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PEN's Biennial Bleeding Disorder Resource Guide 2013

Zoraida Rosado

Books



**Raising a Child With Hemophilia:
A Practical Guide for Parents**

Lauren A. Kelley
LA Kelley Communications, Inc.
2007
www.kelleycom.com

Fourth edition of the world's first parenting book on hemophilia written by a parent of a child with hemophilia. Practical, easy-to-understand information on medical treatment, genetic transmission, child development, consumer issues, school, sports. Includes stories and advice from experienced parents, compiled from interviews with more than 180 families. Sponsored by CSL Behring.

Hemophilia

Michelle Raabe
2008
\$35.00 from amazon.com

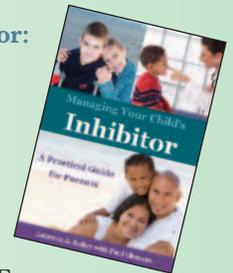
Scientifically detailed, colorfully illustrated, easy-to-read book focusing on the science behind the treatment, symptoms, genetics of hemophilia. Includes stories of hemophilia's history; of how various treatments are made, such as plasma-derived and recombinant; how gene therapy might work.



**Managing Your Child's Inhibitor:
A Practical Guide for Parents**

Lauren A. Kelley with
Paul Clement
LA Kelley Communications, Inc.
2010
www.kelleycom.com

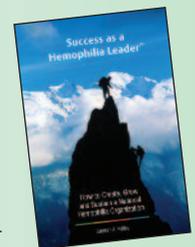
World's first book on inhibitors. From parents' and patients' point of view, extensively covers topics including pain management, surgery, family life, treatment. Sponsored by an unrestricted grant from Novo Nordisk Inc.



Success as a Hemophilia Leader

Lauren A. Kelley
LA Kelley Communications, Inc.
2004
English, Spanish
Free to qualified Hemophilia Leaders
www.kelleycom.com

World's first guide to founding, managing, and growing a grass-roots hemophilia organization, or improving an existing one. Advice on creating vision and mission, forming a board, fundraising, producing a newsletter, programming, establishing an office, working with a medical advisory board. Sponsored by Grifols.



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welcome

Laurie Kelley

Many of you know that I travel to a variety of developing countries to help improve healthcare for hemophilia and other bleeding disorders. I've been to 25 developing countries over 16 years, some as many as four times. I was in Zambia and Zimbabwe in December: Zimbabwe for the fourth time, and Zambia for the first. I especially enjoyed meeting so many families and patients. And I was really thrilled to hand out copies of our new *My First Factor Coloring Book* as gifts.

Besides the major glaring difference—we have so much factor, and they have little or none—I have noticed another vital difference. Most developing countries lack any kind of reading material for patients with bleeding disorders. Imagine raising your child with no reference material. Imagine being totally dependent on what your doctor tells you, even though you live hours from the nearest hospital or can get hemophilia care only during daytime hours. Families often feel unsure and fearful, enduring their loved one's cries of pain.

We are so fortunate to have a wealth of educational material in the US. PEN's Biennial Bleeding Disorder Resource Guide will show you many of the programs and materials you can order free from manufacturers and nonprofits. (I've omitted most of

National Hemophilia Foundation's materials because there are so many—and anyway, you all know the NHF website, right?*) Please order these wonderful books, booklets, and DVDs, and check out the websites. You can learn so much!

Whenever I travel to developing countries, I'm always happy to bring suitcases full of donated clothing, shoes, Beanie babies, and even factor. But what a thrill to see families pick up LA Kelley Communications' books—and then read and ask questions. These materials are a lifeline to the future for their loved ones.

When was the last time you and your child read about hemophilia together? Make a pledge to do it this year! ☺

* Check out NHF's HANDI website at www.hemophilia.org



A young child with hemophilia in Guatemala enjoys Shannon Brush's book

inbox

I JUST LOVED THE MOST RECENT PEN ISSUE!

The stories of the men you highlighted ["The Jobs Journal," Nov. 2012] were inspiring and so hopeful! I was delighted by the advice column that you included. Thanks a bunch for all your hard work!

Danielle Nance, MD
WASHINGTON

THANKS FOR ANOTHER USEFUL AND INTERESTING newsletter. It's great to see and hear about others with hemophilia.

Steve Place
MASSACHUSETTS



THIS IS OUR FIVE-YEAR-OLD SON

Anthony, who has severe hemophilia A. Heck of a ride since his diagnosis two years ago. But we have been blessed and are learning that community means so much. Our doctors are great. Dr. Byron Smith at John Muir Hospital in Walnut Creek introduced us to your publications and to Save One Life. I can only hope to aspire in my advocacy as you have. Eternally grateful!

Susan Grady-Yazurlo
CALIFORNIA

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PARENT EMPOWERMENT NEWSLETTER | FEBRUARY 2013

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PEN is a newsletter for families and patients affected by bleeding disorders. PEN is published by LA Kelley Communications, Inc., a worldwide provider of groundbreaking educational resources for the bleeding disorder community since 1990.

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Jeff Johnson

Prophy for the Soul

When I was in grade school, I remember dreading physical education. Although my sports talent was as developed as a circus clown's talent for subtlety, I enjoyed shooting hoops and throwing a ball. So why the dislike of PE? Because for me, being the crippled kid who was made of glass, PE meant sitting on the bleachers, watching the "normal" kids play dodge ball, floor hockey, and freeze tag.

Luckily, my parents were ahead of their time in their approach to hemophilia, encouraging me to ride my bike, play ball, and be normal. But my teachers (especially in PE) back in the 1980s were fearful. Many of them simply chose to sideline me safely on the benches while they and the normal kids spent an hour having fun. For me, this was dispiriting and humiliating. When recess came and we were all released from the confines of our classrooms, nobody wanted to pick the hemo-whatchacallit kid to be on their team, and why would they? If I couldn't even throw an underinflated dodge ball in PE, then how good could I possibly be on the basketball court? It was a no-win situation and the primary reason I eventually found my way into the school band. It was ironic: all through my school years, our sports teams were Bad-News-Bears terrible while my band won trophies, I dated hot clarinet players, and I eventually got to play my saxophone in China. So it worked out. Mostly. I do still daydream about my unrealized superstardom playing professional dodge ball, but in the end, I wound up where I'm supposed to be.

Still, it hurt that my PE teachers viewed me as a fragile kid they couldn't risk putting into the thick of things because I might break. Granted, this was the 1980s and I, a clumsy and severe hemophiliac, was on cryoprecipitate, so

bleeds were drawn-out affairs. I might fall and bleed a little, but I would gladly have traded an ankle bleed for the chance to participate and be accepted by my peers. But the adults in charge couldn't help looking at me through hemo-colored glasses.

Skip to today. We "hemos" are experiencing a renaissance in living with our condition. Our factor is now safe and effective. We have a vast support structure of hemophilia treatment centers (HTCs), national and local chapters, and foundations. Some of our blood sisters and brothers do continue to struggle with inhibitors, but progress is even being made there. Life isn't perfect, but it's good. I often encounter frazzled parents who lament that their child is a "bleeder," express regret and guilt about passing on the condition, and even proclaim their refusal to have more children. I am conflicted when I meet these parents. On the one hand, they do have a difficult job. Parenting isn't easy even when things are nearly perfect, so throw in a bleeding disorder and you increase the difficulty and stress exponentially. But on the other hand, I can't help thinking, *it's just hemophilia!* Though that may be a shocking statement, I challenge everyone to step back a moment and really reflect on it.

Yes, hemophilia is a bleeding disorder. Yes, it's expensive and time-consuming. But what *isn't* it? It isn't a death sentence. It isn't a barrier. It isn't cancer or MS or sickle cell anemia. It isn't a lot of things that are much worse. For hemos today, the world is as accessible and open as for any clotter, and we hemos are now everywhere, doing all the things they do. We climb mountains. We ride bicycles coast-to-coast. We play golf, soccer, basketball, and yes, even football. For hemophiliacs in the 21st century, there is

truly no logical reason to accept being considered anything other than normal, even by those who love us most: our parents. I often hear a standard set of statements: "I feel guilty that he is in pain," or "I regret that he has to suffer," or "I feel bad when he cries." I understand all of those. Yes, we hemos hurt. We sometimes suffer. We even cry. But who doesn't? What kid doesn't fall down and cry sometimes? Who doesn't suffer from something? Unless Kal-El has landed and hopped from his Kryptonian pod into some cornfield, I doubt that there is a single kid anywhere who doesn't suffer in some way, hemo and clotter alike.

Ultimately, I hope that parents facing guilt or regret can find the strength, courage, peace—or the driving force they need—to take that step back and examine whether their feelings are realistic and beneficial for themselves, and most important, for their little bleeder. Think of this exercise as "prophy for the soul." Kids are far more observant and aware than most adults realize, and regardless of how deeply you've buried your guilty feelings, your child will pick up on them. Your hidden guilt could inadvertently tell your child, "You aren't really normal." After all, would you feel guilty for your child's brown hair? Or green eyes? Then why hemophilia?

Hemo parents have one of two paths to walk: they can eventually choose to wipe away fear and doubt and to fully accept their child's hemophilia *and* normality; or they can wear the hemo-colored glasses my PE teachers wore, acting out of genuine concern and love, but seeing the disorder first and the kid second. We hemos thrive when walking hand-in-hand down the first path—not so much the second. Which path do you choose? ☺

Jeff Johnson lives in Washington with his wife Stephanie.

Will Inhibitor Reimbursement Change under Healthcare Reform?

Unless you've been living in a cave, under a rock, or on a cruise ship, or watching non-stop episodes of *Lost* and *The Tudors* without your cell phone nearby, you can't help but know that healthcare reform will continue with President Obama's reelection. Despite the controversy surrounding ACA, or the Affordable Care Act (its constitutionality was attacked and several states are trying to revoke it), the law offers several immediate positive results for families with bleeding disorders. Notably, children can stay on their parents' insurance until age 26 (regardless of whether they are in college or married); people with bleeding disorders won't be denied insurance just because they have an expensive medical condition; and lifetime limits have been eliminated.

In a nutshell, no insurance company can terminate you because you've used up your insurance money, or prevent you from being insured because you have a bleeding disorder. *Yés!*

But an inhibitor family may wonder, What about us? With higher-than-average hemophilia treatment costs, how will healthcare reform impact inhibitor reimbursement specifically? Because more people with bleeding disorders can now be insured and use as much factor as they need, treatment costs for these disorders will undoubtedly increase—with insurance companies mandated to pay for them. Will more costs be shifted to consumers? Will some treatments be restricted? Good questions.

Background first:

How factor is covered

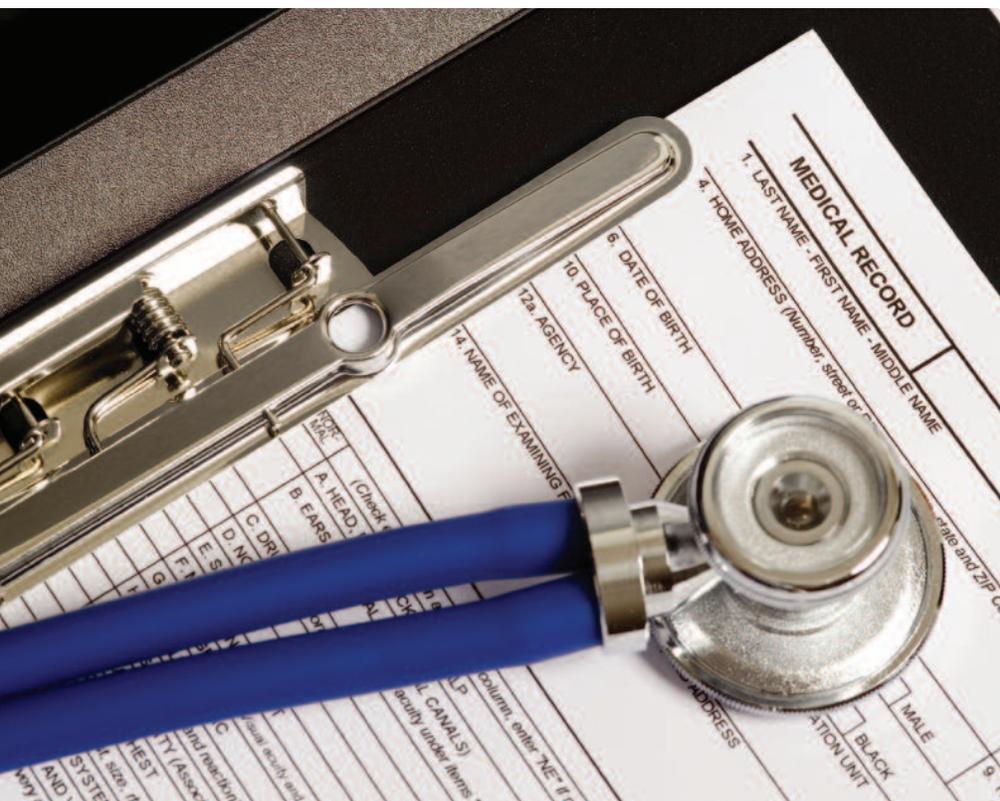
Every health insurance plan has two parts, representing two different budgets:

- **Medical benefit** (major medical) covers all clinical services, including doctor visits, diagnostic tests, surgery, and inpatient drugs.
- **Pharmacy benefit** covers outpatient drugs.

Roughly 75% of hemophilia patients have their factor covered through the medical benefit side of their insurance policy, which usually does not categorize drugs into tiers (see "Tiers" section). This means that copays for drugs are pretty predictable and stable.

Michelle Rice, mother of two with hemophilia and director of public policy at National Hemophilia Foundation (NHF), says, "ACA did not address reimbursement specifically as to prescription drugs. As each state is allowed to develop its own exchange,¹ we don't know exactly

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Check it out:

www.healthcare.gov
www.patientservicesinc.org
[@UnneedPSI \(Twitter\)](https://twitter.com/UnneedPSI)
HFA Weekly Update,
www.hemophiliafed.org

1. Under ACA, every American must have health insurance (with exceptions). To help you choose a health insurance policy, states have constructed a web-based exchange designed to compare many different health insurance policies in your state, based on the personal parameters and financial information you provide. This allows you to find the best plan at the lowest cost that meets your health and financial needs.

a project share story



PROJECT
SHARE

It's time to give back

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've never visited, 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, this 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 we have helped. We must be sure we have valid and accurate information. If you are approached, always realize that there may be missing information, so ask questions. We always ask for diagnosis, physician's name and contact info, whether the patient knows how to self-infuse, and how far he lives from an 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 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 are unsure about duties, penalties, and costs, don't take the risk—don't ship.



Derek, of Kenya

What if the person is asking to come to the States for treatment?

Just say no. Most medical problems related to bleeding disorders can be handled locally, in the country's capital. India and Pakistan, for example, have some of the best hematologists on earth. The biggest obstacle to care is often not the lack of doctors or expertise, but the lack of factor. At Project SHARE, we've found that many requests to come to the States are not for treatment but for job opportunities, college, or the chance to join relatives, either legally or illegally. Hemophilia is a ticket to get in. Be careful!

“It's an emergency!”

Emergencies are hard to fix. Often, by the time Project SHARE ships factor, the emergency has passed—for better or worse. Declaring an emergency is

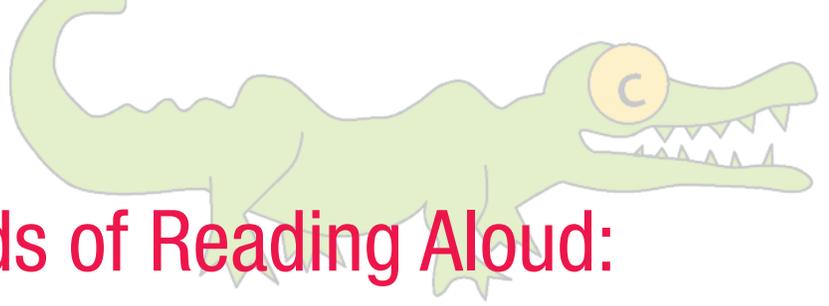
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Richard J. Atwood

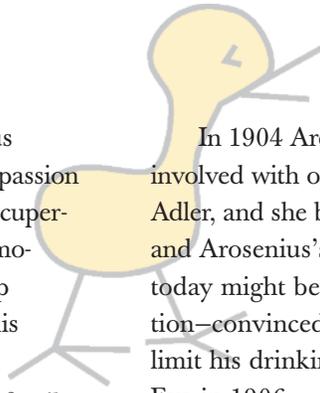


Linda Weaver's Studio

The Rewards of Reading Aloud: *Ivar Arosenius*



Swedish artist Ivar Arosenius (1878–1909) always had a passion for drawing. Even when recuperating from a bleed due to his hemophilia (*blödarsjuka*), he would prop himself up in bed to continue his painting and drawing.



Arosenius knew that life was fragile.

His older brother, who also had hemophilia, died from bleeding complications in 1889 at age 14. As a child, Arosenius was closely supervised; his mother was probably overprotective. Arosenius always wanted to be an artist. Following secondary school, he enrolled in art schools from 1897 to 1901, including the Royal Academy of Art in Stockholm. Arosenius mastered painting but balked at traditional art training—painting from plaster-cast models. Yet he excelled at watercolors, painting left-handed. He was rebellious, and that may be why he also experimented with the humorous, exaggerated cartoon style popular in newspaper comics.

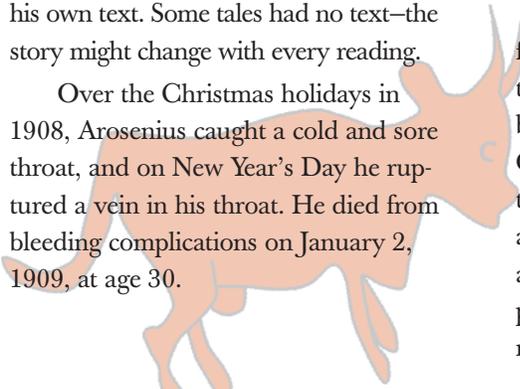
As a student, Arosenius lived a free-spirited life that included excessive drinking with his fellow artists. Anxiety about living with hemophilia may have contributed to this reckless behavior. After art school, Arosenius visited Berlin, Munich, and Paris. In Paris in 1904, he experienced a violent bleed. In spite of his bleeds, the following year he displayed 92 watercolors at a show of his work in Paris, though none sold. Then he moved back to Stockholm.

In 1904 Arosenius became involved with one of his models, Eva Adler, and she became pregnant. Eva and Arosenius's mother—in what today might be called an intervention—convinced the artist to at least limit his drinking. Arosenius married Eva in 1906.

The summer of 1906 dramatically changed the artist's life. Arosenius had another serious bleeding episode resulting in hospitalization. Then Lillan, his daughter, was born on July 4. After these events, Arosenius became more peaceful and more creative, settled down, and stopped drinking. He had successful shows of his artwork at Norrköping and Stockholm in 1907.

Lillan became a model for her father, and Arosenius painted storybooks and fairytales, though these illustrated stories were not published until after his death. His friends encouraged him to publish, but he never did, working just for Lillan. These paintings of Lillan depict life in the family's home. The stories combine morals with humor, and Arosenius read them to Lillan. He either used text written by others, or he wrote his own text. Some tales had no text—the story might change with every reading.

Over the Christmas holidays in 1908, Arosenius caught a cold and sore throat, and on New Year's Day he ruptured a vein in his throat. He died from bleeding complications on January 2, 1909, at age 30.



Arosenius made little money as an artist, though others profited from his work after he died—but that is how his art has been preserved. Today his works can be found in major Swedish museums.

Outside of Sweden, Arosenius is not well known. In fact, books of his works are hard to find, and English translation editions are even rarer. If you can locate copies of any of his books, then treasure them. Several catalogs of his works have been published, beginning the year after he died. Though his artwork is notable and includes about six self-portraits, his storybooks are better known. The most impressive collection is published in *Ivar Arosenius Sagor: Femtiosex Bilder* (1939) by Axel Romdahl. Perhaps the artist's best-known storybook is *Kattresan Bilderbok* (The Cat Journey) that was drawn for—and includes as the main character—Lillan, his daughter and inspiration.



The simple act of reading to a child forms a strong bond, and starts a habit that will last a lifetime. We learn to read by having someone first read to us. Of course, the storybook doesn't have to be one written and illustrated by an artist with hemophilia, but it sure adds a nice touch. Demonstrate your passion, and then enjoy the shared moment, by reading to a child today. ☺

Teach Your Child About Hemophilia

Lauren A. Kelley

LA Kelley Communications, Inc.
2007

www.kelleycom.com

In-depth exploration of how children think and understand hemophilia as they mature. Examines children's understanding, at different ages, of hemophilia concepts: cuts, healing, blood, severity levels, blood clotting, infusions, genetic transmission. Explores how children on prophylaxis understand hemophilia. Prepares parents to answer children's questions and encourage independence. Sponsored by CSL Behring.



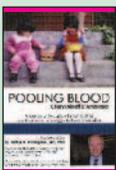
The Gift of Experience: Conversations About Hemophilia

Laura Gray, LICSW, and Christine Chamberlain
Boston Hemophilia Center, 2007

Free from NHF; \$12.50 from amazon.com



Compilation of personal stories from 21 hemophilia patients born before 1965 and caregivers who treated them. Practical information, guidance, support, and insight into caregivers' struggles and achievements.



Pooling Blood

Cheryl Nineff D'Ambrosio
iUniverse, 2010
\$17.90 from amazon.com

Personal recollection of a woman who raised two stepdaughters with factor V deficiency. Harrowing, poignant story of frustrations, fears, joys of raising a child with a blood disorder.

Exercises for People with Hemophilia

Kathy Mulder

World Federation of Hemophilia, 2006
www.wfh.org

English, Spanish, French, Arabic, Russian, Chinese
Illustrated guide includes exercises designed to counteract long-term effects of joint and muscle bleeding and the tendency to develop abnormal postures.



Booklets & Binders

Safety of Hemophilia Therapies: What Patients and Families Need to Know

Grifols

www.grifolsusa.com

Describes the many safety steps in the manufacture of human plasma-derived factor concentrates used to treat hemophilia A and B.

Living with Hemophilia B

Pfizer

www.hemophiliavillage.com

Colorful, comprehensive overview of hemophilia B. Topics include genetic transmission, carrier testing, treatment, resources, bleed symptoms, physical activities, managing hemophilia as your child grows.

Dental Care (series)

CSL Behring Choice Support Center, 2010

www.hemophiliamoms.com

Three-part series on dental care for individuals and families with bleeding disorders.



- ▶ **Dental Care for Infants, Toddlers, and Preschoolers With Bleeding Disorders**
- ▶ **Dental Care for Children With Bleeding Disorders: Ages 5 to 10**
- ▶ **Dental Care for Adolescents With Bleeding Disorders: Ages 11 to 18**

A Family Guide to Hemophilia B

CSL Behring, 2005

www.hemophiliamoms.com

Discusses unique challenges faced by families living with hemophilia B, including treatments, recent advances. Includes easy-to-understand dosing tools, exercise guides, self-infusion directions.

Educational Support Brochures

Novo Nordisk Inc.

www.novonordisk-us.com

Contact your local HTC

Topics include introduction to inhibitors, surgery, traveling with inhibitors, ER visits, school teen issues, adult issues.



Publications on Living with Hemophilia B

Coalition for Hemophilia B
coalitionforhemophiliab.org



- ▶ **B2B Speaking from Experience**
2006

Colorful booklet for adults and teens shares personal experiences of factor IX deficient patients. User-friendly info for people already living successfully with hemophilia B. Sponsored by Pfizer.

- ▶ **B2B Speaking from Experience: A Guide for Mature Adults**

2007

Helpful knowledge for making informed life decisions and remaining healthy today and in future. Sponsored by Pfizer.



- ▶ **B2B Speaking from Experience: A Guide to the Preteen Passage**

2007

How to navigate the important years leading up to adolescence, in your child with hemophilia B. Sponsored by Pfizer.



- ▶ **B2B Perspectives on Hemophilia B in Early Childhood**

2010

Tips from parents who have raised infants, toddlers, and preschoolers with hemophilia B; insights from medical professionals who treat children with hemophilia B. Sponsored by Pfizer.



- ▶ **Hemophilia B: From Your Point of View**

2010

Tips from peers with hemophilia B on dealing with challenges during adolescence and teen years. Sponsored by Pfizer.



booklets binders

Programs & Workshops



Project SHARE

LA Kelley Communications, Inc.
www.kelleycom.com

Humanitarian program donates factor to developing countries. Recipients are patients, doctors, clinics, hospitals in countries where factor is scarce or unavailable.

Pulse *on the Road*

Pulse on the Road

LA Kelley Communications, Inc.
www.kelleycom.com

Unique three-hour program addresses insurance and healthcare reform topics of urgent importance to families with bleeding disorders. Sponsored by Baxter Healthcare Corporation.

Living with Hemophilia

Bayer HealthCare
www.livingwithhemophilia.com

Practical tips and tools for patients and families living with hemophilia. Includes interactive meetings at local HTC's nationwide; online magazine.



*programs
workshops*



School Preparedness Program/Kit

Coram Hemophilia Services
www.coramhemophilia.com

Helps parents of children with hemophilia set the stage for a safe, happy, rewarding educational experience. Series of presentations that teach families and HTC staff how to educate school personnel and students about hemophilia.



Great Escapes™ Travel Program

Coram Hemophilia Services
www.coramhemophilia.com

National program designed to help patients travel comfortably and safely—across the country or across the globe. Includes checklist and travel letter template for patients with hemophilia.



Inalex Communications Workshops

www.inalex.com

A safe place where people in the bleeding disorder community can learn and share insights, support, and practical advice on bleeding disorders' effect on families, relationships, and lives.



North American Camping Conference of Hemophilia Organizations (NACCHO)

Hemophilia Association, Inc.
www.hemophiliaz.org

Weekend workshop for planning, organizing, operating a bleeding disorder summer camp. Nationally known presenters share camp resources and techniques; explore camp programs and activities; facilitate networking and problem solving. Funded by Pfizer.

BioBuddies Workshop

BioRX
www.biorxhemophilia.com

Workshop designed to empower children with a bleeding disorder by presenting specific knowledge of their condition through puppetry, dress up, hands-on crafts, activities.

Multiple Needs

BioRX
www.biorxhemophilia.com
Workshop designed to inform and empower parents and caregivers of children who have a bleeding disorder and another medical or psychosocial need.

Junior National Championship (JNC)

CSL Behring
www.cslbehring-us.com
Series of one-day athletic competitions gives children with bleeding disorders and their families the opportunity to enjoy competing in appropriate sports such as golf and baseball.



Hemophilia Moms

CSL Behring
www.hemophiliamoms.com

Website that connects mothers to help build awareness about bleeding disorders and maintain a support network; offers events and retreats where mothers build friendships and share their unique issues.

Patient Notification System (PNS)

Plasma Protein Therapeutics Association
www.patientnotificationsystem.org

Confidential 24-hour communication system provides information on plasma-derived and recombinant therapy withdrawals and recalls through automatic electronic updates.

Kits

Baxter Healthcare Corporation

www.thereforyou.com
Contact your HTC

▶ Hemophilia Infusion Kit

Learning about factor replacement is an important part of hemophilia management. Infusion kit offers comprehensive overview on venous access options; information on transitioning to home and self-infusion.



▶ Hemophilia School Toolkit



Everything needed to enlighten school staff about hemophilia. Includes guidelines for handling injuries and emergencies; *Teaching the Educator* DVD.

▶ Hemophilia Starter Kit

Information and advice for families just learning about hemophilia; supplements info provided by HTCs.



▶ Beat Bleeds Kit

New way to track bleeding episodes. Includes Beat Bleeds Planner with stickers; Beat Missing Moments brochure; bleed score sheet to track bleeds.



VWD von Willebrand Disease

A Guide to Living with von Willebrand Disease

Renée Paper, RN, with
Lauren A. Kelley
LA Kelley Communications, Inc.
2012

www.kelleycom.com

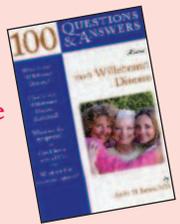
Free to families and patients
Third edition of the world's first book on the world's most commonly inherited bleeding disorder. Topics include learning to cope with VWD, inheritance, the medical system, treatment, women's issues, health insurance. Complete resource guide and real-life stories. Sponsored by CSL Behring.



100 Questions & Answers About von Willebrand Disease

Andra H. James, MD
2008
\$21.95 from amazon.com

Addresses questions relevant to people recently diagnosed with VWD. Up-to-date, authoritative, practical, easy-to-understand info about diagnosis and treatment.



von Willebrand Disease: What Patients Need to Know

Grifols
www.grifolsusa.com
Reviews basics about living with VWD, treatment, general recommendations.



What is von Willebrand Disease?

Grifols
www.grifolsusa.com
Pamphlet for parents of children with VWD.

Children & Teens

What Is Hemophilia? (series)

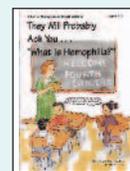
Lauren A. Kelley
LA Kelley Communications, Inc., 1995
www.kelleycom.com

English, Spanish
Developmentally arranged series explains hemophilia to children using language and concepts appropriate for three age levels: preschool, school age, adolescent. Each book covers the same topics in educationally and cognitively different ways. *Note to Parents* for each age level. Sponsored by CSL Behring.



▶ Level 1: Joshua: The Knight of the Red Snake

Empowering story about preschooler with hemophilia. Illustrated large-text format ends on a note of joy and confidence. Ages 3–7.



▶ Level 2: They'll Probably Ask You... "What is Hemophilia?"

Humorous story about Tony, who must explain hemophilia to his fourth-grade classmates. Includes glossary. Ages 7–11.



▶ Level 3: Tell Them the Facts!

Q&A book on hemophilia for pre-adolescents and adolescents. Material on genetics divided into two sections: ages 11–14 & 14–16. Also for teachers and parents of newly diagnosed children. Includes glossary. Ages 11–16.





My First Factor (series)

Shannon Brush

LA Kelley Communications, Inc.
2008, 2010, 2011, 2012

www.kelleycom.com

Series of colorful, chunky books just right for small hands. World's first toddler books for children with hemophilia. Ages 18 mo.-4 yr.

- ▶ **My First Factor Words**
One-word concepts about family and hemophilia. Sponsored by Factor Support Network.
- ▶ **My First Factor: Week**
Regular infusions help a toddler stay active. Brought to you by Bayer HealthCare.
- ▶ **My First Factor: Fitness**
Yoga, playing, laughing, and good food keep a toddler healthy. Brought to you by Bayer HealthCare.
- ▶ **My First Factor: HTC**
Who does a toddler meet at the HTC? Sponsored by Factor Support Network.
- ▶ **My First Factor: Infusions**
What are the steps in an infusion? A first look for toddlers. Sponsored by Factor Support Network.
- ▶ **My First Factor: Joints**
Let's name all our joints! How do they work? Brought to you by Bayer HealthCare.
- ▶ **Mis primeras palabras del Factor**
A toddler's first book about hemophilia in Spanish! Brought to you by Bayer HealthCare.
- ▶ **My First Factor: Safety**
How do I stay safe? Ways a child learns to protect himself. Brought to you by Bayer HealthCare.
- ▶ **My First Factor Coloring Book**
Illustrations from previous My First Factor books help keep your toddler busy and happy. Brought to you by Bayer HealthCare.



Just A Boy

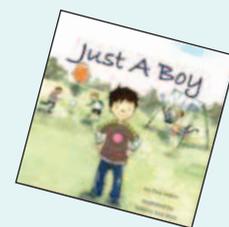
Ziva Mann

LA Kelley Communications, Inc.

2009

www.kelleycom.com

Whimsical storybook about an imaginative child with hemophilia who learns to control his pain as he transitions to needlesticks. Ages 3-6. Sponsored by Baxter BioScience.



Must You Always Be a Boy?

Lauren A. Kelley

LA Kelley Communications, Inc.

1991

www.kelleycom.com

Four illustrated, rhyming tales explore adult reactions to bleeds, overprotective parents, sibling rivalry, classroom bullies. Ages 3-8. Sponsored by CSL Behring.



Alexis: The Prince Who Had Hemophilia

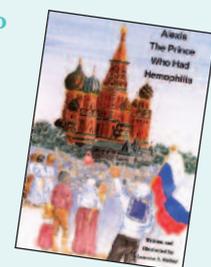
Lauren A. Kelley

LA Kelley Communications, Inc.

1992

www.kelleycom.com

True story of Alexis, youngest child of Tsar Nicholas II, and how hemophilia influenced events leading to the Russian revolution. Age 8 and older. Sponsored by CSL Behring.



Curtis & Jerry on Mount Omega: Adventures with Hemophilia

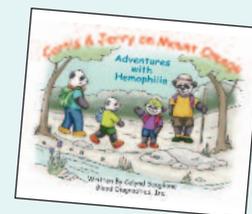
Celynd Scaglione

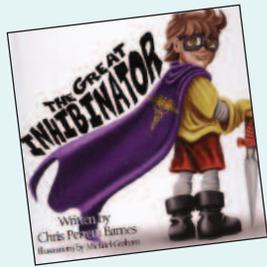
2006

www.bdipharma.com

English, Spanish

Two young pandas go camping with their fathers and learn what it means to live with hemophilia. Includes info about safe activities for children. Provided by BDI Pharma, Inc.





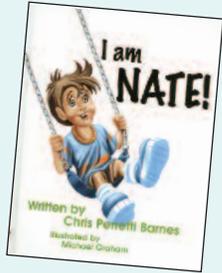
The Great Inhibinator

Chris Perretti Barnes

BioRX, 2006

www.biorxhemophilia.com

Colorful story about Nate, a boy who has an inhibitor, that centers on creating a Halloween costume. Ages 4–7. Produced by Bayer HealthCare and BioRX.



I Am Nate!

Chris Perretti Barnes

BioRX, 2007

www.biorxhemophilia.com

Story about Nate, a boy who explains how having hemophilia affects his life. Ages 4–7. Produced by Bayer HealthCare and BioRX.



Quest for Infusion: It's Always About Nate!

Chris Perretti Barnes

BioRX, 2012

www.biorxhemophilia.com

A look into how Nate's hemophilia affects the lives and feelings of his sisters and parents. Ages 4–7. Produced by Bayer HealthCare and BioRX.



Bob the Puppet Story Books (series)

Pfizer

Contact your local HTC

Positive, colorful, easy-to-read books promote discussions between parents and children about clinic visits and hemophilia.

- ▶ **Bob the Puppet Has His Annual Checkup**
Bob visits an HTC for a routine physical. Ages 4–7.
- ▶ **Bob the Puppet Goes to School**
Bob attends a new school and talks about hemophilia. Ages 4–7.



Periodicals

Parent Empowerment Newsletter (PEN)

LA Kelley Communications, Inc.
www.kelleycom.com

Quarterly. Oldest bleeding disorder newsletter in US

produced and edited by a parent of a child with hemophilia. In-depth medical, scientific, consumer, parenting articles and news to empower parents and patients as educated consumers.



PEN's Insurance Pulse

LA Kelley Communications, Inc.

www.kelleycom.com

Only hemophilia newsletter completely dedicated to insurance issues from the parent's and patient's point of view. Sponsored by Baxter Healthcare Corporation.



Factor Nine News

Coalition for Hemophilia B
coalitionforhemophiliab.org

Quarterly. Easy-to-read scientific information, research, community events.



Dateline Federation

Hemophilia Federation of America (HFA)

www.hemophiliated.org

Quarterly. Healthcare info and news about bleeding disorders, government, healthcare events, innovative programs.



COTT News

Committee of Ten Thousand (COTT)

www.cott1.org



Quarterly. Information, reports, viewpoints about issues and events important to grassroots healthcare advocacy and support; focus on political and policy events in Washington, DC.



Quest

Coram Hemophilia Services

www.coramhemophilia.com

Quarterly. Newsletter for hemophilia patients features patient profiles, news, new products and services.

The Villager

Pfizer

www.hemophiliavillage.com

Hard copy or e-newsletter

Information about hemophilia treatment; tips for living an active life; inspirational stories; news on Pfizer programs and services.

Post Script Informer

Patient Services, Inc. (PSI)

www.patientservicesinc.org



Quarterly. Information on insurance changes for people with chronic disorders.

Hemophilia World

World Federation of Hemophilia (WFH)

www.wfh.org

Triannual. Articles on WFH activities and what hemophilia organizations around the world are doing to improve care.



The Source

Plasma Protein Therapeutics Association (PPTA)

www.pptaglobal.org



Quarterly. Information about the global plasma protein therapeutics industry. Interviews with key leaders; articles on safety and innovation; stories about patients and plasma donors; US and European legislative and regulatory topics.

OneVoice

Save One Life

www.saveonelife.net

Quarterly. Reports on partner organizations, camps, and activities funded by Save One Life, the international nonprofit founded by Laurie Kelley that provides sponsorships to children with bleeding disorders in impoverished countries.



Infusion Inquirer

Walgreens Hemophilia Services

www.walgreenshomecare.com

Quarterly. Latest news and treatments for people living with bleeding disorders; articles from patient and parent perspectives.



HemAware

National Hemophilia Foundation

www.hemaware.org

Bimonthly. Newsletter of largest US hemophilia/bleeding disorder nonprofit. Articles on medical research and treatment; families and children; community events; and people making a difference.



periodicals

Web-Based Resources

Mind Over Matters

Pfizer

www.benefix.com

Story about Bill, a young man with hemophilia B, and his life adventures: opposing forces of fear and confidence battle in his mind as he tries to win the affection of Grace.

AllAboutBleeding.com

CSL Behring

www.allaboutbleeding-us.com

Online resource with info about hemophilia and VWD; patient shared experiences; expert Q&A; program and service listings. Create and print your own first-aid card.

There for You

Baxter Healthcare Corporation

www.thereforyou.com

Online resource to connect patients to resources: local HTC's; info on managing hemophilia; unique Baxter programs; patient and family stories; advice from hemophilia experts; advocacy information.

There's More to Life Than Hemophilia

Facebook page

Information and support for all stages of life with hemophilia. Social media extension of There for You; most posts link back to the website. Specialized info, tools, downloads through tabs such as "Beat Bleeds," "Managing Inhibitors."



HemoAction Online Game

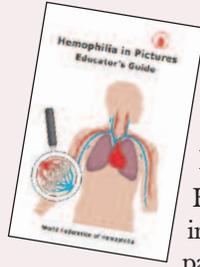
World Federation of Hemophilia, 2012

www.hemoaction.org

English, Spanish, French

Adventure game teaches children about hemophilia: how to prevent bleeds and manage hemophilia; the clotting process; types of bleeds; factor infusions; suitable physical activities.

CD, DVD & Video

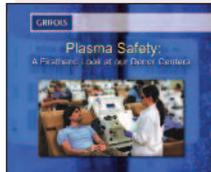


HIP Educator's Guide

World Federation of Hemophilia, 2008

www.wfh.org

English, Spanish, French, Arabic, Russian, Chinese
Hemophilia taught in pictures that provide detailed info for advanced learning. Includes tips for effective patient education, key talking points, review quizzes.



Plasma Safety: A Firsthand Look at Our Donor Centers

Grifols

www.grifolsusa.com

English, Spanish

Tour of the plasma donation process and safeguards that strive to assure donor health and plasma quality and safety.



Product Purity: A Look Inside Our State-of-the-Art Facilities

Grifols

www.grifolsusa.com

English, Spanish

Describes how therapeutic plasma proteins are isolated and purified.



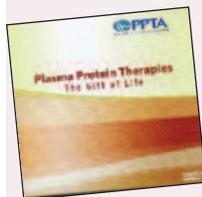
A Bright Future (series)

Inalex Communications

www.inalex.com

DVD series about living with hemophilia. Sponsored by Baxter Healthcare Corporation.

- ▶ **The Hemophilia Diagnosis for Parents:** Parents' testimonials on how they felt and coped inspires new parents to overcome fear and doubt.
- ▶ **The Hemophilia Diagnosis for the Extended Family:** Family members discuss how they coped with the hemophilia diagnosis in their relative.
- ▶ **Teaching the Educators:** How to prepare your child's teachers to handle hemophilia in the classroom.
- ▶ **A Time of Transition:** How to encourage your teen to transition to adulthood and become responsible.



PPTA Gift of Life

Plasma Protein Therapeutics Association

www.pptaglobal.org or llovullo@pptaglobal.org

English; Spanish subtitles

Donors, patients, physicians discuss reasons for donating plasma for plasma protein therapies; demonstrates industry's commitment to safety, quality, innovation.

www

cd dvd video

Hemophilia & HIV

Dying In Vein: Blood, Deception...Justice

Kathy Steward MacKay & Stacy Milbouer
Hollis Publishing Co., 2004

kmackay@aol.com

\$20.00

Stirring photo journal of individuals and families with hemophilia affected by HIV and hepatitis. Portrays people who suffer, who become advocates, and who mourn loved ones.



Bad Blood: A Cautionary Tale

Necessary Films, 2010

Directed by Marilyn Ness

www.necessaryfilms.com

\$19.99

Gripping documentary about how HIV and hepatitis C contaminated the US blood supply in the 1970s and 1980s; the role of various organizations and companies; effects on hemophilic families; how community advocates changed the blood banking system.

Vial023: A Father's Pursuit of Justice

Gary William Cross

2012

\$12.99 from amazon.com

In this memoir, Cross recalls his pivotal role in the nation's "hemophilia HIV pandemic": his 17-year-old son, Brad, died in 1993 after becoming infected with HIV as a child through contaminated clotting factor.



Ordering

Baxter Healthcare Corporation

One Baxter Parkway
Deerfield, IL 60015

800-423-2090

www.thereforyou.com

Bayer HealthCare

6 West Belt
Wayne, NJ 07470

888-606-3780

www.kogenatefs.com

BDI Pharma, Inc.

120 Research Court
Columbia, SC 29203

803-732-1018

orders@bdipharma.com

BioRx

5800 Creek Road
Cincinnati, OH 45242

866-44-BIORX

www.biorxhemophilia.com

Boston Hemophilia Center

300 Longwood Avenue, Fegan 701
Boston, MA 02115

617-355-7165

www.brighamandwomens.org

Coalition for Hemophilia B

825 Third Avenue, Suite 226
New York, NY 10022

212-520-8272

www.coalitionforhemophiliab.org

Committee of Ten Thousand

36 Massachusetts Avenue NE #609
Washington, DC 20002-4971

800-488-2688

www.cott1.org

Coram Hemophilia Services

555 17th Street, Suite 1500
Denver, CO 80202

888-699-7440

www.coramhemophilia.com

CSL Behring

Choice Support Center
1020 First Avenue

King of Prussia, PA 19406

888-508-6978

www.helixatefs.com

Factor Support Network

900 Avenida Acaso, Suite A
Camarillo, CA 93012-8749

877-FSN-4-YOU

www.factorsupport.com

Grifols USA, LLC

2410 Lillyvale Avenue
Los Angeles, CA 90032

888-474-3657

www.grifolsusa.com

Hemophilia Association, Inc.

818 East Osborn Road, Suite 105
Phoenix, AZ 85014

602-955-3947

www.hemophiliaz.org

www.naccho.com

Hemophilia Federation of America (HFA)

210 7th Street SE, Suite 200 B
Washington, DC 20003

800-230-9797

www.hemophilafed.org

Inalex Communications

38 East Ridgewood Avenue, #374
Ridgewood, NJ 07450

201-493-1399

www.inalex.com

LA Kelley Communications, Inc.

65 Central Street
Georgetown, MA 01833

978-352-7657

www.kelleycom.com

National Hemophilia Foundation (NHF)

116 West 32nd Street, 11th Floor
New York, NY 10001

800-42-HANDI

www.hemophilia.org

Necessary Films

167 East 67th Street, Suite 10EF
New York, NY 10065

212-639-9383

Novo Nordisk Inc.

100 College Road West
Princeton, NJ 08540

609-987-5800

www.novonordisk-us.com

Patient Services, Inc. (PSI)

PO Box 5930

Midlothian, VA 23112

800-366-7741

www.patientservicesinc.org

Pfizer

500 Arcola Road

Collegeville, PA 19426

888-999-2349

www.hemophilivillage.com

Plasma Protein Therapeutics Association (PPTA)

147 Old Solomons Island Road, Suite 100
Annapolis, MD 21401

800-UPDATE-U

www.pptaglobal.org

Save One Life

65 Central Street, Suite 204
Georgetown, MA 01833

978-352-7652

www.saveonelifenet

Walgreens Hemophilia Services

517 Ivy Street

Truth or Consequences, NM 87901
866-436-4376

www.bleedingdisorders@walgreens.com

World Federation of Hemophilia (WFH)

Educational Materials Manager

World Federation of Hemophilia

1425 René Lévesque Boulevard West, Suite 1010
Montreal, Quebec H3G 1T7 Canada

514-394-2832

www.wfh.org

headlines

manufacturer

BAX 326: Good Results of Clinical Factor IX Study

Baxter International Inc. announced phase I and III study results evaluating the safety and efficacy of BAX 326, an investigational recombinant factor IX (rFIX) protein. Baxter presented its data at the 54th annual meeting of the American Society of Hematology in Atlanta. In this study, over 40% of patients using BAX 326 as a prophylactic treatment experienced no bleeds. No inhibitors were detected, and no cases of anaphylaxis were reported. **Why this matters:** Although Baxter offers a plasma-derived FIX product in some countries (Immunine®), BAX 326 will be Baxter's first rFIX product, giving the company a broader range of products and offering hemophilia B patients more choice.

For info: www.baxter.com

Source: Dec. 10, 2012, press release

Want to Try Trust?

Bayer HealthCare's BAY 86-6150, a recombinant factor VIIa (rFVIIa) product for patients with hemophilia A or B with inhibitors, is being investigated in a phase II and III study called TRUST (TReatment with Unique recombinant rFVIIa STudy). The multicenter, open-label clinical study will assess safety and efficacy. Recruitment is ongoing around the world, including in the US, where sites are ready to enroll eligible patients. **Why this matters:** Another product to treat bleeds in people with inhibitors would make the marketplace more competitive, but inhibitor patients for clinical trials are always in extremely short supply—so consider volunteering for this study.

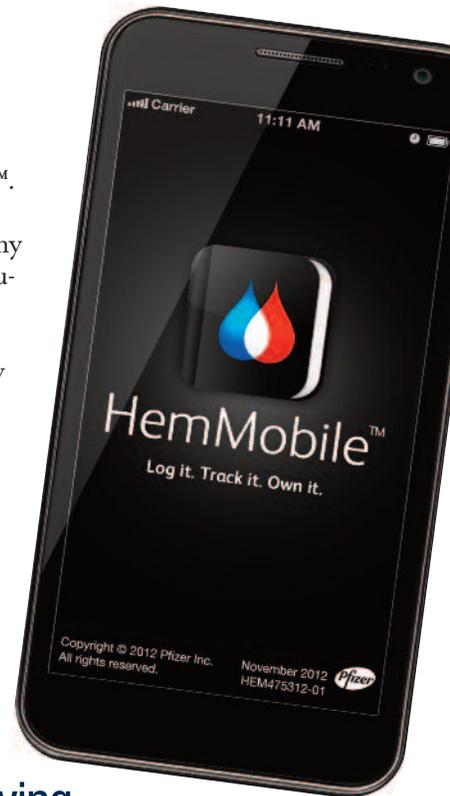
Contact: Jane Ward, Bayer HealthCare
973-305-5248, jane.ward@bayer.com



Get Mobile!

Pfizer Hemophilia has launched a free mobile phone logging app, HemMobile™. The app is designed to help hemophilia patients and caregivers (who are using any factor replacement product) log their infusions and bleeds and monitor general health. HemMobile users can record the date, time, location, and reason for every infusion; add notes; add photos to each bleed log entry; view infusion and bleed log history; and send reports to their care team. **Why this matters:** Mobile apps are becoming the easiest way to log factor usage and track bleeds.

For info: www.hemophiliavillage.com



Largest Multinational Psychosocial Study of Living with Hemophilia

The HERO (Hemophilia Experiences, Results and Opportunities) initiative examined hemophilia's effect on interpersonal relationships, careers, access to care, and quality of life. In the US, 189 adults with hemophilia and 190 parents of children with hemophilia participated. Highlights of the study's results: Despite the physical disabilities of adults with hemophilia and the challenges of caring for a child with the disorder, the majority of both groups have overcome these barriers to maintain employment. Most are satisfied with their medical care, but almost 25% worry about access to treatment, based mainly on financial concerns. Quality of life assessments were lower for people over age 41 with hemophilia, for people with inhibitors, and for people with joint complications. Sponsored by Novo Nordisk Inc.

Why this matters: These results can be used to focus areas of support for people with hemophilia who are in need.

For info: www.changingpossibilities-us.com

Enter Korea

South Korea's Green Cross received US approval of its third-generation *GreenGene F* recombinant factor VIII (rFVIII). Its manufacturing process is plasma- and albumin-free and incorporates a two-step viral exclusion and inactivation process. Clinical trials are being conducted in 20 HTC's in the US. **Why this matters:** As the patents on US products expire, expect more companies to join the hemophilia marketplace, offering greater choice and perhaps lower prices.

For info: eng.greencross.com

nonprofit



Washington Days!

NHF's annual Washington Days empowers people in the bleeding disorder community to influence the legislative process. All participants can meet face-to-face with lawmakers and staff who shape national healthcare policy; become informed on critical issues that affect continued access to quality care; and learn effective grassroots advocacy techniques.

Why this matters: Much of the progress we enjoy today in the safety of hemophilia treatment has come from successful lobbying efforts.

For info: www.hemophilia.org



Download the Get in Gear Fitness App

Hemophilia Foundation of America (HFA) offers a free mobile "Get in Gear" fitness app to encourage people in the bleeding disorder community to become more physically active and improve their overall health.

In five months, almost 7,500 people have downloaded the app. **Why this matters:** Get in Gear allows users to track their fitness activities while learning valuable info about bleeding disorders.

For info: www.getingearapp.com or www.hemophiliafed.org



5th Annual Inhibitor Family Camp!

April 19–22

Painted Turtle Camp in Lake Hughes, California, will host the fifth annual Inhibitor Family Camp for families with children ages 6–18 with active inhibitors. Free for qualified families. Generously supported by an educational grant from Novo Nordisk Inc. **Why this matters:** Children with inhibitors often report that they can't participate in many activities at traditional hemophilia camps due to the threat of injury.

For info: Comprehensive Health Education Services
781-878-8561

international

Iran: Running Out of Factor?

Iran is experiencing factor shortages, according to Ahmed Ghavidel, former CEO of Iran's Hemophilia Treating Association. He cites the cause as the international sanctions imposed by the US and its EU allies on Iran for its uranium enrichment program. Approximately 7,000 Iranians live with hemophilia. Inflation and high prices are hurting blood labs' ability to provide products for patients, and Iran's oil exports have decreased, reducing the national revenue available to purchase drugs. According to the Iranian Hemophilia Society, although the export of drugs to Iran has not been banned, sanctions have made it hard for the Central Bank of Iran and the country's other financial institutions to purchase and import medicine. **Why this matters:** Recently a fifteen-year old boy with hemophilia died because he lacked factor, and the situation is getting worse.

Source: www.guardian.co.uk (Nov. 14, 2012)



how prescription coverage will be addressed under the exchanges either. At this point we are not sure which benefit clotting factor will be covered under, major medical or pharmacy.”

If we don't know, then what do the payers know? Are they knowledgeable about the special drugs needed to treat bleeding disorders, and specifically inhibitors?

Educating payers about hemophilia

NHF is on it, with a series of webinars that began in 2010 to educate payers about hemophilia treatment. The goal is to ensure that payers understand why these drugs are expensive; what they do; how they are used; why prophylaxis differs from on-demand, and how this affects long-term costs (and joint health). Payers also need to understand the differences in competitive brands of factor, and that one brand does not work with all patients. They must also know that biosimilar factors (“follow-on” recombinant factor products) are not all the same—each is made from a different cell line, uses a different fermentation process, and undergoes different purification and viral inactivation processes; any of these can cause the drug to act differently than the similar brand-name drug. And payers must understand the need for access to all therapies. To date, NHF has educated more than 400 participant payers in this valuable series. So, are they getting it?

Rice notes, “The general feeling we receive when talking to payers is that most understand hemophilia, and particularly the uniqueness of an inhibitor. They recognize that there is little they can do to manage the cost. Their understanding might be as simple as ‘an inhibitor is a complication that while expensive, if not treated, could lead to increased costs long term, and potentially fatal outcomes.’ They seem to understand that it’s important to let the physician guide this treatment.”

So far, encouraging. Instead of looking only at per-unit cost, or total cost per year, it’s vital that payers know why a treatment is advised; know the medical and lifestyle outcomes of following a physician’s prescribed regimen; and know the cost over the long run of not accepting a course of therapy. This means educating payers about the cost of lost productivity at work when a patient has a bleed and the cost of joint replacement when a patient is older.

Tiers always win?

Still, as healthcare reform progresses and as costs rise for payers, prescription drug tiers become a way to manage costs. Tiers are classifications of drugs within an insurance formulary that allow insurance companies to charge varying out-of-pocket expenses—the portion of costs you pay. There are four tiers:

- **Generic drugs** (tier 1)
- **Brand-name drugs** (tiers 2 and 3)
- **Specialty drugs** (tier 4)

Tier 1 requires the lowest copayment, usually \$10 to \$50. Copays tend to go up with higher tiers, with tier 4 the highest. Specialty drugs account for only 1% of total drug prescriptions but represent 17% of drug spending by private insurers.² Tiers are a good tactic to encourage consumers to choose lower-cost generic drugs.

But there are no generic drugs for factor. And specialty drugs that fall under tier 4 can incur coinsurance charges, instead of flat copays, for drugs that cost more than \$500 and/or for injectable therapies. Currently, factor is not considered a specialty drug; our national hemophilia organizations are working hard to keep this from happening. But could factor—specifically inhibitor factor—eventually become a specialty drug?

“Unfortunately, I think the answer to this question is yes,” says Rice. “Currently in most plans, all clotting factors are treated the same.” Inhibitor drugs may not be carved out as special, untouchable by healthcare reform. Where hemophilia drugs go, so go inhibitor drugs—at least for now.

What can you do to protect inhibitor reimbursement?

While you wait to see how ACA evolves, there is much you can do to prepare for coming changes and to protect the coverage you have and need. Your first stop should almost always be your HTC social worker. Next stop: meet with your local or state hemophilia organization. You can also meet with your state health officials, Medicaid director, insurance commissioner, and legislators.

You’ll need to educate these officials on inhibitors, on the importance of being able to choose therapy, and on specialty-tier and out-of-pocket cost issues. Tell your story—most state employees and representatives want to know.

Rest assured that your national organizations are working to educate payers on these issues, too. “When NHF speaks with payers, we try to address the entire spectrum of bleeding disorders,” says Rice. “We are sure to include information on...inhibitors.”

If you’re feeling unsure about insurance terms and how to approach your payer or state representatives, ask for help. NHF, Hemophilia Federation of America (HFA), and state hemophilia organizations all have tools, glossaries, and training manuals to get you started. Make it your New Year’s resolution to get informed and proactive. Netflix will still have your favorite TV shows, and you’ll have more peace of mind—and, we hope, coverage. ☺

CORRECTION

In the November issue of PEN, we misidentified the photo of Miguel Brown in *Inhibitor Insights* (“Tired of Being Special”) as Miguel Dominguez. Our apologies to Miguel Brown and his family.

2. IMS Health.

sometimes a way for a patient, HTC, or hemophilia organization to acquire donated factor; whether it will be used for the emergency remains to be seen. We must assess the nature of the emergency to see whether a shipment will even help. If it's surgery that can wait five days, then we can ship. Once, we saw a devastating photo of a baby in ICU with a head bleed...and we knew no factor shipment was going to help. We declined.

Check locally first.

All requests should first be vetted through the local and/or national hemophilia organization in a country. India has more than 65 chapters, so local is best. By contrast, the Dominican Republic has only one national organization. You can hop online and check the World Federation of Hemophilia's website (www.wfh.org) to get the name and email of a national organization. But with over 100 member countries, this can be time-consuming and may not produce all the info you need.

Not speaking the patient's local language may make it hard to communicate! At Project SHARE, we've found that we can resolve a lot of questions by informing the local organizations,



whose staff often speak English, about requests that are coming from their members directly to the United States. Our goal is never primarily to “rescue” a patient, but to turn the request back to the national organization, to allow it a chance to help, and to strengthen its ability to solve problems.

Social media like Facebook creates connections between the developed and developing world. At SHARE we've seen many requests for factor and medical help come through

Facebook to nice—but often inexperienced—hemophilia families and organizations who want to help. Americans are generous but aren't always familiar with the international world. Be careful. Don't risk losing a shipment of factor. Don't weaken the local or national groups by training patients to come to you first instead of to the national organizations. Don't be duped by people who end up getting the lion's share of donated factor because they know how to use Facebook and email—people who pump out simultaneous requests to many developed countries and organizations.

What can you do that will really help? Contact Project SHARE. We have been working with more than 65 countries for 16 years, and we've shipped over 50 million IU of factor. We've seen and heard just about every scenario, and we can make decisions about factor that will give help where it's most needed, strengthen the national or local hemophilia organizations, and ensure that factor goes to patients with bleeding disorders. Consider us your US experts on hemophilia international aid. Like you, we want to help. Let us help you give help, effectively and efficiently. @

Bayer HealthCare

FREE

ANYTIME, ANYWHERE:
Keep your Factor on Track!

The first **FREE**, customizable mobile app designed to help you track and record your hemophilia A Factor VIII infusions:

- ▶ If you're on a prophylaxis regimen, the app reminds you when to infuse.*
- ▶ If you infuse on-demand, use the app to record your bleeds and infusions.

LEARN MORE ABOUT DOWNLOADING FACTORTRACK AT
LivingWithHemophilia.com/FactorTrack

FactorTrack™ is part of Living Fit! A Joint Effort™.

Living Fit!
A Joint Effort™

*Please note that an Internet connection is required to receive infusion reminders.

This app is not intended to offer or replace professional medical advice. Speak to your nurse or physician if you have any health concerns. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

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Project SHARE

I AM WRITING TO LET YOU KNOW THAT

I have received the 18 vials of factor VIII you sent. I am also writing to thank you on behalf of my family. I am most grateful. God bless you.

Chimdi Nwawueze
NIGERIA

THANK YOU SO MUCH FOR YOUR

endless help for my son RJ. On Oct. 25, 2012, we infused six vials of factor due to bleeding in his right thigh. The bleeding also caused the mass in his right hip to grow bigger. Before the surgery, the orthopedic surgeon advised us not to do it because of lack of medicine. We never gave up looking for the needed medicines for my son's operation.

I am very grateful for my son's positive attitude and because he is a prayerful person. We believe that with our fervent prayers a miracle will happen to him, for with God nothing is impossible.

Darisol Bunag
PHILIPPINES

THANK YOU FOR YOUR CARE AND

compassion to our brothers around the globe. The work you do is very inspiring to me and everyone who cares about easing human suffering.

Erik Melde
President, Axiom Therapeutics, LLC
UTAH

inbox

I AM SENDING ALAZAR'S RECENT PHOTO

that illustrates his injury on the left side of his face after he fell at school and the edge of the desk hurt him severely. Part of his face was swollen all last week. If the injury had been a cranial one, the accident would have been more severe.

Thank you and [LA Kelley Communications], for my children have stayed alive though going through such times. We can manage the challenges with the medicine.

Tadesse Belay
ETHIOPIA



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