specialty Clinic in the Hematology/Oncology department as the infusion nurse and began to work even more closely with bleeding disorder patients in the outpatient clinic.

In 2018, Nicole made the difficult decision to leave the Tulane Medical Center and join the staff at the hemophilia treatment center, The Louisiana Center for Bleeding and Clotting Disorders. Ultimately, Nicole knew that it was the best decision for her and her family, and now her favorite part of her job is getting to know new families when a baby is born with a bleeding disorder, and then watching those babies and families learn and grow. She also loves to attend camp every year, where she gets to be a kid again for one week!

Nicole says that the most difficult part of her job is having to stick those new babies and young children with needles to get lab work done and administer medication because when they are too young to understand why they must get a shot, it is hard to watch them cry. Luckily for Nicole, all the practice she has had over the years has made her what some call "the baby vein whisperer," and she is usually able to access the small and hard to hit veins of babies and children on her first try.

Nicole has also experienced challenges as the spouse and caregiver of a person with a bleeding disorder. She notes how hard it has been to wait hours for updates while David was in surgery, or how tough it can be to see him in pain when he is having a joint bleed. Even though those situations can be challenging, she finds comfort in knowing that she can be an advocate for her husband by making sure the medical staff listen to him, as a hemophilia patient is usually the most knowledgeable about what is going on with their own body.

Hemophilia is part of Nicole's family and their everyday life. Nicole and David's daughter, Watson, understands how her dad is affected by his bleeding disorder and helps with his infusions. She also understands how her own carrier status affects her tendency to bruise easily, and she has attended local and national educational events alongside her parents.

Nicole's patients and colleagues all recognize that she is an exceptional and valuable resource to the hemophilia community and care team. Her personal experiences make her uniquely adept and caring for bleeding disorder patients. When asked why she felt Nicole was a Hemo Hero, Connie Thibodeaux, Tulane HTC Social Worker, said, "You could not have chosen a more deserving person to highlight! Nicole's energy and passion for this community goes beyond her family because Nicole's family is the community. She is a fearless advocate and a true 'shero' of nurses. Nicole is an innovator...she always has her mind on what project is next and how can we make it better. She is truly an inspiration to our team."

Jennifer Borrillo, Executive Director at the Tulane HTC, says, "Nicole is a Hemo Hero because she is committed not only in her professional life, but also her personal life to the bleeding disorders community. She works tirelessly every day to address the needs of the HTC's patients. Nicole is a caring, giving, empathetic nurse who stops at nothing to make sure everyone's needs are met efficiently and compassionately. I know our HTC's founder, Karen Wulff, RN, would be pleased to see Nicole in her current role, and so incredibly touched by her steadfast dedication to the bleeding disorders community in Louisiana."

"She was the first person I thought of," says Ashley Castello, LHF Executive Director, regarding why Nicole was chosen for the Hemo Hero feature. "She was the first person who greeted us at Tulane when we brought Max in to be tested, and she has been there for us ever since. I always hope that she will be the one doing Max's bloodwork when we bring him in, as she is always the best at getting it done quickly and effectively. She is kind, compassionate, knowledgeable, and her dedication to the community is evident."

It is our great pleasure to recognize Nicole Reynaud as our inaugural Hemo Hero!





EXPERIENCE MATTERS

BeneFix is FDA approved for once-weekly prophylaxis and on-demand use to fit your dosing needs—
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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.

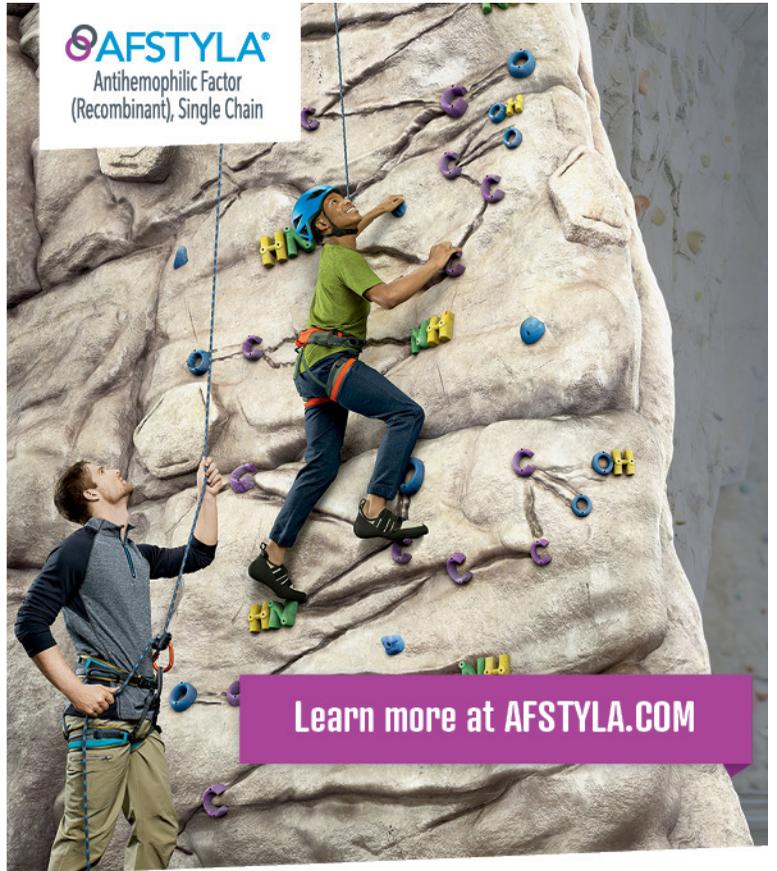
If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about BeneFix that was written for healthcare professionals.

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



Application deadline for the fall 2021 Semester is July 22, 2021. Visit www.LaHemo.org for more information.

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



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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 Globecloggers.

VOLUNTEER



UPCOMING EVENTS

(All dates and programs are tentative and may need adjusting according to any guidelines that may need to be adhered to)

May 24-25, 2021 - Louisiana Capitol Day, Baton Rouge

Connecting with Louisiana Lawmakers to advocate for the needs of the bleeding disorders community

May 15-16, 2021 - 2nd Quarter Community Get Together Weekend, Rock-N-Bowl New Orleans May 15, and Lafayette May 16

June 2021- Camp Globeclotters/Tulane Transition Retreat (Will adjust to any Covid-19 Guidelines in Place)

Annual Summer Camp for youth 7-18 with bleeding disorders. Siblings of campers are welcome.

June 12 - Family Field Day at Camp Istrouma

June 13-24 - 2-3 Virtual Sessions a week

July 30—August 1, 2021- Annual Adult Retreat, New Orleans

September 18, 2021 - 3rd Quarter Community Get Together, Alexandria

October 8- 9, 2021- Annual Meeting and Educational Symposium, Baton Rouge

October-November- Poinsettia Sale, proceeds go to fund assistance and scholarship programs

November 2021- 4th Quarter Community Get Together Weekend, Rock-N-Bowl New Orleans Nov 6, and Lafayette Nov. 7

December 18, 2021- Christmas Annual Family Day, Baton Rouge (Locations TBD)

Lunch and activities for the entire family

***We will continue to add virtual educational sessions and presentations.**

Registrations invites for all events and programs are sent via email and posted on our website and social media pages.





LHF would like to recognize it's kind donors!

Marc & Stacey Taylor

O'Neal Weber Jr.

Ana Paredes

Louis Francis Ledet, Jr.

GFWA Lagniappe Woman's Club

**Along with other anonymous donors through our Social
Media.**

We appreciate each and every one of you!



Let Us Show You How We Put Patients and Science at the Center of Everything We Do

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(Recombinant), Fc Fusion Protein]
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Did you know:



100%

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

These donations help provide MedicAlert services, protective helmets for babies, transportations to HTC appointments and many other things that patients across the state are in need of.

Want to help?

You may make a monthly contribution or a one-time gift.

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.



Quality of Life

PROGRAM

Our team is here to support the bleeding disorder community by providing specialty pharmacy services and clinical resources that empower patients to live their life to the fullest.

PARAGONHEALTHCARE.COM

P: 833.862.4559 | F: 855.862.4373



Visit us at our new
Lakeside Clinic

Opening Spring 2021!

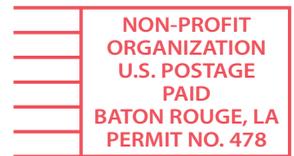
In the Medical Office Building next to Lakeside Hospital

4720 S. I-10 Service Road, Suite 401
Metairie, LA 70001
Office: 504.988.5435 | Fax: 504.988.5442



LOUISIANA CENTER FOR BLEEDING
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Serving the Bleeding Disorders Community Since 1976