



# HEMO-FLO

Newsletter

JULY 2022



A Non-Profit Organization • Serving Louisiana Since 1976

## What's inside...

Executive Director's Corner

3

Friends and Family Day

4

Capitol Advocacy Day

8

Men's Retreat

12

Emergency Preparedness Checklist

16



## Camp Bayou Bruisers

July 24-29

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## Advocate

*Bleeding Disorders Awareness*



**Women Bleed Too!**

*Bleeding Disorders Awareness*



## Director's Corner

Dear Friends,

Dear Friends,

In this issue you will find photos and descriptions of our Spring events - Friends and Family Day and Capitol Advocacy Days. These annual programs are essential to our mission of educating as many people as possible about bleeding disorders. As more and more of our neighbors in Louisiana learn about our community and the health issues that we face, we become better enabled to enlist additional support and resources to continue to implement and advance our mission.

As part of my endeavor to continually grow and improve this organization, I frequently attend workshops and trainings about fundraising and non-profit development. One of the common threads that is continually repeated in these lessons is passion for the mission.

For me, that is an easy task. As a Hemo-mom, the importance of LHF and the ways in which it benefits the bleeding disorders community are easily recognizable. As a member of this community, an ally, a stakeholder, or any other role you may hold in relation to LHF, do you feel that same passion for the mission? Are you aware of how our programming benefits people with bleeding disorders? If not, I challenge you to get involved and find out! I have personally experienced for myself and witnessed in others how being more active in the community can lead to a greater sense of belonging, purpose, accomplishment, and pride.

What else are you passionate about? Do you love to draw? Maybe you could lead an art lesson at camp or annual meeting. Do you prefer your alone time? Maybe you could help contribute to one of the newsletters from the comfort of your home. There are so many ways to be an active part of LHF, and I encourage you to think about your interests and how they might be incorporated into our mission. Every little bit helps, and any contribution of time, talent, or treasure is important and appreciated.

If you'd like to be more involved, but you aren't sure how, please reach out to us.

In gratitude and fellowship,



Ashley Castello



# Friends and Family Day 2022



On April 30, 2022 LHF hosted its annual Friends and Family Day at Camp Istrouma in Greenwell Springs, Louisiana. The event was offered for free to anyone with a bleeding disorder and their immediate family members, and this year, for the first time ever, the event was offered at a small fee to friends and extended family members of persons with bleeding disorders. This change was made because we wanted a way to include our friends and family who don't normally get to attend LHF events. We wanted to extend an invitation to those people to show them what an awesome community we have, and also to give them the opportunity to learn about bleeding disorders.

It was a sunny, beautiful day to spend at Camp Istrouma. Activities included an exhibit hall bingo card, archery, human foosball, basketball, tetherball, gaga ball, swimming, rock wall climbing, water sliding, canoeing, face painting, fishing, and arts and crafts. Outdoor games were spread out in the shade for kids to play and enjoy. Press 1 for English was back with live music to enjoy throughout the day.

Crawfish, hamburgers, and hotdogs were served for lunch, with a snowball truck onsite all day for some cool refreshment. It was such a fun filled day! Over 200 people attended Friends and Family Day! We are thrilled with the turnout, and hope that our community members will invite even more of their friends and family to attend next year.



# Thank You!

## To our Generous Friends and Family Day Sponsors



## Friendship Sponsors



*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](http://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.

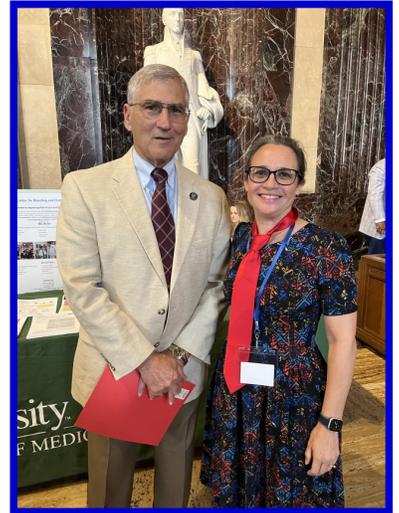
Our programs are designed to meet the  
needs of the community.

# Capitol Advocacy Day 2022



On May 16, 2022, trainees gathered in the Louisiana Room at the Hilton Baton Rouge Capitol Center in Baton Rouge, Louisiana to learn skills for talking to legislators about bleeding disorders and to learn about pending legislation that would affect access to care for bleeding disorders patients. On May 17, 2022, eighteen advocates went to the Louisiana State Capitol, set up informational exhibit tables in the rotunda, and met with legislators. We discussed basic bleeding disorder information and how important access to care is for bleeding disorder patients. We also advocated for the passage of a specific bill, SB 366 by Senator Jimmy Harris that would protect consumers with high deductible insurance plans from copay accumulators. A few weeks later, that bill was passed by both houses of the Louisiana Congress and signed into law by Governor John Bel Edwards!

Thanks to all for the participants for taking the time out of your schedules to advocate for our community, and thanks to our partner, Tulane University, and our sponsor CSL Behring for making the event possible.



**Thank You To Our Sponsors!**



# 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?

**Treasurer position  
and three trustee positions  
are available.**

**JOIN TODAY!**

Call (225) 291-1675 for more information or apply at [LaHemo.org](http://LaHemo.org)



**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](http://www.lahemo.org/medic-alert) and click the PDF, fill it out, and email it back to us at [Outreach@Lahemo.org](mailto: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](mailto:Outreach@lahemo.org)

**The importance and benefits of having a MedicAlert ID and membership service:**

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](http://www.lahemo.org)**

## 2022 Men's Retreat Grand Isle



On June 25-27, LHF held its second annual Men's Retreat. This year, we returned to Grand Isle, where the retreat was originally scheduled last year before Hurricane Ida dealt a devastating blow to the region. Men from Louisiana with bleeding disorders, hemo-dads, and hemo-grandpas came from all over the state to participate in this annual event.

The men arrived in Grand Isle on the evening of Saturday, June 25, and gathered on the beach pavilion to receive info and education from some of our industry sponsors and Tulane's Dr. Garrett over a casual dinner. Sunday morning, the guys had an early wakeup call to board the *Louisiana*, a multi-level fishing vessel, specializing in large groups, and operated by Southern Pride Charters.

When the men returned from the fishing trip at the end of the day, they had over fifty redfish! They concluded their day by frying their freshly caught dinner. There was enough fish left for every participant to take home a bag of fillets to share with their families.

We are excited that our guys had such a nice time and were able to connect with one another. We are so grateful to our sponsors for making this event possible!



**Gold Sponsors**



**Silver Sponsors**



**Friendship Sponsors**



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LET'S GO

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at **UnderstandingPK.com**



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**July 24-30 - Camp Bayou Bruisers - Dry Creek  
Campsite, Dry Creek**

**September 8-9 - Medical Summit - Sheraton,  
New Orleans**

**September 23-25 - Couple's Retreat - Hilton Garden Inn,  
New Orleans**

**October 28-30 - Annual Meeting - Doubletree, Lafayette**



## Connected. Together.

For me, being a Community Outreach and Education (CoRe) Manager for Sanofi Genzyme goes beyond hemophilia support. It's about being a part of and empowering this community.

**Anna Moss**  
CoRe Manager for  
AR/LA/TN

### Stay connected.

504-952-1975  
anna.moss@sanofi.com  
RareBloodDisorders.com

@HemophiliaCoRes

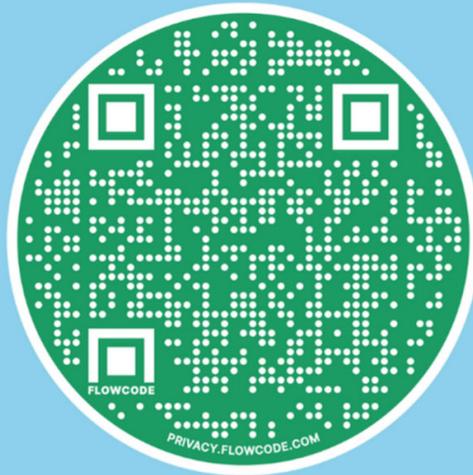


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<https://www.facebook.com/LCBCDTulane/>



**Louisiana Center for Bleeding and Clotting Disorders**



**Application deadline for the fall 2022 Semester  
is July 22, 2022.**

**Visit [www.lahemo.org](http://www.lahemo.org) for more information.**

**Scholarships Provided By:**

**Louisiana Hemophilia Foundation &  
The Wilson's Foundation**



**LHF would like to recognize it's  
generous second quarter donors!**

**Mary Ann Doherty**

**Jesse Fontenot**

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

**Thank you for supporting the LHF  
Mission!**



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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](http://LaHemo.org)) to sign up for different opportunities ranging from help with Advocacy to volunteering for Camp Globeclotters.*

# VOLUNTEER



## LHF Community Events

### Save the Dates!

(Registration information available at [www.LaHemo.org](http://www.LaHemo.org) on our events page)



**Saturday, May 14, 2022**

**1:30—4:00 PM**

**905 Jefferson Street**

**Lafayette, LA 70501**

**Saturday, August 20, 2022**

**2:00—4:40 PM**

**3016 Carrollton Avenue**

**New Orleans, LA 70118**



## EVERY STEP HAS BEEN EVOLVING THE SCIENCE OF GENE THERAPY IN HEMOPHILIA B

We're working to make gene therapy a reality for you.

**HemEvolution**

Explore the advancing science at [HemEvolution.com](http://HemEvolution.com)



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# EMERGENCY PREPAREDNESS CHECKLIST



DID YOU REMEMBER TO PACK?



MEDIC ALERT



TRAVEL OR EMERGENCY LETTER



FACTOR AND MEDICATIONS



MEDICATION LIST





## MEDICAL SUPPLIES



## TO GO BAG

- Medical papers
- Children items
- Cell phone charger
- Sharps container



## ZIP LOCK BAG - FIRST AID



- Tourniquet
- Syringes
- Butterfly needles
- Gloves
- Saline
- Heparin
- Alcohol swabs/wipes
- Gauze (2x2)
- Adhesive bandages
- Adhesive tape
- Port needles

**24-Hour Emergency Line**

**504-988-5433**

[lcbcdcomms@tulane.edu](mailto:lcbcdcomms@tulane.edu)



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Clotting Disorders**

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