FACTOR FRIENDS

Lone Star Bleeding Disorders Foundation

LONE STAR
Bleeding Disorders Foundation

SPRING 2021

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FACTOR FRIENDS

Lone Star Bleeding Disorders Foundation

WHAT A YEAR 2020 WAS AND 2021 HAS STARTED OFF TO BE!!

This time last year, we were looking forward to our Family Education Days, Casino Night, and planning an amazing Texas Bleeding Disorders Conference. All that changed in March with COVID-19, and this year has been a challenge with the pandemic and then a snowstorm! We are so thankful that we have been able to be here for you through it all. We have stayed connected with Zoom meetings, support groups, and care packages sent to our families. You have all proven that we can get through it together.

We are planning to continue virtual events through the first half of 2021. We will evaluate the situation for the last half of the year as that time approaches. We are looking forward to the day we can all get together in person, but we want to make sure we do that as safely as possible. Until then, please continue to join us for our virtual events. We are planning some fun, new, interactive events, and would love to have you! All events are posted on social media, sent by email, and are on our website calendar!

We know this year has been difficult for so many, and are thankful to our donors, Industry Partners, and The Hemophilia Alliance Foundation, who have made it possible for us to help families in crisis through our Helping Hands Program and our COVID relief program. If you are struggling, please reach out to your social worker at your HTC. Also, there are national assistance programs you may be eligible for as well. Hemophilia Federation of America's Helping Hands Program is available on their website – www.hemophiliafed.org

This issue of our newsletter has important information about upcoming events, resources, and opportunities for our community. Please keep in touch with us, and let us know if we can do anything to help you and your family!

ABOUT THIS PUBLICATION

Factor Friends is the official newsletter published free of charge to the members of the Lone Star Bleeding Disorders Foundation community. The Lone Star Foundation does not endorse the products or services of its sponsors or advertisers. Any communication presented in this newsletter is strictly for informational purposes. The recipients are advised to consult with their physician.

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: **: Gail Boggs, Celia Patino, Laura Portales, James Setliff**

Teen Advisor: **Madi Boggs**

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

The Lone Star Bleeding Disorders Foundation would like to thank Aaron Gonzales for serving on the Board as Treasurer for 4 years. Prior to being Treasurer, Aaron was a Trustee for 2 years. We'd also like to thank Heather Pohl and Juan Guzman for serving on the LSBDF Board of Directors this past year.

We'd like to welcome Ashley Wells and Alex Jones to the Board of Directors. Ashley is a Lone Star BDF member, and is an Ambassador in the Advocacy Coalition and serves as Secretary for the Coalition. Her family has participated in the Unite Walk for many years. Alex Jones comes to the Board as our first unaffected Board member. He has served with various other nonprofits, including Camp Periwinkle and Camp YOLO, and is excited to join the LSBDF Board.

SAVE THE DATE
APRIL 15-17TH

FAMILY EDUCATION WEEKEND, INCLUDING WORLD HEMOPHILIA DAY

CLOSING ACTIVITY APRIL 17

TEXAS BLEEDING DISORDERS ADVOCACY COALITION UPDATE

The Advocacy Coalition has been busy! We work to ensure you have access to care at a Hemophilia Treatment Center, to the full range of clotting factor products, and to the specialty pharmacies that provide them. Here's a snapshot of what we have been up to:

- ★ Joined the Texas Accumulator Adjuster Coalition and are working to eliminate these programs on commercial insurance plans in Texas.
- ★ Signed on to the Non-Profits and COVID Relief Letter – this letter asked for COVID Loan forgiveness, tax credits, and access to specific grants for non-profits
- ★ Sent Welcome packages to new and returning Texas Legislators, highlighting issues affecting the bleeding disorders community.
- ★ Hosted a series of Webinars for our Austin Days Advocates leading up to our Virtual Austin Days, where we will ask Legislators to recognize March as Bleeding Disorders Awareness Month and support a Bill eliminating Accumulator Adjusters.
- ★ Honored to have Representative Dr. Tom Oliverson join us on one of our webinars, discussing the upcoming legislative session and why it is so important for us to connect with our Legislators. Cazandra MacDonald helped us craft and make the most impact with our unique bleeding disorders story, and Kollet Koulianos with NHF helped us understand accumulator adjuster programs and why they are so dangerous.
- ★ Participating in NHF's Washington Days the first week of March.
- ★ Monitoring the Preferred Drug List review in April
- ★ Will participate in over 30 legislative meetings with Legislators during our Virtual Austin Days.
- ★ Participated in NHF's Washington Days
- ★ Securing Proclamations in various towns, cities, and counties to celebrate March as Bleeding Disorders Month

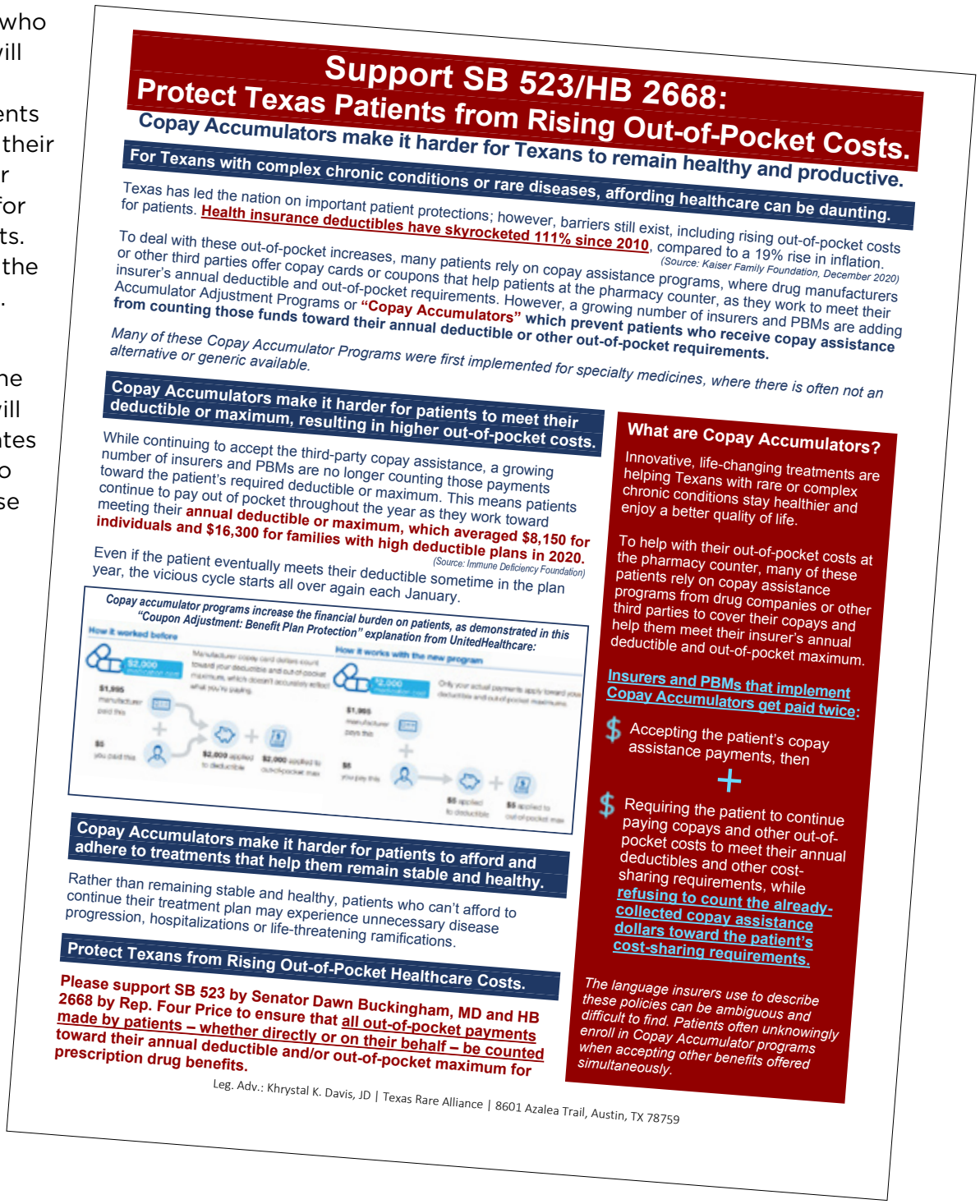

Why Advocate?
Congress shall make no law respecting an establishment of religion or prohibiting the free exercise thereof; or abridging the freedom of speech, or of the press; or the right of the people peaceably to assemble, and to petition the government for a redress of grievances.
Elected officials and their staff enjoy hearing from constituents and your stories impact their decisions
Dillon's saying: "If someone is going to make a decision that will impact your life... don't you want to have a say in it?"
Things to Remember for a Good Visit - Before
Remember that you will have to be brief
Elected officials and their staff may be willing to chat with you for a bit longer virtually but you should still be prepared for a 15-minute meeting
Know the order in which people will speak
This is extremely important in virtual meetings!
Dillon Harp
Recording...
Zoom Meeting
Elizabeth Stoltz

2021 LEGISLATIVE PRIORITY

This year, our legislative priority is eliminating the Accumulator Adjuster programs which make it hard for patients to meet their deductible, to afford and adhere to treatments which help them stay healthy. Basically, insurance companies with accumulator adjuster programs will not accept payment from copay assistance programs, and factor is held hostage until the patient finds a way to pay their copay.

We are so grateful to Senator Dawn Buckingham, MD, who has filed SB523, which will ensure all out of pocket payments made by patients will be counted towards their annual deductible and/or out of picket maximum for prescription drug benefits. We are awaiting a Bill in the House to be filed as well.

As the Accumulator Bill makes its way through the legislative process, we will be calling on our advocates to ask their Legislators to support these Bills. Please let us know if you would like to be involved!



Support SB 523/HB 2668:
Protect Texas Patients from Rising Out-of-Pocket Costs.

Copay Accumulators make it harder for Texans to remain healthy and productive.

For Texans with complex chronic conditions or rare diseases, affording healthcare can be daunting.

Texas has led the nation on important patient protections; however, barriers still exist, including rising out-of-pocket costs for patients. **Health insurance deductibles have skyrocketed 111% since 2010**, compared to a 19% rise in inflation. *(Source: Kaiser Family Foundation, December 2020)*

To deal with these out-of-pocket increases, many patients rely on copay assistance programs, where drug manufacturers or other third parties offer copay cards or coupons that help patients at the pharmacy counter, as they work to meet their insurer's annual deductible and out-of-pocket requirements. However, a growing number of insurers and PBMs are adding Accumulator Adjustment Programs or **"Copay Accumulators" which prevent patients who receive copay assistance from counting those funds toward their annual deductible or other out-of-pocket requirements.**

Many of these Copay Accumulator Programs were first implemented for specialty medicines, where there is often not an alternative or generic available.

Copay Accumulators make it harder for patients to meet their deductible or maximum, resulting in higher out-of-pocket costs.

While continuing to accept the third-party copay assistance, a growing number of insurers and PBMs are no longer counting those payments toward the patient's required deductible or maximum. This means patients continue to pay out of pocket throughout the year as they work toward meeting their **annual deductible or maximum, which averaged $8,150 for individuals and $16,300 for families with high deductible plans in 2020.** *(Source: Immune Deficiency Foundation)*

Even if the patient eventually meets their deductible sometime in the plan year, the vicious cycle starts all over again each January.

Copay accumulator programs increase the financial burden on patients, as demonstrated in this "Coupon Adjustment: Benefit Plan Protection" explanation from UnitedHealthcare:

Copay Accumulators make it harder for patients to afford and adhere to treatments that help them remain stable and healthy.

Rather than remaining stable and healthy, patients who can't afford to continue their treatment plan may experience unnecessary disease progression, hospitalizations or life-threatening ramifications.

Protect Texans from Rising Out-of-Pocket Healthcare Costs.

Please support SB 523 by Senator Dawn Buckingham, MD and HB 2668 by Rep. Four Price to ensure that all out-of-pocket payments made by patients – whether directly or on their behalf – be counted toward their annual deductible and/or out-of-pocket maximum for prescription drug benefits.

What are Copay Accumulators?

Innovative, life-changing treatments are helping Texans with rare or complex chronic conditions stay healthier and enjoy a better quality of life.

To help with their out-of-pocket costs at the pharmacy counter, many of these patients rely on copay assistance programs from drug companies or other third parties to cover their copays and help them meet their insurer's annual deductible and out-of-pocket maximum.

Insurers and PBMs that implement Copay Accumulators get paid twice:

$ Accepting the patient's copay assistance payments, then

+

$ Requiring the patient to continue paying copays and other out-of-pocket costs to meet their annual deductibles and other cost-sharing requirements, while **refusing to count the already-collected copay assistance dollars toward the patient's cost-sharing requirements.**

The language insurers use to describe these policies can be ambiguous and difficult to find. Patients often unknowingly enroll in Copay Accumulator programs when accepting other benefits offered simultaneously.

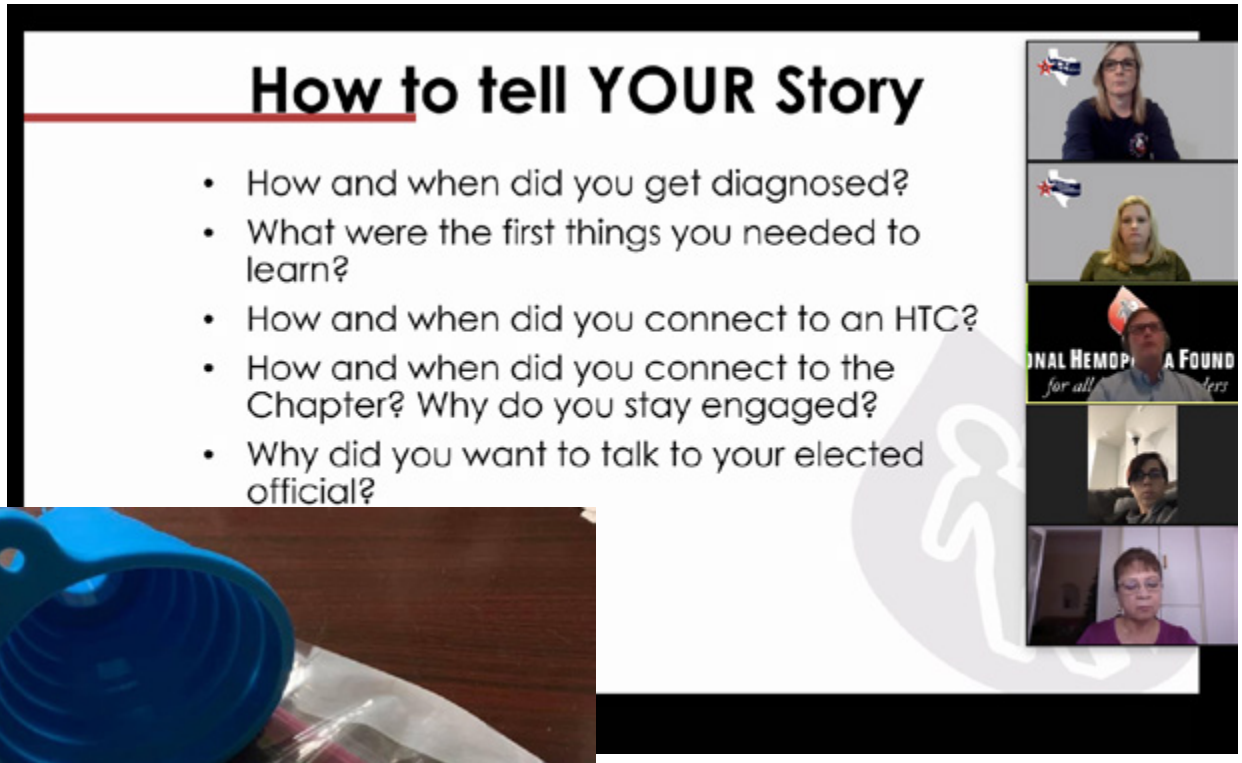
Leg. Adv.: Khrystal K. Davis, JD | Texas Rare Alliance | 8601 Azalea Trail, Austin, TX 78759

TEXAS BLEEDING DISORDERS CONFERENCE

We are hopeful we will be able to have a safe TBDC later this summer, but are also exploring options for holding the event live later in the year, or hosting another virtual event if it is not safe to have a live event. If we do have a live event, it will be much smaller and look quite different than years past. Right now, it is scheduled for August 6-8, in San Antonio. Watch your email and our social media for updates.

Our 2020 Virtual Texas Bleeding Disorders Conference brought us together the best way we knew how during the pandemic. We were so thrilled to see so many of our families participating in our sessions, interacting and sharing stories, and making connections. We were very thankful for the continued support of our Sponsors who helped make this event possible, and Thanks to our Industry Partners for providing a fun and interactive Exhibit Hall throughout the week.

We also enjoyed some magic from Mattias Letelier at our Opening and Closing Sessions! It was fun to see magic tricks done virtually!



We were disappointed when Camp John Marc announced they were unable to host in person camps again this summer. BUT, don't worry - we are working hard to provide some fun Camp activities for our Campers. We have some new ideas and activities that will hopefully connect your camper to other campers they miss so much! More info to come soon!

SUPPORT GROUPS

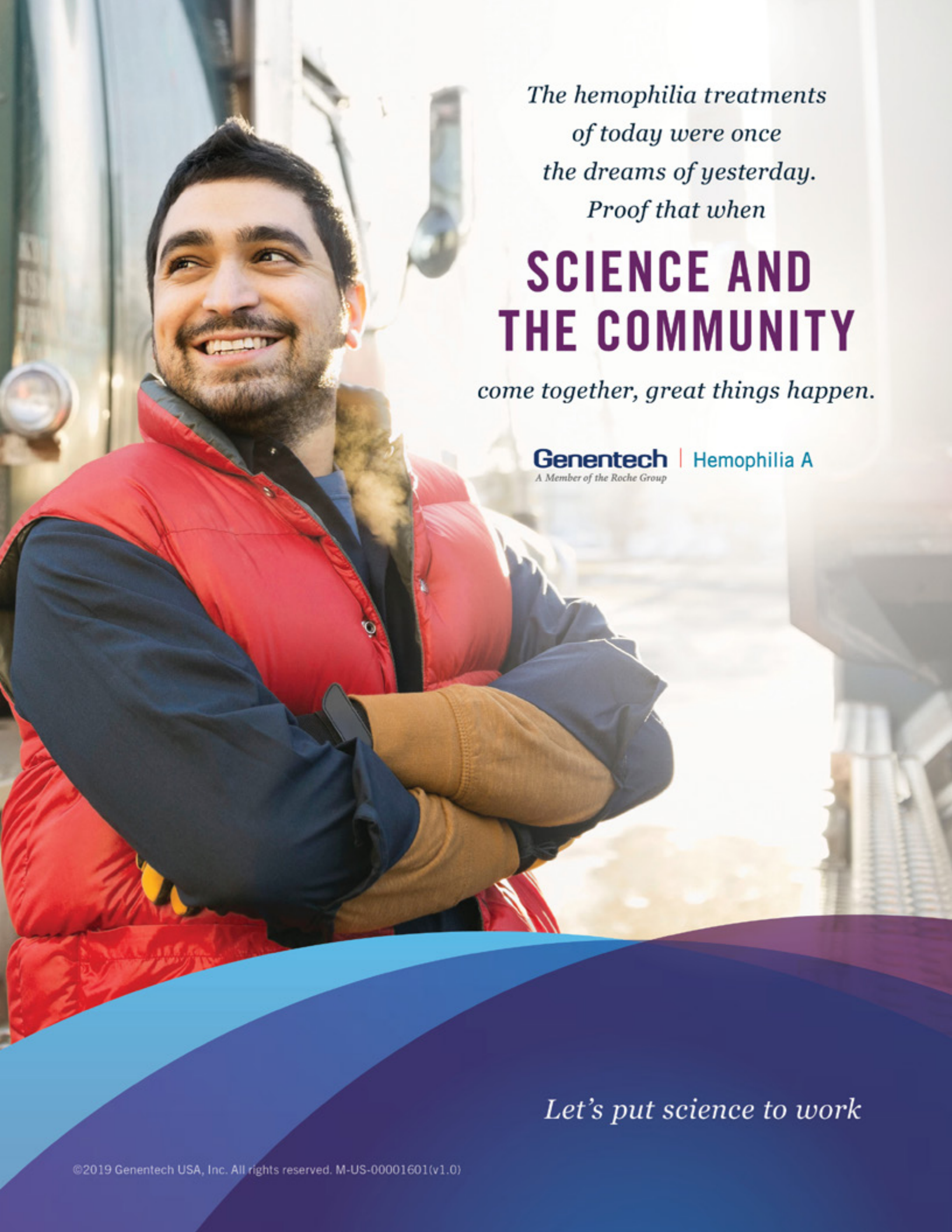
It's been fun to connect with our New Families, Women, Men, Mano a Mano, and Teen groups, even over Zoom! We are looking forward to more support groups this spring!

Last month, our Blood Brotherhood tested their knowledge of bleeding disorders and sports on their Zoom! We are looking forward to a Women's Tea, a Teen Escape Room, a Mano a Mano Siempre Unidos Cinco de Mayo event, and more!

MATTHEW THOMAS MEMORIAL SCHOLARSHIP APPLICATIONS ARE AVAILABLE NOW!

Please visit our website or ask your HTC for an application!
If you are affected by a bleeding disorder, have not been awarded a Matthew Thomas Memorial Scholarship in the past, and are attending any post-high school institution (whether just out of high school or going back to school now), you are eligible!
Applications are due April 30, 2021!

We are grateful to the Thomas Family for providing the grant that makes this scholarship in their son's name possible.



HOW ADOLESCENTS UNDERSTAND HEMOPHILIA by Laurie Kelley

Hailey was trying to explain to her teenage son that he should give himself factor, after he had complained of not being able to walk the dog because he was having a bleed in his calf muscle. Her son shot her one of those give me a break looks.

"Mom," he insisted, "I already know everything about hemophilia."

In a way, her son was right. Adolescents (age 11 and older) represent the most advanced "thinking stage" of child development. Compared to younger children, the adolescent mind can do mental gymnastics. Adolescents, or teens, have the ability to think like an adult. But that's where Hailey's son was wrong: he didn't know everything he needed to know about hemophilia; instead, he was capable of knowing almost everything.

For a younger child, direct physical experience is most useful in understanding the outside world. For a teen, direct experience isn't always needed. In fact, your teen may prefer to learn by mentally exploring abstract ideas. He's an abstract thinker now, a logical thinker ready to tackle complex problems.

Because a teen is eager to find answers, connect the dots, and make sense of his increasingly complex world, he may reach wrong conclusions, even about hemophilia. So along with instructing our teens about sex, drugs, and career choices, we parents must continue the job we began when our children were preschoolers: providing age-appropriate information on hemophilia. In many ways, teaching teens is fun and easy. They're ready to absorb tons of information. The trick, of course, is catching them with the earbuds and cell phones off!

Before you begin teaching your teen, you'll need to know how he understands various concepts related to hemophilia, especially compared with his earlier stages of development.

HOW ADOLESCENTS UNDERSTAND BLOOD

Teens know a lot about blood and the circulatory system. They're studying some biology in school, and they've probably watched TV and movie scenes dealing with blood—of course, not always in a medical way. Far from being just a "red liquid," blood is now classified in abstract, internal terms like cells. Because your teen can competently juggle the concept of a whole and its parts, he now sees blood as one part of an entire circulatory system. As one teen put it, blood "is the circulation system of your body. It's all the cells in your body, mostly red blood cells in your blood—that's why it's red."

Your teen believes that blood's main function is to bring oxygen to the body, specifically to the cells. He may tell you that blood "supplies the body with oxygen and takes carbon dioxide to the lungs."

Your teen has moved through two previous thinking stages: preschool (ages 3–7) and school age (ages 7–11). What's the biggest mental step up from school age thinking? An adolescent can now understand the body's workings by considering the whole system and its parts—all at once. This wasn't possible in the previous two thinking stages. Your teen can now discuss the circulatory system and the veins and arteries, their distinct jobs, and how they work together. He may be able to explain a technical distinction between veins and arteries: "Blood starts in your

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heart, and goes through arteries and capillaries. The veins bring blood back to the heart. The blood gets more nutrients and vitamins, and gets pumped out again." The body has become a complex, interrelated, functioning collection of systems.

HOW ADOLESCENTS UNDERSTAND HEMOPHILIA

Like the school age child he once was, your teen will still categorize hemophilia as a "blood disorder" or "blood disease." But he usually can carry the definition one step further, to describe it as a blood-clotting disorder caused by a "malfunctioning" of the blood. This definition is a long way from the preschooler's definition of hemophilia as "when I get a boo-boo," or the school age child's general description of "something missing" in the blood. Your teen will try to connect everything: "It's a blood-clotting disorder in which it takes longer for the blood to clot, resulting in bruises and internal injuries."

But he may not mention clotting factors as the cause of his disorder. Don't worry. With a little probing, you can help him complete the picture. He'll learn to say, "It's when you bleed internally because you don't have factor VIII to stop it, and you need factor infusions to stop it."

HOW ADOLESCENTS UNDERSTAND BLEEDS AND BLOOD CLOTTING

Although your teen knows that hemophilia is a blood-clotting disorder, the process of blood clotting may still be a mystery, despite living with it daily. When asked what happens when someone gets cut, many teens say, "You bleed," "you clot," and "your skin grows back." But can they offer explanations of things unseen—inside the body, more scientific and abstract? Yes, often with a little questioning. If your teen doesn't volunteer information, you can help him figure it out logically.

If your teen's explanations seem too simple, ask,

"And then what?" "How does that happen?" "Can you explain more?" Because teens are able to think in the abstract, they're aware of unseen blood components. They may mention platelets, white blood cells, or cell regeneration.

They may outline a limited step-by-step sequence of what happens internally:

"Plasma would stop it from bleeding. The cells regenerate and make it heal."

"Blood is clotting so no blood can get out and no bacteria can get in."

"The scab and skin regenerate."

"When the blood clots, it heals itself. It repairs the veins."

But how does blood clot? What's the complete, step-by-step, logical explanation? Teens may mention one or two steps, but there are three basic steps in blood clotting:

1. Vasoconstriction 2. Platelet plug 3. Fibrin net

Are teens able to understand the three steps? Yes. A teen who has been taught how blood clots, by parents or HTC staff, will probably remember it:

"Platelets gather together and make a wall, and blood can't get out. Factor VIII helps make a clot."

"Fibrinogen makes a net and red blood cells start sticking to it. Factor VIII deficient means the net doesn't get made."

"The genes in the blood put a protective cover over the hole, and it gets better."

Each explanation is advanced, giving a limited step-by-step account, but each misses one step. Most teens with hemophilia are eager to give a full explanation. But although they can produce a detailed description of how blood works in the circulatory system (thanks to high school science classes), they're less able to explain how blood clotting works. This process may not be taught in high school, but we should consider teaching it at home.

HOW ADOLESCENTS UNDERSTAND GENETICS

Compared to younger children, teens are more aware of, and ready to learn about, the concept of genetics—which can be very logical. Going through puberty shows your teen genetics in action: his sudden tall stature like his grandfather, nose like his father, or hair color like his mother. He's also learning about genetics in school, so he's now ready to understand hemophilia transmission—and, most important, how he got his hemophilia.

Your teen's first explanations of hemophilia transmission may not include abstract concepts like proteins, genes, or cells. When you start asking him about transmission, let him explain in his own words. You can coax him through it. Asking questions like "Why? And then what?" may help him think it through logically. As he grows from a young adolescent (ages 11–14) into an older one (ages 15–18), you can introduce more abstract concepts and terms, like chromosomes and DNA.

Then again, your teen may surprise you with a detailed description of the pattern of transmission from parent to child, including carrier status transmission. Or he may describe general patterns. He may be confused about details—whether his mother gives an X or a Y; on which chromosome the hemophilia gene is located; perhaps even what genes are. But he can try to solve the transmission puzzle by working it out step-by-step, beginning with the first step: "Genes have pieces of DNA in them. They tell you what you have, like your intelligence. They're strands of something. They give you your characteristics."

TRY THIS

The birth of new nieces, cousins, or grandchildren is always a good time to raise questions about hemophilia and heredity. While holding the new family addition, ask your teen casually, **"Do you think any of your children will inherit hemophilia? Why or why not?"** Even if he doesn't answer, at least you can start him thinking.

Your teen may work it out this way: "Hemophilia comes from the family through your genes. Your genes live in the sperm. If your mom's brother had hemophilia, it might pass through the sperm when it hits the egg. The boy could get it by a 50-50 chance." One teen explained, "It runs in the family. The father with hemophilia has a daughter, so she has a 50% chance of having a boy with hemophilia. But if a guy with hemophilia has a boy, it'll stop right there. I'm not sure how that works."

Teens will eventually be able to explain genetic transmission and apply its patterns consistently. These won't be just genetic rules: "If I marry a carrier female, I may have a daughter with hemophilia." He'll be able to generalize, or explain why each rule is true. And he can apply the rules to different scenarios: "Girls get two X

chromosomes, but boys only get an X and a Y chromosome. So if something goes wrong with the X chromosome, the Y chromosome can't cover it as well.

In a girl, if the X chromosome has something wrong with it, the other X can cover it. But girls can get hemophilia, too."

Teens age 15 and older are ready to attempt, sometimes correctly, more intricate explanations involving genes, chromosomes, and probabilities: "One in 10,000 boys get it. But most women are just carriers." Sometimes, incorrectly:

"A carrier means there's a 99.9% chance you'll end up with a kid with hemophilia."

Teens may have trouble explaining why some children inherit hemophilia while their siblings do not. "Not all the mother's genes contain hemophilia." "The genes didn't go through all the way. The sperm doesn't have it." Or, "Some kids get it on their X and some on their Y. If you get it on your X, you get hemophilia. If you get it on your Y, you don't. It comes from your heritage, or your sister or mother being a carrier."

But the hardest question may be, "When you become a father, will any of your children have hemophilia?" If your teen can try to explain this using X and Y chromosome patterns, he's brave! Most will use percentages or general rules of transmission: "If I marry a carrier, then some of my girls might get hemophilia. If I marry someone who isn't a carrier, then some of my boys would have a chance of getting it."

Some teens mix percentages with general rules: "If I marry a man who has hemophilia, then my girls will all have it definitely, and probably my boys will, assuming that I'm a carrier. There's a 50-50 chance."

Look at the way one teen with hemophilia tried to figure out hemophilia inheritance: "None of my children will have it, but my daughters might be carriers . . . Yes, they'd definitely be carriers. The father gives an X to his daughter, and the mother gives an X. If I gave an X and the mother was a carrier, then my daughter would have both Xs affected, and she'd still be a carrier. She wouldn't have hemophilia."

In truth, she would have hemophilia, but this teen's answer demonstrates a wonderful ability to think logically.

HOW ADOLESCENTS UNDERSTAND FACTOR

By the time your child becomes an adolescent, he has learned that factor is more than his bottle of medicine. He knows that it's related to what's missing from his blood, but he also knows that it is a certain type of factor, which functions in a cascade with all the other factors. "Factor VIII is something your body is supposed to make. It stops internal bleeding."

The exact details may be confusing. He may say, "I'm not sure how many factors there are. Is there a factor X?" Or, "There's different types of white cells. These are factors." Or, "There's probably 100 factors. I'm missing all, well, 1% or something."

Ask your teen to explain how factor works once it's infused. This is a perfect topic to produce a logical explanation, because it involves the circulatory system, which operates step-by-step, with specific cause and effect. Many teens won't be able to give the following step-by-step explanation: "Factor is injected into a vein, travels to the heart, and is pumped through arteries to all sites in the body; it forms the fibrin net that eventually covers the torn blood vessel and allows healing." Yet most teens are capable of understanding this process.

Some school age children describe factor as "fighting," "pushing," or "vacuuming" the blood. Only a few older ones describe a "door" or "plug" forming over the torn blood vessel—the fibrin clot. Surprisingly, when teens lack concrete medical or scientific information, many will offer similar answers. But a school age child will be satisfied with his incomplete answer, while a teen usually will not; he may realize that he lacks information,

that there are gaps in his thinking. This frustrates him! Look at these incomplete answers from some teens:

"Factor eats the bacteria in your arm. It helps it to heal."

"It makes a ball of blood and freezes up so it can't swell. It makes the cells stick together."

"Factor is trying to help the white blood cells get all the blood or red blood cells out of the knee. It pushes its way in."

Some teens explain how factor works by mistakenly describing the function of one of the blood enzymes—that is, factor "removes" excess blood from a joint! It seems that, as parents, our emphasis on treating joint bleeds and swellings has prompted our children to confuse swelling with the role of factor.

Yet other teens recognize that "factor goes to the injured spot. It clots the blood and makes new cells. It clots the hole and keeps the blood from spilling out."

Whatever your teen's response, know this: He is ready to understand a simple, three-step process of blood clotting.

He craves the information. His brain is trying to fill in any information gaps. Help him by exploring what he knows.

How Adolescents Understand Factor Deficiency Type and Severity

Most teens know their factor deficiency and often their severity level. "I have hemophilia A, the most common. I'm missing factor VIII." "Hemophilia B means I'm missing factor IX. I have severe hemophilia. I get bleeds, and they don't go away that easily. Mild bleeds go away faster." Pretty sophisticated!

It's important for teens to know their factor deficiency type—for their medical care, and even for their self-esteem. Imagine a teen admitting he doesn't understand this basic information. It's like not knowing his phone number, address, or birthday. To feel more confident, he should understand that factor deficiency refers to the blood protein that is "missing," or not active, and that this results in prolonged bleeding.

Before you begin teaching your teen, understand that adolescents often confuse factor deficiency with severity level. For example, they may believe that being factor IX deficient means bleeding more often, as with severe hemophilia.

TRY THIS

As parents, we're often in "functioning mode" when completing forms and applications for our children. **Try letting your teen complete his own applications for school, hemophilia camp, or clinic.** The forms will require him to list his factor type and severity level, and which medicine he uses. This good parenting action makes your teen more responsible.

You'll need to find out what your teen believes, to correct any misconceptions.

Of the two concepts, the one best understood by adolescents seems to be severity level. This is probably because the idea is still somewhat concrete—you typically bleed more often when you have severe hemophilia. Teens understand severity correctly as how much factor works or is present in their blood. "Severe means you're missing a lot of factor." Or, "I'm mild to moderate. I don't have to be as careful because I don't bleed as much. Severe is worst."

Severity is simpler to understand than hemophilia type because of direct clinical symptoms. The hardest thing to explain about severity is how it relates to the percentage of factor active in the blood. Compared to school age children, adolescents should be more experienced with

How Children Understand Hemophilia: Summary of Stages of Development

	Preschool (ages 3–7)	School Age (ages 7–11)	Adolescent (ages 11 and older)
Hemophilia	It's when I get hurt. I get a shot. I go to the hospital.	Something's missing in my blood.	It's a blood disorder. I'm missing a clotting factor, which makes my blood not clot.
Heredity	You're just born with it. God gave it to me.	It came from my family, my mother. It gets passed along to the baby. The baby catches the X thing.	It comes from the X, Y chromosomes. The X carries hemophilia and when a boy is made, he gets the mother's X.
Bleeding	You bleed, and then it stops. Bandages make it better. My knee gets puffy, then it goes down.	You bleed, then you get a scab and skin grows back. The knee fills up with blood, then it stops. It takes time to heal.	You bleed, you clot, skin regenerates. Veins are repaired. Platelets make a wall to stop the blood.
Factor	It's my medicine. It makes me better. It's a bottle.	It's what I'm missing in my blood. It pushes the blood away. It scares, fights, vacuums the blood. It blocks the vein.	A blood protein that I'm missing. It makes cells stick together. It pushes blood away, eats bacteria, plugs a leak.
Severity	It's when someone gets factor more than another because he got hurt more.	There's severe, moderate, and mild. Severe means missing a lot of factor. Severe means bleeding more.	*Often confuses type with severity.* Severe means you're missing a lot of factor in your body. I only have 2% of mine.
Factor Deficiency	*May recite factor, or his deficiency, but no knowledge of meaning.* I have factor VIII deficiency. I don't know what that means. It's what I have.	It's one of the factors I'm missing. I'm factor VIII deficient.	It's the factor type I'm missing. There's several types of factor needed to stop bleeding.
Having Hemophilia When Grown	I don't know if I will have it. Hemophilia will go away if the doctor invents a cure.	You'll still have hemophilia when you're old, unless there's a cure. It's in you.	I'll always have it. It's made in the liver (or cells or genes).
Cure	Putting new blood in me makes hemophilia go away. Taking new medicine will cure it.	Hemophilia will go away if you get new blood. If you get someone else's blood, you'll still have hemophilia, because you'll still have your heart, liver.	There's gene replacement, implants, DNA research. I'd still have hemophilia even if I got new blood because I'd still have the same cell, genes, liver, heart.
Overall Stage Characteristics	*Hemophilia is external, perceptual, and what I see or experience personally. No time involved, no varying degrees, no subsets of a whole. Magical thinking.*	*Hemophilia is a condition. Step-by-step external sequence, with time involved. Still perceptual, becoming internal. Analogies are useful for teaching. Concrete thinking.*	*Considers whole and parts, hypothetical situations, internal processes, future. Often feels invincible, in denial. Abstract thinking.*

percentages, but using percentages to describe factor activity may still mystify them. Look at how three teens try to explain severity:

Teen 1: *"I'm 3% moderate. It's 3% factor, something like that. It's better than having zero. With zero you bleed a lot easier."*

Teen 2: *"Severe is less than 1% clotting ability. Moderate is 1% to 15%, and mild is 25% to 50% . . . no, to 100%. Normal is 150% to 200% clotting ability. That means how fast and how well you clot."*

Teen 3: *"Serious factor VIII means less than 1%. That's the amount I have. Normal is 33%. Moderate means you have more factor VIII in your body."*

Even though two of these responses are not technically accurate, these teens have attempted to apply abstract math to abstract blood proteins.

How can you teach your adolescent about severity and deficiency? As always, first find out how he understands each concept. Have him draw pictures if that helps. Explain that factor VIII and factor IX refer to blood proteins vital in clotting blood. Try using a clotting cascade diagram.1 (Please don't use the domino analogy with teens; it's far too simple.) Show what happens when one of the blood proteins is missing. To explain severity, use percentages, but first review what percentages mean. Use pie charts and analogies—batting averages are great! Use the idea of a dollar bill (100 cents as 100% factor working). What would a penny mean?

A nickel? Now translate that into how much of his factor works, and what this means clinically—that is, how often does he bleed?

HOW ADOLESCENTS UNDERSTAND HEMOPHILIA AS A LIFELONG CONDITION

Adolescents are able to think abstractly, understand permanence, and consider scenarios. They realize that simply "changing someone's blood" won't cure hemophilia. Remember that teens now view the entire body as an interrelated system. Hemophilia is just one malfunction in one system that interacts with all other biological systems. This way of looking at it is most obvious in teens when you ask them about a cure.

Teens know that hemophilia doesn't go away by itself; it's a permanent condition. Don't school age children also have a concept of permanence? Yes, but they see hemophilia as a separate entity found in the bloodstream, almost like a germ. To an adolescent, hemophilia is permanent because "it's always in the genes." When asked whether they would still have hemophilia if doctors removed their blood and safely replaced it with the blood of a person without hemophilia, adolescents understand that they would still have hemophilia. They might say, "I would still have the same liver. My liver doesn't make factor IX." Or, as one teen tried to explain, "I would still have hemophilia

because the heart makes my blood, so the heart would make my blood with hemophilia."

A cure in our lifetime is fast becoming a reality. Ask your teen: Will a cure happen in his lifetime? Will scientists insert something into his cells, or into his body? Take something away? Will his children still get hemophilia even if he has been cured? Don't try to correct his thinking, just enjoy his thinking process. Get those wheels rolling!

Teens have sophisticated thoughts about a cure. A cure involves more than just "putting in what's missing," as a school age child might say. A cure may involve putting in a functioning part that would produce the thing that's missing. And they're right! A teen may offer, "Put whatever's missing from the parent into the child so it will produce factor." Or, "They might be able to create a cell to destroy the hemophilia cells. Like a magnet." Or, "They'll probably put the part that makes factor VIII in me, and then I would produce factor VIII."

Try to teach your teen about a cure. But first, you'll need to understand a little about how gene therapy works. With several gene therapies already in advanced clinical studies, it will probably be a treatment option in the next five years. There are many websites from companies with products in clinical trials that can help explain gene therapy.

It's a great idea for a science project—explaining how gene therapy would work. Helping with a project like this would give you quality time with your adolescent, and help educate him and his classmates. Still, don't be too surprised if he chooses instead to explain how lightning happens. Teens aren't always eager to let everyone know they have hemophilia. Your teen may want to put things in perspective, and try to take hemophilia in stride, rather than focus on it as a project.

And that's okay. As long as you, as a parent, have meaningful conversations with your teen about hemophilia, what he knows and how he understands it, it will be up to him to decide who gets to learn about it. The whole goal of raising a child with hemophilia is to have him one day become independent. Understanding how your teen thinks, and then teaching him, opens the door to his future.

For more information on how children understand hemophilia, please read the following:

"Teaching Your Preschooler About Hemophilia," PEN 12, no. 4 (November 2002)

"Three Stages of Childhood Thinking," PEN 16, no. 4 (November 2006)

"Teaching Your School-Age Child About Hemophilia," PEN 28, no. 3 (August 2018)

Article excerpted from Laureen A. Kelley, Teach Your Child About Hemophilia (forthcoming, 2019). Originally published as "My Blood Doesn't Have Muscles!" How Children Understand Hemophilia (1996), and later as Teach Your Child About Hemophilia (2007).

1. The clotting cascade diagram can be found in pamphlets and books on hemophilia. Diagrammed like a waterfall, it shows how all the different factors work in sequence to create a clot.

TAKE CARE by Debbie de la Riva

We are thankful to our community member and former Lone Star Chapter Executive Director for writing this article. Debbie has founded Mental Health Matters Too, an organization with many resources for mental wellness and care, and to help the bleeding disorders community normalize the conversation about mental health.

"Take care" is a phrase commonly used by connected people. It is usually intended to convey that the person cares for you and wants you to be OK. Given the additional stress resulting from recent events, it is time to revisit that simply phrase. What does it mean to take care of yourself? The following is an abbreviate list of some common strategies to help you cope with personal adversity:

- Get a good night sleep, eat right, and exercise regularly
- Be intentional about creating a balance between work, rest, and play
- Create realistic expectations of yourself and others
- Focus on what you can control
- Practice deep breathing coupled with soothing mantras

While all of those concepts make sense intellectually, it is quite another thing to put them into practice. Have you ever wondered why it is so hard to do things that are good for you? The answers to that question are sometimes very apparent. We feel we don't have personal time or we feel depleted and the idea of adding one more thing to do seems impossible. There are also some answers that are not so obvious. In fact, they are locked away from our conscious mind and take the form of lessons learned a long time ago. Here are so possible culprits keeping people from acting in their own best interest:

- You were raised to put themselves last.
- You were told that self-care is selfish and unnecessary.
- Your sense of self and their self-esteem in invested in being seen productive or heroic by others.
- If you were raised in a family where your needs were not seen as important, you later internalize that sentiment and can eventually be unaware of your own needs.

If some of these statements resonate with you, I would like to offer a bit of hope. There is a widely accepted term called neuroplasticity. In the simplest terms, it means that our brains have the ability to form new connections which, in turn, help us to form new thoughts about ourself and the world we live in. So, what does this mean for you? Like any personal changes, it takes deliberate attention; a commitment to look inside and evaluate where these messages came from and what you would like to do about the "truths" that are guiding your life. Here are a couple of questions which can help you get started:

- What did I learn about my self-worth, personal needs and taking care of myself?
- Is that narrative working for me in my adult life?
- Can I make a new decision on who I am and how I take care of me?
- What can I do today that can lead to positive personal change?

The recipe for personal change can be summed up as follows:

Awareness of what is not working for you + taking small intentional steps leading you in a self-loving, self-accepting direction.

Take care friends!

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

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

National Hemophilia Foundation
for all bleeding and clotting disorders
National Hemophilia Foundation
www.hemophilia.org
212-328-3700

South Texas Comprehensive Hemophilia & Thrombophilia Treatment Center
San Antonio
210-704-2187

HFA Hemophilia Federation of America
Hemophilia Federation of America
www.hemophiliafed.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 & Thrombophilia Center
Gulf States Hemophilia Treatment Center
713-500-8360

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.

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