PEN

inside

Back to School: Have You Covered All the Bases?

Paul Clement

Sending your child with a bleeding disorder off to school for the first time can cause a mixed bag of feelings. You may feel relief: you're no longer on duty 24/7 and may even have some "me-time." But your anxiety may skyrocket: you're no longer your child's guardian angel, monitoring her every move and protecting her from harm. You must now rely on teachers and other school staff to protect your young student. And you must rely on your child's ability to communicate if he's experiencing a bleed or injury.

Although you may feel reassured after meeting with the school nurse and your child's teachers, be careful. How much of the information you provided really sank in? How will you ensure that school personnel know what to do in an emergency?

You can make sure that staff are properly trained by requesting an Individualized Healthcare Plan (IHP) and an Emergency Care Plan (ECP). If you haven't heard of an IHP or ECP, or an IEP or 504 Plan, read on: your child's healthcare and academic success may depend on it.

What's an Individualized Healthcare Plan?

An IHP is a variation of a Nursing Care Plan.[1] It's written by the school nurse, based on information and approval from your child's physician, and in collaboration with the student, parent/guardian, healthcare providers (for example, hemophilia treatment center [HTC] physician, nurse, or social worker), and designated school

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1. An Individualized Health Plan may also be called an Individualized School Health Plan or Individualized Healthcare Plan.

welcome

Can you imagine trying to treat your child's bleeding disorder without a treatment regimen? Without a plan? Just winging it, day by day, hoping it all works out? What could happen? I shudder to think of the possibilities!

Then why allow your child to attend school without a plan of some sort? Most parents will meet with the staff of the school, starting with their child's assigned teacher, the school nurse, and the phys ed teacher. You meet, present a bulleted slide show on hemophilia, and answer their questions. Maybe you even get to keep factor at school. But as September rolls into October and then into the holidays, all those bullet points begin to blur. A child on prophy might never have a bleed at school; or might never show any after-effects of a recent breakthrough bleed, like limping.

School staff are swamped with children, needs, curriculum, and policies. To make sure staff will keep your child's safety and educational needs in mind, your best insurance is to have a formal plan in place. Our feature article by Paul Clement explains the differences between the types of plans your school may offer, and which one might be right for your little student. In YOU, Jess O'Donnell shares the thoughts of caregivers, who reflect on how well formal plans worked for their children.

Keep your child healthy, safe, and on track with school by taking advantage of formal plans. What could happen? He turns in his homework on time! Or she gets to rest a joint or see the nurse when she needs to. I smile to think of the possibilities.

Laurie Kelley

inbox

My son is five and still has a hard time understanding what hemophilia is. We've used the typical sayings, like "You have special blood," "Your blood doesn't work right," but he still didn't really get it. Icing and treating was so hard because of his lack of understanding. Then I realized my son is a visual learner, so one day while trying to ice a bruise, as he fought me, I looked at the gel icepack in my hands and had an ah-ha moment. I said, "Okay, buddy, let's think of it this way." I took all of the gel and pushed it to the bottom of the pack. I told Gabe to hit the empty spot and to pretend it was his leg, which had hit the ground when he fell (and we were trying to ice). I slowly started to fill the spot up with the gel, but kept it flat. I said, "See how the gel comes up to the spot where you hit? That's like the bleed under your skin that happens when you bang something. It happens to all of us," and I showed him a bruise I had. Then I had him touch the icepack and showed him it was still pliable, it could move, but the gel "blood" changed the color of the icepack, just like bruises change the color of our skin. I continued pushing the gel to the spot, and clamped it so the icepack bulged and became firm. Then I had him try to move it. When he couldn't bend the icepack, I said, "If you have hemophilia, sometimes the bleeds last a little longer than Mommy's or other people's, and sometimes there is so much blood that it has

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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."

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Steve Place

Be a Part of Making Tough Decisions Now

I have lived for 64 years with mild hemophilia and have voluminous experience, from which I came to my own rock-solid conclusions about how someone with a bleeding disorder can participate in sports and other potentially life-changing activities.

One experience was a significant life change at age 10, when I sustained a serious head injury. I felt able to ride my bike with no hands. Sand and a quick moment of unbalance tossed me off my bike, and my head hit the pavement hard. I got myself up and walked back home with my bike. My sister saw me and screamed. That's when I felt a huge lump on my forehead and knew I was in trouble. Our doctor, who made house calls, wrapped my head with a pressure bandage and told my parents to give me two aspirin every four hours and added that if I made it through the night, I probably would be all right. Aspirin and all, I survived.

All of a sudden, I was prohibited from participating in contact sports. This is tough for a 10-year-old boy. Although I was always the smallest kid in my class and the last to be chosen at sports, it still hurt. Fortunately, my mom and dad and sister were very supportive, and we got through it together. They steered me to other avenues that led me to a happy, healthy, and productive life. I thank God every day for my hemophilia!

I look back and wish I could have accepted at age 10 what I strongly believe about my bleeding disorder today. I went from "Boo-hoo, I can't do certain things!" to "Drop back, punt, and come up with a new plan."

Now that may sound a bit harsh, but the sooner we accept our limitations in life and pursue the best and safest path, the better off our lives and our families' lives will be. Yes, we must think about our families, too; it's not all about the person with hemophilia. Every person with a bleeding disorder has affected and will continue to affect the lives of those we love most. Our bleeds seem to come at the most inconvenient times, for us and for them!

It was traumatic when at age 10, I had to stop doing the things my buddies were doing. But here I am today, happy, married for 40 years with two daughters, successful, and in excellent health. I am physically active in my daily pursuits. I am a professional handyman and sole proprietor, and I work daily with all types of sharp tools, both power and manual. Safety and thinking through a job are paramount. Knee pads and elbow/forearm protection are vitally important. The most dangerous tool in my toolbox is a dull blade.

I treat on demand and prior to some potential bleeding situations. I have 95% mobility in all of my joints. The only time I infuse, apart from surgery, is when I make a mistake.

We all want to be the best parents we can be for our kids. Good, tough prodding and steering today can result in a wonderful life later on for them. I made a very strong, positive personal decision that has guided my life for the last 50-plus years. I decided that I will respect my disorder, but I will not be afraid of it. I will determine what I *will* do, and what I will not do. I basically took charge of my life.

Stephen is 64 and has been married for 40 years. He has two adult daughters, and works 50 hours a week. He is active in his church, both teaching and leading. He believes that life is great, especially when "I respect my disease, but am not afraid of it." scplace122@comcast.net

Cazandra Campos-MacDonald

Why You're Afraid to Switch Products

A few myths about hemophilia linger in the community: "Only men can have hemophilia." "A person with hemophilia will bleed faster than someone without hemophilia." "People with hemophilia can't play sports." "You will outgrow hemophilia." Belief in these myths can spread fear, and can lead to harmful biases or behaviors: for example, prohibiting a child from playing sports, or not believing women who claim to have bleeding issues.

One fear that is still felt by many people with hemophilia, particularly those who've had an inhibitor, is the development or recurrence of an inhibitor as a result of switching factor products. Though there is some evidence to support this,[1] we also know that the risk of developing an inhibitor as a result of switching products is very small—too small to accurately measure. Yet many parents give this risk more weight than it deserves. Fear clouds their judgment when weighing the benefits of finding a better product and treatment regimen with the risk of contracting an inhibitor.

The fear of switching products became ingrained in my mind when my oldest son, Julian, was diagnosed in 1996 with a low-titer inhibitor at age one. I learned to infuse Julian with a first-generation factor VIII product (from which he developed the inhibitor), and after two and a half years of daily infusions, his inhibitor tolerized. My husband and I kept Julian on his treatment regimen while also gathering information about new factor products entering the marketplace. First-generation recombinant factor products reconstituted into 10 cc volumes, while some second-generation products reconstituted into only 2.5 cc. Yet our fear of triggering an inhibitor by switching products outweighed the promise of quicker infusions.

My second son, Caeleb, developed a high-titer inhibitor at age 11 months. He eventually began immune tolerance therapy (ITT) on a recombinant factor product, and after a couple of years of daily infusions, we moved him to a plasma-derived factor, hoping to lower his inhibitor level. Given the many complications Caeleb endured over the years, I feared that switching to a different factor product would cause his titer to spike. And daily infusions meant accessing his port every morning and pushing 30 cc of product from four vials of factor concentrate. This was not conducive to self-infusing, although he stopped experiencing episodic bleeds. Not having bleeds regularly was a great trade-off.

Whenever Caeleb visited the hemophilia treatment center (HTC) to have labs drawn, I brought along an extra-large plastic bag of his factor and supplies. Recently, Caeleb's hematologist, Dr. Shirley Abraham, suggested, "I think it's time to switch Caeleb to Hemlibra."[2] I was stunned. Another switch? I honestly couldn't understand why Caeleb needed to switch. Even though Hemlibra® is not a factor product, I realized that the fear of switching was alive and well in my mind. Caeleb still had an inhibitor, and not knowing how a new treatment would affect him was nerve-wracking. Dr. Abraham pointed to the extra-large bag and said, "*That* is why it's time to switch." Over the years, I had grown accustomed to carrying all those supplies for an infusion, and to accessing his port daily. With Hemlibra, a month of product and supplies fit into a small container, and Caeleb receives one subcutaneous injection weekly into his thigh—no more infusions into his port. In that moment, speaking to Dr. Abraham, I understood. Caeleb's quality of life could be even better if I trusted medical advice and didn't give in to old fears.

Products are chosen—and kept—for many reasons. For example, in families where more than one person has hemophilia, the choice may be based on another family member's experience. And if a treatment regimen or product is working well, change may not be needed. But what if you can do better? A common response to changing products came from one mother on social media. "Same manufacturer for 18 years because [the product] works. No reason to change." Claudia

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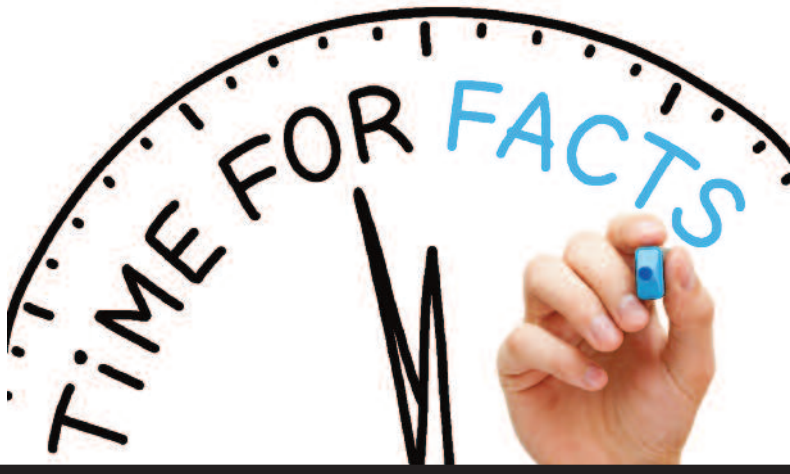


1. F. R. Rosendaal, et al., "A Sudden Increase in Factor VIII Inhibitor Development in Multitransfused Hemophilia A Patients in the Netherlands: Dutch Hemophilia Study Group," *Blood* 81, no. 8 (1993): 2180–86, available at www.bloodjournal.org. Thierry Calvez, et al., "Recombinant Factor VIII Products and Inhibitor Development in Previously Untreated Boys with Severe Hemophilia A," *Blood* 124, no. 23 (2014): 3398-3408, available at www.bloodjournal.org. 2. For more on Hemlibra, see Paul Clement, "ACE910: The First Disruptor," *PEN*, February 2018, 4.

richard's review

Linda Weaver's Studio

Richard J. Atwood

More Hemophilia Literature for Younger Readers

Here are more books about hemophilia for younger readers. In the August issue of PEN, we surveyed books with fictional main and supporting characters who happen to have hemophilia. Other literary genres, such as biography, time-travel fantasy, as well as some unexpected references, also include hemophilia. Something for everyone.

Follow your curiosity by exploring different genres of literature for younger readers. I suggest the following books for your enjoyment and learning.

BIOGRAPHY

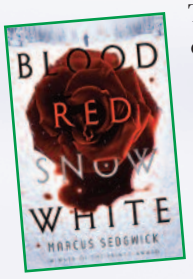
The Uncanny (Sterling, 1998)

Peter Hepplewhite and Neil Tonge

The Unexplained series of children's books for young adults includes this story of how Rasputin, or the Mad Monk, used his powers to heal a joint bleed that Alexei Romanov, son of the Russian tsar, experienced because of his hemophilia in 1907. The text teases the reader, but doesn't supply enough information on the full story of Rasputin.

Blood Red Snow White: A Novel of the Russian Revolution (Orion, 2007)

Marcus Sedgwick



Though this children's biography is based on documented facts, it could also be considered a spy novel. In 1913, Arthur Ransome, a writer of children's books, leaves his family behind in England to become a newspaper correspondent in St. Petersburg. There he learns of Alexei, who has hemophilia, and of Rasputin with his healing powers. Ransome marries the private secretary of Leon Trotsky (1879–1940; a leader of the Russian Communist Party after the 1917 Bolshevik Revolution), becomes a British agent, and returns to England in 1942 to write more children's books.

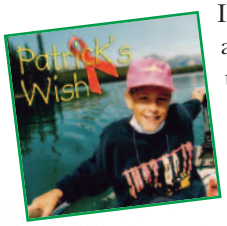
Germ Stories (University Science, 2008)

Arthur Kornberg

These 10 profiles of germs are written for young readers as poetry, with catchy rhymes accompanied by dynamic illustrations and photographs. The story of HIV mentions the fictional Bill, a second grader with hemophilia. The references to hemophilia and AIDS seem dated, but readers may not notice.

Patrick's Wish (Second Story, 2010)

Karen Mitchell with Rebecca Upjohn



In this biography for young readers, with accompanying family photographs, Lyanne tells the story of her older brother, Patrick Fortin (1978–2001), who had hemophilia and AIDS in Canada. Patrick's wish was a cure for AIDS, and before her brother died, Lyanne promised to tell Patrick's story.

The Quiet Hero: A Life of Ryan White (Indiana Historical Society, 2015)

Nelson Price

This young adult biography summarizes the accomplishments of Ryan White (1971–1990), who became a national celebrity because he had both hemophilia and HIV. Ryan wanted to continue attending school in Indiana even with serious medical conditions. Taking advantage of all the publicity, Ryan became a spokesperson for AIDS education. Unfortunately, while hemophilia was controlled, AIDS was deadly. This book helps us remember Ryan.

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504s and IEPs in Action

Jessica O'Donnell

Sending a child with a bleeding disorder to school can be scary, and parents may feel vulnerable and stressed. Many aspects of your child's health and safety are not in your hands. To ensure that healthcare needs are met and your child succeeds academically, it's important to establish good lines of communication between yourself and the school. How do you make sure your child's needs are met? How can parents guarantee that their children are receiving the care and support needed from school nurses, administrators, and teachers?

Parents often look to 504 plans, IEPs, IHPs, and ECPs to establish formal action plans for prevention and treatment of everyday concerns that may arise at school.[1]

504 versus IEP

It's important to distinguish between 504 plans and individualized education plans (IEPs). As defined by the US Department of Education, Section 504 states that students are entitled to receive regular or special education and related aids and services that are designed to meet their individual educational needs as adequately as the needs of students without disabilities. But note that under a 504 in practice, no schools offer special education services, such as various speech or occupational therapies. Section 504 also requires, among other things, that a student with a disability has equal opportunity to participate in athletics and extracurricular activities, and is free from bullying and harassment based on disability. Unlike an IEP, a 504 plan provides for small changes (called accommodations) to a student's regular education program in a regular classroom setting.

IEPs are for students who are entitled to support via IDEA (Individuals with Disabilities Educational Act). IDEA has a much narrower definition of disabilities than a 504 plan, as they relate to education. Also, to receive an IEP, the child's disability must affect educational performance and/or ability to learn. IEPs are available to students who require changes to curriculum and/or special education services. IEPs and 504s serve similar but different purposes within the school system.

Missed School

A main concern is missed school days due to bleeds, injury, or recovery from a bleed. Many parents state that 504s and IEPs not only ensure that missed school days for medical reasons are excused, and their child can make up assignments, but the plans also provide for support services such as tutoring. Again, remember that IEPs can provide many more services than 504s.

Amy Selfridge, mother of an adult son with hemophilia, recalls his early school years: "My son missed over 160 days of school in three consecutive years. He had a 504 plan that explained what hemophilia is and what plans needed to be taken into consideration when he was absent." Amy encouraged her son to take the lead in staying current with schoolwork and communicating with his teachers. "On top of the 504 plan, I had him email all his teachers while he was out of school."

A teacher herself, Amy recalls helping her son with his homework, but she stresses the value of her son's active role in his own education. "It was very import that he take care of his communication with his teachers. It was the first step to being responsible for his own education." Now, says Amy proudly, "he just graduated with a degree in business administration in May."

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1. See our feature article, "Back to School," for details on learning accommodation plans.

staff (for example, vice principal or special education teacher). All these people normally sign off on the plan.

An IHP is designed to ensure that a child's medical requirements are properly met during a school day. It contains all pertinent information about your child's healthcare needs, including information about medications and where they'll be stored at school, as well as emergency contact information. The IHP lists the names of school staff who are responsible for monitoring your child's special healthcare needs: during transportation to and from school; while at school; during field trips; and in afterschool care or activities, such as sports or clubs. The IHP also includes a plan for how and when these staff will be trained. IHPs are reviewed at least annually, updated as needed, and revised when significant changes occur in the student's health.

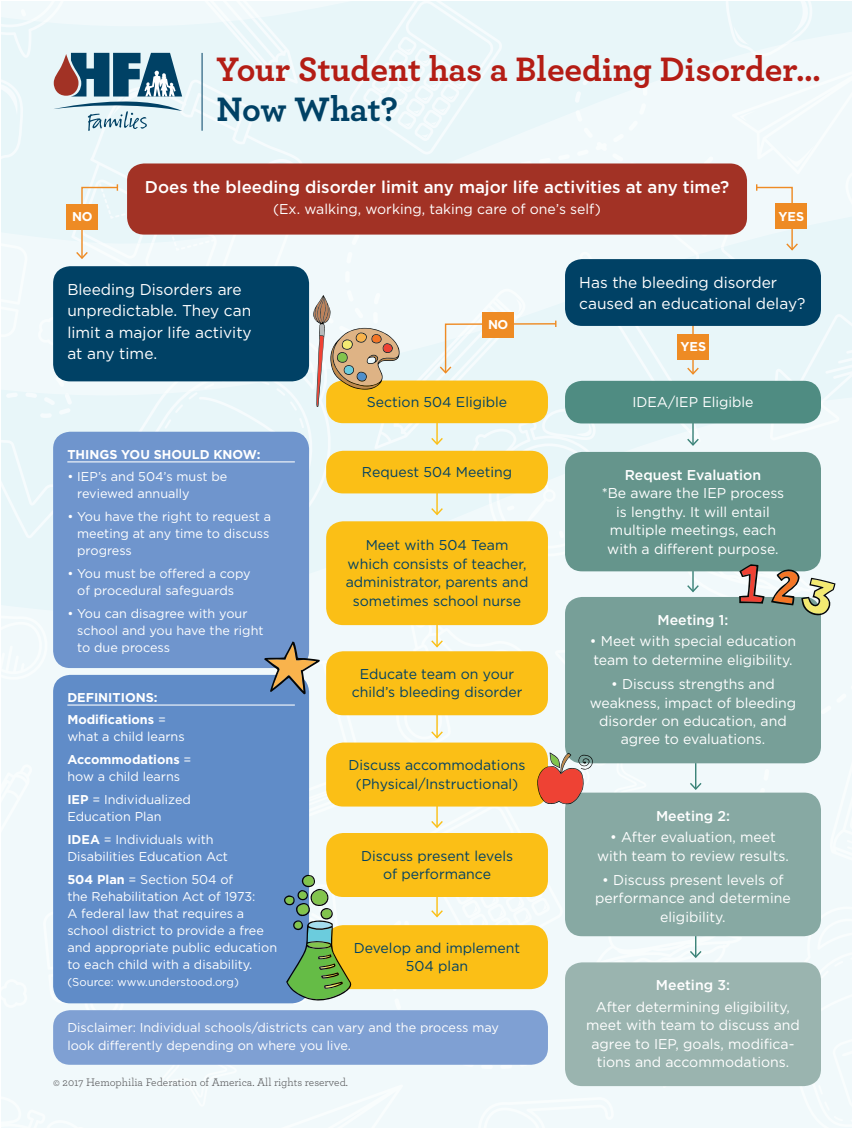
Does My Child Need an IHP?

If your child has a bleeding disorder, the answer is yes. An IHP is the only way to make sure your child's healthcare needs are met at school.

How Do I Get an IHP?

The process for starting to develop an IHP can vary from state to state, and from school district to school district. Here are some general guidelines:

- Contact your child's hematologist and explain that you're requesting an IHP from your child's school. Ask if the doctor has an IHP template for your child's condition. Having a bleeding disorder IHP template will help the school nurse and jump-start the process.
- Contact the school principal or school nurse, preferably in writing, and request a meeting to develop an IHP. If your child is starting at a new school in the fall, begin this process three to six months in advance, so the IHP will be in place when school starts. If you already have an IHP in place, it must be renewed every year.
- After these first steps, the school should contact you to schedule a meeting with the nurse to discuss your child's needs. If your child is old enough, including him or her can be helpful and reassuring for everyone involved. If you're not confident that you can adequately discuss your child's needs, contact your HTC and ask if a nurse or social worker can accompany you to the meeting. Some specialty pharmacies with contracted nursing services may also provide this service.
- Give the nurse as much information as possible about your child's condition and healthcare needs, to help in developing the IHP. Some schools require a physician's letter detailing your child's medical condition and any special care and medications needed at school—ask if this is a requirement before meeting with the nurse.
- Provide emergency contact information for your child's hematologist, as well as emergency contacts for parents/guardians.
- Before you meet with the nurse, sign a HIPAA (Health Information Portability and Accountability Act) Waiver of Authorization with your HTC hematologist. The HIPPA Privacy Rule (1996) is a federal law that established privacy standards related to sharing health information. The waiver is a legal document that allows your physician to share protected health information (PHI) about your child's health condition with the school nurse, who may call the physician to request health information.[2] As a part of the IHP team, you should participate in deciding which staff requires PHI for your child's safety. Staff who are trusted with PHI should be trained on their responsibility to safeguard that information.



2. Your physician does not need the waiver to share medical information with the school nurse, because HIPPA allows this under an exception called "treatment purposes." But medical offices often aren't aware of this exception and may reject a PHI inquiry, so be prepared with a waiver. Once PHI is entered into a school's educational record, it's no longer subject to HIPPA privacy rules. The confidentiality of student education records is weakly protected by another federal law, the Family Educational Rights and Privacy Act (FERPA). Unlike HIPPA, FERPA doesn't generally protect the confidentiality of information; beyond the school nurse, most school staff don't know about FERPA guidelines. Nurses also may not completely understand FERPA, and may violate FERPA regulations by publishing schoolwide lists of student names and health conditions. You have a right to see what's in your child's record: FERPA requires every school district to annually notify parents and eligible students (over age 18) of their right to inspect and review their children's or their own education records.

- Ask the school to give you the quickest contact information to reach the right people, including the nurse and your child's teacher: direct phone numbers (bypassing switchboard or secretary) and perhaps cell phone numbers.
- Request copies of the IHP and ECP when they are completed.
- Document all communications: save emails, and record date, time, person spoken to, and summary of conversations with the school in case there is a dispute.

Don't assume that your child will automatically receive a factor infusion at school in an emergency. Because of budget constraints, many school districts no longer staff each school with a nurse. Instead, schools may have a nurse's aide, with one or two nurses rotating from school to school in the district. *Only a trained and licensed school nurse (RN) can give an IV infusion.* Even if the school has a full-time nurse, don't assume the nurse can, or will, infuse your child. Regulations on IV infusions by school nurses vary by state. Some states allow infusion of IV meds only through a central line and only after specialized training. In other states, infusion of IV meds by the school nurse isn't even an option.

And you can't rely on emergency medical services (EMS) personnel, such as paramedics, to infuse your child. In all states but Missouri, EMS personnel are not permitted to infuse someone with his or her own medication (with some exceptions, such as insulin, Narcan®, and EpiPen®). To further complicate this, some hospitals also prohibit infusing meds brought in by the patient or parent/guardian—even if the hospital doesn't have the medication on hand. Ask the school nurse about the policy on infusing IV meds, and contact your local hospital to ensure that they will infuse your child with his own medication in an emergency (document all communication). Finally, if your child can self-infuse, make sure the IHP includes authorizations from your medical provider and the school nurse allowing him to infuse himself at school.

FIELD TRIPS

Federal law prohibits schools from excluding students with special healthcare needs from attending school-sponsored field trips. If your child needs factor infusions and can't infuse himself, volunteer to accompany him on the field trip (check beforehand if fingerprinting is necessary). If you or a guardian with infusion skills can't attend the field trip, the school can't require you to attend (unless all parents are required to attend), and your child can't be excluded from the field trip. It's the school nurse's responsibility to make sure your child's healthcare needs are met.

Nursing responsibilities for infusing IV meds can't be delegated to nurse's aides or other unlicensed faculty or staff. This means the nurse must accompany your child on the field trip if other arrangements can't be made for emergency factor infusion. The school nurse must arrange for staffing the school health office during the field trip, and the costs of providing nursing or EMS services are the responsibility of the school district. Although a district may ask, parents can't be required to pay for nursing or EMS services for their child on a field trip, and the child can't be excluded from the field trip because of cost.

What Is an Emergency Care Plan?

An ECP differs from an IHP. An ECP is a one- or two-page set of guidelines providing concise, specific directions on what to do in a particular emergency.[3] Unlike an IHP, an ECP is a tool for *nonmedical personnel*, like teachers, to follow in an emergency until medical assistance arrives. An ECP may also have a field trip plan. An ECP is a stand-alone document, included in the IHP.

Does My Child Need an ECP?

Any child with a bleeding disorder should have an ECP in addition to an IHP. The ECP is written for nonmedical personnel, often in a "If this happens, then do this" format. It contains as few words as possible, so someone can do a fast visual scan and quickly learn what to do in an emergency. So, although an ECP may include some of the same medical information found in the IHP, it is only an action plan—it focuses on what to do in an emergency and little else. The ECP is distributed to your child's teachers and to other school staff, such as bus drivers or school aides, who your child may see during the day. Teachers should also include a copy of the ECP in their substitute folder (containing lesson plans and instructions for a substitute teacher, in case the teacher is absent).

3. An Emergency Care Plan may also be called an Emergency Action Plan or Action Plan.

EDUCATION ACRONYMS

ECP: Emergency Care Plan

FAPE: free and appropriate education

FERPA: Family Educational Rights and Privacy Act

HIPAA: Health Information Portability and Accountability Act

IDEA: Individuals with Disabilities Education Act

IEP: Individualized Education Plan

IHP: Individualized Healthcare Plan

ECPs for children with bleeding disorders must stress the importance of early treatment, and of contacting the parent/guardian immediately if the child is injured or reports having a bleed. Also, staff should be told that most bleeds are internal, often with no outward signs; so they must always accept the word of the student.

Academic Help

IHPs and ECPs help protect your child's health at school. But what if your child's bleeding disorder is affecting—or might affect—her academic performance?

All US children are guaranteed the right to a free and appropriate public education, or FAPE. This right is guaranteed by two federal laws: Section 504 of the Rehabilitation Act of 1973 (Public Law 93-112) and the Individuals with Disabilities Education Act, or IDEA (Public Law 101-476). The two laws approach FAPE in very different ways.

Section 504

Section 504 of the Rehabilitation Act is a civil rights law that protects anyone with a disability who attends a federally funded program, activity, or institution. Section 504 states that "no otherwise qualified individual with a disability in the United States…shall, solely by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance."[4] The main goal of Section 504 is to ensure that the educational needs of disabled students are met as adequately as those of the nondisabled. This applies to all public schools, charter schools, and magnet schools; to any class level, including magnet, gifted, advanced placement, and honors; and to private and religious schools that accept any federal funds, such as federal school voucher funds.[5]

To qualify for support under Section 504, a student must have a physical or mental impairment that "substantially limits any major life activities at any time." The Americans with Disabilities Act (ADA), Amendments of 2009, expanded this definition to include "anyone who has a record of such an impairment" and "anyone who is regarded as having such an impairment."

Section 504's definition of "major life activities" is very broad, and includes caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, working…and much more. When your child with a bleeding disorder suffers from a bleed or other complication, he could be greatly limited in several of these activities, and this would qualify him for support under Section 504. Your child doesn't have to be substantially limited in any life activities when you apply for Section 504 support. An impairment that is *episodic* (like a bleed) or is in remission or controlled by medications (like prophylactic factor infusions) is still considered a disability if it would limit participation in a major life activity when an episode is taking place.

If you would like a Section 504 evaluation meeting, email your request to the 504 coordinator in your school district, and copy the school principal. The school will then notify you in writing of its intent to conduct an evaluation, *why* the evaluation is being conducted, and how it will be conducted. And although not required by law, parental/guardian consent for an evaluation is usually requested before convening the 504 team. Section 504 defines "evaluation" as the gathering of data or information from a variety of sources to assist the evaluation

4. www2.ed.gov/about/offices/list/ocr/504faq.html 5. Private schools often deny that they are subject to federal laws. However, pursuing a complaint against a private school has become more challenging, as the current US secretary of education has refused to commit to enforcing federal laws in private schools.

WHEN YOUR 504 OR IEP REQUEST IS DENIED

What if your school refuses to give your child the accommodations needed to succeed?

Section 504 offers parents options for resolving disagreements with the school:

- Mediation
- Alternative dispute resolution
- Impartial hearing
- Complaint to the Office of Civil Rights (OCR)
- Lawsuit (remember that Section 504 provides fewer safeguards and rights than IDEA)

IDEA offers parents specific ways to resolve disputes:

- Mediation
- Due process complaint
- Resolution session
- Civil lawsuit
- State complaint

committee in its work. Common sources of evaluation data for 504 eligibility are the student's grades, disciplinary referrals, health information (including an IHP), language surveys, information from parents or guardians, standardized test scores, and teacher comments.

Don't walk into a 504 meeting unprepared! Before the meeting, look at sample 504 plans and know your state and school policies. Read the US Department of Education resource guide for parents and educators seeking a 504.[6] Make a list of the accommodations you want for your child. Bring your child's IHP and ECP, as well as specific instructions for everyday and emergency management of your child's bleeding disorder. Who should attend the 504 meeting with you? A friend or advocate (who knows the law and represents your interests) to take notes, the school nurse and classroom teacher(s), and the 504 coordinator, at a minimum. The school principal, a counselor, lunch or recess aide, or special education coordinator may also be present. See if your HTC can offer support.

What Are Accommodations and Modifications?

If your child is eligible for Section 504 support, then a 504 accommodation plan (504 Plan) is created. Remember that 504 Plans provide for *accommodations*, and, less commonly, for *modifications*. There are no changes in the curriculum itself for 504 eligible students.

Accommodations are changes in *how* a student accesses information and demonstrates learning. They do not alter the instructional level or content, and they do not lower standards or achievements. 504 Plan accommodations are offered in the "least restrictive environment," meaning the student's regular general education classroom, not in a special education classroom.

Modifications are changes in *what* a student is expected to learn. Modifications may include changes in instructional level, content or curriculum, performance criteria, and assignments. Modifications are the backbone of Individualized Education Plans (IEPs) for special education, but are not common in 504 Plans.

No additional funding is supplied to the school for implementing accommodations or modifications as part of a 504 Plan (though private schools may sometimes charge extra tuition for providing services). Unlike 504 Plans, schools receive additional funding for implementing accommodations and modifications as part of an IEP.

504 Accommodations for a Bleeding Disorder

There are dozens of possible accommodations for a child with a bleeding disorder. Let's review some of the most common. You'll also find lists of accommodations online—these can give you helpful ideas about what's possible, but remember that developing accommodations is highly individualized, and any services and accommodations must match student needs. Avoid the temptation to check off accommodations using a predetermined list or include unnecessary accommodations.

For your child, the most common accommodations will deal with attendance, tardiness, ability and timelines to make up

6. Department of Education Parent and Educator Resource Guide to Section 504 in Public Elementary and Secondary Schools: www.ed.gov.

missed schoolwork, ability to visit the school nurse or restroom, and ability to infuse at school.

Attendance is high on the list of problem areas for students with bleeding disorders. Students may miss school because of a bleed in progress, pain from a recent bleed, heavy or painful periods, physician orders to stay off a limb after a bleed, port infections, and so on. And although students with hemophilia and inhibitors are likely to experience the most absences, everyone is at risk. All it takes is one serious bleed for a student with perfect attendance to suddenly miss several days or even weeks of school. That's why it's good for all students with a bleeding disorder to have a 504 Plan, even if they don't currently need or use the accommodations listed in the plan.

Remember that a student's grade can't be lowered because of excused absences for medical reasons. That is, attendance can't be part of grading (a frequent concern in PE classes). Also, students can't be penalized by assigning them extra work or not letting them participate in an activity. And students must be allowed to make up any work missed.[7]

Accommodations are often written as a series of bullet points and short phrases. But to avoid any confusion, write the accommodation in specific terms. For example, an accommodation for attendance might be "Adjust attendance policy." But what this means isn't clear, so a teacher or attendance clerk might not know exactly how to adjust the attendance policy. A better statement: "All absences for medical reasons, with correct paperwork, will be excused. Parent/guardian will submit a Chronic Illness Verification Form and promptly send in school-required paperwork to excuse each absence. Student will not be penalized by being assigned extra work or being denied participation in an activity due to excused absences." In addition, avoid writing accommodations that would be in conflict with school policies, such as "All absences are excused."

Even though a 504 Plan may offer accommodations for absences, it's not a free pass, and the privilege shouldn't be abused. Avoid the temptation to play the system or encourage your child to do so. A young child who doesn't want to attend school may quickly learn that by faking a stomachache, she gets to stay home. Or an older student with an accommodation that gives him extra travel time between classes may be tempted to use that time to talk to friends. Also, accommodations for absences don't excuse the parent or guardian from following school district guidelines. Failure to submit required paperwork may result in unexcused absences, leading to an "invitation" to the parent and child to attend truancy court or a Student Attendance Review Board.

In addition to accommodations for absences, lateness, and making up missed work, be sure your 504 Plan includes accommodations requiring teachers to send the student missing assignments on each day of an absence. Contacting parents and students is a lot easier for teachers now, thanks to school content management software—a website that allows teachers, students, and parents to interact. Typically, teachers have webpages for the classes they teach. They can upload an assignment to the webpage, and students can view it; or a teacher can send an assignment to a single student. Depending on the software, a teacher may also be able to upload an audio or video of the day's lesson.

Although modifications aren't usually part of a 504 Plan, for children with bleeding disorders, a modification concerning physical education often *is*. This might be permanent, if the child has an inhibitor, target joint, or joint damage; or temporary, until a bleed resolves.

Remember: Accommodations are changes that remove barriers to learning. They level the playing field for children with disabilities. They do not, as some people believe, give your child an unfair advantage over other students.

Individuals with Disabilities Education Act

IDEA is a federal education law that requires schools to serve the educational needs of eligible students with disabilities. IDEA fulfills the right to FAPE by providing special education services, including accommodations and modifications.

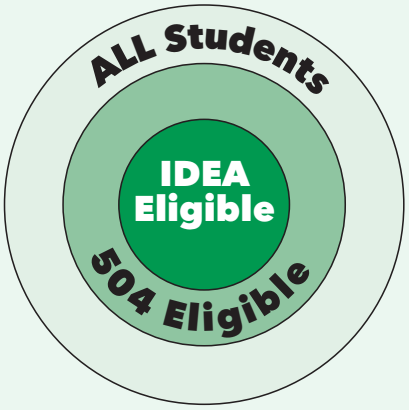
Unlike Section 504, which has a broad and inclusive definition of disability, IDEA's definition is narrow and limited. To be eligible for services under IDEA, a student must have disabilities that fall under one of 13 categories. Your child with a bleeding disorder may qualify under the category "Other Health Impairment." But having one of the 13 disabilities doesn't automatically qualify a child under IDEA. To be eligible, a student must...

- have a disability and, as a result of that disability, must…
- need special education and related services to make progress and benefit from the general education program.

In other words, the disability must negatively affect your child's educational performance; this is not a requirement of Section

7. Parents normally must submit paperwork to excuse absences for medical reasons. Some states, such as California, have a Chronic Illness Verification Form or something similar that make this process easier. After submitting the form, completed by the child's physician, parents can then excuse absences due to a specific medical condition without the need for a doctor's note. States also have a Home and Hospital Instruction Program for students with extended absences (usually three weeks or more): a teacher visits the home or hospital, for a limited time, to keep the student up-to-date on schoolwork.

Eligibility for Section 504 and IDEA



IDEA-eligible students are protected by ALL laws

Note:
Medical disabilities *do not always* qualify as educational disabilities under IDEA

Adapted from Disability Rights Education & Defense Fund document: info@dredf.org

504 support. Students who are eligible under IDEA need more support to succeed in school than just 504 Plan accommodations that "level the playing field." Almost all students with bleeding disorders are eligible for 504 Plan accommodations, but the restrictive IDEA requirements mean that relatively few qualify for special education services provided by IDEA. (See diagram above.)

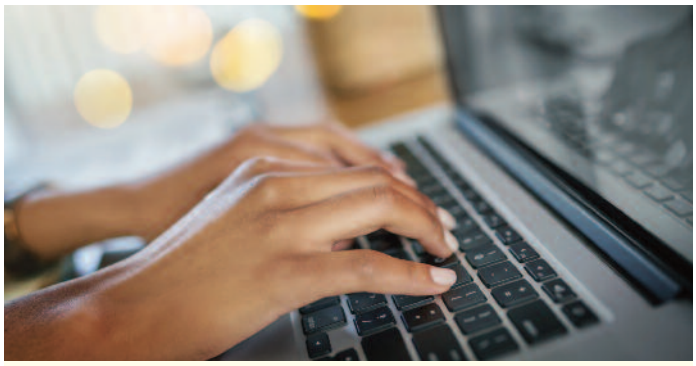
Students who qualify for support under IDEA are offered an Individualized Education Program. An IEP is a legal document that spells out a child's educational goals and the services and support the school will provide. It's written specifically for your child's needs by members of a multidisciplinary team including the parent/guardian, general education teachers, special education teachers, special education coordinator (or someone with the authority to commit resources), school psychologist, and people who know your child or his condition and are invited by you or the school district.

IDEA recognizes that the parent/guardian is the child's most important advocate; unlike Section 504, IDEA assigns the parent many rights and responsibilities. You might be overwhelmed by your first IEP meeting: many people are present, education jargon is confusing, and you're unaware of your rights and what services are available. That's why it helps to bring a friend, so you can discuss things later. Your HTC may be able to send a social worker to the IEP meeting, or prep you on services. You may want to bring an advocate with you, someone familiar with your rights under IDEA who can represent your interests. Parents of other special education students may be able to recommend an advocate. In many cities, you can find special education advocates and lawyers who will assist you for free.

Warning: Set ground rules ahead of time for whoever you invite to the IEP meeting. The people you bring should be friendly, collaborative, and professional—you and the rest of the IEP team are all on the same side with the same goals. Some advocates who view IEP meetings as "us versus them" may be confrontational or combative—definitely not the way you want to start your first IEP meeting! On the other hand, every state, school district, and sometimes schools within a district have different viewpoints and cultures. If your child's school refuses to provide the services your child needs (and which are prescribed by law), then initiate a grievance process to get help. (See box, p. 10, "When Your 504 or IEP Request Is Denied.")

For students who are eligible under IDEA, the extra support can mean the difference between academic failure and success. Yet some parents of children with bleeding disorders refuse to take advantage of Section 504 or IDEA. Why? Sometimes, it's because of a single word: "disability." Some parents resent even the suggestion that their child has a disability. Some parents don't want their child to be stigmatized by the label "special ed." But the special ed of a few decades ago is not the special ed of today. Negative perceptions of special ed are based on outdated, false information and myths.[8] Don't let the fear that your child may be labeled "special ed" stop you from getting her the help she needs. And don't hide the fact that she's using these services—let your family and friends know what special ed really is.

So, before sending your child off to school, cover all your bases. Ensure your child's healthcare by starting the process of developing an IHP and ECP early—several months before school starts. And to protect your child from falling behind academically, ask for a 504 Plan or an evaluation for IDEA eligibility. And don't worry about labels! Do what's best to help your child succeed in school.



RESOURCES FOR PARENTS AND GUARDIANS

Understood.org: www.understood.org
Good information on 504 Plans and IEPs, with many excellent resources (though sometimes buried on the website, and found only by following links in articles)

Department of Education: www.ed.gov
Parent and Educator Resource Guide to Section 504 in Public Elementary and Secondary Schools

WrightsLaw: www.wrightslaw.com
Deals with special education law and advocacy, with articles on most aspects of special ed

8. "10 Myths Parents May Hear About Special Education," available at www.understood.org.

headlines

manufacturer

New Form of rFVIIa in Pipeline

Catalyst Biosciences announced positive interim data from the phase 2/3 clinical trial of its new subcutaneous (SQ) prophylactic factor VIIa variant, marzeptacog alfa. MarzAA is in development for treating hemophilia A or B with inhibitors. Daily SQ prophylaxis with MarzAA has been very effective at preventing bleeds. **Why this matters:** With its easier SQ dosing and 9.5-hour half-life, MarzAA is a big improvement over the 3-hour half-life of conventional IV dosed rFVIIa.

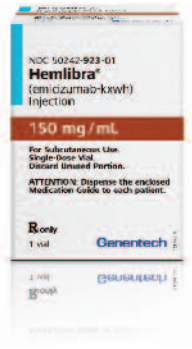
For info: ir.catalystbiosciences.com

Takeda Takes Over

Takeda Pharmaceuticals announced a $62 billion acquisition of Shire. After rejecting four offers between March 29 and April 20, 2018, Shire agreed to Takeda's offer, the largest-ever international takeover by a Japanese company. Takeda cleared a hurdle after receiving unconditional approval of the acquisition by the US Federal Trade Commission, and now awaits antitrust reviews in other major markets such as Japan, Europe, and China, as well as approval by shareholders of both companies. **Why this matters:** Takeda gains greater access to the US market, while Shire's product portfolio gets greater exposure in Japan and emerging markets.

For info: www.shire.com

Good News on Hemlibra®



Results of a phase III HAVEN 3 study with Hemlibra showed that prophylaxis every week or every two weeks with Hemlibra in adults and adolescents with hemophilia A and no inhibitors resulted in a 96% to 97% reduction in treated bleeds, as compared to no factor VIII prophylaxis. And in those who previously received factor VIII prophy (the standard of care), Hemlibra reduced bleeds by 68% compared to their prior therapy. No unexpected or serious adverse events related to Hemlibra happened in anyone enrolled in the study. **Why this matters:** Roche is preparing to apply to the US FDA for Hemlibra to be indicated for patients without inhibitors, and safety is crucial to having it approved.

For info: www.emicizumabinfo.com

NEWEST

Factor Product: Jivi®

Bayer's new extended half-life (EHL) treatment for hemophilia A has been approved by the FDA for routine prophylaxis in previously treated patients, age 12 and older. Jivi, a recombinant PEGylated factor, has a half-life of 17.9 hours. The recommended regimen is twice weekly (30–40 IU/kg), but dosing can be every five days (45–60 IU/kg).

Jivi is also approved for on-demand treatment and the perioperative management of bleeding. **Why this matters:** Bayer now offers three hemophilia A products: standard recombinant Kogenate® FS, Kovaltry®, and EHL Jivi.

For info: www.jivi.com

nonprofit

HFA's 25th Anniversary

San Diego

April 4–7, 2019

Hemophilia Federation of America celebrates its 25th year of education and advocacy for the bleeding disorder community. Guest speakers, games, and social events make this a valuable time for all. **Why this matters:** A special history room will display materials, books, newsletters, and photos paying tribute to the community's legacy of struggle, sacrifice, advocacy, and perseverance, as well as HFA's role in this history.

For info: www.hemophiliafed.org

soundbites

Grifols is voluntarily recalling one lot of **Profilnine®**, due to an incorrect amount of diluent in the box: lot number A1PBB00072, 1,000 IU, expiring Jan. 31, 2020.

Genentech has a new web portal for patients and caregivers, to provide timely, accurate info on any serious adverse events for **Hemlibra**: www.emicizumabinfo.com

The US FDA has approved a new 3,500 IU vial size for **Idelvion®**, CSL Behring's long-acting recombinant albumin fusion protein for treating hemophilia B.

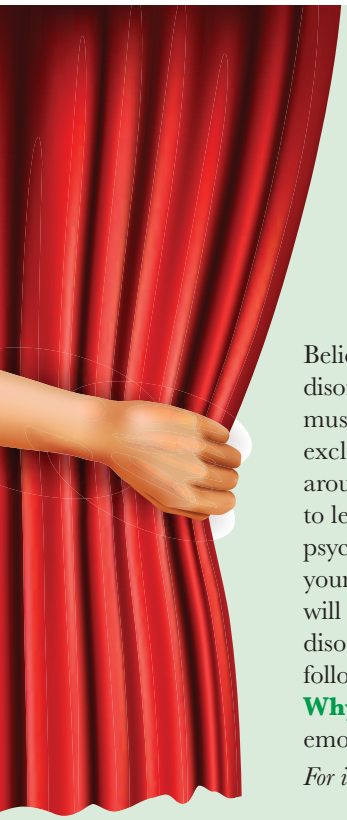
Due to decreased demand, Shire will discontinue manufacture and distribution of **Bebulin®**, a plasma-derived factor IX complex concentrate to treat hemophilia B. Current available inventory is estimated to have been depleted in September 2018.

Iran spends **$38 million** annually on about 5,000 hemophilia patients through health insurance coverage.

The US District Court in Delaware ruled against **Shire** in its request for a preliminary injunction against Genentech/Chugai (subsidiaries of Roche AG) to prevent certain US patients from receiving Hemlibra. Physicians no longer have legal limitations on prescribing Hemlibra.

PBM giant **Express Scripts** is in talks with BioMarin Pharmaceuticals, Spark Therapeutics, and Bluebird Bio about exclusive distribution of their new gene therapies for treating hemophilia, expected to be FDA approved in 2019.

patient programs



BREAKING THROUGH! The Musical!

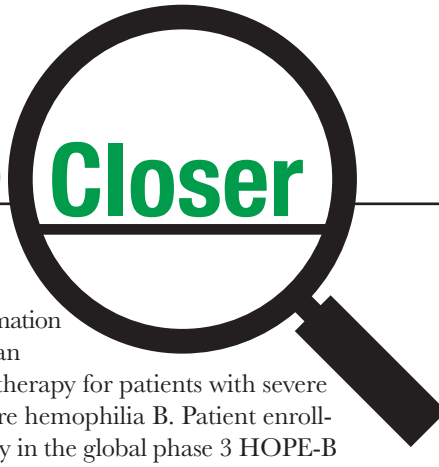
November 9–12, 2018

Believe Ltd.'s newest teen program for the bleeding disorder community, Breaking Through! is a three-day musical theater and arts workshop. Sponsored exclusively by BioMarin. Teen participants from around the country will be flown to New York City to learn and perform a six-song musical about the psychosocial and general health aspects of being a young person with a bleeding disorder. The weekend will culminate in a performance for local bleeding disorder community members, family, and friends, followed by a talk-back with the 25 participants. **Why this matters:** Some teens can better face emotional concerns through theater and creativity.

For info: www.breakingthroughhemophilia.com

science

One Step Closer



uniQure has treated the first patient in its phase 2B dose-confirmation study of AMT-061, an investigational gene therapy for patients with severe and moderately severe hemophilia B. Patient enrollment is also underway in the global phase 3 HOPE-B clinical trial to evaluate the safety and efficacy of AMT-061. **Why this matters:** AMT-061 could be a major advancement in gene therapy for hemophilia B patients, says Dr. Steven Pipe, principal investigator of the HOPE-B clinical trial.

For info: www.uniQure.com

Inhibitor Insights... from page 4

Mackaron, a retired HTC nurse coordinator in Albuquerque, New Mexico, says, "Even though a new product could be more beneficial, the old saying 'if it ain't broke, don't fix it' creeps in. It's very frustrating as a clinician to fight with patients in switching, knowing [a new product] could help them." Fear of the unknown may stop a patient from changing products even if the data shows that a specific product could be a better fit. "Psychologically, the fear of the unknown, and a potentially harmful and difficult unknown, can shape bias tremendously," says Dr. Mike Wang, associate professor of pediatrics at University of Colorado's School of Medicine. Inhibitors are frightening, and it's possible someone could develop an inhibitor after switching products. The fear lives on, even with no clinical evidence that the inhibitor resulted from a new product.

Why do some people embrace change without fear? Debbie Porter has an adult son with hemophilia and inhibitors who always "thought the idea of staying with the same product forever was counterproductive to advancing new and better treatments." Debbie wanted more for her son Matt, who suffered for years from inhibitor complications. Matt infused recombinant products, plasma-derived products, and bypassing agents over the years, so switching wasn't a fear. The day Hemlibra became available, Debbie immediately requested it for Matt. He has been bleed-free for seven months now, and his veins get the rest they desperately need. And of course, because Hemlibra isn't factor, it can't cause an inhibitor to factor VIII. Yet some people may be reluctant to switch, because they experience few complications with their inhibitors and their current treatment works. But for people like Matt and Caeleb, the severity of complications pushes them to anxiously wait for new products that promise better results.

We are learning more about why inhibitors form, and who is most likely to develop one. Physicians can identify patients who are more susceptible to inhibitor development based on genetics, environmental factors, race, and family history. But people seemingly not at high risk may still develop an inhibitor, and this has continued to feed fears about treatments and products. One HTC provider admitted that for years, he and his colleagues encouraged patients without inhibitors not to switch factor brands because they *might* get an inhibitor. While there is a risk of inhibitor development when switching products, "current evidence does not suggest that switching products significantly influences inhibitor development," declared a finding in the Eleventh Zürich Haemophilia Forum.[3] Yet fears persist, even in the face of scientific evidence.

Letting go of old beliefs isn't easy. Once a myth has taken root in your belief system, it takes a lot of effort to remove it. We remain captive to treatments, protocols, and products that may not be the most effective. Staying where we are now—based on assumptions not rooted in the facts—prevents us from embracing the many possibilities that exist today.

Have the courage to overcome fear and seek out what's in the best interest of your loved ones. Gather the facts, and communicate your treatment needs and concerns to your physician. Trying a different regimen or product may change your life.

3. Elena Santagostino, et. al., "Switching Treatments in Haemophilia: Is There a Risk of Inhibitor Development?" *European Journal of Haematology* 94 (2014): 284–89.

Richard's Review... from page 5

TIME-TRAVEL FANTASY

Travel through the space-time continuum is a popular topic for young readers.

The Curse of the Romanovs (Margaret K. McElderry, 2007)
Staton Rabin

Alexei Nikolaevich Romanov, 12-year-old son of the Russian tsar, has hemophilia. He uses visualization techniques taught by Rasputin to save his own life by escaping Russia in 1918. Alexei travels through time and space to New York City in 2010. There he meets Varda Ethel Rosenberg, his 15-year-old distant cousin whose father with hemophilia died of AIDS. Varda saves Alexei by traveling back to St. Petersburg in 1918. Ages 12 and up.

Secrets of the Survivors (Xlibris, 2008)
Mark L. Eastburn

This young adult fantasy novel, written by an author with von Willebrand disease, tells the story of 10-year-old Alex Hidalgo and his younger sister Katherine, from Philadelphia. The siblings are contacted by survivors of an intelligent ancient reptilian civilization from 65 million years ago. In their struggle to save planet Earth, Alex and his sister enlist three other classmates, one of whom has hemophilia.

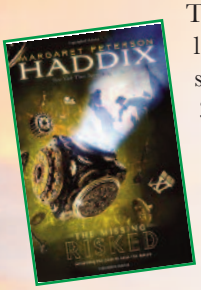
The Queen Must Die: Chronicles of the Tempus (Atlantic, 2010)
K.A.S. Quinn

The author admits that she "tinkered" with the facts in this children's novel, part of a trilogy that involves travel through time and space. Katie Berger-Jones falls asleep in New York City while reading the letters of Queen Victoria's daughters, and then wakes up in Buckingham Palace in London, 1851. There Katie meets Prince Leopold, who has hemophilia, before she struggles to return home on the same day she left. Leopold was actually born in 1853.

What's Up with Louis? Medikidz Explain Hemophilia (Medikidz, 2011)
Dr. Kim Chilman-Blair and Shawn deLoache

This storybook comic features five Medikidz who live on the planet Mediland. When Louis, on Earth, is mocked by his friends for having hemophilia, the Medikidz teleport him to their planet. Once he discovers his potential, Louis returns to Earth knowing how to properly treat his hemophilia.

Risked (Simon & Schuster, 2013)
Margaret Peterson Haddix



This science fiction novel tells the story of 13-year-old Jonah Sizemore and his younger sister Katherine, from Ohio, who help rescue 36 famous missing children from the past. These missing children, now using aliases, include Anastasia Romanova and Alexei Romanov, who has hemophilia. With the aid of a time-travel device, the children attempt to alter history by traveling back to Russia in 1918. Ages 8–12.

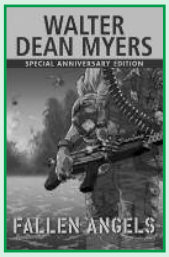
HEMOPHILIA IN UNEXPECTED PLACES

Authors of fiction for young readers may refer to hemophilia in unexpected ways.

Tiger Eyes (Bradbury, 1981)

Judy Blume

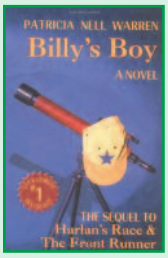
This young adult novel follows 15-year-old Davey Wexler when she moves with her family to Las Alamos, New Mexico. At her new school, Davey views a film on hemophilia, but she already knows about hemophilia because she read *Nicholas and Alexandra* in eighth grade.



Fallen Angels (Scholastic, 1988)

Walter Dean Myers

In this young adult novel, Richard Perry graduates from high school in Harlem, New York, and enlists in the army in 1967. Richard declines a bonding ritual of mixing blood with other black soldiers by claiming to have hemophilia. Another soldier notes that hemophilia is a medical deferment from military service.



Billy's Boy (Wildcat, 1997)

Patricia Nell Warren

Included in a series on gay family life, John William Heden is age 12 in 1989. He moves with his single, lesbian mother to Malibu, California. Searching for his father, supposedly a gay Olympic track medalist who donated his sperm before he died, John William meets Michael, who is conducting research at UCLA on inherited blood diseases like hemophilia.

Summertime Blues (Oxford University, 2001)

Julia Clarke

In this coming-of-age novel for young adults, 17-year-old Alexander Harling, from London, responds to a rude comment about his mother. Alexander beats up the guilty classmate, who bleeds so much that Alexander thinks the boy is hemophilic and needs a transfusion.

The Healing Time of Hickeys (Polestar/Raincoast, 2003)

Karen Rivers

In this teen novel written as a diary, Haley Andromeda Harmony is a 16-year-old Canadian high school senior in 2002. Because she's a hypochondriac, Haley searches internet sites for a definition of hemophilia. When she skins her knuckles, Haley then believes she is bleeding to death due to her supposed hemophilia.

Birthmarked (Roaring Brook, 2010)

Caragh M. O'Brien

As part of a fiction trilogy for young readers, this novel follows 16-year-old Gaia Stone, who lives in a divided country and trains as a midwife in the year 2409. Gaia learns about the health problems of dying children and infertile mothers due to inbreeding in the privileged city. The biggest concern is an increasing number of children with hemophilia. Sadly, hemophilia is not cured in the future.

The Truth About Celia Frost (Usborne, 2011)

Paula Rawsthorne

In this young adult thriller, 14-year-old Celia Frost is born with a rare blood-clotting disorder for which there is no treatment—or so her overprotective mother claims. When a classmate cuts Celia, she goes to the local hospital. Her mother refuses to allow any blood tests. After arguing with her mother, Celia learns the truth: her mother abducted her from a research laboratory, where as a child, Celia had been experimentally injected with live viruses. To prevent the spreading of the viruses, her mother employed what is now called Munchausen Syndrome by proxy,[1] imposing a fake medical diagnosis on a child. Meanwhile, the research doctor tries to capture his escaped research subject, putting Celia's life in danger.

You can find hemophilia included in a wide variety of literary genres. Literature meant for younger readers can be enjoyed by all ages, including adults. Find something you and your child like, pick up a book, and read.

1. Unfortunately, the author never uses the label Munchausen Syndrome by proxy (MSBP), or ever attempts to fully explain the fictional mother's psychiatric condition. In this rare condition, parents fabricate the physical symptoms in the child, producing a chronic fictitious disorder, most often without the child's awareness or willingness. For hematology MSBP, this usually involves parents forcing their child to ingest an anticoagulant to induce bleeding symptoms.

YOU... from page 6

Empowering your child to take responsibility for missed schoolwork and maintain open lines of communication with teachers can be a great supplement to the 504 and IEP plans offered. These skills will also carry on into adulthood.

Tammy Jones has a grandson with von Willebrand disease (VWD), and has found that a 504 plan works well for his needs. The 504 plan not only ensures that her grandson's absences for doctor's appointments are excused, and outlines how he will make up work due to VWD-related absences, but also allows the family to communicate needs for specific scenarios, such as school field trips. Tammy notes, "We have a meeting at the beginning of each year with the principal, homeroom teacher, school nurse, counselor, and special ed representative. Everyone hears the history and needs of his bleeding disorder at one time and what needs to be done in case of a bleed."

When a 504 Isn't Enough

504 plans are designed to level the playing field by providing accommodations for students who have impairments that may make it hard to complete schoolwork. But IEPs can go much farther, allowing families to work with the school district to create an individualized learning plan to help students reach their goals. Like 504 plans, IEPs provide for accommodations, but they can also provide for *modifications* (changes to the curriculum) and can offer specialized education services. However, because of more restrictive eligibility requirements, few students with bleeding disorders will qualify for an IEP.

Jane Cavanaugh Smith's son used both a 504 plan and, later, an IEP to meet his needs. "My son has a high inhibitor," says Jane, "which was at its worst during high school. We were fortunate to have a very proactive school system and worked out many accommodations via a 504 plan. He was basically home tutored by the school due to so many absences."

Yet after a certain point, it became clear that Jane's son needed more than accommodations to find his way to graduation. "We finally got an IEP during his senior year because it helped streamline his path to graduating on time with his class—his report card was always full of incompletes." Jane points out that the IEP is what really helped her son find a clear path to graduation by providing adjustments to curriculum for his individual circumstances.

While some parents have success using various school supports, others are inspired to go above and beyond. Priscilla Oren earned a BS in elementary education and decided to teach first grade. Her classroom was across the hall from her son's. "I could infuse him at school," recalls Priscilla, "and we both didn't miss work. When he was in fourth grade, I got my MEd in special education from Lehigh University so I could understand the system. I became an advocate for other parents. I also ran for a seat on the local school board and won. This was back in the 1970s and 1980s. I've been retired for many years, and I'm sure things have changed. But being knowledgeable about the laws helped us a lot."

Not all parents feel supported by accommodation plans, and many schools need guidance in helping a child with a bleeding disorder. School districts differ in their approaches to accommodating for various medical conditions. Even so, Hemophilia Federation of America (HFA) has great resources to advise you in dealing with a variety of issues that arise when guiding your children through school to become young adults who can advocate for themselves. These excellent worksheets, booklets, and PowerPoint presentations provide specific information on the basics of bleeding disorders as well as customizable sections to detail your preferred plan of action when something comes up at school. These resources can help you and the school design a 504 plan to meet your child's needs.[2]

When developing a 504 or IEP plan, the message is clear: Be proactive. Communicate your child's needs to school administrators. Advocate for your child at school. This not only helps ensure your child's academic success, but also allows you to model what advocacy is and how to advocate for oneself—a useful skill for your child to carry into the future.

2. Visit hemophiliafed.org for downloadable resources.

Hemophilia Federation of America provides great resources for use in communicating your child's needs.

Visit these links for Toolkits and Educational Resources:

- **ToolKids**
  hemophiliafed.org/for-patient-families/resources/toolkits
- **Back to School**
  hemophiliafed.org/for-patient-families/resources/toolkits/back-to-school
- **Sports / After-School Activities**
  hemophiliafed.org/for-patient-families/resources/toolkits/sports-toolkit

nowhere to go, so the bruise gets a bump along with it, like the one on your leg." I told him this is why it's important to ice—it helps the blood slow down and stop, so it doesn't have to make a bump or hematoma. We took it a step further to talk about joint bleeds we can't see, but that is still a work in progress!

Karen Thibeault
Rhode Island

Thank you for sending us this fantastic magazine!

Lina Martinez
Puerto Rico

inbox

Project SHARE

My warmest thanks for giving us factor for free. Truly, it was a big help for Lola to ease the pain she is suffering. We are very thankful for your help. You have a really big heart. God bless you. So far, we were able to provide 10 mg of NovoSeven®. The factor was given early on a Saturday morning, and after that, we were able to transfer her to a recovery room on Sunday morning.

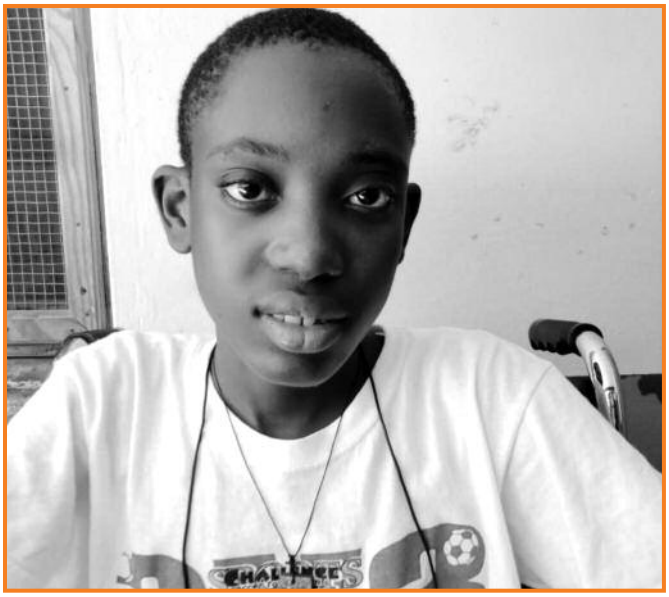
Lyneth Jayme Saler
Philippines

I am pleased to inform you that the factor has been received, and we were pleased to find 10 vials of factor IX. We hope our little Hirwa will improve as soon as possible! May God bless you!

Sylvestre Mulindabyuma
Rwanda

I am happy to write this letter with all my heart and love. When I was sick, I had lost all hope. God used you to help me with the medicine. Your actions were precious because in life, one's health is the most valuable thing. Your help also helped me progress in my education. You chose to help me in the best way possible because without health, I could not get educated. I hope one day God will allow us to meet face to face. Thank you so much!

Jamesly Altes
Haiti



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