



# LIFELINE

*The Official Newsletter of the Florida Hemophilia Association*

FALL 2020

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## UPCOMING EVENTS AND PROGRAMS

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

**Lighten Up**  
TBD

**11th Annual Unite Walk**  
May 16

**FBDC**  
July 23 - 25



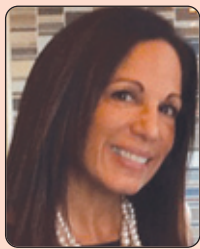
**W**e had a fantastic time at the 2020 End of Year event on December 2nd!! Santa and Mrs. Claus dropped in all the way from the North Pole to visit and we were all so excited to add our wishes to Santa's Big List! There were also holiday ornament making demonstrations, healthy snack recipes and even a performance from Matias the Magician! Red the Blooddrop attended and tried his very best to behave himself! A special thank you to Ronnie and Virginia Walker for always supporting this fantastic event year after year!

**THANK YOU TO OUR SPONSORS**

♥ **CVS specialty**™

*Colburn Keenan Foundation, Inc.*

# Executively Speaking



It has been a whirlwind of activity here at FHA the past few months! We have adapted to a whole new way of connecting and serving our community. Like so many other organizations, we too have learned and created several successful virtual learning programs. It is so rewarding to see so many of you connecting and enjoying these virtual

events with one another!

In September we celebrated our 10th anniversary of the FHA Unite Walk. Many of our Team Captains created their own videos to participate in the virtual walk. Everyone pulled together and we were able to raise close to \$60,000. MC Alex and I were virtual hosts and we were able to unite our walkers for the 10th anniversary after all! A special thanks to everyone who participated.

Just a couple of weeks later the 35th Annual Florida Bleeding Disorders Conference took place – you guessed it, virtually again! We are so thankful to our amazing speakers/facilitators who gave up their weekend to deliver many of the valuable educational sessions provided.

In addition, the End of Year program took place on December 2nd virtually. It was so much fun to see families and children in our community enjoying a magic performance from Matias the Magician, learning holiday ornament crafts and how to make fun healthy snacks. The highlight of the event was a visit directly from the North Pole from Santa and Mrs. Claus!

And finally, our last event of the year, the 2nd Annual Conferencia Latina was held virtually on December 11th and 12th. It was such a success, and we were thrilled to have Latino families represented from many states and countries, including Florida, New York, New England, California, Puerto Rico, Panama, and Nicaragua! The conference opened with a virtual concert performed by two-time Grammy Award winner, Marlow Rosado and his 7-piece band. During the concert breaks, we joined our conference committee/community members, Jose Carnero and Javier Aguilu in their very own kitchens where they prepared typical Latino dishes. We all enjoyed an action packed weekend of interactive educational sessions and it seemed no-one really wanted the event to end!

I hope that you and your families are safe and well! We are looking very forward to seeing all of you at an in-person event one day soon. In the meantime, wishing you all a very happy and peaceful holiday season!! Virtual hugs to all!!

Debbi Adamkin  
FHA Executive Director

# Mensaje Ejecutivo

¡Ha sido un torbellino de actividad aquí en la FHA los últimos meses! Nos hemos adaptado a una nueva forma de conectarnos y servir a nuestra comunidad. Como muchas otras organizaciones, también hemos aprendido y creado varios programas de aprendizaje virtual exitosos. ¡Es muy gratificante ver a tantos de ustedes conectándose y disfrutando de estos eventos virtuales!

En septiembre, celebramos nuestro décimo aniversario de la Unite Walk de la FHA. Muchos de nuestros capitanes de equipo crearon sus propios videos para participar en la caminata virtual. Todo el mundo se unió y pudimos recaudar cerca de \$60,000. ¡MC Alex y yo fuimos anfitriones virtuales y pudimos juntar a nuestros caminantes para el décimo aniversario después de todo! Un agradecimiento especial a todos los que participaron.

Solo un par de semanas después tuvo lugar la 35ª Conferencia Anual de Trastornos de la coagulación de la Florida y, sí, adivinó, de nuevo fue virtual. Estamos muy agradecidos con nuestros increíbles oradores y facilitadores que renunciaron a su fin de semana para presentar muchas de las valiosas sesiones educativas que disfrutamos.

Además, el programa de fin de año tuvo lugar el 2 de diciembre virtualmente. Fue muy divertido ver a familias y niños de nuestra comunidad disfrutando de una actuación mágica de Matías el Mago, aprendiendo a hacer artesanías de ornamentos festivos y cómo hacer bocadillos saludables y divertidos. ¡Lo más destacado del evento fue una visita directamente desde el Polo Norte de Santa y la Sra. Claus!

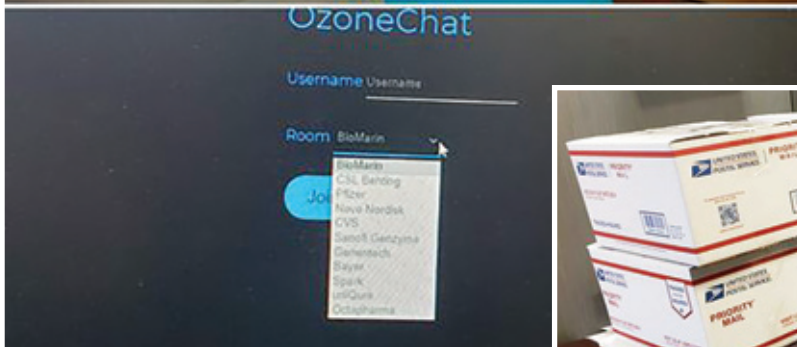
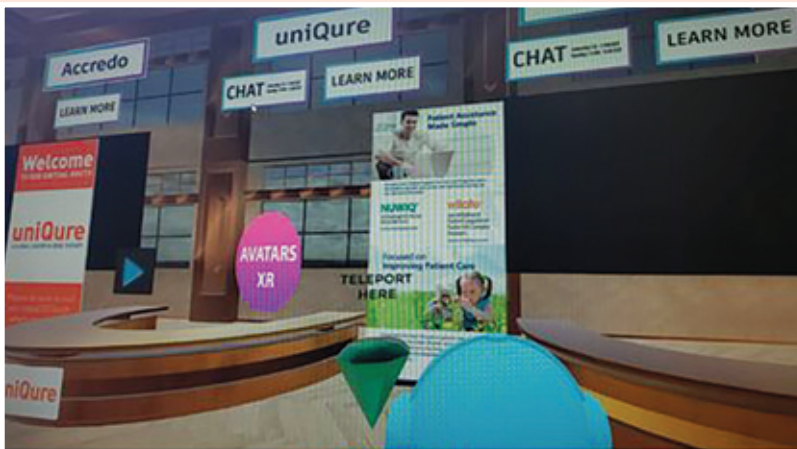
Y finalmente, nuestro último evento del año, la Segunda Conferencia Anual Latina se celebró virtualmente el 11 y 12 de diciembre. ¡Fue un éxito, y estuvimos encantados de tener familias latinas representadas de muchos estados y países, entre ellos Florida, Nueva York, la región de Nueva Inglaterra, California, Puerto Rico, Panamá y Nicaragua! La conferencia se inauguró con un concierto virtual realizado por el ganador de dos premios Grammy, Marlow Rosado y su septeto. Durante las pausas del concierto, nos unimos a los miembros de nuestro comité de conferencia/comunidad, José Carnero y Javier Aguilu en sus propias cocinas donde prepararon platos típicos latinos. Todos disfrutamos de un fin de semana repleto de acción de sesiones educativas interactivas y parecía que nadie quería que el evento terminara.

¡Espero que usted y sus familias estén seguros y bien! Esperamos verlos a todos ustedes en un evento en persona muy pronto. Mientras tanto, les deseamos a todos una muy feliz y tranquila temporada festiva. ¡Abrazos virtuales para todos!

Debbi Adamkin  
Directora Ejecutiva de FHA

# Florida Bleeding Disorders Conference (FBDC)

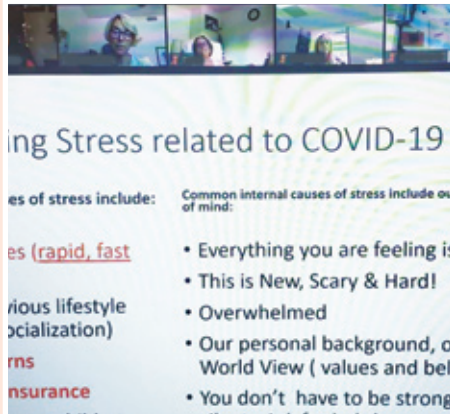
We have been busy working on several virtual events over the past few months. Thank goodness we can continue to present our educational programs and reach out to our community in this new and temporary virtual world! The FBDC was very well received by over 100 families who were provided with a variety of relevant and very timely educational sessions to choose from. Our families also received beautiful packages filled with information and fun treats to enjoy during the event!



(Continue next page)

# Florida Bleeding Disorders Conference (FBDC)

...Continued



## THANK YOU TO OUR SPONSORS



B:OMARIN

SANOFI GENZYME

Genentech  
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♥ CVS specialty™



uniQure  
The leader in gene therapy



## THANK YOU TO OUR NATIONAL ORGANIZATION HEMOPHILIA FEDERATION OF AMERICA

## THANK YOU TO OUR SPEAKERS AND PRESENTERS!

Jeanette Cesta  
Dr. Joanna Davis  
Debbie de la Riva  
Patricia Espinosa Thomson  
Sabrina Farina, LMSW  
Sue Geraghty, MBA, RN

Liliana Gomez  
Dr. Shveta Gupta  
Ed Kuebler, BA, MSW  
Laurel Pennick, LCSW  
Dr. Edwin Porras  
Dr. Robert Sidonio

Dr. Len Valentino  
Cristie Vidal-Strub  
Dr. Chris Walsh  
Erin Wiegel, MSN, RN, CPN  
Dr. Tung Wynn

### **VOLUNTEERS**

Jeanette Cesta  
Ed Kuebler

## MY DECIDING FACTOR:

*Making time for what matters most.*

As an adult living with von Willebrand disease (VWD), you may share a bleeding disorder with others, but you have your own life, and your own needs. You may also have your own Deciding Factor—something that drives you to talk to your healthcare provider about finding a treatment that's right for you. For Erica, it was that her frequent bleeding episodes were taking time away from things that mattered most to her. She talked with her healthcare provider, and together they decided that VONVENDI® [von Willebrand (Recombinant)] was right for Erica's VWD.

Erica  
Surprise, AZ  
Diagnosed with VWD in 1981

**Are you ready to ask about  
VONVENDI for your VWD?  
Visit [VONVENDI.com](http://VONVENDI.com) to  
learn more.**

### VONVENDI

- Is used in adults (age 18 and older) diagnosed with VWD to **treat and control bleeding episodes** and **prevent excessive bleeding during and after surgery**
- **Is the first and only recombinant von Willebrand factor (VWF)**, meaning it is manufactured without human plasma or blood
- **May be used with or without a recombinant factor VIII (rFVIII)**, as instructed by your healthcare provider

### VONVENDI Important Risk Information

#### Who should not use VONVENDI?

You should not use VONVENDI if you:

- Are allergic to any ingredients in VONVENDI.
- Are allergic to mice or hamsters.

Tell your healthcare provider if you are pregnant or breastfeeding because VONVENDI may not be right for you.

**Please see additional Important Risk Information below.**

### Important Risk Information (continued)

#### How should I use VONVENDI?

Your first dose of VONVENDI for each bleeding episode may be administered with a recombinant factor VIII as instructed by your healthcare provider. Your healthcare provider will instruct you whether additional doses of VONVENDI with or without recombinant factor VIII are needed.

#### What should I tell my healthcare provider before I use VONVENDI?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VIII.

#### What else should I know about VONVENDI and von Willebrand disease?

Your body can form inhibitors to von Willebrand factor or factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop VONVENDI or factor VIII from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to von Willebrand factor or factor VIII.

#### What are the possible side effects of VONVENDI?

You can have an allergic reaction to VONVENDI.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with VONVENDI include: nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate.

Tell your healthcare provider about any side effects that bother you or do not go away.

**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.**

**Please see VONVENDI Consumer Brief Summary on the following page and talk to your healthcare provider.**

## Important facts about VONVENDI®:

This leaflet summarizes important information about VONVENDI. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider.

  
**[von Willebrand factor  
(Recombinant)]**

### What is VONVENDI?

VONVENDI is a recombinant medicine used to replace low levels or not properly working von Willebrand factor in people with von Willebrand disease. Von Willebrand disease is an inherited bleeding disorder in which blood does not clot normally.

VONVENDI is used in adults (age 18 years and older) diagnosed with von Willebrand disease to:

- Treat and control bleeding episodes
- Prevent excessive bleeding during and after surgery

### Who should not use VONVENDI?

You should not use VONVENDI if you:

- Are allergic to any ingredients in VONVENDI.
- Are allergic to mice or hamsters.

Tell your healthcare provider if you are pregnant or breastfeeding because VONVENDI may not be right for you.

### What should I tell my healthcare provider before I use VONVENDI?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if VONVENDI passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if VONVENDI can harm your unborn baby.
- Have been told that you have inhibitors to von Willebrand factor (because VONVENDI may not work for you).
- Have been told that you have inhibitors to blood coagulation factor VIII.

### What is the most important information I need to know about VONVENDI?

VONVENDI can cause blood clots particularly in patients with known risk factors for blood clots. Discuss this risk with your healthcare provider.

You can have allergic reactions to VONVENDI. Symptoms may include generalized itching; rash or hives; rapid swelling of the skin or mucous membranes; chest pain or tightness; tightness of the throat; low blood pressure; shock; drowsiness; nausea; vomiting; tingling, prickling, burning, or numbness of the skin; restlessness; wheezing and/or difficulty breathing; lightheadedness; dizziness; or fainting. If symptoms occur, stop using VONVENDI immediately and get emergency treatment right away.

Your body can form inhibitors to von Willebrand factor or factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, they may stop VONVENDI or FVIII from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to von Willebrand factor or factor VIII.

### What are the possible side effects of VONVENDI?

Side effects that have been reported with VONVENDI include: nausea, vomiting, tingling or burning at infusion site, chest discomfort, dizziness, hot flashes, itching, high blood pressure, muscle twitching, unusual taste, blood clots and increased heart rate. These are not all the possible side effects with VONVENDI. You can ask your healthcare provider for information that is written for healthcare professionals.

Tell your healthcare provider about any side effects that bother you or do not go away.

### What else should I know about VONVENDI and von Willebrand Disease?

Consult with your healthcare provider to make sure you are carefully monitored with blood tests to measure levels of von Willebrand factor and factor VIII so they are right for you.

You may infuse VONVENDI at a hemophilia treatment center (HTC), at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or HTC. Many people with von Willebrand disease learn to infuse VONVENDI by themselves or with the help of a family member.

Call your healthcare provider right away if your bleeding does not stop after taking VONVENDI.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use VONVENDI for a condition for which it is not prescribed. Do not share VONVENDI with other people, even if they have the same symptoms that you have.

**The risk information provided here is not comprehensive. To learn more, talk with your healthcare provider or pharmacist about Vonvendi. The FDA approved product labeling can be found at [https://www.shirecontent.com/PI/PDFs/VONVENDI\\_USA\\_ENG.pdf](https://www.shirecontent.com/PI/PDFs/VONVENDI_USA_ENG.pdf) or call 1-800-828-2088.**

**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.**

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SAVE  
THE DATE

# 11<sup>TH</sup> ANNUAL UNITE WALK

May 16, 2021



## ***The Far Reaching Effects of COVID-19 and Coping in the Bleeding Disorders World***

*Submitted by Kim Madeiros*

*In the year 2020 it does not matter where on the globe we live, we are all feeling the effects of COVID-19 in one way or another. It is not easy to ignore how abruptly life changed early this year due to a new virus that we knew nothing about and continue to learn more of each day. The subsequent measures health and government institutions put into place have resulted in isolation and communication changes.*

*As we did not know about the virus and continue to learn and discover new information each day, the feeling of uncertainty follows. Many of our daily schedules and ways we work and socialize have changed and we are uncertain about the future. It is currently difficult to plan ahead. Also, most of us know someone either directly or indirectly who was affected by COVID-19. Since it is global, these social and work changes are happening in one way or another everywhere without exception.*

*Medical experts and Social Workers agree that paying more attention to your physical and mental well-being is more important than ever during these times. Simple daily habits of good nutrition, regular exercise and sleep are essentials of physical health. Reaching out to friends*

*and family by phone or facetime and staying involved in activities or hobbies you enjoy are also key to maintaining your mental as well as physical health. As humans, it is important for us to connect with one another and maintain our relationships.*

*Uncertainty can cause or exacerbate anxiety. With so much uncertainty in this time it may help to remind ourselves of the things that are certain in our lives. For example, our loved ones, pets, favorite meals and places we enjoy spending time at like the beach, bike riding, park and so on. Dealing with uncertainty along with a bleeding disorder can also cause anxiety. It is important to follow the advice of your HTC or Physician. Also, remember to focus more than usual on good physical care and maybe add some new mental health practices such as meditation, yoga, even watching a funny show more often. There is an old saying, "laughter is the best medicine" and it's true!*

*Reach out to your friends in the community and stay connected to your local Hemophilia Chapter. They will be glad to hear from you. Most importantly, remember that you are not alone!*

# The Power In Knowing Your Numbers

This content is brought to you by Pfizer.



For more information, scan the QR code with your smartphone camera to access *Know Your Numbers: Knowledge Is Power*.



*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.*

For those who live with hemophilia and their caregivers and families, it's important to understand how specific sets of numbers, test values, and data about the condition can impact patients throughout their lifetimes. It's important for all people with hemophilia to understand their numbers in order to communicate effectively with their health care professionals (HCPs).

## Replacement Factor

One important number to know is how the dose of replacement factor is calculated and how that number may vary from person to person:

- For treating hemophilia A, the factor VIII dosage = body weight (kg) × desired factor VIII level increase (%) × 0.5<sup>1</sup>
- For treating hemophilia B, the number of factor IX units required = body weight (kg) × desired factor IX increase (%) × product-specific multiplier (varies by factor IX replacement product)<sup>2,3</sup>
- For severe bleeding associated with both hemophilia A and B, an appropriate dose of factor should yield a factor level of 80% to 100%<sup>1-3</sup>
- Because of the wide variation in recovery time, further adjustments may be needed. Talk to your treatment team to determine the right treatment<sup>3</sup>

**"I have encouraged my patients with hemophilia to communicate with the hemophilia treatment team about all aspects of their condition. When it comes to test results and what they mean, patients should never hesitate to seek a discussion with the health care team."**

**-PATRICK F. FOGARTY, MD**

## Drug Half-life

The half-life of a drug is important because it can help guide the appropriate drug dosage.<sup>3</sup> The drug half-life is helpful for HCPs when recommending a particular dose regimen.

- The half-life is the length of time it takes for the body to eliminate 50% of the amount of drug in the bloodstream<sup>4</sup>
- The half-life measures how quickly or slowly the factor breaks down in the body
- The amount of factor in the bloodstream is highest right after an infusion and then subsequently decreases

## Keep a Log

As part of a total self-management program, keep a log that includes all your health information such as dates of bleeds, types of bleeds, how bleeds were treated, factor levels when known, and the dosage of any other medications you are taking. Tracking day-to-day information may help your health care professional or treatment team develop a treatment plan. Knowing how many bleeds you have had or your child has had will provide important information to your health care professional or HTC treatment team.

## Know Your Numbers—Know Yourself

Being an active advocate for your health care can be part of living with hemophilia. Part of effective communication with your treatment team is knowing and understanding your numbers. Finally, making sure family members and caregivers also understand your numbers can be part of a comprehensive plan for living with hemophilia.

**References:** 1. Hemophilia A. ClinLab Navigator website. <http://www.clinlabnavigator.com/hemophilia-a.html>. Accessed April 8, 2020. 2. Hemophilia B. ClinLab Navigator website. <http://www.clinlabnavigator.com/hemophilia-b.html>. Accessed April 5, 2020. 3. Srivastava A, Brewer AK, Mauer-Bunschoten EP, et al. Guidelines for the management of hemophilia. *Haemophilia*. 2013;19:e1-e47. doi:10.1111/j.1365-2516.2012.02909.x 4. Half-life definition. Beltina.org Encyclopedia of Health website. <https://www.beltina.org/half-life-definition>. Accessed April 5, 2020.



Patient Affairs Liaisons are Pfizer employees who are dedicated solely to providing support to the community. Your Pfizer Patient Affairs Liaison is available to help you access the support and information you need. To find your Patient Affairs Liaison, go to [pfizerpalfinder.com](http://pfizerpalfinder.com) or call Pfizer Hemophilia Connect at 1.844.989.HEMO (4366).



# CONFERENCIA LATINA

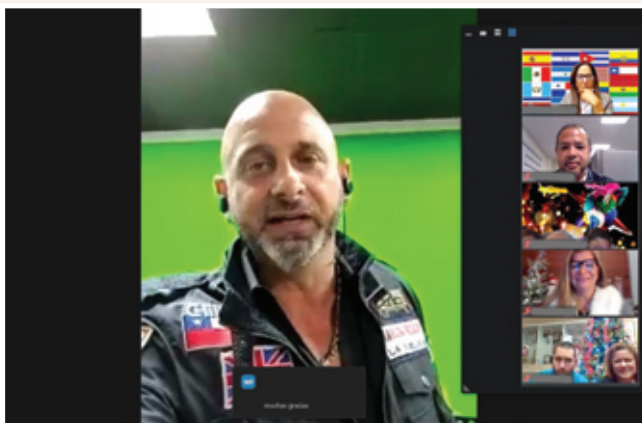
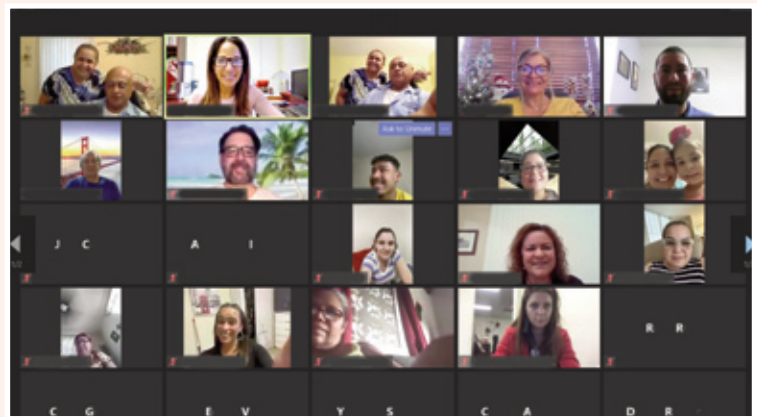
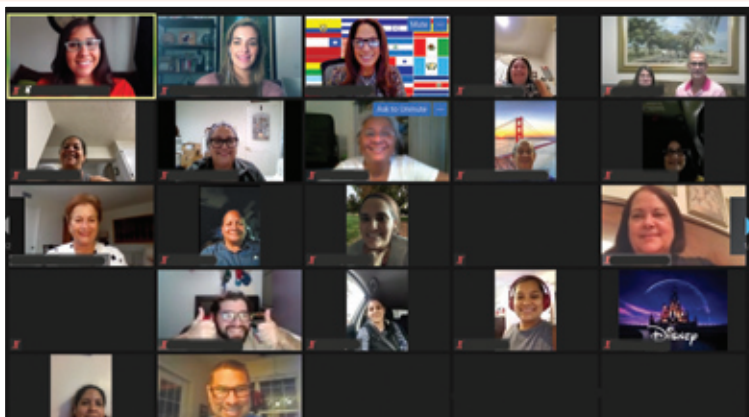


**T**he Second Annual Conferencia Latina had an outstanding turnout of over 100 families! They were treated to a super fun goodie box before the event even started! It was chock filled with fun surprises and even included a very special keepsake Conferencia Latina backpack!

Marlow Rosado and his 7-piece orchestra kicked off the conference with an energizing performance.

A special thanks to all our amazing speakers, facilitators, and volunteers for their support and dedication in helping to make this a very interactive program. The varied program agenda included over 20 unique topics such as a Medical Forum, Pain Management, Nutrition/Cooking demonstrations, Gene Therapy, Rap sessions, etc.

The final session was on Sunday evening with a stand-alone presentation by our Emerald Sponsor Takeda. And last, but not least, I applaud all of the participants for being engaged and so enthusiastic throughout the entire conference.



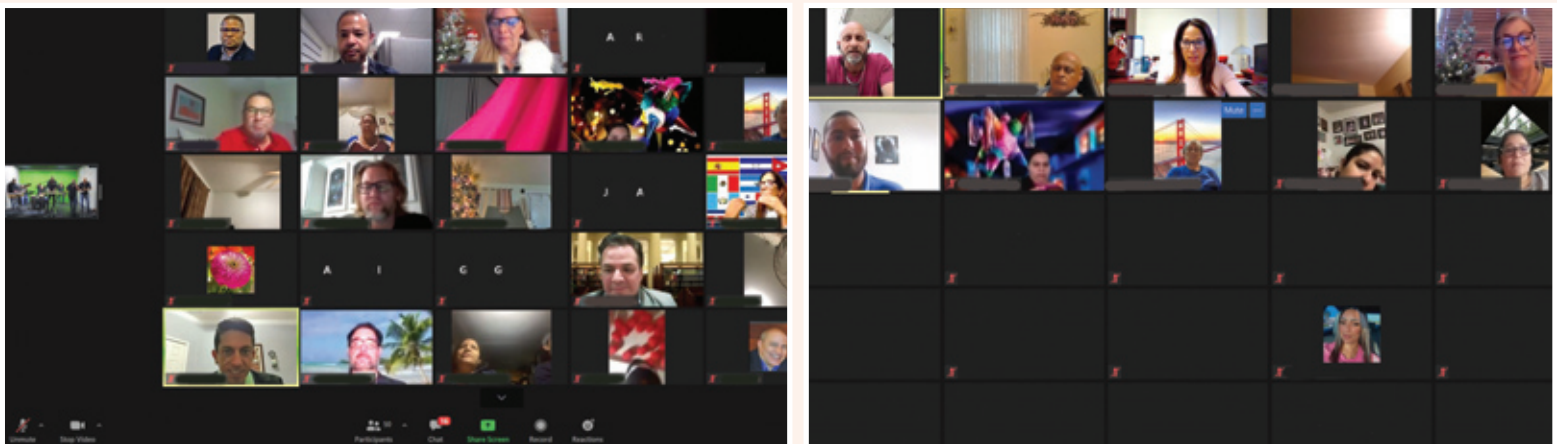
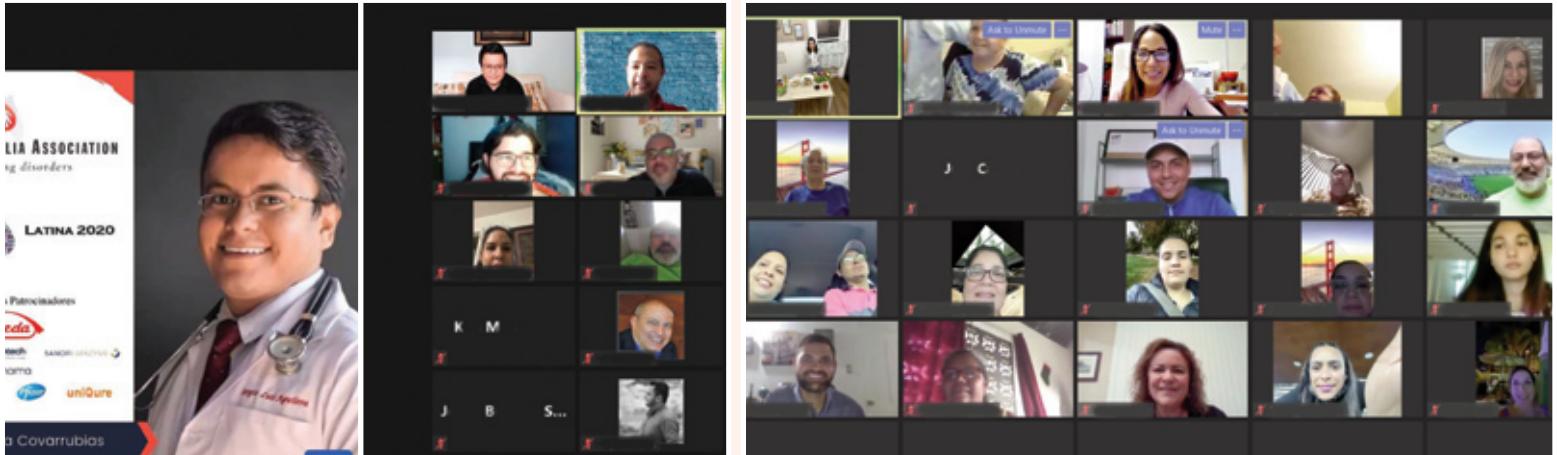
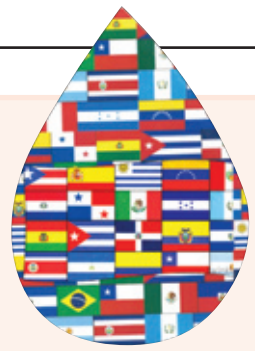
**Dolor**

- Es un mecanismo de protección que aparece cada vez que hay una lesión presente de forma real o potencial capaz de producir una reacción del sujeto.
- Es por esto que el dolor como instinto es capaz de activar al cerebro en su totalidad y poner en marcha potentes mecanismos que están encaminados a una reacción de huida, retiro y/o evitación.

HFA

*(Continue next page)*

# CONFERENCIA LATINA *...Continued*



## LO QUE CUBIREMOS HOY

1

Conocer a Genentech

2

Cómo se coagula la sangre

3

Qué sucede en la hemofilia A

4

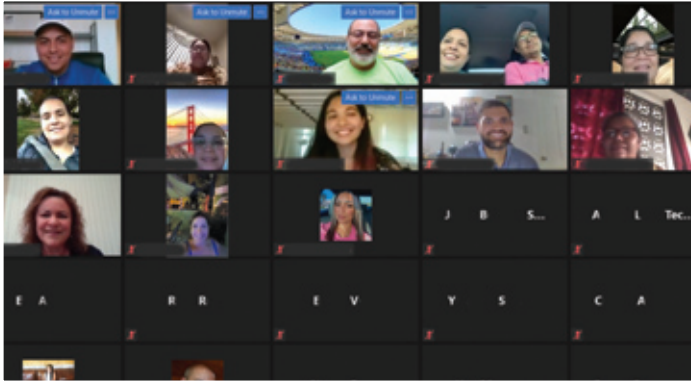
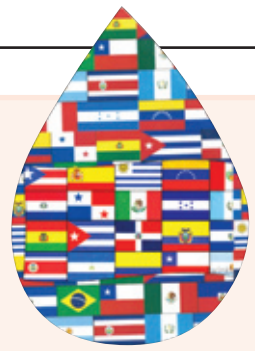
Enfoques que los científicos están explorando

R R

Genentech Hemofilia A

*(Continue next page)*

# CONFERENCIA LATINA *...Continued*



## THANK YOU TO OUR SPONSORS



## THANK YOU TO OUR SPEAKERS AND PRESENTERS!

Dr. Sergio Luis Aguilera  
Lisette Sanchez, RN, BSN  
Dr. Fernando Corrales-  
Medina  
Susana Esojido

Patricia Espinosa-Thomson  
Sabrina Farina, LMSW  
Liliana Gomez  
Dr. Ana Santos De Jimenez  
Fernanda Leal

Anthony Llanes  
Marlow Rosado  
Dr. Claudio Sandoval  
Dr. Leslie Soto  
Sandra Valdovinos-Heredia

### **VOLUNTEERS**

Javier Aguilu - Martha Boria  
Jose Carnero - Anthony Lanas  
Jonathan Lebron - Angelo Lopez  
Carlos Moreta



## WE'RE IN THIS TOGETHER.

**Sunday 2:16 pm**

Jogging in the park  
with his girlfriend

Ben, living with  
hemophilia A

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)



# Pfizer vaccine — F.D.A. Clears Pfizer Vaccine, and Millions of Doses Will Be Shipped Right Away

By Katie Thomas, Sharon LaFraniere, Noah Weiland, Abby Goodnough and Maggie Haberman  
The New York Times - December 11, 2020

The Food and Drug Administration authorized Pfizer's Covid-19 vaccine for emergency use on Friday, clearing the way for millions of highly vulnerable people to begin receiving the vaccine within days. The authorization is a historic turning point in a pandemic that has taken more than 290,000 lives in the United States. With the decision, the United States becomes the sixth country — in addition to Britain, Bahrain, Canada, Saudi Arabia and Mexico — to clear the vaccine. Other authorizations, including by the European Union, are expected within weeks.

The F.D.A.'s decision followed an extraordinary sequence of events on Friday morning when the White House chief of staff, Mark Meadows, told the F.D.A. commissioner, Dr. Stephen Hahn, to consider looking for his next job if he didn't get the emergency approval done on Friday, according to a senior administration official who spoke on condition of anonymity because he was not authorized to discuss the matter. Dr. Hahn then ordered vaccine regulators at the agency to do it by the end of the day.

The authorization set off a complicated coordination effort from Pfizer, private shipping companies, state and local health officials, the military, hospitals and pharmacy chains to get the first week's batch of about three million doses to health care workers and nursing home residents as quickly as possible, all while keeping the vaccine at ultracold temperatures. Pfizer has a deal with the U.S. government to supply 100 million doses of the vaccine by next March. Under that agreement, the shots will be free to the public.

Every state, along with six major cities, has submitted to the federal government a list of locations — mostly hospitals — where the Pfizer vaccine is to ship initially. In populous Florida, the first recipients will be five hospitals, in Jacksonville, Miami, Orlando, Tampa and Hollywood. In tiny, rural Vermont, only the University of Vermont Medical Center and a state warehouse will get supplies.

McKesson Corporation, a giant medical supplier, is sending kits of syringes, alcohol pads, face shields and other supplies to the same sites, where they will meet up with the vaccines that Pfizer is shipping in special boxes, packed with dry ice, designed to keep them at minus 94 degrees Fahrenheit.

The Pfizer packaging will include a device that tracks the location of the box, plus a thermal probe that will make sure the deep freeze is maintained throughout the journey from the company's distribution sites in Michigan and Wisconsin.

The decision is a victory for Pfizer and its German partner BioNTech, which began working on the vaccine 11 months ago. Vaccines typically take years to develop. The companies' late-stage clinical trial, which enrolled nearly 44,000 people, was found to be 95 percent effective.

An expert panel advising the F.D.A. on Thursday gave its approval of Pfizer's vaccine for people 16 and older, and the agency was planning to release the formal authorization on Saturday. That timeline was accelerated by half a day after President Trump attacked Dr. Hahn for failing to authorize a vaccine more quickly. But the accelerated announcement was not expected to speed up the delivery of vaccines around the country.

Mr. Trump told Dr. Hahn on Twitter on Friday morning to "stop playing games and start saving lives!!!" He called the F.D.A. "a big, old, slow turtle," flush with funds but mired in bureaucracy. Mr. Trump has repeatedly accused the F.D.A. and the drugmakers themselves of slow-walking the approval process in order to harm him politically. Allies of Dr. Hahn have been on tenterhooks for weeks, expecting him to be fired any day. The president wrote that with "my pushing," the administration had shaved years off the development of vaccines. "Get the dam vaccines out NOW, Dr. Hahn," he wrote, misspelling the expletive.

The threat to Dr. Hahn's job was first reported by The Washington Post. In a statement, Dr. Hahn denied that Mr. Meadows told him he should consider seeking another job, calling it "an untrue representation of the phone call." Instead, Dr. Hahn said, his agency was "encouraged to continue working expeditiously."

Even though the F.D.A. was going to approve the Pfizer vaccine in any case, some experts warned that the pressure from the White House could undermine public trust in the agency's decision-making. "This may actually do more harm than good, because all it will do is inject more politics into a scientific process," said Dr. Aaron S. Kesselheim, a professor at the Brigham and Women's Hospital and Harvard Medical School.

A similar vaccine, developed by Moderna, is also under review by the F.D.A. and could soon be cleared for emergency use. On Friday, the federal government announced it had ordered another 100 million doses from Moderna, adding to a deal this summer for an initial supply of 100 million doses. Other vaccines, including ones developed by Johnson & Johnson and AstraZeneca, are in late-stage trials and could be authorized in the next few months.

In anticipation of the vaccine arriving across the country, Americans expressed both hope and anxiety. Dr. Samu Queen, a physician in Portland, Ore., said her geriatric patients are especially eager to receive the vaccine. "They are all very anxious," she said. "Pretty much everyone, at every appointment, is ready to get it."

Dr. Queen said she was watching closely to see how initial subjects in Britain were responding. She described herself as "somewhat apprehensive about how safe it is, versus not."

Joshua Ball, the associate executive director of Shaping Our Appalachian Region, an economic development group in eastern Kentucky, has been a primary caretaker for his father, who had a stroke earlier this year and has other health issues. During the pandemic, he has had to try and help remotely as much as possible.

A vaccine could change that. It could also allow him to go back to church, and to attend the seasonal festivals that are cultural staples for many small towns in his region. "I miss the fellowship of shaking hands, and seeing people, and celebrating birthdays and church meals and vacation bible school," he said.

Still, state health officials remain deeply concerned about what they describe as insufficient funding for the biggest immunization campaign the country has ever embarked on. State health officials have asked Congress for at least \$8.4 billion to do the job well. But so far, they have received only about \$350 million from the Centers for Disease Control and Prevention for vaccine distribution and administration tasks. Those tasks include expanding online systems to track and share information about who has been vaccinated; recruiting and training doctors, nurses and pharmacists to administer the shots; and convincing the public of the importance of getting immunized.

Supplying enough of the vaccine has also proven to be a challenge without a clear resolution. Pfizer had to scale back earlier estimates because of manufacturing setbacks, and has said it will be able to supply up to 25 million doses before the end of the year, and 100 million total vaccines by March.

This week, federal officials said that rather than using all 6.4 million doses that the government initially ordered from Pfizer to vaccinate people, it is holding back half of the supply for a booster shot to recipients three weeks after their first vaccination. But even though only about three million people will receive a vaccine in the first week, officials have held firm on their estimate that, between the Pfizer and Moderna vaccines, which each require two shots, they hope to give at least 20 million people their first dose of a vaccine by the end of the year.

Questions also persist about how quickly a vaccine will be available to anyone that wants one. Federal officials have said they expect to be able to vaccinate the bulk of the U.S. population by the middle of next year, but recent setbacks have challenged those estimates. Pfizer has told the federal government that it may not be able to provide an additional 100 million doses to the United States before the middle of next year because of agreements it has with other countries. And three other experimental vaccines, developed by Novavax, Sanofi and AstraZeneca, have faced delays in their clinical trials.

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## 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**  
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92 West Miller St., MP 318  
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www.orlandohealth.com  
*\*HTC*

**Joe DiMaggio Children's Hospital**  
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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  
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**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

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

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**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

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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



**FLORIDA HEMOPHILIA ASSOCIATION**

*for all bleeding disorders*

Florida Hemophilia Association  
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915 Middle River Drive, Suite 501  
Ft. Lauderdale, FL 33304

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