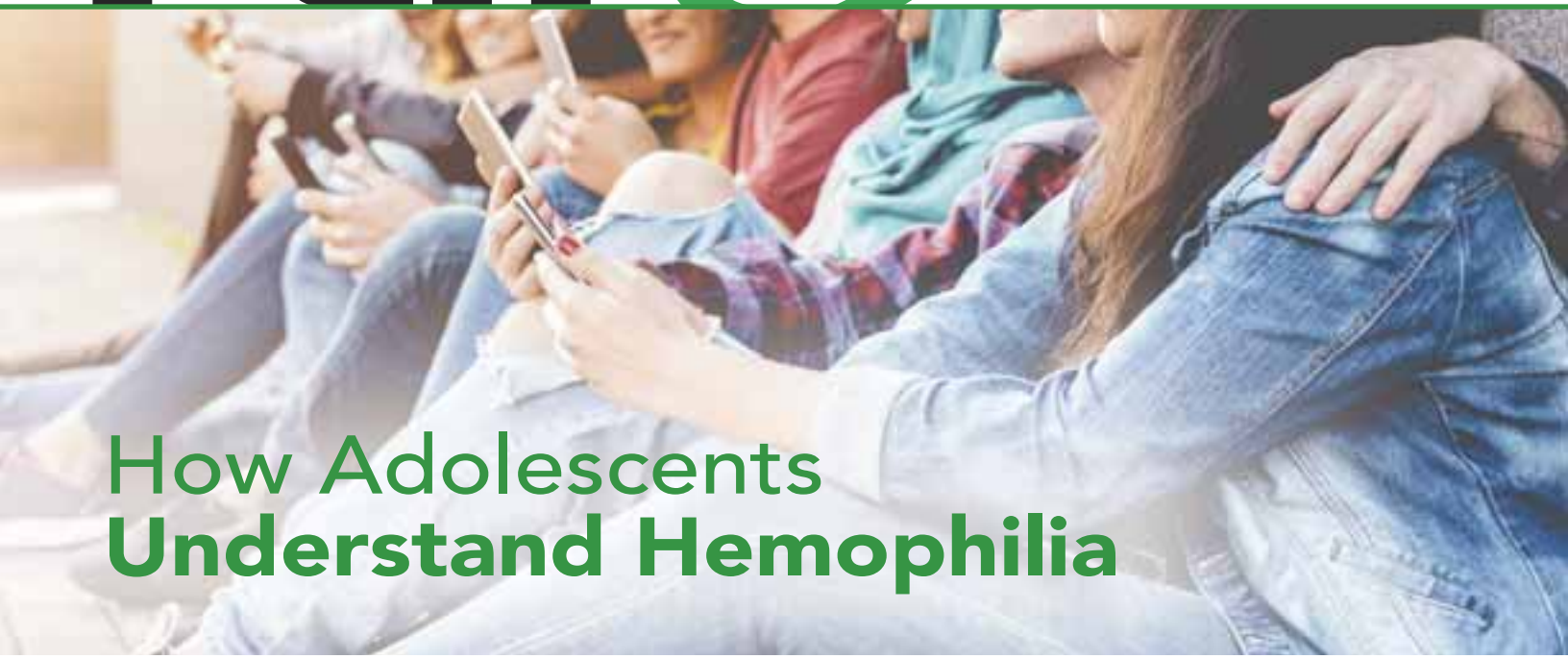
PEN

inside



How Adolescents Understand Hemophilia

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*.

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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).

welcome

"Welcome" is always the last part of PEN to be written, after I review and edit all the submissions. I missed my deadline as I headed off to Hemophilia Foundation of Michigan's 2019 Springfest. I'm so glad I did! At Springfest, I had the loveliest chat with a young man with hemophilia, age 19, just entering adulthood. I've known his mom for a long time, but had never met him. We had a relaxed conversation about his plans, hopes, and dreams. He had just watched the documentary *Bombardier Blood*, and expressed his dream to join an overseas trip as part of Save One Life. So we talked about why he wanted to go: to help others like him, and to learn from them... where he'd like to go: Nepal... and what his future career might be: film and stage—that was a curve ball!

It's so rare for me to have time to chat like this with teens; we adults always seem to be doing, going, busy. I sense that many young people want to open up and enjoy sharing their thoughts. Perhaps the film sparked this young man's curiosity. Perhaps the relaxed atmosphere afterward made him feel comfortable. Or it may be easier for teens to open up with someone they don't know well—and who has no reason to be judgmental or reactive. Though I'm not financially or emotionally invested in this young man, by the end of our conversation, I was invested. I hope to help make this intelligent, thoughtful, respectful young man's dream come true.

If you have a teen with hemophilia, read our feature article about how adolescents understand hemophilia, and try to spend some time just listening to them. Also read Pat "Big Dog" Torrey's article about outdoor experiences as a way to help teens learn about themselves and hemophilia. You don't have to go to Nepal to have wonderful chats and experiences! A nearby park or river or mountain, and an open afternoon, can encourage amazing conversations and relationship-building. Enjoy your teens while you can, and use this issue of PEN to guide you in helping them learn about hemophilia.

Laurie Kelley

inbox

FANTASTIC ISSUE OF PEN. Very informative. I'm making copies to give the doctors and hemophilia clinic in Armenia. Keep up the good work.

Dr. Steve Kashian
ILLINOIS

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In the past, it was incorrectly believed that only men could have hemophilia, and women with the gene were labeled asymptomatic "carriers." It's now recognized that women are not just carriers of hemophilia, but can also have hemophilia and experience symptoms if less than 50% of their factor is active. Most diagnosed patients are male. For editorial simplicity in PEN articles, when we refer to a person with hemophilia, we may alternately use "he" or "she," or just "he."

PARENT EMPOWERMENT NEWSLETTER
AUGUST 2019

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as i see it

On Time Can Be Too Late

Michael Joshua

Off to college: Michael Joshua

CSL Behring

I have hemophilia, but it doesn't have me. And it won't hold me back as I prepare to head off to college in August.

On time can be too late when preparing to transition from high school to college. Because I have a diagnosis of severe hemophilia B, my mother always started preparing for the next school year before the end of the current school year. During that time she would meet with the school nurse or administrative staff for a medical packet and to schedule an in-service if necessary. My mom always told me that my medical history is my personal business, and it's up to me to decide to share with others. However, it's very important that I inform those who need to know about my hemophilia and educate them on what's necessary in case I require medical attention and assistance.

Waiting until you graduate from high school is too late to prepare for college. When you grow up with a bleeding disorder, you learn that your normal is different from the normal of people without a bleeding disorder. I researched and determined which schools were the best options for me to attend. After campus visits, I began the application process and was able to discuss my medical needs with an admissions counselor. By October, I had submitted an application for early action admission and completed the FAFSA (Free Application for Federal Student Aid). Immediately after receiving acceptance in November, I reached out to an accessibility counselor at the Office of Accessible Education to discuss available resources and what I will need to manage my disorder. I got the necessary paperwork via email, and had it in hand to present to the hematologist during my six-month visit to the hemophilia treatment center. During this visit, I was able to get my hematologist involved and discuss what I will need to move out on my own and have access to care. In January I also met with a rehabilitation counselor at the Office of Workforce Development Rehabilitation Services regarding available resources for college.

In February I attended the admitted student visit. Not only did I participate in the activities scheduled, I also took the time to personally meet the counselor at the Office of Accessible Education. Among other accommodations, it was confirmed that I would receive a private dormitory room with no additional cost. Next, I familiarized myself with the location of Student Health Services, and met the staff there. I informed the nurse about my treatment schedule and learned about their hours, their services, and campus emergency numbers. Because factor is shipped by motorized delivery service and not by the US Postal Service, there is a specific process that has to be followed in order for the package to be received.

When preparing to transition from high school to college, it's very important to plan ahead, be assertive, know available resources, and establish a support network. Although it didn't take a long time to navigate this situation, if I had waited until orientation, after move-in, then the time of a shipment or an emergency would not have been the best moment to learn. A new chapter of my life begins this August, but I am ready and not afraid of the challenge. I have always challenged the limits rather than limiting the challenges. As Malcolm X once said, "The future belongs to those who prepare for it today."

Michael is set to graduate from Baton Rouge Magnet High School in 2019, with plans to study political science and English at Loyola University in New Orleans in the fall. He aspires to practice law or become a sports analyst. Michael has a strong passion for helping others and enjoys spending time with family and friends, volunteering in the community, watching sports, and participating in competitive swimming and weight lifting.

inhibitor insights

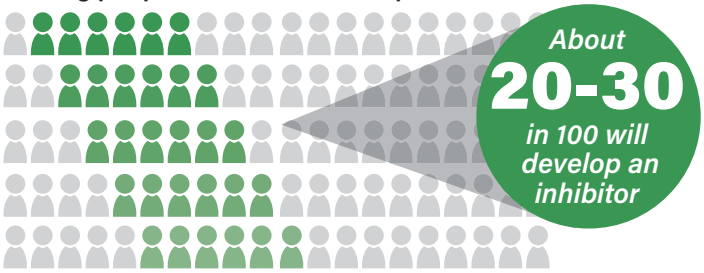
Paul Clement

Inhibitors at a Glance

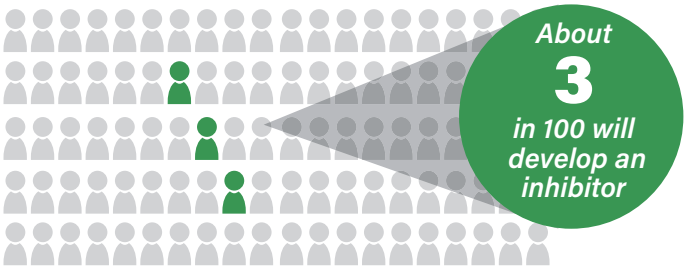
INCIDENCE OF INHIBITORS

(number of people who develop inhibitors)

Among people with severe hemophilia A



Among people with severe hemophilia B

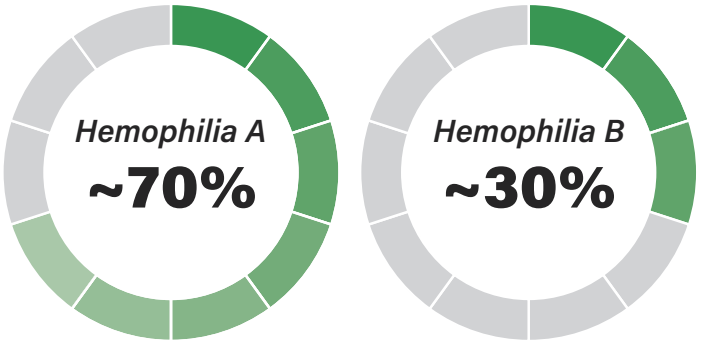


HIGH VS LOW TITER INHIBITORS AGAINST FACTOR VIII

~60% ***high titer*** greater than 5 BU

~40% ***low titer*** less than 5 BU

SUCCESS OF IMMUNE TOLERANCE INDUCTION (ITI)



TIME NEEDED TO ACHIEVE SUCCESSFUL ITI IN HEMOPHILIA A[1]

Average time to achieve tolerance
~1 year

From negative titer to first normal factor recovery
7–14 months

For "good-risk" patients, the median time from start of ITI to a negative inhibitor titer
5–9 months

From normal factor recovery to tolerance
11–16 months

THERAPIES FOR HEMOPHILIA A INHIBITORS

Bypassing agents such as FEIBA and recombinant factor VIIa (NovoSeven®RT)

High-dose factor concentrates (for low titer/low responding inhibitors only)

Hemlibra® (a novel antibody therapy for prophylaxis only)

1. C. R. Hay and D. M. DiMichele, "The Principal Results of the International Immune Tolerance Study: A Randomized Dose Comparison," *Blood* 119(6) (2012): 1335–44.

RISK FACTORS FOR DEVELOPING AN INHIBITOR

1 Non-modifiable factors that increase risk

- Having severe hemophilia
- Being black or Hispanic
- Having a family member with an inhibitor
- Certain gene mutations

2 Potentially modifiable factors that increase risk

- Trauma/surgery
- Intense exposure, especially early in life
- Factor concentrate type[2] *(conflicting evidence)*
- Inflammation/infection

3 Possible protective effect against developing inhibitors

- Early initiation of prophylaxis

PREDICTORS OF SUCCESS OF IMMUNE TOLERANCE INDUCTION[3]

Pre-ITI inhibitor titer less than 10 BU

Historical peak inhibitor titer less than 200 BU

Low-risk factor VIII mutation

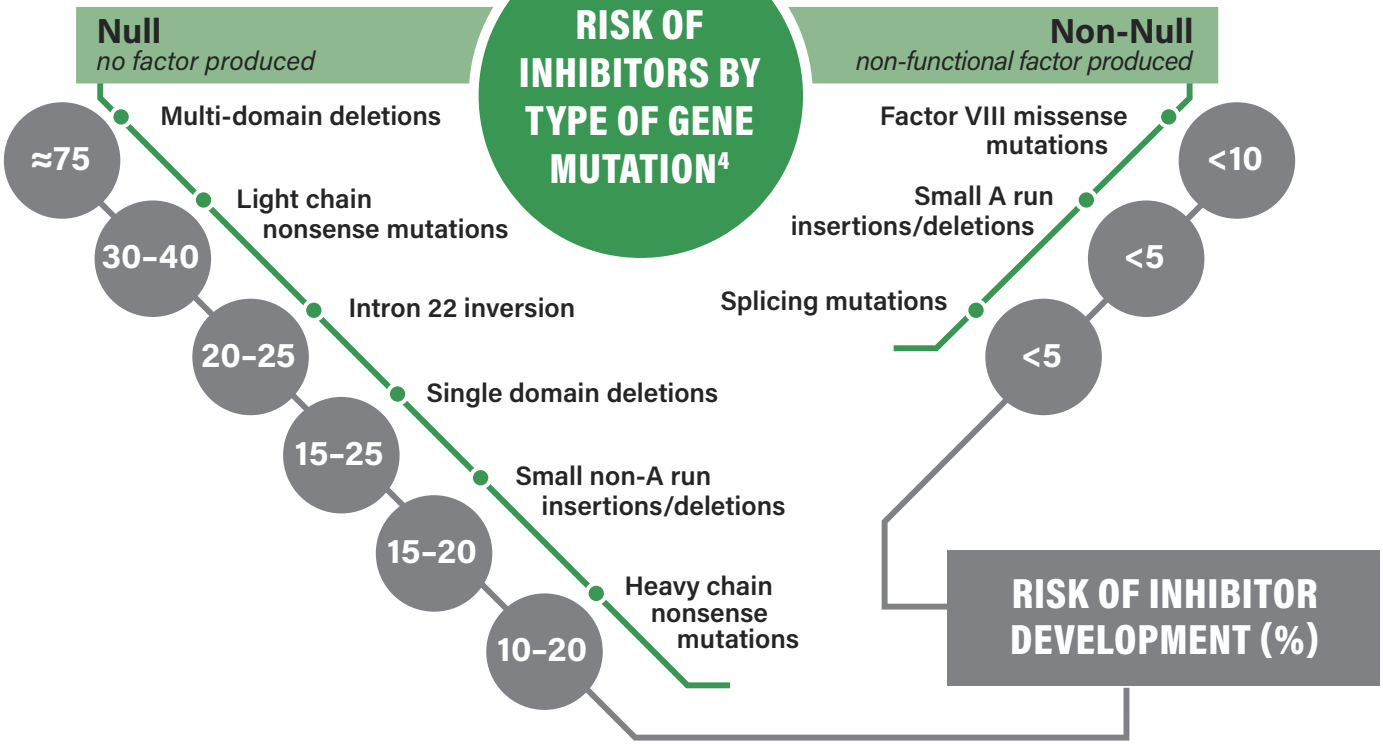
PREDICTORS OF FAILURE OF IMMUNE TOLERANCE INDUCTION

Interval greater than 5 years before start of ITI

Interruption of ITI

High peak titer during ITI

RISK OF INHIBITORS BY TYPE OF GENE MUTATION[4]



2. The SIPPET study indicates that treatment with plasma-derived factor VIII containing VWF may be associated with a lower incidence of inhibitors as compared to treatment with recombinant factor VIII. Flora Peyvandi, Pier M. Mannucci, et al., "A Randomized Trial of Factor VIII an0d Neutralizing Antibodies in Hemophilia A," *New England Journal of Medicine* 374 (May 2016): 2054-64. 3. Char Witmer and Guy Young, "Factor VIII Inhibitors in Hemophilia A: Rationale and Latest Evidence," *Therapeutic Advances In Hematology* 4(1) (2013): 59–72. 4. Manuel Carcao and Jenny Goudemand, "Inhibitors in Hemophilia: A Primer," World Federation of Hemophilia, Treatment of Hemophilia Series 7 (2018): 7.

richard's review

Linda Weaver's Studio

Richard J. Atwood

Mentoring for Hemophilia

Benjamin Rush and John C. Otto

As we advance in our careers, some of us try to do it all on our own. In time, we realize that we could use a little help from our friends. A formal term for this encouraging advice is *mentoring*. A mentor has a certain skill set or professional qualifications, and offers guidance to someone else.

One of the key examples of hemophilia mentoring occurred in Philadelphia in 1803. Dr. Benjamin Rush (1746–1813) provided guidance for his young colleague, Dr. John Conrad Otto (1774–1844). Otto then published a groundbreaking medical journal article on "hemorrhagic disposition," now known as hemophilia. This article inspired other physicians worldwide to investigate bleeding disorders.

The medical careers of Rush and Otto overlapped for 20 years in Philadelphia. Beginning in 1793, Otto progressed from being Rush's student to becoming his colleague, and eventually his successor. Otto was also his mentor's friend. Before starting their medical careers, both men graduated from the College of New Jersey (now Princeton University), Rush in 1760 and Otto in 1792.

Otto moved to Philadelphia in 1793 to begin his medical studies under Rush as apprentice and student. The deadly yellow fever epidemic that summer—with its 10% mortality rate—compelled Rush to send Otto out of the city, most likely because he was a medical novice and also to protect his health. Returning in the fall, Otto attended medical lectures conducted by Rush, who was then a professor at the University of Pennsylvania. Otto was a favorite pupil, and he made hospital rounds and private calls with Rush. Otto earned his medical degree in 1796 with a thesis on epilepsy. He survived an attack of yellow fever in the 1798 epidemic during a visit to his hometown of Woodbury, New Jersey.

Settling in Philadelphia to practice medicine, Otto was elected to the Philadelphia Dispensary for the Medical Relief of the Poor, serving as physician there for five years. Rush had been instrumental in founding the dispensary in 1786 as the nation's first free clinic for the poor. In addition to his private practice, Otto was also a physician at the Orphan Asylum for 20 years, and at the Magdalen Asylum.

Otto visited New England in the summer of 1802. Rush gave Otto a letter of introduction, dated August 6, to Dr. John C. Warren (1753–1815), a professor at Harvard University in Cambridge, Massachusetts. Nothing is documented about Otto's trip, yet we can guess that Rush's letter was a catalyst for Otto to subsequently publish information he collected about a family with cases of hemophilia. Returning to Philadelphia, Otto married Eliza Tod (1790–1860) on December 18, 1802. Eliza, a merchant's daughter, was only 12 when she married. She would go on to deliver nine children, seven of whom survived.

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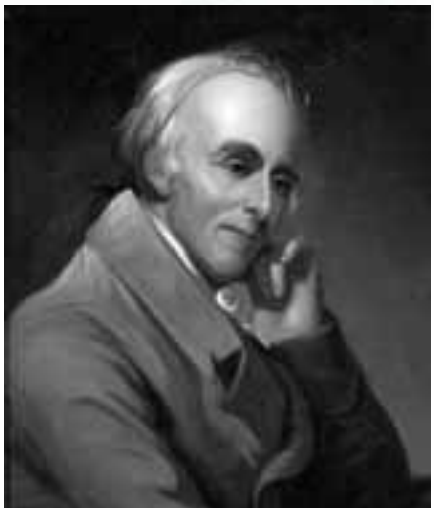

Benjamin Rush

John C. Otto

Learning for Experiential Education

Patrick "Big Dog" Torrey

At GutMonkey, we talk a lot about "adventure education." What does that mean? An adventure is an unusual, exciting, and somewhat risky endeavor with an unknown outcome—think Frodo and the ring here. Adventure education seeks to create experiences that let us explore not only the literal terrain of that adventure, but also what it teaches us about ourselves, our capacity, and the shared capacity of a community—think *Fellowship of the Ring* here.

I started working with this model 22 years ago, with teens in the remote wilderness of northern Idaho. The kids I worked with had troublesome stories that had hardened them deeply. These were kids who had been on their way to jail, who believed in violence as power, who believed they were bad people. How do you teach a different way of framing yourself? How do you teach self-love and forgiveness? And more important, how do you show people what they are capable of, and how to be vulnerable in front of other people?

There is no PowerPoint deck or book report that will engage the core of a teenager to grapple with himself. To help teens discover the best version of who they are, an adventure is the ticket. Taking a young person on a literal quest gives us a way as mentors and teachers to quietly introduce the inner journey; we can begin to talk about the really unknown, risky stuff called "feelings." When teens get to experience themselves in new ways, it helps them open up about beliefs they've been holding about who they are, what they can and can't do, and who they want to

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Adventure is the ticket: "Big Dog" Torrey and young participants

GutMonkey

Adolescents... from cover

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 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:

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.*

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

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.

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 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)

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.

hemablog

When Donating Factor

Laurie Kelley

"I only want to help..."

It's disturbing when we see the photo of an impoverished African child with hemophilia who is in pain or has chronic joint damage.

And we feel helpless when we get a Facebook request for factor from a desperate young man with hemophilia in Asia. As patients, we can feel their pain. As parents of children with bleeding disorders, we want to alleviate their suffering. Yet in our desire to do good, we may end up doing something not so good. We may send factor, on our own, to a place we're not familiar with, to people we don't know.

But won't our generosity help them? What could be wrong with that?

Plenty. In our efforts to help, we may make several serious mistakes. Here's what to look for if you receive an international request for help.

Is the request for real?

This is your first question. Just because someone says he has hemophilia and needs factor, that doesn't mean he actually does. At Project SHARE, we do extensive background checks with the local physicians and hemophilia organization (if there is one) to verify the need. And even if the request is valid, don't forget that English is not the first language in most developing countries; it's easy to get request mix-ups, dosage errors, even incorrect diagnoses.

SHARE keeps reference files on every one of the hundreds of people we have helped. We must be sure we have valid and accurate information. If you are approached, always remember that you may be missing information, so ask questions. SHARE always asks for diagnosis, physician's name and contact info, whether the patient knows how to self-infuse, and how far he lives from a hemophilia treatment center (HTC), for starters.

Should a private citizen ship factor?

Factor is a biological drug that requires careful shipping and handling. It's expensive to ship and must travel via international carrier, such as FedEx. Factor can't be left on trucks, on planes, or in warehouses. And addresses can be tricky overseas! In India, for example, one of my favorite addresses is "Next to Camel Lot, behind Cinema."

Are you familiar with the country's customs laws? Who will pay the duties, or the tax on the shipment? It may even be illegal

Laurie Kelley with a family in Pondicherry, India

Getting an infusion of Project SHARE factor in Vijayawda, India

for you to ship these products; do you know the penalties for shipping a prescription drug over international borders? If you are employed by a hemophilia organization or HTC, are you putting that entity at risk? Whether you're a private citizen or employed by a healthcare agency, if you're unsure about duties, penalties, and costs, don't take the risk—don't ship...

Read the rest of the adventure at Kelleycom.com/HemaBlog

headlines

patient programs

What's the Copay Accumulator?

Episode 24 of Believe Limited's "Ask the Expert" podcast covers the latest insurance challenge that could affect your family. Insurance companies and pharmacy benefit managers are implementing copay accumulator adjustment programs, which significantly increase out-of-pocket spending for patients. Many patients first learn about this sudden, costly program when the cost-sharing assistance they've relied on no longer applies toward their deductible or out-of-pocket costs. Episode 24 educates chapter leaders, social workers, advocates, and families: how to know when an adjustment program happens, and how to advocate for the patient. Why this matters: Insurers are increasingly using methods to raise out-of-pocket costs, and consumers need to challenge payers to preserve their income.

For info: www.bloodstreamexpert.com

New Books on Hemophilia for Youths!

Global health education company Jumo Health, in collaboration with NHF, has created four new comic books that provide age-appropriate info for children, teenagers, and families managing hemophilia. The books cover topics including what clotting factor is and how to successfully manage hemophilia. Why this matters: Children and teens often learn best from books targeting their age group and learning stage, with appropriate concepts and words.

For info: www.hemophilia.org

soundbites

Visit www.hemophilia.org to view "Meet The Joint: Muscle Bleed" with Grace Hernandez, PT, on the latest Make Your Move: Physical Therapy **Webinar** Series.

Genentech's web portal for patients and caregivers gives accurate info on any serious adverse events for **Hemlibra**: www.emicizumabinfo.com

Roche/Genentech joined the World Federation of Hemophilia humanitarian aid program, and will be **donating** Hemlibra to 1,000 people with hemophilia A over five years in countries with little or no access to hemophilia treatment.

The US FDA issued a public statement and a technical advisory, **warning** consumers "to be cautious about establishments offering infusions of plasma obtained from young human donors with the claim that the infused plasma will treat a variety of conditions ranging from normal aging to memory loss."

uniQure's phase III clinical trial of AMT-061, a **gene therapy** candidate for severe and moderately severe hemophilia B, has treated its first patient.

The global hemophilia market is expected to reach **$17 billion** by 2026, according to Acumen Research and Consulting.

nonprofit

NHF Annual Conference

Anaheim, California
October 3–5, 2019

National Hemophilia Foundation holds its 71st national bleeding disorder conference this fall. Registration includes three days of educational sessions, networking opportunities, and access to the Exhibit Hall, where dozens of companies and nonprofits display products or services. Why this matters: With thousands of participants, NHF Annual Conferences are one of the largest bleeding disorder community gatherings.

For info: www.hemophilia.org

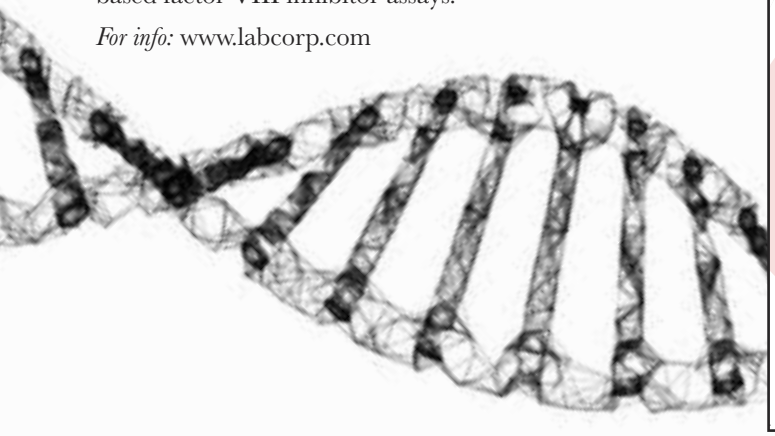
science

Inhibitor Assay for Patients on Hemlibra®

LapCorp, and its specialty testing group Colorado Coagulation, has launched a new test (assay) for detecting factor VIII antibodies (inhibitors) in patients on Hemlibra. The test uses a bovine-based factor VIII chromogenic Bethesda assay (two-stage assay), required because standard clotting-based Bethesda assays using human proteins give false readings. The test measures inhibitors to factor VIII in the presence of circulating levels of Hemlibra. It's not intended to measure anti-drug antibodies to Hemlibra.

Why this matters: Using the correct test to quantify the level of antibodies (the inhibiter titer) is important because Hemlibra interferes with standard clotting-based factor VIII inhibitor assays.

For info: www.labcorp.com

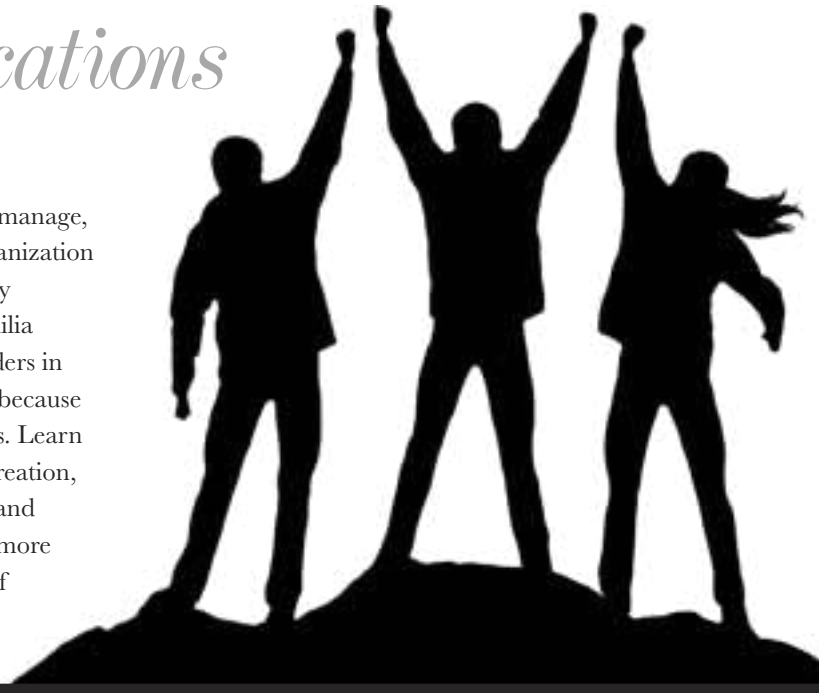


news from LA Kelley Communications

Guidebook for Leaders

It's back—the handbook for leaders who manage, grow, or want to create a hemophilia organization or chapter. *Success as a Hemophilia Leader* by Laureen A. Kelley is mainly for hemophilia leaders in developing countries, but leaders in developed countries find it helpful too, because leadership principles transcend borders. Learn about leadership, vision and mission creation, goal setting, board composition, PR, camps, and more. Free to qualified leaders. Why this matters: Leaders become more effective by learning about principles, guidelines, and experiences of other leaders.

For info: www.kelleycom.com



Richard's Review... from page 6

In 1803, at age 29, Otto published "An Account of an Hemorrhagic Disposition in Certain Families" in *Medical Repository*, America's first medical journal, founded in 1798 in New York City. This article is considered the first clear description of hemophilia in the world, and was reprinted in England in 1808. Otto did not mention his visit to Boston, but he noted that Rush was familiar with similar cases of hemophilia in the town of York and in Northampton County, both in Pennsylvania, and also in Maryland.

In his article, Otto described the Smith family from Plymouth, New Hampshire. Otto probably gathered his information from secondary sources, rather than ever interviewing any Smith family members. We know that Otto learned of the Smith family from residents of nearby Holderness, New Hampshire, including Judge Samuel Livermore (1732–1803), Dr. John Porter, and Dr. John Rogers. These men, while personally knowing about some of the "bleeders" in the Smith family, were secondary sources. Judge Livermore traveled to Philadelphia, the nation's capital, serving as a member of the Continental Congress, a US Representative, and a US Senator (1780–1801). He traveled with Captain Thomas Shepard, a relative of Captain John Shepard who also served with Robert Rogers' Rangers, a mercenary regiment of soldiers from New Hampshire. Otto recorded many secondary sources who knew members of the Smith-Shepard family. But his encouragement from Rush seems to have sparked this investigation.

Around 1752, Susannah Smith (1739–1818) of Durham, New Hampshire, married Captain John Shepard (1730–1779) of Barrington. Captain Shepard served in the British army and in Robert Rogers' Rangers. He and Susannah are usually credited with seven children, though some sources list more. Some of the Shepard sons (not specifically identified) are reported to have been "bleeders" and died young. After Captain Shepard died in 1779, and his property was confiscated because he was a Loyalist,[1] Susannah and several of her adult children moved to Holderness, to what is now called the Shepard Hill Historic District.

Otto supported Rush's contention that a cure-all for diseases, especially when blood vessels and nerves are in an "excitable state," is a purgative. Rush treated yellow fever with bloodletting,[2] usually about 10 ounces of blood taken three times a day, along with emetics and laxatives for purging. These medical procedures, though commonly practiced, were critically disputed by some physicians. Otto stated that sulphate of soda, a purging medicine, was the best treatment for hemorrhagic disposition. To be curative, he said, the purging dose needed to be administered two or three days in succession. Administering more often was sure to produce the "cure" even with its debilitating side effects.

When he learned more about a Maryland family of "bleeders," Otto published an update in his 1805 article "Singular Cases of Hemorrhagy" in the new journal *Philadelphia Medical Museum*. Otto wrote that all four sons of Benjamin Binny were victims of fatal hemorrhages, while the daughters were not affected.

In 1805, Rush became dean of the University of Pennsylvania Medical School. When Rush died in 1813, Otto replaced his former teacher as a physician and clinical lecturer at the Pennsylvania Hospital, a position he would hold for 22 years. Regrettably, Otto never published again on hemophilia.

We don't know why Rush didn't publish information on the cases of hemophilia known to him. We also don't know why Rush, as a mentor, seems to have prompted Otto to investigate the Smith family in New Hampshire. Perhaps Rush,[3] as a Founding Father and one of 56 signers of the Declaration of Independence, was busy with other matters. Fortunately, Otto wrote an influential article on hemophilia, clearly describing its bleeding pattern, the current treatment, and its genetics, and even introducing the term "bleeders" in the literature. We can be thankful that Otto's 1803 article was the consequence of successful mentoring for hemophilia.

1. Another twist to this story concerns the political spectrum extremes involved here: Rush and Otto were Revolutionaries for America, while Shepard was a Loyalist for England. 2. Bloodletting means to open up a vein. Rush's practice was controversial. But he published his results, so his methods were well known. Rush had some success, but some of his patients died. Other physicians who did not practice bloodletting had some success, and also had some patients die. A purging remedy for hemophilic bleeding may have been effective, or it may have distracted the patient enough to stop any bleeding. To us, this sounds barbaric, but it fit the medical theories at the time and remained popular for another half-century. 3. Recent biographies of Rush include *Rush* (2018) by Stephen Fried, and *Dr. Benjamin Rush* (2018) by Harlow Giles Unger. Unfortunately, a comprehensive biography of Otto is missing.

YOU... from page 7

be. These beliefs and values are all based in emotions, and we can't change behavior or make logical choices unless feelings are validated and understood.

When I started working in the hemophilia community 17 years ago, I saw so many immediate parallels: these teens were trying to navigate their journey to young adulthood, struggling with self-infusion, for example. I saw adult counselors still carrying trauma from the blood contamination of the 1980s and 1990s. I immediately recognized a use for adventure education to build metaphors that would help people tackle these complex issues of self-efficacy, adherence, positive risk as a tool for growth, and making change when change is hard. Let me share a story that captures what I'm talking about.

Years ago, I was running a program at a hemophilia summer camp, and I asked a group of early teens, "Does anyone know how to play poker?" One of the kids knew how to play, so we played a quick round. I held up an invisible hand of cards, and he quickly caught on. "Okay," I said, "you've got a two, five, six, and two jacks." "I've got three kings, a seven, and an ace." Then I asked the group which one of us had the better hand. Everybody responded, "You do!" I nodded. To my poker partner, I said, "Okay, for now, put down your 'cards.' Now, raise your arms, and get them way out there in front of you like you're carrying a huge box." Once his arms were really, really far up in the air and out in front of him, I said, "That's your pile of poker chips." The kid grinned. He was rich! Then I showed him all my chips, as if I held them in just one hand: "I have one red, two whites, and one blue." Again I asked, "So, who's got the better hand of cards?" They all pointed at me. "Great. I've got the better hand, but let's take a look at how we're going to bet."

I told my opponent, "You have a lower hand, but how are you going to bet with all those chips?" Everyone responded that my opponent was going to bet BIG. I then asked how I would probably bet, and everyone responded, "Conservatively, even though you've got the better hand." I mused, "Sure...or I might go all in, but if I lose, that's it, I'm done. The thing is, poker chips are a lot like self-confidence. When you've got a lot of it, you can bet big, and lose big. On the flipside, if you don't have much of it, you tend to live small, and you're really, really cautious about the steps you take, and what you choose to do. If you make that choice to go all in, and you lose, it can be really easy to lose the self-confidence that you do have, and not want to get back in the game."

The next day we ran a ropes course activity called the Flying Squirrel. You're in a harness, wearing a helmet, and you're attached to a rope that is rigged to a pulley high up in the trees. At the command "Flying!" your group runs while pulling your rope, and you fly up in the air like Superman! The group of kids from our poker game all participated in the Flying Squirrel that morning. That afternoon, as the group was walking back into camp, one of the kids said, "Hey Big Dog, I've got to tell you something." He said, "Check this out. This morning, I went on the Flying Squirrel, and I was really, really scared. But I did it, and I went about halfway up. I got some really great poker chips from doing that, and then I went to ride horses this afternoon. I'm really scared of horses, but since I had more poker chips from doing the Flying Squirrel, I felt a lot better about going, and I rode for the first time, and it was awesome."

I was so moved that this kid wanted to share all of this with me, and now we also had an opening! First, I validated that it was okay that he had been afraid, and then I praised him: it was so awesome that he'd taken the risk to gamble a little. Now it was time to take a deeper look, and ask some great follow-up questions, like "How many poker chips do you think you'll need to be able to self-infuse this week?" or, "What are the things that are holding you back from having more poker chips in other places in your life?" or, "Where else could you be playing with more poker chips in life?"

A metaphor that started with a silly game of make-believe, combined with outdoor adventures, gave this kid a way to talk about his self-confidence and self-esteem. As adults working with teens, we need to create space for these conversations, and seize the opportunity when a teen broaches the subject. We also need to give teens tools to help them talk about their experiences—tools like poker chips. Ropes courses, horseback riding, and a make-believe game are all opportunities to create unusual, exciting, novel experiences that leave the outcome open to individual interpretation. *Our job from there is to support kids in seeing their own value, exploring what the experience means to them, and relating it to other places in their lives—like their bleeding disorder—where they have power over how they're playing their own game.*

Pat is founder and CEO of GutMonkey, an adventure education company that provides foundational, life-changing experiences for communities with chronic health conditions, to improve health outcomes, build communities, dismantle stigma, and increase awareness. To learn more, follow GutMonkey on Facebook and Instagram, and sign up for the newsletter at gutmonkey.com.

Inbox... from page 2

Response to April Communiqué

A GREAT WRITE-UP ON WORLD HEMOPHILIA DAY and your observations. My dad, Frank Schnabel, was an American. He was born in Spokane, Washington, in 1926 (his birthday and World Hemophilia Day are April 17). Frank moved to Canada in 1952 because his stepfather was Canadian and could help him find work. It was definitely a move made for better hemophilia healthcare. At the end of his life, my dad considered giving up his US citizenship to be Canadian, but he couldn't, since he had great affection for his country of birth.

Gina Schnabel
CALIFORNIA

Raising a Child with Hemophilia

TODAY AS WE CLEAN OUT some of my mom's things, I found this book, *Raising a Child with Hemophilia*. Reading through this and seeing all the things my mom underlined and highlighted brought tears to my eyes. I try to put myself in her shoes as a new mother of a child with a bleeding disorder. There's a lot she underlined, but there was a pattern I noticed: she starred or put stickers on things that sounded hopeful. Sometimes it's hard to stay positive, but my mom always taught us to trust in God and keep moving forward. I've noticed that "keeping your hopes up" is a skill, and no matter how much it may hurt to be let down, you can't lose that skill. I'm so grateful for the amazing mom she was, and that she did the greatest job raising a difficult, super-flawed young man all by herself. Shout-out to all the moms raising kids with a chronic illness or disorder. My love goes out to you because I see my mom in you, and you're stronger than you know.

Alberto Gonzalez
TEXAS

HOW MANY MOMS HAS THIS book helped and given light when our sons grew up? Thank you, always thank you!

María Andrea Robert
BRAZIL

MENTAL HEALTH MATTERS TOO®

Mental Health Matters Too

Mental Health Matters Too is an organization that holds presentations and programs catered to helping people cope with the emotional challenges of living with a bleeding disorder. MHMT was founded by Debbie de la Riva, a licensed professional counselor and certified mental health first aid instructor, to increase awareness of mental health issues within the community.

UPCOMING EVENTS

Coalition for Hemophilia B Men's Retreat
September 20–22, 2019

Coalition for Hemophilia B Women's Retreat
September 27–29, 2019

New England Hemophilia Association
Fall Fest 2019
October 25–26

For more information or to book an event:
Debbie de la Riva, LPC
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MentalHealthMattersToo.com

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Hey! Did you visit your HTC this year?

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For more information, please visit
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[Antihemophilic Factor (Recombinant), PEGylated]

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