



# LIFELINE

The Official Newsletter of the Florida Hemophilia Association

FALL 2021

## INSIDE

**Executively Speaking**  
Page 2

**Events / Program News**  
Pages 3-10

**Advocacy Alert**  
Page 12

**NHF eNews**  
Page 13

**FHA Resource Center**  
Page 15

## UPCOMING EVENTS AND PROGRAMS

**Advocacy Days**  
February 7-8



**(B)LEAD:**  
**Action League of Bleeders**  
TBD

**Womens Retreat**  
TBD

## The 3<sup>rd</sup> Annual CONFERENCIA LATINA was a huge success!



**W**e hosted our first in-person event on December 10 – 12 at the Cape Coral Westin after almost two years of virtual only programming. On opening night, participants visited the Exhibit booths to learn about each of the Company's products and resources. It was exciting to see all the new faces and of course our veteran families.

Everyone enjoyed the delicious Latino selections at the different food stations that included tapas, tacos, and tostones with pulled pork! Many of the participants shared their musical talents during Karaoke as well as some fabulous dance moves. The evening concluded after several competitive games of BINGO!



(Continue page 3)

# Executively Speaking



It has been another whirlwind year!

It has been a time of challenges and growth. As we all learned to appreciate and unite virtually through

many months FHA has continued to adapt and support the Florida bleeding disorders community during these unique times. We are privileged to lift our community members as always by offering relevant educational programs, compassionate care and much needed advocacy. Remember, current program news, many resources and much more information can always be found on the FHA website. If you have not taken a look recently, please visit our beautiful new website update which was a highlight of this year.

We always appreciate and welcome community involvement. You are the reason we are here! Reach out to us any time with your thoughts or ideas. You can call or email us if you would like to be involved as a volunteer also.

Although many programs were virtual we have been so excited to begin in-person events in 2021. I was just thrilled to see many of you in person and even give hugs at the 11th Annual FHA Unite Walk, Conferencia Latina and most recently – our End of Year celebration. It has been heartwarming and rewarding to see the community again reuniting with one another, many of you travelling to participate in FHA events.

We are looking forward to more in-person programs and events for 2022!

Hugs to all!!!

 Debbi Adamkin  
FHA Executive Director

# Mensaje Ejecutivo

¡Ha sido otro año de torbellino!

Ha ido una época de retos y crecimiento. Como todos aprendimos a apreciar y unirnos virtualmente a través de muchos meses, la FHA ha continuado adaptándose y apoyando a la comunidad de trastornos hemorrágicos de Florida durante estos tiempos únicos. Tenemos el privilegio de elevar a los miembros de nuestra comunidad, como siempre, ofreciendo programas educativos relevantes, atención compasiva y la muy necesaria abogacía. Recuerde, las noticias del programa actual, muchos recursos y mucha más información siempre se puede encontrar en el sitio web de la FHA. Si no lo han mirado recientemente, visiten nuestra nueva y hermosa actualización del sitio web, que ha sido uno de los aspectos más destacados de este año.

Siempre apreciamos y agradecemos la participación de la comunidad. ¡Ustedes son la razón por la que estamos aquí! Póngase en contacto con nosotros en cualquier momento con sus pensamientos o ideas. Puede llamarnos o enviarnos un correo electrónico si desea participar como voluntario.

Aunque muchos programas fueron virtuales hemos estado muy emocionados de comenzar los eventos presenciales en 2021. Me encantó ver a muchos de ustedes en persona e incluso darles abrazos en la 11ª Caminata Anual Unite de FHA, la Conferencia Latina y más recientemente, nuestra Celebración de Fin de Año. Ha sido reconfortante y gratificante ver a la comunidad reunirse de nuevo entre sí, muchos de ustedes viajando para participar en los eventos de la FHA.

¡Esperamos más programas y eventos presenciales para el 2022!

¡Abrazos a todos!

 Debbi Adamkin  
Directora Ejecutiva de FHA

# 3rd Annual CONFERENCIA LATINA *(Continued...)*

All of the conference participants were so enthusiastic and engaged in the programming. We are pleased to have received such positive feedback about the sessions, venue, and the entire Conferencia Latina so far! Everyone enjoyed seeing each other in person and reuniting after so many months apart. Our Florida Latino community gave a warm welcome to our extended families that flew in from other parts of the country!

The Final Night was an awesome family dinner party with the chef's signature paella dish. The highlight of the night was an in-

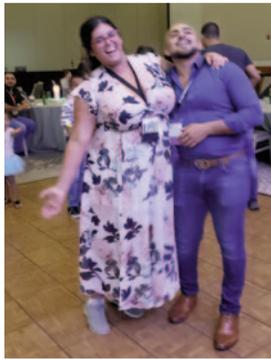
person performance by Grammy award winning artist, Marlow Rosado and his 7-piece orchestra. The performance was extra meaningful and memorable as the inspiring and energetic Marlow actually performed for the Second Conferencia Latina virtually making this in-person performance that much more exciting!

We are so grateful and thankful for our expert speakers, facilitators and volunteers for their support and dedication. You truly make this very special program come together and happen!



*(Continue next page)*

# 3rd Annual CONFERENCIA LATINA *(Continued...)*



*(Continue next page)*

# 3rd Annual CONFERENCIA LATINA *(Continued...)*



## THANK YOU CONFERENCE SUPPORTERS AND SPONSORS

EMERALD SPONSOR



EXHIBITOR PLUS SPONSOR



EXHIBITORS



CSL Behring

GRIFOLS



SANOFI GENZYME

# 11th Annual FHA **UNITE** Walk



**T**his year we were so filled with excitement to once again unite in person for bleeding disorders! For the first time in over two years we united LIVE with hugs, smiles and filled with anticipation for a great day to raise awareness and funding for our community! The Walk took place at Okeehetee Park in West Palm Beach and it was a picture perfect Florida day! With a fantastic turn-out of walkers and many with their dogs we were a lively and colorful group. The Equestrian Police made a special appearance with their stunning horses and delighted our families and kids! Meanwhile, Burnie of the Miami Heat bounced from place to place bringing the giggles out of everyone he approached with his fun-filled antics! At the same time there were crafts for the kids, a doggie t-shirt contest, delicious

food and prizes! Oh – and did we mention we even had our very own Mrs. Florida walking with all of us!! What a day!

A huge and very special thank you to our truly dynamic volunteers. We simply could not have our Walk without you!! Your time, dedication and sacrifice for the cause is over the top and you are appreciated!!

Thank you to all for making the FHA Unite Walk another super success with funds raised over \$80,000. These critical funds will help us continue our mission to provide educational scholarships, financial assistance and advocacy for the community. **Thank you for making another successful Walk possible!**



*(Continue next page)*

# 11th Annual FHA **UNITE** Walk *(Continued...)*



*(Continue next page)*

# 11th Annual FHA UNITE Walk *(Continued...)*



*(Continue next page)*

# 11th Annual FHA **UNITE** Walk *(Continued...)*



*(Continue next page)*

# 11th Annual FHA UNITE Walk *(Continued...)*

**Thank You!**  
to all of our Teams



Pookie

## TOP TEN FUNDRAISING TEAMS

- |                        |                         |
|------------------------|-------------------------|
| 1. FHA Blood Drops     | 6. Team Princeton       |
| 2. We Are CSL          | 7. DMRO                 |
| 3. Team Alex Dones     | 8. Super S              |
| 4. Hemophilia Warriors | 9. All My Grandchildren |
| 5. Aydin's Avengers    | 10. Sanofi Genzyme      |

## MOST CREATIVE TEAM SHIRT

Team Princeton

## BEST DOGGIE T-SHIRT

Pookie *(Peruvian Princesses and Friends)*

## THANK YOU TO ALL OF OUR SPONSORS

### National Sponsors

#### Co-Presenting Partners



#### National Community Partners



#### National Partners



### Local Sponsors

#### Gold Sponsors



#### Silver Sponsor



#### Bronze Sponsors



#### Supporter, Photobooth, Balloon Arch Sponsors



#### In-kind Sponsor





# JIVI<sup>®</sup>

## ADYNOVATE<sup>®</sup>

---

### PK (Pharmacokinetics) Study Data



Talk to your doctor  
about the study.



Scan the QR code to learn more  
about PK at [UnderstandingPK.com](https://www.understandingpk.com)

## SIGN UP FOR STATE ADVOCACY DAY AND TRAINING TODAY

The **Bleeding Disorders Coalition of Florida (BDCF)** is comprised of both statewide chapters, Florida Hemophilia Association, Hemophilia Foundation of Greater Florida and advocacy ambassador volunteers. We will head to Tallahassee on February 7 – 8 for our Annual State Day Training and Advocacy Days!

Training will be on Feb. 7, and we will bring you up to speed on this year's initiatives, Accumulator adjusters and provide you with talking points to prepare you for the discussions you'll have with your local Senator/Representative.

If you're interested in participating in this year's State Days and Training, please email us at [info@floridahemophilia.org](mailto:info@floridahemophilia.org) before **Monday, January 19.**



---

## Do You have an Accumulator Adjuster Story?

**D**o you use copay assistance to afford treatment for your bleeding disorder? Have you faced high out-of-pocket costs for your treatment? If you answered yes to either of these questions, we want to hear from you!

A new insurance program has put copay assistance at risk. These programs collect the copay assistance but do not count it toward your deductible or out-of-pocket maximum, which could increase what you pay for treatment, sometimes by hundreds or even thousands of dollars.

FHA is working to make every dollar count – whether it is paid by you or copay assistance – through legislation in Florida, but we need to hear from you. Tell us why copay assistance is important to you.

Together, we can help our community access the treatments they need.

**Send your story to [info@floridahemophilia.org](mailto:info@floridahemophilia.org)**

## Clinical Study and New Website to Focus on von Willebrand Disease and Pregnancy

**T**he onset of childbirth and the postpartum period are times when women with von Willebrand disease (VWD) are at an increased risk for excessive bleeding, exposing them to further, and in some instances, serious complications. While there exist therapies with VWD-specific indications, it is not uncommon for these patients to still experience excessive bleeding while receiving treatment. These scenarios are challenging as there is sparse clinical data and a subsequent lack of clear guidance on the optimal management of bleeding in these particular settings.

The von Willebrand factor in pregnancy (VIP) study was therefore developed to enhance understanding of how best to manage bleeding during delivery and the postpartum period in women with VWD. Investigators for this prospective, multicenter trial will focus on maintaining von Willebrand factor (VWF) levels at a specific target level using VWF replacement therapy, and assessing the impact on bleeding rates during and after childbirth.

The VIP study is being stewarded by a trio of experienced principal investigators including Drs. Jill Johnsen (Bloodworks and University of Washington), Barbara Konkle (University of Washington), and Dr. Peter Kouides (Mary M. Gooley Hemophilia Center and University of Rochester). The VIP Study is currently recruiting pregnant women in the U.S. above 18 years of age with VWD of any type.

An exciting component of the VIP is a new companion website, created to keep patients and healthcare professionals informed about the study. It will provide information on VIP's design, patient eligibility, and locations of participating centers.

The site was officially launched on December 10th during an educational webinar that preceded the American Society of Hematology Annual Meeting.

## Estudio Clínico y Nuevo Sitio Web para Centrarse en la Enfermedad de von Willebrand y de el Embarazo

**E**l inicio del parto y el período posparto son momentos en los que las mujeres con la enfermedad de von Willebrand (VWD, por sus siglas en inglés) corren un mayor riesgo de sufrir una hemorragia excesiva, lo que las expone a nuevas y, en algunos casos, graves complicaciones. Aunque existen terapias con indicaciones específicas para el VWD, no es raro que estos pacientes sigan experimentando una hemorragia excesiva mientras reciben el tratamiento. Estos escenarios son un reto, ya que hay pocos datos clínicos y una subsiguiente falta de orientación clara sobre el manejo óptimo de las hemorragias en estos escenarios particulares.

Por lo tanto, el von Willebrand factor in pregnancy (VIP) study estudio del factor von Willebrand en el embarazo, se desarrolló para mejorar la comprensión de la mejor manera de gestionar las hemorragias durante el parto y el periodo posparto en mujeres con VWD. Los investigadores de este ensayo prospectivo y multicéntrico se centrarán en mantener los niveles del factor von Willebrand (VWF, por sus siglas en inglés) en un nivel objetivo específico utilizando la terapia de

reemplazo del VWF, y en evaluar el impacto en las tasas de hemorragia durante y después del parto.

El estudio VIP está dirigido por un trío de experimentados investigadores principales, entre ellos los doctores Jill Johnsen (Bloodworks and University of Washington), Barbara Konkle (University of Washington), y Dr. Peter Kouides (Mary M. Gooley Hemophilia Center y University of Rochester). El estudio VIP está reclutando actualmente a mujeres embarazadas en Estados Unidos mayores de 18 años con VWD de cualquier tipo.

Un componente interesante del VIP es un new companion website, (nuevo sitio web complementario) creado para mantener a los pacientes y a los profesionales de la salud informados sobre el estudio. Proporcionará información sobre el diseño del VIP, la elegibilidad de los pacientes y la ubicación de los centros participantes. El sitio se lanzó oficialmente el 10 de diciembre durante un seminario web educativo que precedió a la Reunión Anual de la Sociedad Americana de Hematología.

# COVID-19 and Hemophilia

## Preparedness and Self-Care in a Pandemic

*This information is provided for educational purposes only and is not intended to replace discussions with a health care provider. Speak to your treatment team if you have any questions about your/your child's care.*

This content is brought to you by Pfizer.

**The COVID-19 pandemic brought with it many lessons that can be carried into the future, including ones on preparedness, health care provider (HCP) communication, and self-care.**

### HCP Communication

Good communication with your hemophilia treatment center or care team can be an important part of living with hemophilia. During a pandemic, your team can help you understand possible risks based on your condition, as well as advise on treatment and vaccination.

### Being prepared and proactive in hemophilia care<sup>1</sup>

One of the lessons of the COVID-19 pandemic is that it is important to be prepared, and that also applies to the hemophilia community. National Hemophilia Foundation's (NHF's) Medical and Scientific Advisory Council recommends:

- Having a 14-day supply of factor products available during crisis for those who treat at home
- If an ER visit is required, call in advance so staff knows you are coming and why; this will help them prepare
- Staying in contact with your doctor's office or hemophilia treatment center (HTC). They can explain what to do if you need to visit in person or can help get you connected with telehealth appointments, if available

### Caring for yourself<sup>2</sup>

Events such as the COVID-19 pandemic can create uncertainty for many, which can stir up emotions such as anxiety, fear, anger, sadness, discouragement, or a sense of being out of control. Self-care is important to help you

address these feelings. Here are a few tips you can use to take care of your mental health:

- Set and maintain a routine
- Focus on things you can control
- Use technology to maintain social connections with your loved ones
- Focus on reasons to be grateful
- Read books or listen to music
- Take a break from news and social media if it makes you anxious
- Look for ways to help your community
- Acknowledge and appreciate what others are doing to help

### Further information

Many of the larger advocacy groups have sites to keep you in the know, see below:

- **The Coalition for Hemophilia B**  
hemob.org
- **Hemophilia Federation of America**  
hemophiliafed.org
- **Hope for Hemophilia**  
hopeforhemophilia.org
- **National Hemophilia Foundation**  
hemophilia.org
- **World Federation of Hemophilia**  
wfh.org

These websites are neither owned nor controlled by Pfizer. Pfizer does not endorse and is not responsible for the content or services of these sites.

Be sure to also inquire of your local chapter/advocacy organization and speak to your HTC's social worker for more information about available assistance programs.

**References:** 1. Supplemental MASAC statement regarding home delivery and refill under state of emergency declaration. National Hemophilia Foundation website. Published March 30, 2020. Accessed July 27, 2021. <https://www.hemophilia.org/news/supplemental-masac-statement-regarding-home-delivery-and-refill-under-state-of-emergency-declaration> 2. Reichert S. Self-care tips during the COVID-19 pandemic. Mayo Clinic Health System website. Published April 7, 2020. Accessed March 30, 2021. <https://www.mayoclinichealthsystem.org/hometown-health/speaking-of-health/self-care-tips-during-the-covid-19-pandemic>



Patient Affairs Liaisons are a team of non-sales, non-promotional field-based professionals. Pfizer's Patient Affairs Liaisons are dedicated to serving the rare disease community by connecting patients and caregivers with Pfizer Rare Disease tools, including educational resources, access support, and community events in your area.

**Visit [www.pfizerpal.com](http://www.pfizerpal.com) to connect with your Patient Affairs Liaison.**



## MISSION STATEMENT

The Florida Hemophilia Association, Inc (FHA) is a Not-for-Profit organization that 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)

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

Pediatric Cancer and Blood Disorders Center  
601 5th Street South,  
Third Floor

St. Petersburg, FL 33701

Phone: (727) 767-4931

www.allkids.org

\*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

\*HTC

#### Joe DiMaggio Children's Hospital

Pediatric Specialty Center  
1150 N. 35th Ave.

Suite 520

Hollywood, FL 33021

Phone: (954) 986-2234

#### 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

\*HTC

#### Nicklaus Children's Hospital

Kidz Medical Services  
Division of

Hematology/Oncology

3100 SW 62 Ave

Suite 121

Miami, Florida 33155

Phone: (305) 662-8360

\*HTC

#### University of Florida

Hemophilia Treatment Center  
Division of Pediatric Hematology/Oncology

1600 SW Archer Road

Gainesville, FL 32610

Phone: (352) 273-9120

www.peds.ufl.edu/

divisions/hemonc/

\*HTC

#### Nemours Children's Clinic, Orlando

Department of Pediatric Hematology/Oncology  
13535 Nemours Parkway  
Orlando, FL 32827

Phone: (904) 697-3789,

(904) 697-3600

#### Sacred Heart Pediatric

Hemophilia Program,

Pensacola

Phone: (850) 416-7712

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

Pediatric Hematology

Oncology Out-patient

Clinic

3001 W. Dr. Martin

Luther King Jr. Blvd.

Tampa, FL 33607

Phone: (813) 554-8294

or (813) 554-8937

\*HTC

#### The University of Miami Hemophilia Treatment Center Pediatrics and Adults 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

\*HTC

#### USF Adult Hemophilia Center

Hematology 4th Floor

13220 Laurel Drive

Tampa, FL 33612

Phone: (813) 974-3725

\*HTC

## CONTACT NUMBERS

#### Florida Hemophilia Association Office

(888) 880-8330

#### Executive Director

Debbi Adamkin

(305) 235-0717

dadamkin@floridahemophilia.org

#### National Hemophilia Foundation

(800) 424-2634

#### Hemophilia Federation of America

(800) 230-9797

#### LA Kelley

Communications, Inc.

Free resource material on

Hemophilia

(978) 352-7657



FLORIDA HEMOPHILIA ASSOCIATION

for all bleeding disorders

## ABOUT THIS PUBLICATION

**LIFE LINE** is the official Newsletter of the Florida Hemophilia Association. It is produced quarterly and distributed free of charge to requesting members of the bleeding disorder community.

#### Florida Hemophilia Association Headquarters

915 Middle River Drive, Suite 501

Ft. Lauderdale, FL 33304

Toll Free: (888) 880-8330

www.floridahemophilia.org

#### Translation:

Roxanna Delgado

#### Design and Production:

Group M, Advertising & Design

305-235-2538

## 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



**FLORIDA HEMOPHILIA ASSOCIATION**

*for all bleeding disorders*

Florida Hemophilia Association  
(Formerly known as Florida Chapter, NHF)  
915 Middle River Drive, Suite 501  
Ft. Lauderdale, FL 33304

NON PROFIT ORG  
U.S. POSTAGE  
PAID  
MIAMI, FL  
PERMIT #4883



**FLORIDA HEMOPHILIA ASSOCIATION**

*for all bleeding disorders*

**Looking for ways to give back?  
Shop Amazon Smile! For every purchase**

Amazon donates a percentage to the Florida Hemophilia Association

**amazon**smile  
*You shop. Amazon gives.*

**HOW DOES IT WORK?!**

On the "Shop Now" link below you'll be taken to AmazonSmile. Here you will be able to select the charity of your choice.

"Florida Hemophilia Association"  
Shop now>

*Amazon will donate 0.5% of the price of your eligible AmazonSmile purchases to Florida Hemophilia Association Inc whenever you shop on AmazonSmile. You can select a different charitable organization after signing in. • AmazonSmile is the same Amazon you know. Same products, same prices, same service. • Support your charitable organization by starting your shopping at smile.amazon.com.*

***Happy Shopping!***