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FOR IMMEDIATE RELEASE

9/23/2019

INFORMATIONAL MEETING FOR BLEEDING DISORDER PATIENTS

The Louisiana Hemophilia Foundation's annual meeting provides educational resources for those affected by bleeding disorders.

BATON ROUGE, Sep. 23, 2019 – The Louisiana Hemophilia Foundation's (LHF) 43rd Annual Meeting will be held October 11 and 12 at the Embassy Suites Hotel, 4914 Constitution Ave, Baton Rouge. The annual meeting is an opportunity for members of the bleeding disorder community to come together. The LHF is a non-profit organization that supports people who have been diagnosed with Hemophilia, which is a rare, life-long disorder with no cure. The meeting is open to those affected with Hemophilia.

This year's theme for the meeting is "Mission: Possible!". The goal is for every attendee to leave feeling supported, empowered, and equipped with the knowledge to know that anything is possible. The meeting is for members connect, share information, learn about new advancements, and get involved with an organization dedicated to making a difference in the lives of patients and their families.

"Our top priority is making sure that patients have access to the resources they need to survive, and everything else comes secondary," said Sharon Doucet, outreach director.

Hemophilia is the most expensive chronic condition that someone can have. The mission of LHF is to improve the quality of life and assist persons effected by inherited bleeding disorders by providing education, advocacy, support services, and promoting research.

There will be a Halloween costume party to help bring together the bleeding disorder community and their loved for a fun event. It will be held at the Hilltop Arboretum and food, games as well as prizes, will be enjoyed. There are hotel rooms, and transportation, and cost funding opportunities available to attendees with a bleeding disorder. Space is limited.

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For more information, visit our website www.lahemo.org. We are a nonprofit organization serving the bleeding disorder community since 1976. The Louisiana Hemophilia Foundation provides educational programs, networking opportunities, and access to medication and care. Add the website info.

PITCH:

SUBJECT LINE: Coming together to support chronic disorder

Good morning Ms. Faris,

I have been following your recent stories and really loved the one about osteoarthritis. After reading your biography, I know you will be interested in covering the 43rd Louisiana Hemophilia Foundation (LHF) Annual Meeting that supports those affected with chronic bleeding disorders.

I am confident your readers will love a story about a community of people coming together to support and provide for one another. LHF is putting on the 43rd Annual Meeting on October 11 and 12 at the Embassy Suites Hotel, 4914 Constitution Ave, Baton Rouge. The meeting is an educational event that helps members of the bleeding disorder community connect to share information and get involved.

I can set up pre and day-of interviews with someone closely effected by the disorder and the executive director of the foundation, Erica Simpson. I will be in contact over the next few days and look forward to hearing from you. For your convenience, I attached the news release for the Annual Meeting to this email.

Thanks for your time,

Gabrielle Seguin
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ALTERNATIVE PITCH:

SUBJECT LINE: Come together to help the ones who need it most!

Good Morning Mr. Foster,

I really enjoyed your article two weeks ago on deaths being caused by vaping and thought you would be interested in a foundation that supports people with chronic bleeding disorders.

The Louisiana Hemophilia Foundation is putting on its 43rd Annual Meeting. This gathering is to support people who are affected by hemophilia, which is a life-long blood disorder with no cure as of now. Hemophilia is the most expensive, chronic, life-long disorder someone can have so support and information is essential.

I will be in touch over the next few days and look forward to hearing from you. For your convenience, I have attached the news release for the Annual Meeting.

Thanks for your time,

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LOUISIANA
HEMOPHILIA FOUNDATION

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FOR IMMEDIATE RELEASE
9/17/19

MEDIA ADVISORY

BRINGING TOGETHER THE BLEEDING DISORDER COMMUNITY

The Louisiana Hemophilia Foundation comes together for the 43rd Annual Meeting to educate those effected by bleeding disorders.

WHO: The Louisiana Hemophilia Foundation

WHAT: 43rd Annual Meeting and Educational Symposium

WHEN: October 11-12

WHERE: Embassy Suites, 4914 Constitution Ave., Baton Rouge, LA

WHY: The annual meeting is an educational event where members of the bleeding disorders community connect to share information, learn about new advancements, and get involved.

Hope you will be joining us October 11-12 for our 43rd Annual Meeting, for more information go to www.lahemo.org

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For more information, visit our website www.lahemo.org. We are a nonprofit organization serving the bleeding disorder community since 1976. The Louisiana Hemophilia Foundation provides educational programs, networking opportunities, and access to medication and care. Visit lahemo.org for more information.



LOUISIANA
HEMOPHILIA FOUNDATION

The Louisiana Hemophilia Foundation

By: Gabrielle Seguin

Hemophilia is a life-long disease that has no cure. It is the most expensive chronic condition that someone can have. Patients with severe hemophilia can spend millions or more a year, just on medication. Since the medication is dosed by body weight, the older someone gets, the more expensive the medication becomes.

One of the patients in the LHF's community is 10-years-old and has hemophilia since he was born. (His name cannot be stated due to the privacy standards set by Healthy Insurance Prospective Payment System.)

Both of his parents are professionally employed and thought that with their insurance that they would be able to cover all of his medical needs. By the time he was 3-years-old, his parents had gone through three different insurance policies and spent over a million dollars out-of-pocket to pay for his necessary medications.



FACT SHEET

The Louisiana Hemophilia Foundation has been bringing together and helping the bleeding disorder community for decades. The 43rd Annual Meeting provides education, resources, and fun for those affected by bleeding disorders.

- The Louisiana Hemophilia Foundation (LHF) was founded in 1976 by Huey and Angelina Wilson.
- The mission of LHF is to improve the quality of life and assist persons effected by inherited bleeding disorders by providing education, advocacy, support services and by promoting research.
- Hemophilia is the most expensive chronic illness someone can have. Patients with severe hemophilia can spend millions a year, just on their medication.
- The LHF is a nonprofit organization supported by volunteers that want to help provide for the bleeding disorder community.
- The annual operating budget for the nonprofit foundation is around \$360,000. Eighty percent of the foundation's revenue comes from program funds that are recycled back through in order to produce educational resources for the hemophilia community. Ten percent of the revenue comes from donations and the last ten percent comes from fundraising.
- Hemophilia is an inherited disorder that has no cure.
- Patients with Hemophilia cannot go see a regular doctor, they must be seen by a specialist. In Louisiana, there are only two treatment centers and LHF works with these centers to help patients get support through the foundation.
- In recent years, there has been a new product put on the market that has revolutionized patients' lives. Gene Therapy acts as a bridge between factor-7 and factor-9, so that factor-8 is not needed in order for blood to clot.

For more information, you can contact:

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OP-ED

BRINGING TOGETHER THE BLEEDING DISORDER COMMUNITY!

The Louisiana Hemophilia Foundation comes together for the 43rd Annual Meeting to educate those effected by bleeding disorders.

The Louisiana Hemophilia Foundations urges you to vote in this upcoming Louisiana Governor's Election. The three candidates for governor: John Bel Edwards, Eddie Rispone and Ralph Abraham.

It is so important to vote in the upcoming governor's election and make our voices heard. We cannot go another year with inadequate health care in our state. If you go vote and keep health care a priority, you can help not only yourself but bleeding disorder patients.

Hemophilia is a life-long disease that has no cure. It is the most expensive chronic condition that someone can have. Patients with severe hemophilia can spend millions or more a year, just on medication. Since the medication is dosed by body weight, the older someone gets, the most expensive the medication becomes.

The mission of the LHF is to improve the quality of life and assist persons effected by inherited bleeding disorders by providing education, advocacy, support services and by promoting research. The annual operational budget for the foundation is around \$360,000. Eighty percent of the foundation's revenue comes from program funds that are recycled back through in order to produce educational resources for the hemophilia community. Ten percent of the revenue comes from donations and the last ten percent comes from fundraising.

"Around 85 percent of that is spent on services for patients, while the other 15 percent goes towards administrative expenses," said Erica Simpson, executive director of the foundation.

There are only two treatments centers in Louisiana and both of them are located in New Orleans. The LHF works with these treatment centers are connected with patients to provide support through the foundation.

Not only should the bleeding disorder community come together, but all of Louisiana should come together and vote. We deserve better healthcare. Our friends and family diagnosed with chronic and life-threatening disorders, like hemophilia, deserve to have better health insurance. Nobody deserves to have to pay millions per year, just to survive. Go out, do your part, make your voice heard, AND GO VOTE!