Quarterly Newsletter of the Louisiana Hemophilia Foundation

LOUISIANA
HEMOPHILIA FOUNDATION
for all bleeding disorders

HEMO-FLO Newsletter

DECEMBER 2022

A Non-Profit Organization • Serving Louisiana Since 1976

What's inside...

Executive Director's Corner 3
Camp Bayou Bruisers 4
Couple's Retreat 8
Annual Meeting 12
Young Adult Retreat 18
Wellness Day 20
Hayden LeBrun Attends JNC 21

2022

That's A Wrap!

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Bleeding Disorders Awareness

LOUISIANA HEMOPHILIA FOUNDATION

Director's Corner

Director's Corner
December 2022

Dear Friends,

As we embark on the holiday season and get ready for the new year, I can't help but reflect on this year, which I'm sure is the case for many of you as well. In 2022, LHF had a full year of educational events, community gatherings, advocacy efforts, and lots of work behind the scenes helping our community members with financial assistance, scholarships, Medic Alert, and other services. So many wonderful memories were created at our events and retreats, and it brings me so much joy to think back over the year and remember all of the friendships that were created and strengthened. I am extremely proud of this community, and the ways in which we are growing together!

I am very grateful to all of the people who have helped make this year a success. I would like to extend a special thanks to Danielle Rowley for her dedication and hard work, as well as our board members for their volunteer service, and the team at the Louisiana Center for Bleeding and Clotting Disorders for their partnership and continuous support.

The remarkable thing about a community like ours is that the camaraderie among us allows us to celebrate our successes and learn from our mistakes together, always with support from one another. As LHF continues to grow and strengthen, so does our optimism for the future. To all of you and your families, I wish you a healthy and prosperous 2023!

In gratitude and fellowship,

Ashley Castello

Camp Bayou Bruisers

For 2022, our annual bleeding disorders summer camp got a new name and a new home. Camp Bayou Bruisers took place at Dry Creek Baptist Camp in Dry Creek, Louisiana (about halfway between Lake Charles and Alexandria), from Sunday July 24 until Friday July 29. We were so excited to finally be back in person after hosting camp virtually for the last two years.

Staff and counselors arrived on Saturday to prepare for the campers. The Louisiana Center for Bleeding and Clotting Disorders staff trained the counselors on the basic of bleeding disorders, and then the counselors trained us on Spirit Time chants, song, and dances.

On Sunday, Campers arrived, and for the next six days, their schedules were jam-packed from 8AM to 9PM with activities, including swimming, archery, riflery, sling shots, spirit time, daily news, arts and crafts, high ropes, canoeing, relay races, and more.


Peter wins messiest camper at the Mega Messy Relay


Green Team wins the Pool Boat Relay, one of the Color War challenges


Yellow Team wins the chant battle

Thank you to our 2022 Camp Bayou Bruisers Sponsors!

Tulane University

Takeda

HFA Hemophilia Federation of America

SANOFI

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BAYER

SpecialtyCareRx

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These brave Bruisers earned their Big Stick this year for self-infusion


Kenny is all smiles after losing a tooth at camp!


The pool was a favorite of all of our campers

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for all bleeding disorders

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.

Couples Educational Retreat

LHF held its annual Couples Retreat on September 23-25, 2022 at the Hilton Garden Inn Convention Center in New Orleans, Louisiana. Couples in attendance were provided with educational sessions specific to navigating life with a bleeding disorder as a partnership. Some of our couples had a spouse with a bleeding disorder, while others were parents to a child with a bleeding disorder, and some were both.

Session topics included midlife changes and partner support, bleeding disorders in the workplace, emotional challenges faced when living with a bleeding disorder, keeping a positive mindset, planning for retirement, and couples communication. After a long day of learning, our couples were able to let their hair down, relax, and have fun at our Karaoke night!

Next year, we are excited to announce that we will partner with our Texas neighbors to host a regional couples retreat in or around the Houston area.

Thank you to our Couples Retreat sponsors for your generous support!

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Brothers HEALTHCARE BAYER HEMA Biologics SANOFI

BRONZE

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Sands RX

Our couples enjoyed the educational, interactive sessions, and of course - karaoke!

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**

LOUISIANA
HEMOPHILIA FOUNDATION
for all bleeding disorders

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.

MEDIC ALERT

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:

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

Annual Meeting

The 2022 Annual Meeting and Educational Symposium was held October 28-30, 2022, at the Doubletree hotel in Lafayette, Louisiana. We were happy to welcome bleeding disorder families from across the state to come together for a weekend of fellowship and learning.

Over the course of the weekend, attendees learned about financial assistance programs for college, Hemophilia A therapy options, genetics in hemophilia, communicating in crisis situations, infusion best practices, mental health solutions, the importance of staying connected with the community, gene therapy research, von Willebrand's disease, and women's issues in bleeding disorders.

Our camp director and camp counselors were also in attendance to offer our children and teens their very own program for the weekend.

We closed out our meeting with a costume party and trick-or-treating for the kids. We all had a great time and can't wait to do it again next year!

Save the date: the 2023 Annual Meeting will be November 10-12 at the Sheraton downtown New Orleans!

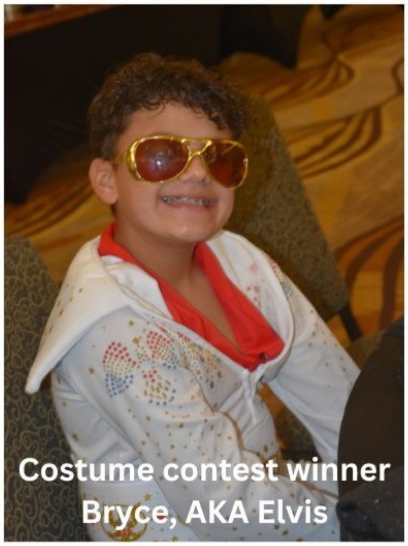
Excellent mental health panel

Kids and teens get ready to go on a field trip

The team greets attendees as they register

Arts and crafts for the kids

Cuties in costumes!



Costume contest winner
Bryce, AKA Elvis

Learning in a breakout session

Thank you to our 2022 Annual Meeting Sponsors!

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Tulane University

Gold Sponsor:

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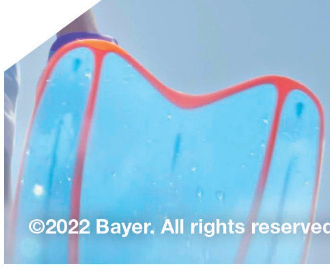

Teen/Young Adult Retreat

LHF hosted its first ever Teen/Young Adult Retreat on November 6, 2022 at Golf Suites in Baton Rouge. CSL Behring sponsored the event, and brought in one of their Junior National Championship leaders, Pete Dyson, a golfer and educator with Hemophilia. Over lunch, Pete spoke to our young leaders about staying positive while living with a bleeding disorder and ways to turn negative experiences into leadership lessons. After lunch, Pete led the participants in stretching exercises before they hit the golf bays for some driving experience, games, and personal instruction from Pete. We had a great day with our young leaders, and we are excited about this new program!

Thank You

CSL Behring

For sponsoring our first Teen/Young Adult Retreat!

LHF

Partner:

Tulane University

LHF

Congratulations to our Fall 2022 Semester Scholarship Recipients

Akesha Allen	*Aiden Peterkin*
Brooke Bergeron	*Jack Richard*
Tristan Conway	*Madden Major*
Michael Joshua	*Adaline Perkins*
Andrew Morrison	*Reese Dupont*
	Benjamin Pethe

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

Visit www.lahemo.org for more information

LHF would like to recognize its generous fourth quarter donors!

Lucy Alleman
Ajie Attawia
Joshua Privat
Millard & Diane Gottschalck
Shonda Joshua
James & May McMahon
Scott Carthy

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

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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 Globeclotters.

We Are On Facebook!

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

Tulane University

Louisiana Center for Bleeding and Clotting Disorders

Tulane University

Our partner, The Louisiana Center for Bleeding and Clotting Disorders, very own Chancellor Donald, MD along with a few of his peers are being honored by the American Society of Hematology (ASH) with the 2022 Exemplary Service Award. ASH is the largest organization devoted to equitable high-quality care, to improve the lives of patients with blood and bone marrow disorders.

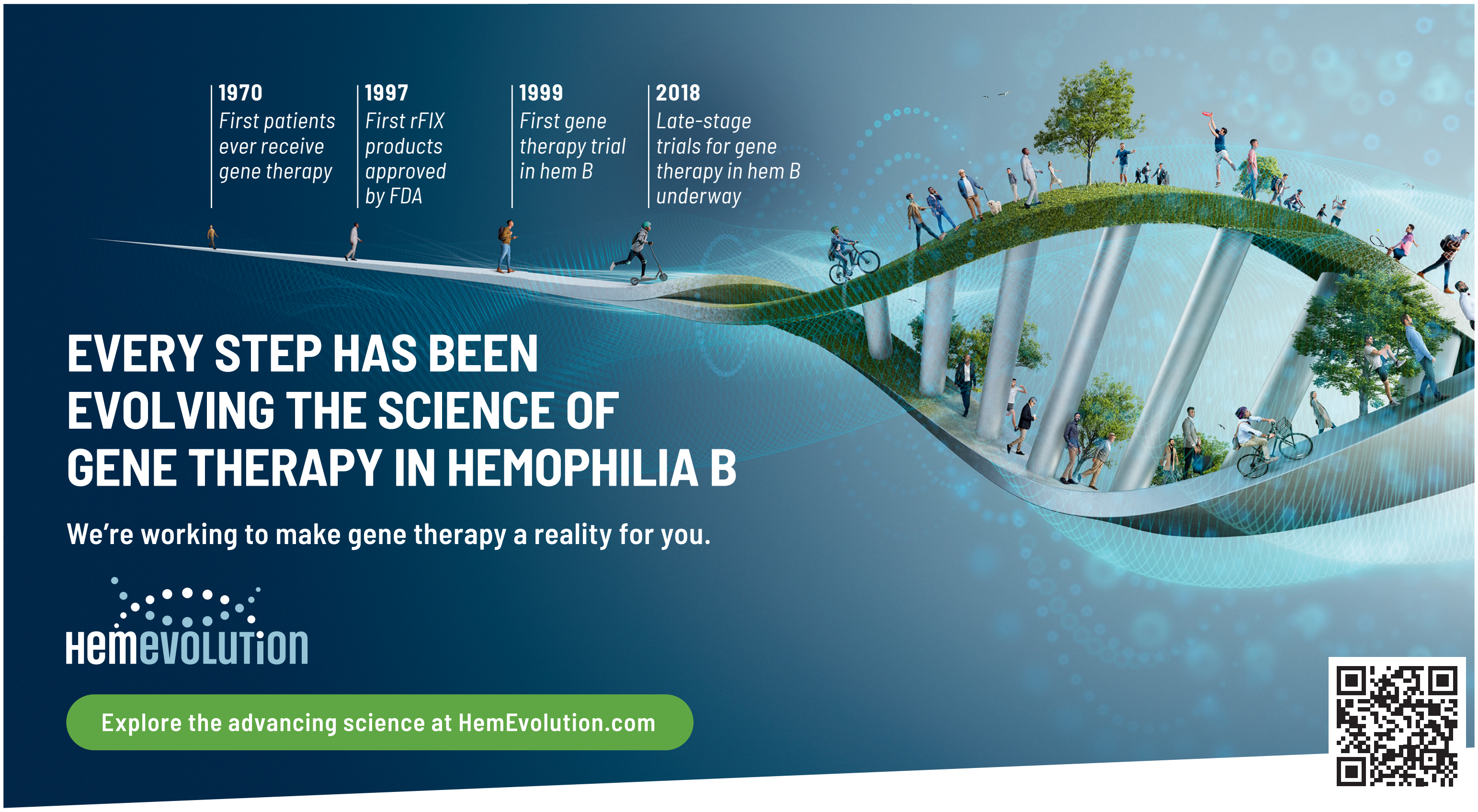
The Exemplary Service Award was established in 1998 to recognize individuals whose outstanding service has significantly advanced the interests of ASH.

This award specifically recognizes Dr. Donald and his peers for their “extensive contributions to the COVID-19 content curation group to ensure that the hematology community had access to the most trustworthy and up-to-date resources in the rapidly evolving pandemic environment.”

This award will be presented during ASH’s 64th Annual Meeting and Exposition in New Orleans, Louisiana, this December.

Congratulations Dr. Donald, on this prestigious award and dedication to the hematology community.

For more information about the American Society of Hematology and the Exemplary Service Award please visit https://www.hematology.org/newsroom/press-releases/2022/exemplary-service-2022



CSL Behring Wellness Day

LHF, in partnership with CSL Behring, hosted its first Wellness Day on Saturday, December 10, 2022, at the Bluebonnet Swamp Education Center in Baton Rouge. This half-day retreat featured patient advocate speakers from CSL Behring, with healthy activities woven into the day. Participant families heard the stories of bleeding disorder patients who used physical activity and mental health practices to increase their overall wellness. Attendees participated in stretching, Tai Chi, a nature walk, and team building games. We thank CSL Behring for bringing this program to our community!

GETTIN' IN THE GAME℠ JUNIOR NATIONAL CHAMPIONSHIP Presented by CSL Behring

Congratulations to our young community member, Hayden LeBrun, who was selected to attend CSL Behring's Junior National Championship (JNC). The JNC finally returned this year after being cancelled several years in a row due to the Covid pandemic. More than 50 children and their caregivers representing 54 chapters across the country, traveled to Phoenix, Arizona on October 27–30, 2022 to participate in this annual event. The JNC was the first and currently only national sports competition designed specifically for the bleeding disorders community. The program gives children with bleeding disorders an opportunity to learn golf and baseball and provides education and information-sharing opportunities for participants and their parents/caregivers. Attendees learned the fundamentals of baseball or golf, participated in friendly competitions, and connected with their peers. Educational seminars focusing on the importance of physical fitness and other related topics were provided on site.

At the conclusion of the JNC, each child was recognized for his or her participation and the champions were announced. We are so proud of Hayden for representing the Louisiana bleeding disorders community at this national event!

A word from Hayden:

I just want to say that how thankful I am to LHF and CSL Behring for the honor of being able to go to JNC in Arizona. It was truly a blessing to go and meet so many great people and to be able to play golf and learn from some of the best players. This trip helped me realize that I shouldn't let anything hold me back from following my dreams, not even a bleeding disorder! I made some lifelong friendships and will remember my trip forever!

Bleeding Disorder Word Search

R	P	V	F	E	X	M	K	T	S	E	R	O	X	L	K	L
Z	H	E	J	J	C	A	S	L	S	M	G	R	D	C	M	E
J	L	I	B	C	F	I	B	I	T	V	F	I	A	M	S	I
Q	Q	R	L	Q	Z	F	U	Q	B	F	X	P	M	Q	C	H
L	N	F	O	G	A	R	A	C	T	W	E	H	U	O	Z	N
I	T	O	O	T	B	S	S	T	J	C	L	H	M	U	U	G
T	C	R	D	R	F	K	Y	J	I	J	B	P	X	G	R	E
J	D	R	O	W	J	O	I	N	T	S	R	U	B	M	W	N
I	Y	Q	Y	T	U	J	J	H	R	E	R	C	U	X	H	E
N	R	B	F	C	I	W	H	U	S	Q	C	W	T	U	I	T
F	T	P	Y	N	F	B	J	S	Q	T	L	S	G	Q	B	I
P	N	M	H	H	K	Q	I	T	H	L	O	T	Z	F	J	C
H	E	U	Q	M	M	O	Q	H	R	V	T	F	Z	Q	F	W
D	E	E	L	B	N	O	R	I	N	E	L	E	V	A	T	E
H	C	L	C	H	E	M	O	P	H	I	L	I	A	O	B	J
E	O	I	S	K	U	Y	M	A	A	X	M	K	T	K	U	Q
A	F	S	G	J	O	F	U	X	I	B	F	A	C	T	O	R

- joints
- bleed
- blood
- rest
- inhibitor
- clot
- elevate
- icepack
- genetic
- hemophilia
- ice
- bruise
- factor
- compression

LHF

Mission Moment

When community members are impacted by LHF services they often reach out with their stories. Please read one of those stories from the Burdine Family!

Shortly after my ten year old daughter Lyla was diagnosed with ITP (a bleeding disorder), we found out that she also had Hemophilia (25%).
During the LHF meeting in October, we spoke to Ms. Shonda Joshua and learned her story of being diagnosed with Hemophilia and the importance of knowing prior to any procedure.
When my son Elijah was born 18 years ago, Hemophilia was thought to be a male disorder. Females could be carriers, but not show symptoms. I was tested at the time and found out I was a carrier, but my levels were not tested.
Because of my daughter’s Factor 8 levels being low and Ms. Shonda's story during one of the breakout sessions, I decided to get tested to see what my levels were. My results came back last week and they are 23%. I have Hemophilia too!
Thank GOD I have had no previous complications. But it is definitely good to know going forward. Hopefully, older females (moms, grandmas, aunts) will consider getting tested and advocate for a diagnosis.
Thank you for doing all you do for the Bleeding Disorder Community. The events are a great way for families to get together to share stories.
Thank you for letting me share my story.
Shanna Burdine

If you have a story you would like to share how LHF has impacted your family please send it to Outreach@lahemo.org.

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