



# LIFELINE

The Official Newsletter of the Florida Hemophilia Association

SPRING 2023

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## UPCOMING EVENTS AND PROGRAMS

**World Hemophilia Day Event**  
April 29

**40th Annual Florida Bleeding Disorders Conference**  
June 23-25

**Guys' Day Out**  
July 8

**B|LEAD Teen & Young Adult Retreat**  
July 14-16

**Full 2023 Calendar of Events**  
continued on page 7

## A VERY MERRY TIME AT THE

# End of Year Event!



**T**he End of Year Event was the cherry on top of a memorable 2022. To help us celebrate the holiday season and impending new year, many friends within our bleeding disorders community joined us on Sunday, December 18th for an exciting afternoon at C.B. Smith Park in Pembroke Pines.

*(Continue on page 3)*



# Executively Speaking

**March is Bleeding Disorders Month** and I'm so honored to serve the bleeding disorders community as your new Executive Director at Florida Hemophilia Association! Mark your calendars- it's an amazing time to celebrate **FHA's 40th Anniversary!** This year promises a mix of tradition, celebration and innovation as FHA continues to serve our mission dedicated to enhancing the quality of life in the bleeding disorders community.



Whether you've been volunteering or attending events for years or you've just begun participating with a new diagnosis, each of you has given a gift to Florida Hemophilia Association in which we are so grateful:

***Thank you for sharing 40 years of your lives, experiences, lessons and successes as you have navigated our ever - changing bleeding disorders world- your stepping stones have paved the way for the next 40 years of Florida Hemophilia Association's remarkable work.***

I'm looking forward to meeting as many members in our community as possible at our 2023 events and so appreciative for the warm welcome I've received from so many of you I've met over the last several months- families, friends, volunteers, committees, supporters, partners and board members. I'm also thankful and inspired by my predecessor Debbi Adamkin, whose experiences and leadership fostered connections in the community for over 25 years. Her dedication to connecting the community as one bleeding disorders family laid the groundwork to build those stepping stones that paved this way forward!

As your new Executive Director, I'm excited to meet you and listen to your experiences. I'm committed to learning more about the unique barriers and obstacles our community faces as we assist in innovative ways to serve our growing and diverse community. I'm dedicated to speaking and advocating on behalf of you, ensuring the bleeding disorders community is represented everywhere we go. Lastly, I'm proud to join Florida Hemophilia Association and celebrate 40 years of service with you and continue our dedication to delivering the latest to our community through our conferences, events, newsletters, website, social media channels and emails.

**PEPPER ADAIR**  
FHA Executive Director

# Mensaje Ejecutivo

**Marzo es el Mes de los Trastornos Hemorrágicos** y me siento muy honrado de servir a la comunidad de trastornos hemorrágicos como su nuevo Directora Ejecutiva de la Asociación de Hemofilia de Florida! Marque sus calendarios: ¡Este año celebramos **el 40 aniversario de la FHA!** Este año promete una mezcla de tradición, celebración e innovación a medida que la FHA continúa sirviendo a nuestra misión dedicada a mejorar la calidad de vida en la comunidad de trastornos hemorrágicos.

Ya sea que haya sido voluntario o haya asistido a eventos por años o que haya comenzado a participar con un nuevo diagnóstico, cada uno de ustedes ha dado un regalo a la Asociación de Hemofilia de Florida por lo que estamos muy agradecidos:

***Gracias por compartir 40 años de sus vidas, experiencias, lecciones y éxitos mientras navegaban este mundo de trastornos hemorrágicos que cambia constantemente-- los pasos que ustedes han dado han allanado el camino para los próximos 40 años del trabajo notable de la Asociación de Hemofilia de Florida.***

Espero conocer a tantos miembros de nuestra comunidad como sea posible en nuestros eventos de 2023 y estoy muy agradecida por la cálida bienvenida que he recibido de tantos de ustedes que he conocido en los últimos meses: familias, amigos, voluntarios, comités, partidarios, socios y miembros de la junta. También estoy agradecida e inspirado por mi predecesora Debbi Adamkin, cuyas experiencias y liderazgo fomentaron conexiones en la comunidad por más de 25 años. ¡Su dedicación a conectar a todos en la comunidad ha sentado las bases para la familia unida en la que se ha convertido esta comunidad!

Como su nuevo Directora Ejecutiva, estoy emocionado de conocerlos y escuchar sus experiencias. Estoy comprometido a aprender más sobre las barreras y obstáculos únicos que enfrenta nuestra comunidad mientras que ayudamos de maneras innovadoras a servir a nuestra comunidad creciente y diversa. Me dedico a hablar y abogar en su nombre, asegurando que la comunidad de trastornos hemorrágicos esté representada dondequiera que vayamos. Por último, me enorgullece unirme a la Asociación de Hemofilia de Florida y celebrar 40 años de servicio con ustedes y continuar nuestra dedicación a ofrecer lo reciente e invaluable a nuestra comunidad a través de nuestras conferencias, eventos, boletines informativos, sitio web, canales de redes sociales y correos electrónicos.



**PEPPER ADAIR**  
Directora Ejecutiva de FHA

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# A VERY MERRY TIME AT THE *End of Year Event!*

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(Continued...)

**A**s luck would have it, we could not have asked for more comfortable weather that Sunday for our End of Year Event! It was a beautiful day at the park, made all the more special by getting to spend time with our bleeding disorders community. Many attendees showed up holiday-ready in their best outfits to celebrate this time of cheer. Most importantly, this program served as one more opportunity in 2022 for everyone to gather and share their experiences with one another, reveling in the unity of this community and learning together. We were grateful to have event sponsors eager to share information with attendees and answer any of their questions at their respective decked out booths.

Thanks to a grant from the Colburn-Keenan Foundation, we kept things cool with delicious snow cones from Kona Ice. Traffic Man BBQ delivered on providing an excellent variety of tasty burgers, hot dogs, pulled pork and more that had many attendees going back for seconds!

Red the Blood Drop joined in on the fun, mingling and striking a pose with attendees throughout the day. We also had a special guest appearance from Mr. and Mrs. Claus, having made the trek all the way from the North Pole to sunny Florida with gifts for every child and teen present. Many adults walked away with their own gifts as some lucky attendees took home fabulous raffle prizes!

We are so thankful to Ken Okum of Kenography One for being there and doing what he does best, capturing the day's magic moments. Thank you to our volunteers for their dedication and contribution to making this day as jolly as possible. And, lastly, we want to extend a special thank you to our sponsors for their support and help in making this event possible. Seeing our community members one more time before the end of the year meant so much to us, as they are always the reason we do what we do each day. Here's looking forward to another year of exciting events, making memories, learning, and growing together as a community.



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# A VERY MERRY TIME AT THE *End of Year Event!*

*(Continued...)*



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# A VERY MERRY TIME AT THE *End of Year Event!*

*(Continued...)*



*Thank You for Supporting the 2022 **End of Year Event!***



*CK Collburn Keenan Foundation, Inc.*

**sanofi**

*Photography provided by Ken Okum of Kenography One*



## POWERFUL PROPHYLAXIS

# LIFE IS TOO GOOD TO MISS OUT BECAUSE OF A BLEED

### — IDELVION DELIVERS —

## 0 SPONTANEOUS BLEEDS\*

People who went from 7-day to 14-day dosing in pivotal trials discovered that no matter which schedule they chose, they still had an average of 0 spontaneous and joint bleeds.\* That means the powerful bleed protection of IDELVION sticks around while you plan your next adventure.

\* The average AsBR for people who started and stayed on 7- or 14-day prophylaxis was 0. For people who switched to prophylaxis from on-demand, the average AsBR was 0.7. AsBR-annualized spontaneous bleed rate.

† Hemophilia FIX Market Assessment. Third-Party Market Research.

### IMPORTANT SAFETY INFORMATION

IDELVION®, Coagulation Factor IX (Recombinant), Albumin Fusion Protein (rFIX-FP), is used to control and prevent bleeding episodes in people with hemophilia B. Your doctor might also give you IDELVION before surgical procedures. Used regularly as prophylaxis, IDELVION can reduce the number of bleeding episodes.

IDELVION is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Do not inject IDELVION without training and approval from your healthcare provider or hemophilia treatment center.

Tell your healthcare provider of any medical condition you might have, including allergies and pregnancy, as well as all medications you are taking. Do not use IDELVION if you know you are allergic to any of its

ingredients, including hamster proteins. Tell your doctor if you previously had an allergic reaction to any FIX product.

**Please see additional Important Safety Information and brief summary of prescribing information on adjacent page and full prescribing information including patient product information at IDELVION.com.**

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

You can also report side effects to CSL Behring's Pharmacovigilance Department at 1-866-915-6958.

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# CSL Behring

Biotherapies for Life®





FLORIDA HEMOPHILIA ASSOCIATION  
for all bleeding disorders

# 2023 Calendar of Events

**MARCH**  
**14 & 15**

## LEGISLATIVE DAYS

THE BLEEDING DISORDERS COALITION OF FLORIDA VISITS TALLAHASSEE FOR ADVOCACY TRAINING AND MEETING WITH LEGISLATIVE DECISION MAKERS AT THE FLORIDA STATE CAPITOL ON BEHALF OF THE BLEEDING DISORDERS COMMUNITY.

**APRIL**  
**29**

## WORLD HEMOPHILIA DAY EVENT

A SPECIAL EVENING BRINGING THE COMMUNITY TOGETHER FOR DINNER AND HANDS-ON ACTIVITIES IN CELEBRATION OF WORLD HEMOPHILIA DAY, A DAY TO RAISE AWARENESS AND ADVOCATE FOR THOSE WITH BLEEDING DISORDERS!

**JUNE**  
**23 - 25**

## 40TH ANNUAL FLORIDA BLEEDING DISORDERS CONFERENCE

A WEEKEND OF FUN FOR FAMILIES FROM ALL ACROSS FLORIDA TO LEARN IMPORTANT INFORMATION FROM INDUSTRY PROFESSIONALS, SHARE THEIR EXPERIENCES, AND CONNECT WITH OTHERS AFFECTED BY BLEEDING DISORDERS!

**JULY**  
**8**

## GUYS' DAY OUT

FOR GUYS OF ALL AGES IN THE BLEEDING DISORDERS COMMUNITY, INCLUDING SONS, DADS, AND GRANDFATHERS. A RELAXING AND FUN OUTING OF GOLF, FOOD, AWARDS, AND NETWORKING!

**JULY**  
**14 - 16**

## B|LEAD TEEN & YOUNG ADULT RETREAT

A RETREAT FOR TEENS AND YOUNG ADULTS TO TAKE ON TEAM-BUILDING CHALLENGES, LEARN AND PRACTICE LEADERSHIP AND LIFE SKILLS, AND CONNECT WITH THEIR PEERS IN THE BLEEDING DISORDERS COMMUNITY!

**AUGUST**  
**4 - 6**

## WOMEN'S RETREAT

A WEEKEND GETAWAY FOR WOMEN IN THE BLEEDING DISORDERS COMMUNITY TO BOND AND NETWORK, PARTICIPATE IN ENGAGING AND INFORMATIVE DISCUSSIONS, AND UNWIND WITH NEW AND OLD FRIENDS!

**SEPTEMBER**  
**1 - 3**

## 5TH ANNUAL CONFERENCIA LATINA

A GRAND EVENT UNITING THE HISPANIC AND SPANISH-SPEAKING MEMBERS OF OUR BLEEDING DISORDERS COMMUNITY FOR A WEEKEND OF CONNECTING, LEARNING, SHARING, CELEBRATING HISPANIC HERITAGE, MUSIC, AND MORE!

**OCTOBER**  
**14**

## 13TH ANNUAL UNITE WALK

OUR ANNUAL WALK TO RAISE AWARENESS AND CRITICAL FUNDS TO SUPPORT PROGRAMS AND SERVICES FOR THE BLEEDING DISORDERS COMMUNITY. THIS IS AN EXCITING DAY WITH FUN, GAMES, MUSIC, AND MORE FOR THE WHOLE FAMILY!

**DECEMBER**  
**17**

## END OF YEAR EVENT

A DAY OF FAMILY FUN AND EDUCATION TO CELEBRATE THE HOLIDAY SEASON AND UNITY OF OUR BLEEDING DISORDERS COMMUNITY WITH DELICIOUS FOOD, MUSIC, GAMES, AND PRIZES!



# Florida Hemophilia Association *turns 40!*

## A Brief Look Back at the Last 40 Years in Bleeding Disorders History

- 1983** – Florida Hemophilia Association is established

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- 1985** – The first product for von Willebrand Disease becomes commercially available

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- 1989** – The first World Hemophilia Day is observed to increase awareness of bleeding disorders

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- 1992** – FDA approves first recombinant FVIII products

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- 1995** – Prophylaxis becomes standard of treatment in the U.S.

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- 1997** – FDA approves first recombinant FIX products

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- 1998** – President Clinton signs the Ricky Ray Hemophilia Relief Fund Act

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- 2000s**– The bleeding disorders community sees a resurgence of camps and local and national meetings

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- 2011** – The first FHA Unite Walk takes place

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- 2013** – Gene therapy trials underway at three sites in the U.S.

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- 2017** – A subcutaneous antibody therapy becomes commercially available to Hemophilia A patients

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- 2018** – The first Conferencia Latina takes place

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- 2023** – Florida Hemophilia Association turns 40

**O**n October 14, 1983, Florida Hemophilia Association (FHA) was established. Since that day, FHA has dedicated itself and worked diligently to improve the quality-of-life of thousands of people affected by bleeding disorders throughout the State of Florida and beyond.

This year will mark 40 years of FHA being a vital educational resource, network of support, and advocate for the bleeding disorders community of Florida. We have had the opportunity to meet countless new families, providing an outlet for invaluable education about bleeding disorders, offering opportunities to connect with other families who can share their own experiences, fostering a network of guidance and

emotional support for those living with costly and sometimes debilitating bleeding disorders. It is a great honor to be able to help this community, without whom none of these achievements would have been possible.

We are proud to announce that the 13th Annual Unite Walk will take place on October 14, 2023, the exact date of the Florida Hemophilia Association's 40-Year Anniversary! We look forward to seeing you all there to help us raise awareness and funds for the community while celebrating this momentous occasion.







## WE'RE IN THIS TOGETHER.

Friday 6:26 pm

Sharing stories by the campfire with friends

Isaac, living with hemophilia B

Not an actual patient

### Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world is stronger than ever.

 [bleedingdisorders.com](https://bleedingdisorders.com) | 

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# Important Changes Coming to Florida's Statewide MEDICAID MANAGED CARE PROGRAM

**D**o you or a family member currently have health coverage through Medicaid or the Children's Health Insurance Program (CHIP)? If so, you may soon need to take steps to find out if you can continue your coverage. Soon, states will resume Medicaid and CHIP eligibility reviews. It's important that you respond to any communications you receive from your CHIP or Medicaid program. This means some people with Medicaid or CHIP could be disenrolled from those programs. Here are some things you can do to prepare right now:

## 1. *Make sure your address is up to date*

Make sure the State of Florida has your current mailing address, phone number, email, or other contact information. This way, they'll be able to contact you about your Medicaid or CHIP coverage.

## 2. *Check your mail*

The State of Florida may mail, email you, or even text you about your Medicaid or CHIP coverage. This message will also let you know if you need to complete a renewal form to see if you still qualify for Medicaid or CHIP. If you get a renewal form, fill it out and return it to your state right away. This may help you avoid a gap in your coverage.



## 3. *What if you don't qualify for Medicaid or CHIP*

If you or a family member no longer qualify for Medicaid or CHIP, you may be able to buy a health plan through the Health Insurance Marketplace. Plans are:

- **Affordable.** 4 out of 5 enrollees can find plans that cost less than \$10 a month.
- **Comprehensive.** Most plans cover prescription drugs and provider services such as, doctor visits, urgent care, hospital visits, and more.

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Visit [HealthCare.gov](https://www.healthcare.gov) to find Marketplace plans and see if you might save on premiums. When you apply, don't forget to include current information about your household, income, and your state's recent decision about your Medicaid or CHIP coverage.

### GET MORE INFORMATION:

- Visit [Myflorida.com/accessflorida](https://www.myflorida.com/accessflorida) or call 1-800-300-4323 for more information on Florida Medicaid.
  - Or visit [Medicaid.gov](https://www.Medicaid.gov) for more information about Medicaid or CHIP renewal.
- Call the Marketplace Call Center at 1-800-318-2596 to get details about Marketplace coverage

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## DO THE 5!

1. Get an annual comprehensive check-up at a hemophilia treatment center.
2. Get vaccinated – Hepatitis A and B are preventable.
3. Treat bleeds early and adequately.
4. Exercise to protect your joints.
5. Get tested regularly for blood-borne infections.

# WFH Launches Global Registry to Monitor Gene Therapy Outcomes

Source: Marisa Wexler, MS, Hemophilia News Today / January 20, 2023

**T**he World Federation of Hemophilia (WFH) has launched a registry to monitor long-term outcomes of safety and effectiveness for people with hemophilia who receive gene therapy treatment.

The aim of the WFH Gene Therapy Registry (GTR) is to collect data for all patients who have gene therapy, whether through clinical trials or an approved product. The data will be combined in a single global registry, which will serve as a resource for the hemophilia community to answer important questions about its long-term safety and efficacy.

Treatment centers and national registries interested in enrolling their patients can contact the registry via email at [GTR@wfh.org](mailto:GTR@wfh.org).

“Patient safety is all of our responsibility. Collecting data in one global registry — the WFH GTR — is essential to ensure that rare adverse events, in a small patient population over a large geographical area, will be detected,” said Glenn Pierce, MD, PhD, WFH’s vice president, in a press release.

Hemophilia is caused by genetic mutations that interfere with the production of clotting proteins, factor VIII in hemophilia A and factor IX in hemophilia B. Gene therapy is a one-time treatment designed to deliver a healthy version of the mutated gene to cells in order to restore functional clotting factor production. Two hemophilia gene therapies have won regulatory approvals.



Roctavian (valoctocogene roxaparvovec) was developed by BioMarin Pharmaceutical to treat hemophilia A. It was granted conditional approval in Europe last year and a decision from the U.S. Food and Drug Administration (FDA) is expected in the coming months.

Hemgenix (etranacogene dezaparvovec), by CSL Behring, was approved by the FDA to treat adults with hemophilia B late last year. It’s under regulatory review in Europe, where it received a positive recommendation for conditional approval from the Committee for Medicinal Products for Human Use (CHMP).

Both therapies have demonstrated positive results in clinical trials and shown they can lower bleed rates and substantially reduce the need for replacement therapies. The WFH GTR will expand collection of data on these and other gene therapies, making for a more comprehensive picture of their safety and efficacy.

The registry was developed in collaboration with experts as well as several organizations, including the International Society on Thrombosis and Haemostasis (ISTH), the European Haemophilia Consortium (EHC), the U.S. National Hemophilia Foundation (NHF), and the American Thrombosis and Hemostasis Network (ATHN). Its sponsors include BioMarin, CSL Behring, Pfizer, Spark, and Takeda.



# CURRENTLY ACCEPTING APPLICATIONS FOR

# FLORIDA HEMOPHILIA ASSOCIATION'S DANIEL L. CARLIN MEMORIAL SCHOLARSHIP PROGRAM



Daniel L. Carlin was a wonderful young man who will forever be a part of our bleeding disorders community in Florida. He was a friendly, outgoing, and very thoughtful person with a big heart who never missed a birthday or anniversary of those most special to him. Daniel had severe hemophilia A and unfortunately passed away in July 2000 at the age of 24 from complications of AIDS. Shortly after their son's passing, Daniel's parents Bob, a former FHA Board Member, and Beth created the scholarship program in his memory.

Florida Hemophilia Association is proud to have awarded eight scholarship recipients in 2022. FHA is now accepting applications to award scholarships for the upcoming 2023/2024 academic year. FHA sponsors these scholarships to encourage post high-school education for students within the bleeding disorders community.

For more information on the Daniel L. Carlin Memorial Scholarship, visit:  
[floridahemophilia.org/scholarships](http://floridahemophilia.org/scholarships)

## WHO CAN APPLY?

Current or upcoming students enrolled or accepted into a postsecondary educational institution

**AWARD** Up to \$1,500

**DEADLINE** May 31, 2023

## WHERE DO I APPLY?

Scan the QR code below





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**CSL Behring**

## Patients at Risk of Financial Burden and Health Complications

- Patients with bleeding disorders often rely on copay assistance programs to afford the specialty medications essential to their health.
- Copay Accumulator Adjustment Programs exclude copay assistance payments from counting toward a patient's out-of-pocket maximum or annual deductible.
- Health insurance companies are increasingly applying these programs to patients in Florida.

**With Copay Accumulator Adjustment Programs, patients can be required to cover the full amount of their out-of-pocket maximum if the copay assistance is not counted.**

**Patients with bleeding disorders should not be punished for using copay assistance to afford necessary treatments and prescriptions.**



### State Bill (SB) 46 and House Bill (HB) 1063

would protect Florida patients by requiring insurance companies to count copay assistance payments toward patient deductibles and out-of-pocket maximums. Over 16 states & Puerto Rico have protected patients by passing legislation to ensure all copays count.

Florida Hemophilia Association and Hemophilia Foundation of Greater Florida continue to join forces with our volunteers (Bleeding Disorders Coalition of Florida) and meet with representatives at the state and national level in heavy efforts to garner support for bills that need to pass to provide affordable healthcare for our community and all people with complex chronic conditions.

### WHAT ARE SOME RISKS?

Severe financial burden, difficulty affording life-saving specialty medication, difficulty adhering to a treatment plan, increased medical issues and costs



### Lend your voice, share your story

Contribute your story to the Bleeding Disorder Coalition of Florida's advocacy efforts, if you have experienced your copay assistance not being counted toward your deductible or out-of-pocket max. Send your story to:

[info@floridahemophilia.org](mailto:info@floridahemophilia.org)

To learn more, visit [allcopayscount.org](http://allcopayscount.org) or scan the QR code





## MISSION STATEMENT

Florida Hemophilia Association is dedicated to enhancing the quality of life in the bleeding disorders community by creating programs and services that provide education, emotional support and advocacy. We are contributing toward research to ultimately find a cure.

## CENTERS FOR BLEEDING DISORDERS

*\*Hemophilia Treatment Center (HTC)*

### Arnold Palmer Hospital for Children\*

The Haley Center for Children's Cancer and Blood Disorders  
92 West Miller St., MP 318, Orlando, FL 32806  
Phone: (321)841-8588  
www.orlandohealth.com

### Joe DiMaggio Children's Hospital

Pediatric Specialty Center  
1150 N. 35th Ave. Suite 520, Hollywood, FL 33021  
Phone: (954) 986-2234

### Johns Hopkins All Children's Outpatient Care Clinic\*

Pediatric Cancer and Blood Disorders Center  
601 5th St. South, 3rd Floor. St. Petersburg, FL 33701  
Phone: (727)767-4931  
www.allkids.org

### Lee Memorial Hospital

Department of Pediatric Hematology & Oncology  
9981 So. Healthpark Dr. - Suite 156  
Ft. Myers, FL 33908  
Phone: (239) 332-1111

### Nemours Children's Clinic, Jacksonville\*

Department of Pediatric Hematology/Oncology  
807 Children's Way. Jacksonville, FL 32207  
Phone: (904) 697-3789 / (904) 697-3600  
www.nemours.com

### Nicklaus Children's Hospital\*

Kidz Medical Services - Division of Hematology/Oncology  
3100 SW 62 Ave - Suite 121, Miami, FL 33155  
Phone: (305) 662-8360

### Nemours Children's Clinic, Orlando

Department of Pediatric Hematology/Oncology  
6535 Nemours Parkway, Orlando, FL 32827  
Phone: (407) 650-7715

### St. Joseph's Hospital Center for Bleeding and Clotting Disorders\*

Pediatric Hematology Oncology Outpatient Clinic  
3001 W. Dr. Martin Luther King, Jr. Blvd.  
Tampa, FL 33607  
Phone: (813) 554-8937

### University of Florida\*

Hemophilia Treatment Center  
Division of Pediatric Hematology/Oncology  
1600 SW Archer Road, Gainesville, FL 32610  
www.peds.ufl.edu/divisions/hemonc/

### University of Miami Hemophilia Treatment Center – Adult and Pediatric\*

University of Miami Miller School of Medicine  
Department of Pediatrics Div. of Hematology /Oncology - Locator Code D820  
1601 NW 12th Ave., Room 5019, Miami, FL 33136  
Phone: (305) 243-0834  
www.htcextras.org

### University of South Florida Adult Hemophilia Center\*

Hematology 4th Floor  
13220 Laurel Drive, Tampa, FL 33612  
Phone: (813) 974-3725

## CONTACT NUMBERS

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### Hemophilia Federation of America

(800) 230-9797



**FLORIDA HEMOPHILIA ASSOCIATION**  
*for all bleeding disorders*

## ABOUT THIS PUBLICATION

**LIFELINE** is the official newsletter of the Florida Hemophilia Association. It is produced quarterly and distributed free of charge to requesting members of the bleeding disorders community.

To receive **E-CONNECT**, the electronic edition of our quarterly newsletter, visit [Floridahemophilia.org/contact](http://Floridahemophilia.org/contact)

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For free books and resource materials on bleeding disorders, contact  
**LA Kelley Communications** - [Kelleycom.com](http://Kelleycom.com) (978) 352-7657

*Reference to any specific medical product or provider of medical services or products does not constitute or imply an endorsement or recommendation by Florida Hemophilia Association. These references, written or verbal, are provided as an informational resource and service. Please consult your physician for all treatment options.*



**FLORIDA HEMOPHILIA ASSOCIATION**

*for all bleeding disorders*

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Follow us on  
**SOCIAL MEDIA** for all  
the latest updates  
on our year-round  
programs and services!



**SCAN ME**



***Happy 40-Year Anniversary!***

***See Page 8 for a special look back at 40 years of Florida Hemophilia Association!***