



HEMO-FLO

Newsletter

JUNE 2023

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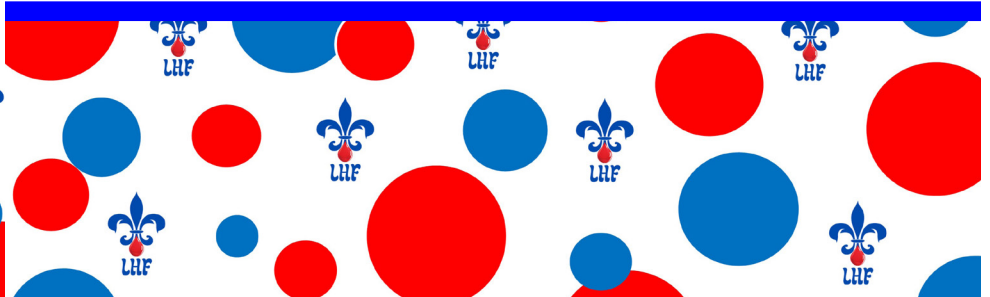
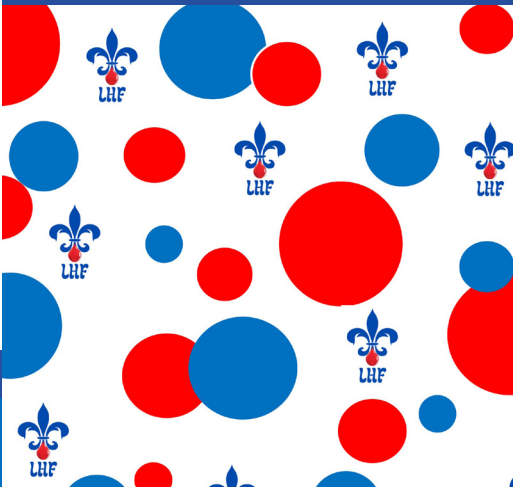
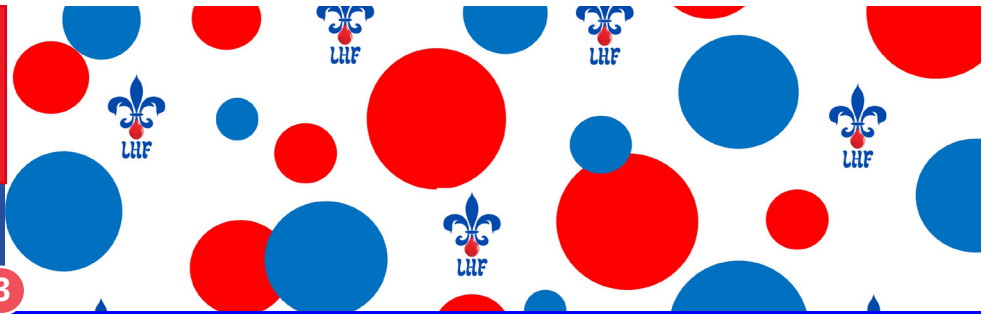
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Advocate

Bleeding Disorders Awareness



Women Bleed Too!

Bleeding Disorders Awareness



Director's Corner

Director's Corner
Summer 2023

Bleeding disorder management, treatment, and care has changed drastically over the last ten years, and even more changes are here or on the horizon. Gene therapy has just been approved for Hemophilia B, and similar therapies for Hemophilia A are in clinical trials. A new, long-lasting factor replacement therapy for Hemophilia A has just been approved as well. With so many advances in treatment improving outcomes for so many patients, many wonder if the need for community is as important today as it has been in the past, and the answer is a resounding YES!

Even though new and improved treatments are available and are very exciting for our community, they are currently only available to a specific segment of bleeding disorder patients. And although gene therapy will likely be a complete game changer for many, its long-term efficacy, though very promising, is still unknown. In addition, there are a multitude of patients that will prefer to stick with the method of treatment that has worked for them and that they are used to.

New and improved treatment options are thrilling, but as there is still no cure, we will remain affected by our bleeding disorders, even when receiving the most up to date and innovative therapies. We will continue to need one another for support, community, and fellowship. Bonding over our shared experiences is therapeutic for all of us. Offering support to newly diagnosed families or accepting support from more seasoned families are equally valuable. Although progress in bleeding disorder care has given us a sense of security that many have never experienced before, it is wise to stay vigilant, as it can be more difficult to adjust to physical hardships now that they may occur more rarely.

Having just returned from a week at camp (LHF's Camp Bayou Bruisers for children affected by bleeding disorders), I have a renewed enthusiasm for how meaningful the support of this community can be. It is truly inspiring to watch young people connect and create friendships that will serve as a protective support system for them throughout their journey with bleeding disorders throughout their lifetimes.

If you haven't been active in our community, I encourage you to start now. We can all use more friends to lean on, even in good times.

In gratitude and fellowship,

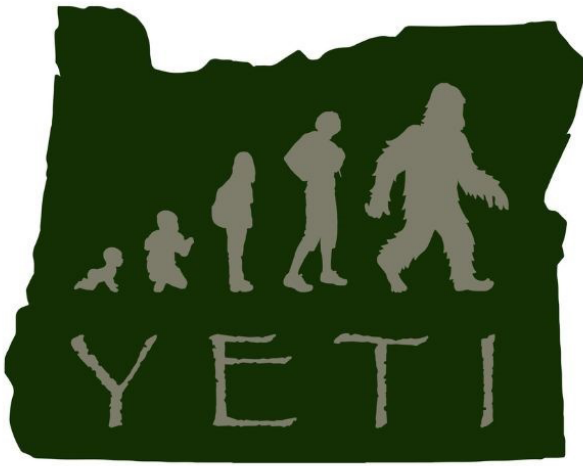
Ashley Castello





On February 9-12, 2023, LHF staff members Ashley Castello and Danielle Rowley, Louisiana Center for Bleeding and Clotting Disorders Nurse Coordinator Nicole Reynaud, and two outstanding teenagers, Isabella Peterkin and Zha'Ki Pittman attended the YETI (Youth Effectively Transitioning to Independence) Teen Leadership Conference at YMCA Camp Collins in Portland, Oregon.





YETI is an experiential train-the-trainer weekend conference created by Pacific North West Bleeding Disorders (PNWBD). This teen program that effectively addresses topics around successful transitions into young adulthood provides a wonderful opportunity to build community, increase parent, teen and young adult engagement with local chapters, and get medically essential information to “stick.”

The YETI conference was dreamt up and designed by people who believe in the positive impact of quality youth programming, and this immersive weekend workshop will put you directly into the types of experiences that we know result in high impact teen events. Beyond that, bleeding disorder organizations will learn to build a map of how events become a program, and how a program can become a powerful driver of chapter and hemophilia treatment center (HTC) engagement. YETI also provides for the beginnings of a national network of teens, aged 14 – 20.

We are especially thankful to Madonna Maguire Smith, the Executive Director of PNWBD, and her team for offering this experience to our Louisiana teens. We hope to make this an annual event, bringing Louisiana teen leaders to experience YETI every year.



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NHF'S WASHINGTON DAYS. 2023

MARCH 8 - 10



NHF held its annual Washington Days advocacy event on March 8-10, in person for the first time since Covid, in Washington DC. NHF's Washington Days is an opportunity for people affected by inherited blood disorders to advocate for issues important to our community such as federal funding for bleeding disorder programs and supporting policies that increase affordability of coverage, and access to care. LHF was proud to bring representatives from Louisiana and Mississippi to advocate for the bleeding disorder community! (continued on next page)





(continued from page 1)

Louisiana was represented by Executive Director Ashley Castello and her son Leo, and Sharrolyn Jackson and her daughter, Katelynn. Mississippi was represented by Shanna and Chuck Burdine and their children, Eli and Lyla. The Louisiana group and the Mississippi group each met with three congressional offices to educate them on the basics of bleeding disorders and ask for support for funding for federal bleeding disorders programs and for support of House Bill 830, the HELP Copays Act to ensure that all copays made on behalf of a patient count. Since Washington Days, 16 additional bipartisan Members have cosponsored the bill, bringing the total number to 22 since this Congress began a couple months ago. We are so proud to have been a part of this advocacy effort. We look forward to bringing families again next year!



The Burdines meet with Representative Ezell's office (above)
The Louisiana crew meets with Representative Graves' office (right)



**LHF is now accepting scholarship applications for the fall 2023 semester.
Visit www.LaHemo.org for more information on applying. Application deadline is July 22, 2023.**

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.**

2023 Women's Retreat

Our 2023 Women's Retreat was held on March 31-April 1 in New Iberia, Louisiana. Women affected by bleeding disorders from all over the state came together for a weekend of fun, fellowship, and education. Women in attendance were diagnosed with a bleeding disorder, caregivers of a person with a bleeding disorder, or partners/spouses of someone with a bleeding disorder.

Educational topics covered throughout the weekend included women's issues in bleeding disorders, self-advocacy, new treatment possibilities, self-care, and a World Hemophilia Day celebration and activity.

On Saturday afternoon, the ladies went on a tour of the beautiful grounds and facilities of Avery Island, home of Tabasco.

Thanks to all of the ladies in attendance and to all of our sponsors for making the event possible!



LHF

receives national recognition!

On April 15, 2023 at the Hemophilia Federation of America's Symposium Annual Awards Celebration, LHF was honored with the Member Organization Spotlight Award. In a speech given by Luke Runion, HFA's board president, LHF was commended for their dedication to the community and passion for the mission. Executive Director Ashley Castello accepted the award and was congratulated by the other member organizations present at the conference. Everyone on the LHF team is extremely humbled and proud to have been recognized as an outstanding local bleeding disorder service organization.



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?

**Secretary, Treasurer and
three trustee positions available.**

JOIN TODAY!

Call (225) 291-1675 for more information or apply at 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 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:

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CAMP BAYOU BRUISERS

2023

The 2023 LHF Camp Bayou Bruisers took place May 28-June 2 at Camp For All in Burton, Texas. This was a new campsite for us, and we are thrilled with our new camp home! Camp For All offered so many amenities for our campers to enjoy, including a giant swing, high ropes course, zipline, rock wall, horseback riding, petting zoo, archery, swimming, arts and crafts, canoeing, kayaking, fishing, an escape room, a recording studio, a costume room, and a photography studio. Our campers had a wonderful time trying out all of the different activities each day. Campers also learned about bleeding disorders and infusions. Camp Bayou Bruisers grew this year, and we hope it continues to grow in the future. It is truly magical to see our young people grow and learn together and form friendships that will last a lifetime. Today's campers are tomorrow's leaders in this community!

CAMP BAYOU BRUISERS

2023



Campers are greeted with enthusiasm as they arrive



The first group to escape from the escape room



Lots of fun in the costume room



Kicking off the Color War

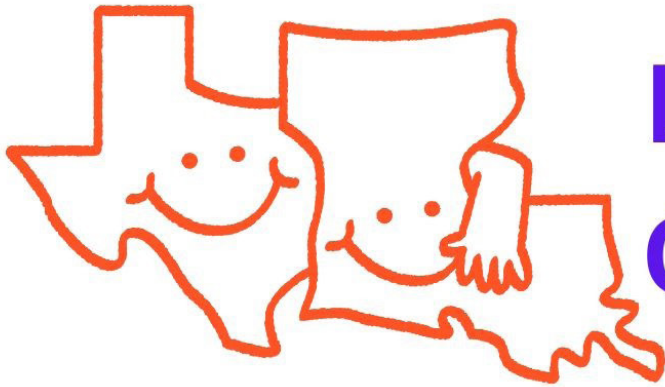
*Thank
You*

Camp Bayou Bruisers is made possible by grants provided by Tulane University, the Huey and Angelina Wilson Foundation, and our generous sponsors - CSL

Behring, Bayer, Optum, and CVS. We are extremely grateful for their support in making camp available to our kids.



Hufflepuff Cabin getting ready for their photo scavenger hunt



Louisiana/Texas Couples Retreat

May 5-7, 2023, the Louisiana Hemophilia Foundation, Texas Central Bleeding Disorders Foundation, and Lone Star Bleeding Disorders Foundation co-hosted a couples retreat for couples affected by hemophilia and other bleeding disorders. Couples participated in educational sessions focused on navigating living with a bleeding disorder as partners. Louisianians were also introduced to some Texas-style fun when couples played a few rounds of Loteria on our opening night. We will bring the couples retreat back to Louisiana, as it was difficult for many of our LA couples to make the journey to Houston, but we enjoyed working with our Texas neighbors and bringing something new and different to our community!

Thank you to our Couples Retreat sponsors!

CSL Behring



sanofi

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Infucare, Optum Rx, Paragon, and Sands Rx**

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.



SCAN TO DONATE

LHF would like to recognize its generous donors!

Marc & Stacey Taylor
Louis F. Ledet

GFWC LA Lagniappe Woman's Club
Joy Stoneham – In Memory of Libby Fisackerly
Lillian Oubre – In Memory of Libby Fisackerly
Camryn Hebert

Along with the other anonymous donors
on our social media.
Thank you for supporting the LHF mission!

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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
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- Adhesive bandages
- Adhesive tape
- Port needles

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**Louisiana Center for Bleeding and
Clotting Disorders**



Louisiana Center for Bleeding and Clotting Disorders

Press Release



Tulane University's Louisiana Center for Bleeding and Clotting Disorders and Acadian Health Partner to Enhance Care for Individuals with Bleeding Disorders

New Orleans, LA — Tulane University is pleased to announce a groundbreaking partnership between the Louisiana Center for Bleeding and Clotting Disorders (LCBCD) and Acadian Health, aimed at reducing unnecessary emergency department (ED) visits and hospitalizations for individuals with bleeding disorders. This collaboration will significantly improve patient outcomes, enhance quality of care, and promote value-based healthcare principles.

Acadian Health plays a vital role in supporting patients of the LCBCD, a renowned center specializing in bleeding and clotting disorders. By providing in-home assistance with blood clotting medication infusion, Acadian Health ensures that patients receive the care they need in the comfort and convenience of their own homes. In cases where patients lack access to their medication, Acadian Health providers assist with medication management and the infusion process, ensuring prompt and appropriate treatment.

This innovative approach streamlines the patient's experience by empowering them to initiate contact with the LCBCD when in need of assistance. LCBCD providers then collaborate with Acadian Health to address the patient's bleeding episode effectively. Upon arrival at the patient's location, Acadian Health providers conduct a comprehensive assessment and communicate the patient's condition to the LCBCD, allowing for tailored care planning and precise dosage of clotting factor infusion to manage the bleeding event.

“This partnership between the LCBCD and Acadian Health marks an exciting milestone in the journey towards improving the lives of individuals with bleeding disorders,” said Director of Acadian Health Benjamin Swig. “Together, we are breaking new ground in delivering patient-centered care, reducing unnecessary ED visits and hospitalizations, and promoting value-based healthcare principles.”



In May 2023, Acadian Health demonstrated the effectiveness of this partnership when a patient experienced two bleeding episodes. In both instances, Acadian Health promptly responded and delivered crucial in-home assistance to the patient in coordination with an LCBCD provider. This seamless collaboration ensured that the patient received the appropriate dose of clotting factor, minimizing the need for hospitalization or ED visits.

The benefits of this partnership extend to various stakeholders in the healthcare ecosystem. First, patients with bleeding disorders now have access to specialized care and support in the comfort of their own homes, eliminating unnecessary travel and reducing stress associated with seeking emergency medical attention. This patient-centric approach fosters a stronger sense of empowerment and control over their condition.

For healthcare providers at the LCBCD, this collaboration streamlines the coordination of care, enabling timely interventions and reducing the burden of hospital-based treatments. The direct communication between Acadian Health and LCBCD providers ensures accurate and up-to-date information exchange, allowing for the development of individualized care plans that cater to each patient's unique needs.

Furthermore, health plans benefit from this partnership through the application of Institute for Healthcare Improvement (IHI) and value-based healthcare principles. By minimizing unnecessary ED visits and hospitalizations, the associated costs can be significantly reduced. The emphasis on in-home care and proactive management of bleeding events aligns with the overarching goal of enhancing patient outcomes while optimizing resource utilization.

About the Louisiana Center for Bleeding and Clotting Disorders (LCBCD)

Tulane University's LCBCD, a leader in bleeding and clotting disorder care, is dedicated to advancing research, education, and patient care in this specialized field. Their multidisciplinary team of experts is at the forefront of providing comprehensive care to individuals with bleeding disorders, ensuring that patients receive the best possible care. The LCBCD is a federally designated Hemophilia Treatment Center, serving patients throughout their life-span with clinics in New Orleans, Metairie, Lafayette and Alexandria.

About Acadian Health

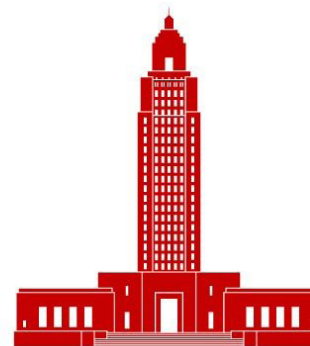
Acadian Health, a division of Acadian Companies, was founded to complete the last mile of healthcare by bridging the gap between patient and provider, offering the highest-quality at-home healthcare. With five decades of mobile healthcare experience through our ambulance division, the Acadian Health mobile community healthcare team members arrive at a patient's location with the knowledge, skill, and equipment to act as our partners' eyes, ears, and hands.

When you can't be there – send Acadian Health, your partner, for at-home care.





Capitol Advocacy Days



New and experienced advocates from around the state gathered at the Embassy Suites in Baton Rouge on the evening of May 23, 2023 to learn strategies to be an effective advocate. The next day, we all went down to the Louisiana State Capitol to put those advocacy skills to work! LHF operated an information table in the rotunda of the Capitol to educate visitors about bleeding disorders and the mission and services of LHF.



We were also able to meet with several of our participants' state representatives and/or state senators. Advocates communicated our support for House Bill 548 by Representative Chris Turner of Ruston, and we are happy to report that the bill was passed shortly after our visit. HB 548 protects 340b programs, like the one that helps to fund our partner, the Louisiana Center for Bleeding and Clotting Disorders. The 340b program is imperative to the care of hemophilia patients, and we are so happy that the bill passed!



**ANNOUNCING THE
2023 GETTIN' IN THE GAMESM
JUNIOR NATIONAL CHAMPIONSHIP**

October 6 – October 8, 2023
Henderson, Nevada



CSL Behring Patient Engagement

Developed by CSL Behring, the Gettin' in the Game Junior National Championship (JNC) is the only national sports competition designed specifically for the bleeding disorders community. The JNC features accomplished Gettin' in the Game Athletes who themselves have been diagnosed with a bleeding disorder. During the program nominees will have the opportunity to:

- Take part in baseball, basketball, golf, or swimming activities to learn the fundamentals and enhance their skills in that sport.
- Learn about the importance of physical fitness in managing a bleeding disorder and receive instructions on proper stretching techniques and good athletic form.
- Show off their abilities in a national competition with fellow nominees from around the country.
- Connect and build relationships with fellow members of the bleeding disorders community by sharing their personal experiences with one another.

CSL Behring will sponsor each chapter nominee and one accompanying caregiver to participate in the program. This sponsorship will include the coordination and cost of airfare, ground transportation in Henderson, Nevada, and hotel arrangements (attendees will be responsible for transportation to/from their hometown airport).

- Nominees are asked to arrive by 11 am on Friday October 6, 2023
- Nominees are free to depart any time on Sunday October 8, 2023.

To apply visit www.lahemo.org

In Loving Memory of Libby Fisackerly



We are saddened to report that earlier this year we lost one of our founders and long-time supporters. Mrs. Libby Fisackerly passed away in March at the age of 87. As a founding member of the Louisiana Hemophilia Foundation, Mrs. Libby spent over forty years in service to the hemophilia community of Louisiana, and served as a regional director for the National Hemophilia Foundation. Mrs. Libby was a frequent visitor to our office, and an active seller in our annual poinsettia sale fundraiser. We are grateful to her for her role in creating our organization, and for her many years of service. Mrs. Libby will be greatly missed by this community.

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