

FACTOR FRIENDS

Lone Star Bleeding Disorders Foundation



LONE STAR
Bleeding Disorders Foundation

FALL 2021

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FACTOR FRIENDS

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LETTER FROM THE EXECUTIVE DIRECTOR

As we write this newsletter, it has been over a year and a half since we have seen so many of you in person. We are excited to be moving back to in-person events, and look forward to seeing all of you soon!

It has been quite a year, one that has pushed us to our limits in many different ways. One thing I have noticed in our virtual events on Zoom, is our sense of community. Even though we are talking and waving at each other through a computer screen, we have stood together, supporting and learning from each other. We are thankful that we were able to stay connected to so many of you. Even though it was a difficult time, we have proven that we are strong and have an amazing community of support. As we move to in-person events, some events may look a little different for a while, but we are working hard to create meaningful, fun events for our community! Please be patient as we keep your safety our top priority but continue to fulfill our mission of educating, empowering, and advocating for you!

LSBDF will be following CDC guidelines, as well as any guidance received from our Hemophilia Treatment Centers. We will ask that everyone attending our events follow the protocols put in place so we can safely have in person events again.

As we look towards 2022, we will continue to provide educational events for patients with bleeding disorders, support groups to provide a time for those with similar needs to gather, network, and learn from each other. We are SO looking forward to our Texas Bleeding Disorders Conference in 2022, now scheduled for July 29-31 in San Antonio, as well as our traditional family education days, and maybe even some new events! Please be patient, as Texas is a BIG state. Many states have only one or two events for the entire state. We know Texas is big, but please be flexible if an event isn't right in your backyard. You are welcome to come to any event we host that meet the needs of your family. We know our families in Houston sometimes have to drive over an hour to get to a 'local' event. And, for cost-effectiveness, it is hard for us to host multiple events just an hour or two away from each other. It's also hard for us to expect our Industry Partners to attend 4, 5, or 6 events just for one Chapter, when many of them work with multiple other Chapters as well. We will do our best to alternate locations of events too, so it is equally accessible to everyone in our community.

Be sure to watch your email and our social media pages for updates on our upcoming events! See you soon!



UNITE FOR BLEEDING DISORDERS WALK

The Unite Walks brought us back together this fall, as we raised crucial funds that enable the Lone Star BDF to provide programs and services to the bleeding disorders community throughout the year. It was great to see everyone, and welcome several new teams and families to our community!! A great time was had by everyone who attended! We are so grateful to our Sponsors.



Many thanks to our Teams who reached out to friends, family, coworkers, and local businesses for support! At the time of printing of this newsletter, thank you to the following teams:

Hank's Heroes, Mettlesome Dude, Kyle's Crazy 8's, Amini Law Firm, PLLC, Brandon's Bruisers, Team Luke, Gulf States Hemophilia Treatment Center, Team X-Men, Team de la Riva, Texas Children's Hospital HTC, Destyn4Greatness, Team Frank, Carlos Team, K6 Tactical, Ana Michel, Blood Warriors, Rex's Bruisers, Lexie's League, JJ Team, Gonzalez Family, Charity Dynamics, The SanFees, XII Warriors, LadyBugs, D3, Grifols Texas Plasma Testing Labs, Team Lukestrong, Jace's Aces, Brave4Beckett, Acosta Family Team

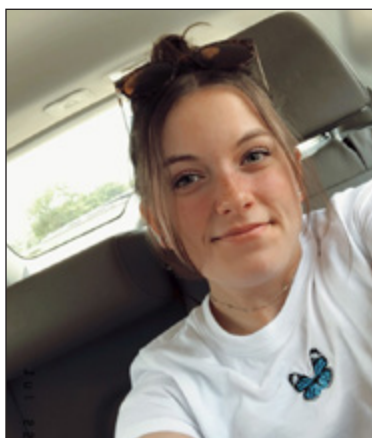
So far, we have raised \$50,000 but the Walk websites will remain open until the end of November! This is our first fundraiser since the pandemic began, and we are so thankful for everyone who has supported so far!

MATTHEW THOMAS MEMORIAL SCHOLARSHIP WINNERS

Each year, the Lone Star Bleeding Disorders Foundation awards deserving high school graduates in our community the Matthew Thomas Memorial Scholarship. This Scholarship is made possible by a generous grant made in memory of Matthew Thomas by his family to Lone Star BDF. Matthew was a member of the Lone Star Chapter, loved golf, and had a bright future ahead of him. Each year, we remember Matthew and the fight he fought against complications of his hemophilia. The Lone Star Bleeding Disorders Foundation would like to congratulate our 2021 Matthew Thomas Memorial



SCHOLARSHIP WINNERS:



Madison Boggs

Howard Payne University,
studying Communications



Carlos Gasca

Northwest Vista College,
studying Biology



Kyle Hansz

Texas Tech University,
studying Engineering

WE WISH YOU ALL THE BEST IN YOUR STUDIES!

2022 Scholarship applications will be available in early 2022. Anyone with a bleeding disorder pursuing any post-high school education (vocational, trade school, junior college, or university) is eligible to apply! Applications will be found on our website, www.lonestarbleedingdisorders.org



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PK (Pharmacokinetics) Study Data



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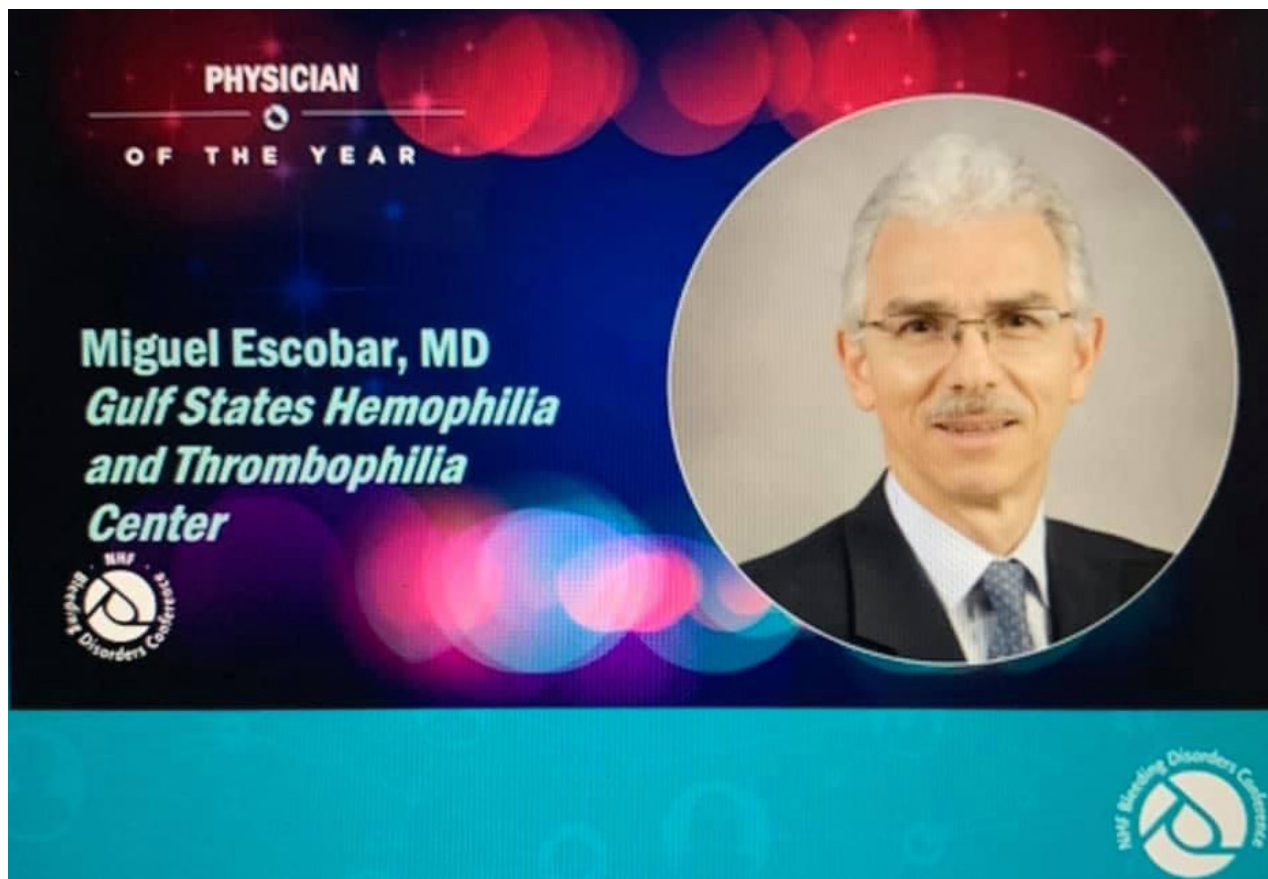
Scan the QR code to learn more
about PK at **UnderstandingPK.com**

TEXAS BLEEDING DISORDERS CONFERENCE

Our 2021 Conference was not what we were expecting! A week before we were to meet in San Antonio for our first live event in over a year, our plans changed as COVID spiked once again. Our Medical Directors at the Hemophilia Treatment Centers advised it was just not safe to host such a large, indoor gathering. We were so disappointed, but the Staff of the Lone Star BDF and Texas Central Bleeding Disorders worked tirelessly to move the Conference fully virtual in less than a week! We were still able to provide important education for our community, and although it was over Zoom, we were able to see each other!

The **2022 Texas Bleeding Disorders Conference** will be held at the JW Marriott Hill Country Resort in San Antonio, JULY 29-31, 2022, the same location we were to be at this year. Registration will open in Spring 2022.

****NEW THIS YEAR - ONLINE REGISTRATION** – stay tuned for details!



Many thanks to our Speakers and Sponsors
who remained flexible throughout the planning process and graciously made the switch
from in person to virtual, and continued to support us.

PLATINUM



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THANK YOU TO OUR 2021 EXHIBITORS

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America
Kedrion Biopharma
Medexus Pharma, Inc
National Hemophilia Foundation
Novo Nordisk

Octapharma
Pfizer
Sanofi Genzyme
Specialty Therapeutic Care
Takeda

TEXAS BLEEDING DISORDERS COALITION “ADVOCACY – IT’S IN OUR BLOOD”

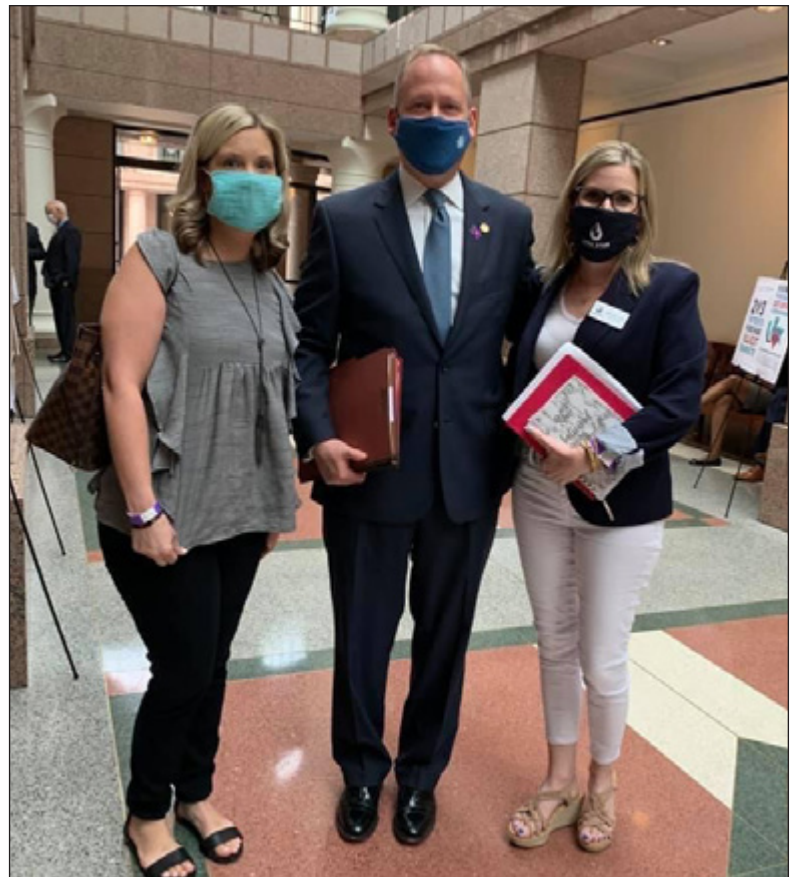
Maya Angelou once said, “I learned a long time ago, the wisest thing I can do is be on my own side, be an advocate for myself and others like me.” The Lone Star BDF and Texas Central Bleeding Disorders have a dedicated group of people who do just this! They share their stories, advocate for their care and the care of those they love, and in doing so, advocate for the entire bleeding disorders community. This year, we had over 20 people commit to meeting with legislators at the State Capitol, to raise awareness about bleeding disorders, and issues that affect our community. However, this year looked quite a bit different and provided us some challenges as we prepared for the meetings. Most of our meetings were all virtual due to the COVID-19 pandemic, but that did not stop our advocates from telling their powerful stories and making an impact with each of our legislators. We spoke to them about two Bills – one attempting to eliminate harmful accumulator adjuster programs, and one to prevent insurance companies from the practice of non-medical switching. We were thankful to be a part of a larger Coalition of disease states supporting these two issues – strength in numbers!! We held over 40 meetings, and our own Rachel Neyland testified in front of the House Insurance Committee on how accumulator adjuster programs impacted her family. While we gained a lot of support from our legislators on these issues, the bills were not able to meet deadlines in the Session. However, we won’t stop there. We plan to re-introduce both of these bills in the 2023 session, and in the meantime, continue to educate and find ways to help our community members avoid these problems. Many thanks go to Senator Dawn Buckingham and Representative Four Price (accumulator adjuster bill) and Senator Judith Zaffirini and Representative Stan Lambert (non-medical switching) We were successful in passing and having Governor Abbott sign a bill that will lessen the delays often encountered in prior authorization requirements set by insurance companies. Thank you to Senator Dawn Buckingham and Representative Dr. Greg Bonnen for all of their work on this bill, as well as Senator Jane Nelson for her support.



The Texas Bleeding Disorders Coalition also testified in front of the Drug Utilization Review Board, along with Dr. Miguel Escobar from Gulf States Hemophilia Treatment Center, recommending all factor replacement therapy drugs remain on the Medicaid Preferred Drug List. After the review by the Board, we are happy to announce these drugs will remain on the PDL!

If you are interested in participating in the Coalition, please reach out to Melissa at mcompton@lonestarbleedingdisorders.org.

We can never have enough advocates telling their story and raising awareness for our community!



Help Texans Stay Healthy and Stable. Reform Non-Medical Switching.

For patients living with complex chronic or progressive diseases, it can take months or even years to find a treatment that works effectively with manageable side effects. Even if patients and their physicians find the right medication to control their condition and keep them stable, arbitrary insurance policy changes at the beginning of a new plan year – such as formulary changes, higher copays or new prior authorization requirements – can force these Texans to forgo the treatments they depend upon.

When insurance companies change the rules and push patients off prescribed treatments that are working well, those patients may experience a recurrence of symptoms, further disease progression, missed work and family time and even hospitalization.

**Please allow Texans to remain on the medications that keep them stable,
as long as they remain enrolled in the same health insurance plan.**

Being forced off the right treatment is **COSTLY FOR TEXANS**

Medication nonadherence annually costs the U.S. health care system **\$100 billion.**

Annual indirect costs exceed

**\$1.5 billion in lost earnings &
\$50 billion in lost productivity.**

Source: Goldman D.P., et al. "Pharmacy benefits and the use of drugs by the chronically ill." JAMA, 291(19):2344-2350

Being forced off the right treatment is **COMMON FOR TEXANS**

67.7% of Texas patients reported their health plan's formulary change switched their medication to one different from what their physician prescribed.

73.6% reported being financially coerced by their health insurer to change their prescribed medication for non-medical reasons.

Source: GHJ and NICA survey of 266 Texas patients, June-August 2010

Employers, hospitals, families and insurers save money when people are allowed to avoid missed work, additional tests, outpatient care and hospitalizations that often accompany a gap in treatment or a change in physician-prescribed care.

The Legislature can help Texans stay healthy ...

- ✓ Patients who stay on the same health plan can remain stable on the prescribed medication that works for their condition.
- ✓ Out-of-pocket costs remain predictable not only throughout the health plan year, but also from one year to the next within the same health plan.
- ✓ Patients and their physicians can trust that the treatment plans they make will continue to be covered as they had been the previous year.
- ✓ Stable patients won't have to forgo the treatments they depend upon while they and their providers try to appeal coverage denials or reductions.

while still preserving health insurers' autonomy.

- ✓ Health insurers may still make changes to their health plans that improve patients' access to their stabilizing medications.
- ✓ Health plans may still remove drugs from the formulary that are deemed by the FDA to be unsafe or ineffective.
- ✓ Health insurers may still adjust their formularies and remove medications from their formularies at the start of a new plan year for patients who are not already stable on the affected medications or for patients who are new to the health plan.

Lawmakers can make healthcare work better for Texas families and our state by helping patients stay stable on the treatments that keep them healthy.

SAY HELLO TO JAMES

He has hemophilia A and has gone through two major surgeries while keeping to his factor regimen with the support of his hemophilia care team

"RECOVERY WAS TOUGH,
BUT I LEARNED I HAD
MORE SUPPORT THAN
I THOUGHT POSSIBLE."



Read stories like James' in
Hello Factor magazine:
BleedingDisorders.com



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LONE STAR BDF AND THE PANDEMIC

When the world shut down in March of 2020, we weren't sure what our next steps would be. The Staff of LSBDF knew we needed to continue to reach out and serve our families, but we weren't quite sure what that would look like! At first, we hoped it would only be a few weeks, but we quickly learned it would be much longer than that, and a plan was put in place to continue to educate, empower, and advocate for the bleeding disorders community. We are so thankful for our Supporters and Industry Partners who have helped us get through this time, and provide many meaningful educational programs, via Zoom. Your support in unique and creative ways is so very much appreciated!

We've continued to provide programs for our families, our SHE Women's group, Mano a Mano group, Teen B'Leaders, our Blood Brotherhood, and parents. We supported Virtual Camp Ailhpomeh, and participated in virtual National Hemophilia Foundation and Hemophilia Federation of America Conferences. While it looked VERY different, we hosted TWO virtual Texas Bleeding Disorders Conferences, because not having conference at all wasn't an option for us! As you read in our Advocacy Coalition update, we have also been very busy advocating for access to care. This has been such a difficult time for so many, and we were glad we were able to provide almost three times the normal amount of Helping Hands assistance to families in crisis.

We would also like to thank our Hemophilia Treatment Centers who provided guidance to the Chapter and our families throughout the pandemic. Your expertise and compassion was crucial to us safely moving through the pandemic.

Please continue to follow guidance from the CDC, your doctor,
and your Hemophilia Treatment Center. Stay safe!





Camp was virtual again this year, but what a week we had! We loved seeing all the campers enjoying some great activities! Thanks to all the Camp Staff who put together a fun week!

Congratulations to the Goosechase winners – we LOVED seeing you complete the missions in so many creative ways!



We are so looking forward to seeing you at Camp John Marc next summer,
July 17-22!



Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information on the basics and beyond.

What questions do you have? Get them answered. Explore gene therapy at HemDifferently.com

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

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WHAT'S NEXT? YOU DECIDE.

At Genentech, we're committed to creating programs for you, with you. From a web series focused on finding the *magic* in life, to a tournament for gamers, to workshops designed to help you think well, do well, and be well, we're here to help you take on what comes next.

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TO SEE HOW WE'RE CREATING
WHAT'S NEXT, TOGETHER.



**GENENTECH IN
HEMOPHILIA**

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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 care¹

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 yourself²

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 to connect with your Patient Affairs Liaison.

COVID-19

In the past 18 months the world has been transformed by a virus called Coronavirus. This virus is miniscule and can only be seen by an electron microscope. Its size averages 0.125 microns, just slightly larger than a dust or gas particle, and can spread easily from one person to another. Despite its size, it is responsible for over 232 million cases and 4.7 million deaths worldwide. After getting infected some people have no symptoms, others may have a mild illness, and others can have severe complications needing prolonged hospitalization. This virus can infect anybody, from children to older individuals. Very early in the pandemic we learned about ways to prevent the spread of the infection by physical distancing, hand hygiene, and most importantly wearing masks. There are many variants of the virus and some of them may be more contagious than others.

In 2020, a few vaccines got emergency approval to try and prevent further spread of the infection and as of today, there are more than 6 billion people vaccinated around the world. Unfortunately, there are still an estimated 93 million people in the US that are refusing to get vaccinated, especially young individuals. The recent surge of cases and hospitalizations were due to the Delta variant infecting mostly unvaccinated people.

There is a vast degree of misinformation about COVID-19 vaccines, especially coming from social media.

FAQS

These are some frequent questions that we get asked in our clinics:

Q Does having a bleeding disorder like hemophilia or von Willebrand disease put me at a higher risk to get infected with COVID-19?

A No. You have the same risk as someone without a bleeding disorder. People that have the following conditions are at risk of having severe infection: pulmonary disease, chronic kidney disease, heart disease, diabetes, obesity.

Q Is a bleeding disorder like hemophilia a contraindication to get the vaccine?

A No. Having a bleeding disorder is not a reason to avoid vaccination.

Q Do I need to get factor before vaccination?

A All the vaccines for COVID-19 are given intra-muscularly. If you have severe or moderate hemophilia (levels below 5%) you can consider infusing factor prior to or right after the vaccination. Individuals receiving Efficzumab, may be vaccinated without receiving factor. For more information, please call your hemophilia treatment center.

Q If I have a bleeding disorder, is there a particular type of vaccine that I should receive?

A No. There is no reason to choose a particular vaccine.

Q Is one dose of the vaccine enough for me?

A There are many types of vaccines used in the USA. The recommendation for the Pfizer and Moderna is to receive 2 doses and for the Johnson & Johnson, one dose.

Q Do I need to get the booster dose of the vaccine?

A So far, only the Pfizer vaccine has been approved to receive a booster after 6 months of the second dose. It has been approved for the following population: age greater than 65, residents and staff in long-term facilities, age +18 and have underlying medical conditions including lung disease (asthma), diabetes, and obesity, age +18 and working in high-risk environments including healthcare workers, teachers, grocery store workers and immunocompromised people.

Q Where can I schedule an appointment to get vaccinated?

A You can visit the following webpage: www.vaccines.gov and enter your zip code.

Q Will the vaccines change my DNA?

A The vaccines do not interact with a person's DNA or cause any genetic changes in your body.

Q Can I get vaccinated if I am pregnant?

A Any currently authorized vaccine can be offered to pregnant people. The American College of Obstetricians and Gynecologists recommends that COVID-19 vaccines should not be withheld from pregnant individuals. If you have questions about getting vaccinated, please talk to your primary doctor or OBGyn.

Q When will vaccine be available for children younger than 12 years-old?

A We have to wait for the results of the ongoing studies from both Pfizer and Moderna vaccines in children 6 months to 11 years of age.

Q Is it safe for me to get the Flu vaccine and the COVID-19 vaccine?

A Yes. It is safe to receive both vaccines. They can be given at the same time or on different days.

Q Will getting the COVID-19 vaccine protect me from getting the Flu, or vice versa?

A No, one is not going to protect you against the other infection. The recommendation is to get both vaccines.

Miguel A. Escobar, M.D.

LONE STAR BLEEDING DISORDERS FOUNDATION 2021 BOARD OF DIRECTORS

In December, we held our annual elections for our Board of Directors. Thank you to those who have stepped up to volunteer their time for the Lone Star BDF:

President: **Amanda Wolgamott**

1st Vice President: **Dan Bond**

2nd Vice President: **Allison Pohl**

Secretary: **Ashley Wells**

Treasurer: **Alex Jones**

Trustees: **Celia Patino, Laura Portales, James Setliff**

HTC Representative: **Sabrina Farina**, LMSW, Gulf States Hemophilia Treatment Center,
Trinh Nguyen, DO, Texas Children's Hospital, Hematology and Oncology



LIFE HAPPENS

AND ADVATE WILL BE THERE WHEN IT DOES

***In clinical trials, ADVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen.**

Not an actual patient.

ADVATE has over 15 years of treatment experience in the real world and provides clinically proven bleed protection* for patients with hemophilia A.¹


ADVATE
[Antihemophilic Factor (Recombinant)]
REAL LIFE. REAL BLEED PROTECTION.*

AdvateRealLife.com

Prophylaxis with ADVATE prevented bleeds¹

The ability of ADVATE to treat or prevent bleeds was evaluated in a clinical study using a standard prophylaxis, pharmacokinetic driven prophylaxis, and on-demand treatment. 53 previously treated patients (PTPs) with severe to moderately severe hemophilia A were analyzed. For the first 6 months of the study, patients received on-demand treatment. For the following 12 months of the study, patients received either standard prophylaxis every 48 hours or a pharmacokinetic-driven prophylaxis every 72 hours. The primary goal of the study was to compare annual bleeding rates between those receiving prophylaxis treatment and those receiving treatment on-demand. The number of bleeds per year for the 2 prophylaxis regimens were comparable.

- Those patients experienced a median of 1 overall bleed per year on either prophylaxis treatment vs 44 overall bleeds per year with on-demand treatment.[†] This represented a 98% reduction in overall bleeds per year.
- Zero bleeds were reported in 42% of patients (22 out of 53 patients) during 12 months on prophylaxis

[†]Median is the middle number in a group of numbers arranged from lowest to highest.

ADVATE Important Information

What is ADVATE?

- ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia).
- ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
- ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADVATE?

Do not use ADVATE if you:

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

Tell your HCP if you are pregnant or breastfeeding because ADVATE may not be right for you.

What should I tell my HCP before using ADVATE?

Tell your HCP 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 ADVATE passes into your milk and if it can harm your baby.

What should I tell my HCP before using ADVATE? (continued)

- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP 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.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADVATE?

- Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

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

Please see Important Facts about ADVATE on the following page and discuss with your HCP.

For Full Prescribing Information, visit www.ADVATE.com.

Reference: 1. ADVATE Prescribing Information.

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[Antihemophilic Factor(Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

This leaflet summarizes important information about ADVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADVATE. If you have any questions after reading this, ask your healthcare provider.

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

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADVATE so that your treatment will work best for you.

What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

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

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

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADVATE to use based on your weight, the severity of your hemophilia A, and where you are bleeding.

You may have to have blood tests done after getting ADVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

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

What should I tell my healthcare provider before I use ADVATE?

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 ADVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

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 ADVATE include:

cough	headache	joint swelling/aching
sore throat	fever	itching
unusual taste	dizziness	hematoma
abdominal pain	hot flashes	swelling of legs
diarrhea	chills	runny nose/congestion
nausea/vomiting	sweating	rash

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

These are not all the possible side effects with ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADVATE and Hemophilia A?

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

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ADVATE for a condition for which it is not prescribed. Do not share ADVATE 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 health care provider or pharmacist about ADVATE. The FDA-approved product labeling can be found at www.ADVATE.com or 1-877-825-3327.

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

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FACTOR FRIENDS

Lone Star Bleeding Disorders Foundation

The Lone Star Bleeding Disorders Foundation would like to thank all of the businesses, foundations, and individuals who have so generously donated to us the last quarter with general donations, Honorariums, and Memorials. Your support is truly appreciated.

HELPFUL RESOURCES - AT A GLANCE



Lone Star Bleeding Disorders Foundation
www.lonestarbleedingdisorders.org
713-686-6100



Texas Children's Hemophilia and Thrombosis Center
832-822-4240



National Hemophilia Foundation
www.hemophilia.org
212-328-3700

South Texas Comprehensive Hemophilia & Thrombophilia Treatment Center

San Antonio
210-704-2187



Hemophilia Federation of America
www.hemophiafed.org
202-675-6984

children's Blood and Cancer Center of Central Texas

Children's Blood and Cancer Center of Central Texas
Austin
512-628-1999



Gulf States Hemophilia Treatment Center
713-500-8360

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Please contact us at 713-686-6100 or mcompton@lonestarbleedingdisorders.org for more information or to discuss wonderful sponsorship opportunities for any of our many camps and programs.