February 2009 • Volume 19 • Issue 1

Parent Empowerment Newsletter

PEN'S BIANNUAL
Bleeding Disorders Resource Guide
2009

BY ZORAIDA ROSADO

BOOKS

Raising a Child With Hemophilia: A Practical Guide for Parents

Laureen A. Kelley, 2007
LA Kelley Communications, Inc.
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: www.cslbehring.com

Raising a Child With Hemophilia in Latin America

Laureen A. Kelley with Ana L. Narváez, 2006
LA Kelley Communications, Inc.
www.kelleycom.com
English (PDF only), Spanish, Portuguese

First book about hemophilia in Latin America. Based on interviews with dozens of families and patients in five countries. Written for parents by a parent of a child with hemophilia. Topics include differences in hemophilia treatment, genetics, transmission, family dynamics, government policies, being a smart consumer, medical complications. Sponsored by Baxter BioScience: www.hemophiliagalaxy.com

Success as a Hemophilia Leader

Laureen A. Kelley, 2004
LA Kelley Communications, Inc.
www.kelleycom.com
Free to qualified Hemophilia Leaders
English (CD only), Spanish

World's first guide to founding, managing and growing a grassroots hemophilia organization, or improving an existing one. Valuable 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 Talecris Biotherapeutics, Inc.: www.talecris.com

Teach Your Child About Hemophilia

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

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

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inside PEN

All listed resources are free, although some restrictions may apply. Visit the publishers' websites to register and learn more. See page 15 for a list of publisher mailing addresses.

welcome

Sherrell Portrait Design

This is one of my favorite issues of *PEN*. This quarter we review an amazing number of educational resources available to the bleeding disorder community. We provide this issue every two years. While LA Kelley Communications has created and published many good resources, this review always encourages me to order items, read more about hemophilia, and ask if I am personally educating within my own family. That's harder to do now that Tommy no longer lives with us.

But he came home for the holidays, and sure enough, he got a shoulder bleed. I was reminded of so many holidays spent in the hospital, being infused, x-rayed, MRI'd, and observed. Because the bleed affected Tommy's ability to use his hand, and because he was in such pain, I got to infuse him. Hooray for me. But I was nervous. I had not infused a person with hemophilia in two years. The only product in the house happened to be a product that Tommy doesn't normally use (a gift from someone wishing to donate it overseas). And it came with an unfamiliar needle transfer device.

It was embarrassing. Me, author and publisher of all things hemophilia, fumbling and procrastinating, trying to figure out how to get the saline into the factor bottle, and forgetting the many steps in infusing. Alcohol wipes, tape, tourniquet, veins… How did I do all this when Tommy was a baby? When we were in line at Animal Kingdom with two other children? On an airplane over Texas?

Wake-up call: you really lose your skills when you don't use them. And I don't live with hemophilia anymore. As I marveled over what I had forgotten, I decided to see what Tommy might have forgotten. The day after the infusion, when he was feeling better, I plied him with an omelet and orange juice, and asked, "Tommy, do you know your chances of having a baby with hemophilia? Do you know what brands of factor there are? What's the difference between plasma-derived and recombinant? What are the symptoms of a head bleed?"

He answered my questions correctly – thankfully. I mail things his way, but I'm not sure he reads them. Long gone are the days when I can sit and instruct him like a student. He's a man now. I had my shot at educating him, and I think he's going to do fine. If you have an under-21-year-old in the house, now's the time to educate him or her – and yourself – about hemophilia or VWD, and most of all about insurance. Don't wait for a holiday visit to find out what your child doesn't know. Order the free resources listed here: get one for your child, and one for yourself! In education, as in staying fit, if you don't use it, you *will* lose it.

inbox

THANK YOU SO MUCH FOR SENDING YOUR LITERATURE. My father had hemophilia B, which makes me a carrier. I was blessed that my son did not inherit it, but my daughter is a carrier. Now that my grandson has been diagnosed, I am trying to educate myself on all the advances made over the past 50 years. My goal is to get our family out of the mindset of fear so that my grandson can lead a normal, happy life. Thank you again for educating us.

Susan Francis
Florida

AS A GRANDMOTHER OF A GRANDDAUGHTER WITH SEVERE hemophilia A, I want to thank you for all the information you send out. It has helped me so much as I care for her five days a week, and every day is a challenge. I read all the information in *PEN*. Even though I am a nurse, so many changes are taking place, and all the information is helping me every day to deal with these challenges. Keep up the good work, you and your staff, and God bless you all.

Margaret B. Jones
South Carolina

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PARENT EMPOWERMENT NEWSLETTER FEBRUARY 2009

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PEN is a newsletter for families affected by bleeding disorders that is produced and edited by a parent of a child with hemophilia. It is a forum that promotes an active exchange of information and support among divergent groups in the national and international hemophilia community.

PEN does not accept advertising and uses brand product names and company names pertaining only to news and education.

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Understanding How — and When — Children Learn about Hemophilia

BY DIANE HORBACZ

I still remember so clearly, when I was ten, asking my father a question about math – statistics, to be exact. Dad was a former math teacher and, at that time, principal of an elementary school. A real expert in the field of education. Lucky me!

My simple math question, however, led to a detailed lecture on *mean*, *median*, *mode*, and mumble jumble. My father's explanation left me baffled, and I remembered only the mumble jumble.

All kids want their parents to be proud of them, and I knew that grasping challenging math concepts quickly would earn my father's pride. So I played it cool and pretended that I understood. It would have been humiliating for me to admit that I actually didn't understand. I didn't want Dad to think I was stupid. The outcome? Over time, I learned to believe that I didn't have what it takes to be good at math.

The brain processes information differently as a child develops. Things that are too hard to understand at one age may be better understood a few years later. If parents or teachers educate at a level too far above a child's current level of understanding, he may become discouraged and abandon learning about that topic. A child's confidence can be very fragile; mine was easily broken.

All too often I see this scenario when children are trying to understand hemophilia (which can be even harder to understand than statistics). Many parents think they need to teach their children complex concepts about hemophilia; so they may teach them too much, too early. A parent with a medical background gave her son, a kindergartener, an impressive explanation of blood clotting. She told me, "The more he understands now, the more confident he will become." But was her child able to comprehend that level of learning?

We must ensure that our children understand their bleeding disorder. But more often than not, we tend to overlook the importance of matching the information we teach to our child's level of *cognitive development* (level of thinking and understanding). This parent was confident that her son was going to understand hemophilia perfectly. I could see the door to understanding hemophilia beginning to close, and I could only imagine the thoughts crossing his mind... "I don't get what you mean. I'll never be able to learn this stuff. Hey, I wonder how high I can stack those dominos?" Door closes, key locks, parent thinks she did a great job educating, and a child walks away with mumble jumble.

How do we teach our children about hemophilia at an age-appropriate level? Understanding hemophilia requires the ability to grasp *abstract* concepts. Abstract thinking, however, doesn't develop until about age ten or older. Until then, hemophilia education is a *concrete* process. It's normal for a five-year-old to think, "Hemophilia means that I get shots" (a very concrete explanation) rather than "I'm missing a factor component in my blood" (too abstract for age five). If your seven-year-old wants to know where his hemophilia came from, avoid discussions using the letters X and Y, which describe chromosomes. Instead, say, "Hemophilia is a characteristic, like the color of your eyes, that gets passed along from parent to child."

Fortunately, many age-appropriate resources and programs are available to the hemophilia community. Many are listed in this issue of *PEN*. We can't all be experts in cognitive development, but we can use the right tools to guide our teaching. As we educate our children, we must ask questions and probe in order to determine how much they *really* understand. We need to keep that door open and their minds available. And, just for the record… I'm excellent in math!

Diane Horbacz graduated from Seton Hall University with a degree in psychology. Her focus was on child psychology and the use of play therapy with chronically ill children. Diane earned a master's degree in special education from William Paterson University, where she studied behavior management and emotional disorders. Diane's professional background includes teaching children with special needs at various age levels. She has two sons with hemophilia.

BY SONJI WILKES

Show and Tell: *Not Just for Elementary School*

My seven-year-old daughter recently had a show-and-tell project at school and decided to speak about her summer camp experience this past year. While helping her prepare for this project, I explained to Nora that the reason she was able to go to camp is that her brother has hemophilia. Our family talks about hemophilia quite a bit, but this was the first time any of my children had to talk about it in front of others.

Nora struggled, trying to define hemophilia in a sentence or two beyond "My brother gets pokes." To help steer her, I turned to our boxes of hemophilia education resources. I honestly hadn't realized that our collection of brochures, kids' literature and journal articles had grown so vast in five short years. I literally pulled out three boxes of information for one simple, five-minute, first-grade presentation!

Then and Now

I took an interesting stroll down memory lane, looking through the non-inhibitor hemophilia literature our HTC staff had dropped off at the hospital shortly after Thomas's birth and hemophilia diagnosis. That stack of information was nearly a foot tall. I remembered carefully reading each brochure, digesting a little at a time as soon as I felt ready to tackle the shock of a hemophilia diagnosis. I recalled how thankful I was to have varying pieces of education, in varying degrees of detail.

Then, as I dug through the papers, I came across the solitary brochure we received after Thomas's inhibitor diagnosis. At the time, very little consumer-friendly inhibitor education was available. It was a completely different diagnosis and information-gathering experience. Ultimately, I found the inhibitor resources I needed, but they didn't fit in a dusty cardboard box.

The Buddy System: How Not To Get Lost

Our family attended the first Inhibitor Education Summit, sponsored by Novo Nordisk in 2005. It was truly inspiring. Sitting in educational sessions specific to life with an inhibitor satisfied my craving for information. But I found that simply talking with other parents and patients who live with an inhibitor gave me all the resources I needed. Brochures, scientific data, and papers can teach you the technical aspects of inhibitors, but patients and caregivers embody the practical aspects of surviving and thriving with an inhibitor. For instance, at that meeting I heard useful tips for storing ancillary supplies; and this was the first time I heard another parent lament about a son who developed a bleed just walking across a large parking lot.

Many inhibitor patients have told me about the value of networking with other patients. Because our community is small, inhibitor patients often become close and speak regularly via phone calls, email, and internet social networking sites. The Inhibitor Education Summits and inhibitor rap sessions at NHF annual meetings are widely popular: these are great opportunities to not only gain "book" knowledge, but to form lasting, meaningful relationships and gather tried-and-true tips. As in the show-and-tell days of elementary school, there is much to be learned from your peers. Thanks to relationships developed at such meetings, buddies can help you navigate the maze of inhibitor care, from bleed management and treatment to insurance, coping, and inhibitor eradication strategies. My buddies are invaluable as our family weaves its way through the intricacies of inhibitor management.

Ask and Ye Shall Receive

Since that inaugural Inhibitor Education Summit, more inhibitor education materials have been written. A book is currently being written about raising a child with inhibitors;[1] a children's book features a child with an inhibitor;[2] and researchers are digging deeper into the mystery of inhibitors. The Inhibitor Education Summits have increased in scope by offering summits specific to adults living with inhibitors. When the inhibitor community spoke with a collective roar, declaring a need for more resources, our pharmaceutical, home healthcare, national and local hemophilia organizations and partners delivered. Anyone who has done research projects for school can attest that sources of information come from all areas; in the inhibitor community, we're lucky to have our technical sources – and each other.

Visit www.inhibitorsummits.com for information on Inhibitor Education Summit meetings in 2009, sponsored by Novo Nordisk.

1. For more information or to reserve your copy, contact LA Kelley Communications, 800-279-7977.
2. *I am Nate*, by Chris Barnes (see page 15 for order information).

Blood, Sweat and Tiers

storm watch

BY LAURIE KELLEY

One way health insurance companies – known as *payers* – try to reduce overall healthcare costs is by increasing the amount of money you, the consumer, must pay out of pocket. The rationale: the more you pay directly, the more you'll think twice about whether you really need that medicine. This makes sense up to a point; it keeps patients from abusing or wasting drugs. This approach also encourages patients to switch to less expensive but equally effective generic drugs. And rather than ask you to pay just one fixed co-pay amount (like $10) per prescription, payers have instituted *tiers*, or levels of co-payments, depending on the drug and how it is used. A tier represents the level of coverage (what the payer pays) and the co-payment (what you pay).

Fine for the general public, but payers are rapidly adopting this pricing for specialty pharmaceuticals, which include treatments for growth hormone deficiency, multiple sclerosis, rheumatoid arthritis – and hemophilia. The problem? There are no generics for these drugs, so there are no choices. Yet these are expensive and necessary treatments to maintain life and quality of life. Here's a typical tier scheme from a payer:

Tier 1 generic medications; lowest copayment

Tier 2 payer-preferred brand-name medications; second-lowest copayment

Tier 3 payer non-preferred brand-name medications; second-highest copayment

Tier 4 specialty drugs prescribed by a specialist; unique uses; special dosing and administration; higher costs; members must pay coinsurance[1]

Each tier means a higher cost as deemed by the payer, but the actual drugs might not be more expensive. For example, suppose that the payer prefers a patient to use Drug A, not Drug B. And suppose that Drugs A and B have exactly the same chemical formula, with the same commercial cost. Because the payer decides that Drug A is preferred (tier 2), it will cost the patient less. If the patient insists on using Drug B, a non-preferred tier 3 drug, this results in a higher out-of-pocket cost for the patient.

The co-payment for some tier 4 drugs is a percentage of the cost of the drugs, usually 20% to 33%, which can amount to thousands of dollars monthly for a patient with hemophilia. How serious is this for the hemophilia community? Dan Mendelson of Avalere Health,[2] a research organization in Washington, notes that five years ago, tier 4 was virtually nonexistent in private plans. Now established in 10% of all plans, tier 4 is the fastest growing segment in private insurance.

Glenn Mones, director of public policy at NHF, singled out tiers in a compelling portrait of the current state of affairs in hemophilia healthcare in the United States. At the NHF 60th annual meeting in Denver, November 2008, Glenn warned the audience that many barriers currently confront access to hemophilia care. Premiums are increasing as benefits are decreasing. A weak economy has led to massive state budget deficits, with reduced benefits and services like Medicaid. Payers will notice that we have five or six recombinant factor VIII drugs and ask, Why not restrict our plan formulary to one or two brands? Why not further restrict choice and increase payment by instituting tier 4? Make no mistake, cautioned Glen, for the hemophilia community, "Tier 4 is coming."

For families already troubled with mortgage payments, credit card debt, higher medical co-payments and inflation, tier 4 is one more burden. Now it's up to the hemophilia community to rally before tier 4 becomes another step we struggle to climb.

1. www.bcbsnc.com/medicare 2. Kolata, Gina, "Co-Payments Soar for Drugs With High Prices." *New York Times*, April 14, 2008.

richard's review

BY RICHARD J. ATWOOD

A Flaw in the Blood

by Stephanie Barron
New York, NY: Bantam Books, 2008

Beginning in mid-December, 1861, the lives of Patrick Fitzgerald, an Irish lawyer separated from his wife, and Dr. Georgiana "Georgie" Armistead, a young female physician, are endangered due to their knowledge of secrets kept hidden by the British royal family. Though the romantic characters of Patrick and Georgie are fabrications, this suspense novel is based on historical fact.

Georgie has trained with Dr. John Snow, the medical consultant who provided chloroform to Queen Victoria for pain relief at Prince Leopold's birth. Victoria's Consort, Prince Albert, before his untimely death in 1861, asks Georgie to consult on Prince Leopold's bleeding condition. But Queen Victoria wants no information released about hemophilia, the "flaw in the blood." So an ally of Prince Albert, the German count Wolfgang von Stuhlen, and his thugs are enlisted to silence Georgie and Patrick. To save their lives, the couple flee London to the Isle of Sheppey, and then to France, where Prince Leopold helps them escape their pursuers. As Patrick and Georgie search for evidence to prove their innocence after being accused of murder and other crimes, their romance blossoms.

Georgie summarizes the bleeding condition of eight-year-old Prince Leopold: "He bleeds very often from his nose and gums, and must rub the latter with sulfate of soda when they appear swollen and red. He takes mercury and chalk as an emetic – to avoid straining at the bowels…He nearly died from an outbreak of measles…and a sore throat is dreadful; if he

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BY KEVIN CORREA

Be Honest.
Just Not Too Honest.

Transitions is a *PEN* column sponsored by Baxter BioScience

Your first job interview. You stayed up late last night researching the company on the Internet. This morning you retied your tie three times until it was perfect. You remembered to offer a firm handshake and maintain eye contact. So far so good. The interviewer seems to like you and even says she thinks you'd be a good fit for the position. And then it happens. She asks if you have a medical condition that she should know about. How should you answer? Should you lie? Is it even legal for her to ask? Unfortunately, not knowing how to maneuver through the stressful interview process is costing many young applicants with hemophilia a shot at jobs.

Cat Out of the Bag

Tim Ochoa is a hemophilic young man who applied for a food service position, confident that his hemophilia would not prevent him from performing the responsibilities of the job. During his interview, Tim disclosed that he had hemophilia. Suddenly the tone of the interview changed, and Tim was asked to obtain documentation from his doctor stating that he was fit to work. As requested, Tim obtained the letter. But he did not get the job.

Being a novice and an honest applicant, Tim told a potential employer that he had hemophilia *prior* to being offered the job. Like scores of hemophilic young people, he simply wasn't prepared to address his hemophilia in an interview setting.

Bobbie Kincaid, community advocate with Acreedo's Hemophilia Health Services, said that Tim isn't alone when it comes to spilling the beans about hemophilia during an interview: "We're not doing enough to educate job seekers on the interview process." Bobbie is passionate about increasing efforts on this front because she sees firsthand the positive effect holding a job has on the lives of young people.

"Getting that first job – regardless of what it is – is an important step that starts young people with hemophilia on their way to realizing their dreams," says Bobbie. "And it's a shame when a young man is excited about a job, is a good fit for the job, and then doesn't get it because he innocently discloses that he has hemophilia."

Confusion Over Rights

"There's definitely a lack of education on the subject of employment rights in the hemophilia community," observes Beth Sufian, an attorney who runs the Bleeding Disorders Legal Information Hotline. With respect to employment issues, she notes, many of the people she speaks with either don't know or have serious misconceptions about their legal rights. Of the calls Beth fields, those involving employment discrimination are surpassed only by those relating to insurance.

Many job applicants with hemophilia are at least vaguely aware that they may receive some protection under The Americans with Disabilities Act (ADA). But what they may not realize is that protection under the act is as much about the employer as it is about the applicant.

For instance, in order for a company to be covered by ADA, it must have at least fifteen employees. As for the applicant, ADA defines an individual with a disability as a person who

- has a physical or mental impairment that substantially limits one or more major life activities;
- has a record of such an impairment; or
- is regarded as having such an impairment.[1]

Assuming both the company and applicant are covered by ADA, then certain aspects of the act are particularly important to people with hemophilia: "Employers *may not* ask job applicants about the existence, nature, or severity of a disability. Applicants *may* be asked about their ability to perform specific job functions."[2]

In other words, an employer covered by ADA can't ask if you have a disability, but can ask if anything prevents you from doing the job for which you're interviewing. If you're asked whether anything would inhibit your ability to perform specific job functions, responding with a simple "no" is appropriate.

But the situation gets muddled if you're asked directly whether you have a medical condition the employer should know about. Legal or not, if you push back on this issue, you're likely to raise red flags. Again, your response can be simple:

"No, I don't have any condition that would prevent me from performing the job."

Once the company offers you a job, you *can* be asked questions that might reveal a disability – as long as the same questions are asked of all applicants. At this point, if you decide to disclose your hemophilia, the company cannot withdraw its offer unless it determines that your condition prevents

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1. For the full text of the The Americans with Disabilities Act of 1990, Titles I and V: www.ada.gov
2. Emphasis added. This excerpt is from the Equal Employment Opportunity Commission's website, a good resource for questions employers are allowed to ask: www.eeoc.gov

BY ZIVA MANN

When "we" have a bleed

If I have to tell one more person that parenthood changes the parent, I think I'll fall asleep mid-sentence. Yes, parenthood changed us. Hemophilia changed us. But it's not as if Shai burst into the world like a juggernaut, smashing things in his wake. He was just there, simply and relentlessly waiting for us to become the parents he required. With love, we wrapped the threads of our lives around him, tight, tight – and then too tight, in what psychologists call *enmeshment*. Soon, I couldn't find my old self inside the mom I'd become, or unravel my mom-self from Shai. But I needed to. While I worked to separate myself from him, Shai eventually showed me that we aren't so very different. Even a carrier, it seems, can have a bleed.

When he was a baby, on the day of his *bris*,* Shai bled. His blood dried and cracked on my hands and clothes, and I couldn't quite look at it – but I couldn't quite look away, either. Blood washed away every other thought, narrowing my world down to hemophilia. I bored people with lab results; read books, magazines and blogs about bleeding disorders; ate, slept (sort of) and breathed hemophilia.

Then, when inhibitors hit us, they came as a cold, black wall of water, washing all else away. They left only a clean, fierce purpose: Shai. Whatever he needed, whatever it took. I moved fast, trying to keep up with labs and ports and bleeds, my eyes full of Shai, my head full of little else. And I succeeded too well. One day, instead of saying, "Shai has a bleed," I heard myself saying, "We've got a bleed going." *We*. Alarms rang, warning me that something was wrong. "I am not Shai," I reminded myself. "I am his mother – and I clot."

Motherhood wrapped itself around me and hung on tight, as I looked for ways to be just me, rather than Mom. "I am I and Shai is Shai," I recited, but it wasn't that simple. Caring for Shai filled my days, forcing me to take a leave of absence from school. "I'm sorry," I told my professor, and walked away with my chest tight. At home, the walls closed in on me. "*Separate, separate, need to be separate*" chanted my brain. I took a deep breath, sat myself down, and lectured. "Hemophilia is just one piece of one member of our family – it is *not* allowed to hog the limelight. And for heaven's sake, woman, get a hobby."

But having sat so long and so patiently in my own DNA, hemophilia wouldn't fade quietly into the background now. "Shai is Shai and you are you," hemophilia snickered, "but the distinction isn't so simple." Which is, unfortunately, true. Carriers are called *symptomatic* because our factor levels are low enough to affect us. I've always had heavy, curl-up-in-an-anemic-ball periods, big colorful bruises with white solid centers, easy nosebleeds that start and stop for days, and let's not get into postpartum, shall we? But *I* don't have hemophilia, *Shai* does. I'm just symptomatic.

Or I was, until I fell down the stairs.

Over the next few days, my back swelled and pain uncurled inside me. My primary care doctor scratched his head. "Hey, Mom," said Shai, "you have a bleed!" I stared at him. Really? "Really," said the HTC, checking my factor levels and sending over a box of factor with my name on it. I held the box, worried. I am I and Shai is Shai, but why is my name on the prescription label?

"Hold still," Shai told me, reaching for the butterfly needle. Carefully, intently, Shai slid the needle into my vein. Years of infusing my son were flipped upside down as he pushed the factor into my bloodstream. I am I and Shai is Shai, but oh, this overlap worried me. The fierce specter of the hemo-mom loomed over me. Her world now seemed so narrow and scared, and I knew I wouldn't go back to it. Watching Shai's hand on the syringe, I relaxed, proud of Shai.

Days of infusions followed. The swelling faded slowly and my pain faded faster. The bruising was immense, still spreading after the infusions ended, as old blood rose to the surface. Shai was fascinated. "I love your colors," he sighed.

Months later, a hematologist grumbled about the label *symptomatic carrier*. I blinked. "We could just call it mild hemophilia," he said. I shook my head, skeptical. But, well, that's my box of factor, my factor log, my Amicar and – maybe – my diagnosis. I yanked out a crayon and wrote, "Hemo. Mom." I looked at the words, thinking hard.

I am not him, and he is not me. We just…overlap.

* *ritual circumcision*

Resource Guide... continued from cover

Legacy: The Hemophilia of Yesterday

Matthew Dean Barkdull, 2006

A teen with a passion for writing begins a journal in 1942, during World War II. What mysterious illness plagues him? Ralph Dean Rytting's wartime journal may be the earliest published personal account of hemophilia. Eloquent yet simple, these intimate recollections reveal a stoic teen whose suffering deepened his appreciation for all tender mercies in life. Sponsored by and available through Bayer HealthCare: www.kogenatefs.com and Accredo's Hemophilia Health Services: www.HemophiliaHealth.com

The Gift of Experience: Conversations About Hemophilia

Laura Gray, LICSW, and Christine Chamberlain, 2007
Boston Hemophilia Center
Free from NHF; $12.50 from Amazon.com

Compilation of personal stories from transcripts of 21 hemophilia patients, 40 and older, who are treated at BHC. Includes quotes from doctors, nurses, and a social worker who cared for patients for 40 years. Describes life with hemophilia during HIV and hepatitis C infections. Offers insightful testaments to optimism, determination, resilience.

books

BOOKLETS & BINDERS

A Consumer's Guide to Hemophilia and von Willebrand Disease Products

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

Comparative, concise guide to all factor concentrate and specialty products for bleeding disorders. Designed for consumers. Factor VIII, factor IX, factor IX complex, inhibitor and VWD products are color-coded and easy to cross-reference. Binder can be inverted as a stand for flip-chart teaching. Sponsored by Factor Support Network: www.factorsupport.com

Empower Yourself About Hemophilia

Kelley, Laureen A., 2004
LA Kelley Communications, Inc.
www.kelleycom.com

For families of children newly diagnosed with hemophilia. Includes goal-setting methods and ways to change perceptions of hemophilia to take charge of your life. Before-and-after illustrations offer concrete methods of regaining control during the rocky first year of hemophilia. Sponsored by Grifols USA: www.grifolsusa.com

Living with Hemophilia (series)

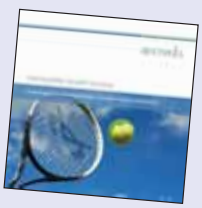
Accredo's Hemophilia Health Services, 2008
www.HemophiliaHealth.com
English, Spanish

Age-specific educational booklets cover developmental events of different life stages: 0–12 months, 1–5 years, 6–11 years, 12–18 years, adult.

An Educator's Guide to Bleeding Disorders

Accredo's Hemophilia Health Services, 2008
www.HemophiliaHealth.com

Gives educators a general overview of bleeding disorders; answers common questions about recognizing and responding to bleeds. Includes list of risk categories of sports and activities; fill-in page for parents to note critical contact information in the event of a bleed.



A Coach's Guide to Bleeding Disorders

Ruth Mulvany, MS, PT, 2008
Accredo's Hemophilia Health Services
www.HemophiliaHealth.com

For sports coaches, scout leaders, physical education teachers who supervise students with a bleeding disorder. Includes overview of bleeding disorders; guidelines for recognizing and responding to bleeds; list of risk categories of sports and activities.

A Guide to Venous Access Devices

Accredo's Hemophilia Health Services, 2008
www.HemophiliaHealth.com
English, Spanish

Outlines types of venous access devices for people with hemophilia, highlighting major benefits and drawbacks. Co-sponsored by Bayer HealthCare: www.kogenatefs.com.

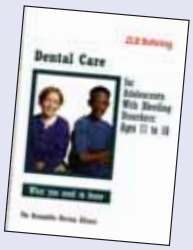
Inhibitors in Hemophilia A: What Patients and Families Need to Know

Grifols
www.grifols.com

Overview of hemophilia. Topics include *What is an inhibitor?* and *What can be done about inhibitors?* Provides inhibitor log for long-term use.

booklets

Dental Care (series)



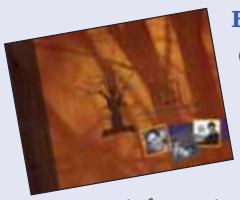
CSL Behring Choice Support Center, 2005
www.helixatefs.com

Four-part series on dental care for individuals and families with hemophilia A, hemophilia B, VWD: *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; Dental Care for Adults With Bleeding Disorders.*

Educational Support Brochures

Novo Nordisk Inc.
www.novonordisk-us.com/biopharm
Contact your local HTC

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



B2B Speaking from Experience

Coalition for Hemophilia B, 2006
www.coalitionforhemophiliab.org

Colorful booklet for adults and teens shares personal experiences of factor IX deficient patients. User-friendly information for people already living successfully with hemophilia B. Sponsored by Wyeth Pharmaceuticals: www.hemophiliavillage.com

binders

B2B Speaking from Experience: A Guide for Mature Adults

Coalition for Hemophilia B, 2007
www.coalitionforhemophiliab.org

Provides helpful knowledge for making informed life decisions and remaining healthy today and in future. Sponsored by Wyeth Pharmaceuticals: www.hemophiliavillage.com

Living with Hemophilia B

Wyeth Pharmaceuticals
www.hemophiliavillage.com

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

A Family Guide to Hemophilia B

CSL Behring Choice Support Center, 2005
www.helixatefs.com

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

What is Mild Hemophilia?

National Hemophilia Foundation, 2008
www.hemophilia.org

Educates young consumers about coagulation, prolonged bleeding, inheritance, common myths. Includes tips on prevention, basic treatment options. Developed by HTC nurses with support by Centers for Disease Control and Prevention.

PROGRAMS & WORKSHOPS

First Step

National Hemophilia Foundation
www.hemophilia.org

Local parents work with a professional team, including local hemophilia organization and HTC representatives, to provide small meetings, social gatherings, networking opportunities, and mentoring relationships for parents of newly diagnosed children. Includes Train-the-Trainer program, First Step brochures, welcome kits.

program

National Youth Leadership Institute (NYLI))

National Hemophilia Foundation
www.hemophilia.org

Leadership training for ages 18–26 in developing skills to become future leaders in the hemophilia community. NYLI hosts winter retreats for young people; leadership training opportunities at summer camps; chapter events through Team Hemophilia on Tour program.

Karing for Kids®

Accredo's Hemophilia Health Services
www.HemophiliaHealth.com

Educational, creative workshops for children and families with bleeding disorders. Emphasizes learning through play; includes interactive learning stations. Parents learn how children understand hemophilia at different ages, while children enjoy fun activities. Workshops can be customized for age groups: Hemophilia Basics (ages 2–6), My Amazing Blood (ages 7–10), Junior Scientist (ages 11–15). Directed by Diane Horbacz, MA, MEd.

Customized Workshops

Accredo's Hemophilia Health Services
www.HemophiliaHealth.com

Workshops offered as a community service. Topics include ART of Communication; stress management; assertive communication; identifying and accessing community resources; grief and loss; clients and families in crisis; making wise educational choices; hepatitis; school/workplace issues. Presented by John Jarratt, MEd, LPC.

Living with Hemophilia

Bayer HealthCare
www.livingwithhemophilia.com

Provides practical tips and tools for patients and families living with hemophilia. Includes interactive meetings at local HTCs across the country and an online magazine. Patients and families can share experiences and insights; find interactive resources, including articles to rate for usefulness; download forms and checklists.

School Preparedness Program

Coram Hemophilia Services
www.coramhemophilia.com

Series of educational presentations helps families and HTC staff learn how to educate school personnel and students about hemophilia: what it is, how it feels, how it's treated, how schools should respond. Families receive tools and materials to make school preparation easier.

Inalex Communications Workshops for Men

www.inalex.com
Programs presented in English, Spanish

Fun interactive workshops, retreats, teleconferences led by nationally renowned experts who discuss practical advice on family relationships and hemophilia.

Gettin' in the Game℠

CSL Behring Choice Support Center
www.helixatefs.com
Available through HTCs or local NHF chapters

Encourages kids with bleeding disorders to exercise, play sports, be active. Exercise can help build stronger muscles and joints; improve venous access; build self-confidence; teach teamwork; create a sense of community. Offers local events where children and families can learn sports tips, participate in exercises and warm-ups, and meet other kids with bleeding disorders.

NHF-CSL Behring Junior National Championship

CSL Behring Choice Support Center
www.cslbehring.com

Encourages kids with bleeding disorders to be active and stay fit by participating in four baseball and golf regional competitions. Competitions include clinics, art programs, group exercises, awards. Four regional winners in golf and baseball receive a trip for themselves and two accompanying adults to compete against other regional winners in the final round.

Puppets as Teachers in Hemophilia (PATH)

Wyeth Pharmaceuticals
www.hemophiliavillage.com
Available through HTCs only

Helps healthcare professionals teach children with hemophilia about their disorder using Bob, a specially designed puppet. Facilitates instruction about bruises; healthy vs. bleeding knee joints; venous access though an external catheter and prominent vein.

Dads in Action

Hemophilia Federation of America (HFA)
www.hemophiliafed.org

Network of involved fathers to help other fathers face the challenges of raising children with bleeding disorders. Provides answers, resources, educational programs to address questions about a child's growth and development with a bleeding disorder.

Coram Community Conference Calls

Coram Hemophilia Services
www.coramhemophilia.com

Series of conference calls to listen, learn, interact with others in the bleeding disorder community. Patients, parents, community leaders, renowned clinical experts speak on range of topics. Participate from home anonymously. No registration fee. Visit website for current list of speakers and topics.

Camp SuperFly

Baxter BioScience
www.thereforyou.com
Contact your chapter or HTC

Annual nationwide competition brings together hemophilia patients, families, chapters, HTCs. Players earn team points and learn about hemophilia through mail-in challenges. Chapters can earn up to $15,000 in grants for their summer camps.

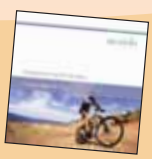
FOR VON WILLEBRAND DISEASE PATIENTS & PARENTS

A Guide to Living With von Willebrand Disease

Renée Paper, RN, with Laureen A. Kelley, 2006
LA Kelley Communications, Inc.
www.kelleycom.com

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: www.cslbehring.com

Living with von Willebrand Disease



Accredo's Hemophilia Health Services, 2008
www.HemophiliaHealth.com
English, Spanish

Comprehensive booklet provides general overview of VWD, including diagnosis, genetics, treatment options, Q&A.

von Willebrand Disease: What Patients Need to Know

Grifols
www.grifols.com

Reviews basics about living with VWD, treatment, general recommendations.

CEO

Baxter BioScience
www.thereforyou.com
Contact your chapter or HTC

Full day of interactive activities helps ages 15–20 develop skills in career planning and financial understanding; consider their interests and skills; manage real-world finances; explore career options. Facilitated by professionals experienced in career development.

Facts First

Baxter BioScience
www.thereforyou.com
Contact your chapter or HTC

Series of educational events hosted by a chapter or HTC that helps people and families with hemophilia learn in a unique way. Topics include pain management, joint health, emergency care, nutrition.

HemophiliaMoms

CSL Behring
www.hemophiliamoms.com

Advice from real moms raising children with bleeding disorders. Offers mentoring on day-to-day challenges through community events, website, Mom2Mom e-newsletter.

Patient's Guide to Understanding VWD

CSL Behring
www.helixatefs.com

Discusses VWD symptoms and diagnosis; offers general information on treatment options.

Healthy Body, Healthy Mind: Von Willebrand Disease

Grifols
www.grifols.com

DVD provides interviews of physicians and patients with VWD; includes patient journal.

North American Camping Conference of Hemophilia Organizations (NACCHO)

Arizona Hemophilia Association, Inc.
www.hemophiliaz.org

Weekend workshop for planning, organizing, operating a bleeding disorder summer camp. Attendees include camp counselors, camp directors, infirmary staff, fundraisers, activities leaders, camp committee members. Nationally known presenters share camp resources and techniques; explore camp programs and activities; facilitate networking and problem solving. Funded by Wyeth Pharmaceuticals: www.hemophiliavillage.com

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.

My Journal

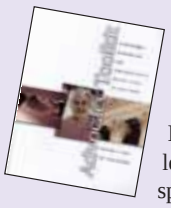
CSL Behring
www.helixatefs.com

Educates women with bleeding disorders about menstruation. Includes easy-to-use bleeding journal to keep track of the menstrual cycle.

Wyeth Self-Infusion Training Kit

Wyeth Pharmaceuticals
www.hemophiliavillage.com
Available through HTCs

Synthetic hand and elbow model for practicing infusion techniques. Includes replaceable skin and veins for inserting a butterfly needle and infusing factor; infusion mat, tourniquet, butterfly needles, biohazard disposal container; sample ReFacto R2 Kits to practice product reconstitution.



Advocacy Toolkit

Bayer HealthCare
www.kogenatefs.com

Explains how to write effectively to legislators; organize meetings or speak at hearings; write for newspapers or speak on radio; convey a strong understanding of insurance issues. Comprehensive, easy-to-read, colorful toolkit offers strategies to help the bleeding disorder community protect against threats to factor coverage. Copies are limited.

Kits from Baxter

Baxter BioScience
www.thereforyou.com
Available through HTCs

Flight Gear – For the Newly Diagnosed

Helps newly diagnosed patients and families understand care and management of hemophilia. Includes brochures, treatment log entry forms, evaluation checklists, and two Inalex videos: *The Hemophilia Diagnosis for Parents* and *The Hemophilia Diagnosis for the Extended Family*.

Home Infusion Kit

Helps caregivers start their child's factor replacement at home. Includes educational activities, step-by-step guides, infusion logs, infusion CD/DVD, emergency contact card.

kits from baxter

Self-Infusion Kit

Provides tools for factor replacement for patients who are ready to self-infuse. Includes step-by-step instructions, bleeding/infusion log, tools to use at infusion time.

Venous Access Toolkit

Customized binder of venous access resources for caregivers and clinicians.

Hemophilia – A School Toolkit

Helps healthcare professionals provide school personnel with resources to understand hemophilia. Offers specific guidelines for dealing with injuries or emergencies. Includes Inalex video *Hemophilia: Teaching the Educators*.

RPM Road to Pro Moves Transition Kit

Series of brochures to help initiate dialogue between clinicians, patients and caregivers about transition issues. Illustrated stories show typical challenges and situations faced by young people with hemophilia. Topics include self-infusion; managing school and life; taking ownership of one's care.

CHILDREN & TEENS

Books

What is Hemophilia? (series)

Laureen A. Kelley, 1995
LA Kelley Communications, Inc.
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: www.cslbehring.com

Level 1: Joshua, 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)*

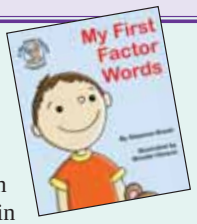
Level 2: They'll Probably Ask You "What is Hemophilia?"

Humorous story about Tony, who must explain hemophilia to his fourth-grade classmates. Includes glossary for children. *(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 and 14–16. Also for teachers and parents of newly diagnosed children. Includes glossary. *(ages 11–16)*

My First Factor Words



Shannon Brush, 2009
LA Kelley Communications, Inc.
www.kelleycom.com

The world's first toddler book for children with hemophilia reviews basic, one-word concepts in a colorful, chunky book just right for small hands. *(ages 18 m–4 yr)* Sponsored by Factor Support Network: www.factorsupport.com

Must You Always Be a Boy?

Laureen A. Kelley, 1991
LA Kelley Communications, Inc.
www.kelleycom.com

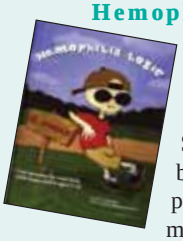
Four illustrated rhyming tales explore adult reactions to bleeds, overprotective parents, sibling rivalry, classroom bullies. *(ages 3–8)* Sponsored by CSL Behring: www.cslbehring.com

Alexis: The Prince Who Had Hemophilia

Laureen A. Kelley, 1992
LA Kelley Communications, Inc.
www.kelleycom.com
English, Spanish

True story of Alexis, youngest child of Russian Tsar Nicholas II, and how his hemophilia influenced events leading to the Russian revolution. *(age 8 and older)* Sponsored by CSL Behring: www.cslbehring.com

Hemophilia Logic



Diane Horbacz, 2005
LA Kelley Communications, Inc.
www.kelleycom.com

Sherlock Bones guides children through activity book about hemophilia, body functions, independence, treatment, self-esteem. Colorful mazes, matching, glyphs, games, puzzles. *(ages 7–13)* Sponsored through grant from Factor Foundation of America: www.factorfoundation.org and Wyeth: www.hemophiliavillage.com

children

teens

Factor Fun!

Diane Horbacz, 2006
LA Kelley Communications, Inc.
www.kelleycom.com

Illustrated activity book teaches about hemophilia, safety and self-esteem with colorful mazes, matching, glyphs, counting. Activities arranged by color-coded topic. *(ages 4–7)* Sponsored by Accredo's Hemophilia Health Services: www.FactorCare.com

Infusion Time

Diane Horbacz, 2007
Accredo's Hemophilia Health Services
www.HemophiliaHealth.com

Teaches basic steps of infusing through a port. Interactive, rhyming, multi-sensory book perfect for child who is curious and eager to be involved in his medical care. Includes teaching tips for parents to promote confidence and self-esteem. *(ages 3–11)* Co-sponsored by Bayer HealthCare: www.kogenatefs.com

Infusion Time 2

Diane Horbacz, 2006
Accredo's Hemophilia Health Services
www.HemophiliaHealth.com

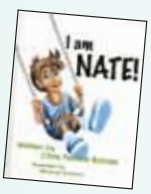
Teaches children how to infuse using venous access. Colorful graphics, activities and rhymes make it easy to remember basic steps to complete an infusion, and encourage participation. *(age 3 and older)* Co-sponsored by Bayer HealthCare: www.kogenatefs.com

The Great Inhibinator

Chris Perretti Barnes, 2006
BioRX
www.biorx.net

Colorfully illustrated story about Nate, a boy who discovers he has an inhibitor, centers on creating a Halloween costume. *(ages 4–7)* Sponsored by Bayer HealthCare: www.kogenatefs.com

I Am Nate!



Chris Perretti Barnes, 2007
BioRX
www.biorx.net

Story about Nate, a boy who tells how having hemophilia affects his life. *(ages 4–7)*
Sponsored by Bayer HealthCare: www.kogenatefs.com

Bob the Puppet Story Books (series)

Wyeth Pharmaceuticals
www.hemophiliavillage.com

Positive, colorful, easy-to-read hardcover books to open 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. *Bob the Puppet Goes to School:* Bob attends a new school and talks about hemophilia. *(ages 4–7)*

Rafting Rescue!

Susan Zappa, Madeline Cantini, Sue du Treil, Ed Kueblier, Karen Wulff, 2004
Cook Children's Medical Center
susanz@cookchildrens.org

Illustrated chapter book about adventures at camp and how to handle and treat VWD. *(ages 10–16)*

CD, DVD & Video

Every Step of the Way

Bayer HealthCare
www.kogenatefs.com

Animated "Factor 8" character connects with Jimmy, who has factor VIII deficiency, in an online chat room. Factor 8 guides Jimmy through the factor VIII manufacturing process. Translates technical manufacturing processes into entertaining, straightforward, step-by-step overview.

Games

Wooden Peg Puzzle

Accredo's Hemophilia Health Services
www.FactorCare.com

Helps children develop fine motor skills and dexterity while focusing on language development, with medical items familiar to treatment. *(ages 3–7)* Sponsored by Bayer HealthCare: www.kogenatefs.com

Factor Match: The Memory Challenge Game

Baxter BioScience
www.thereforyou.com

Stack of illustrated cards about hemophilia creates a memory card game to help children remember what to do if they get hurt and how to take factor. Reminds children of things they can do just like everyone else. Play as matching game or use as flash cards.

The Thumball™ Camp Program

Wyeth Pharmaceuticals
www.hemophiliavillage.com

Educational activity featuring three different custom-designed Thumballs, each serving to stimulate conversation, encourage every camper (and counselor) to participate, and link learning with fun.

FactorQuest

Coram Hemophilia Services
www.coramhemophilia.com
Download through Coram's website or as CD

Action/adventure video game for kids with bleeding disorders challenges them to learn about their bleeding disorder, master its treatment, and "evolve" to independence. In debut episode, *Cavern of Bones*, players face a common challenge of bleeding disorders: maintaining healthy joints.

PERIODICALS

Parent Empowerment Newsletter (PEN)

LA Kelley Communications, Inc.
www.kelleycom.com

Quarterly. Only newsletter produced and edited by a parent of a child with hemophilia. Provides medical, scientific, consumer, parenting articles and news. Investigates current topics in balanced, objective style. Empowers parents and patients as educated consumers.

Living With Hemophilia®

Bayer HealthCare
www.LivingWithHemophilia.com

Quarterly. Electronic newsletter features expert advice; columns from hemophilia community members; practical tips for living with hemophilia.

eNotes

National Hemophilia Foundation
www.hemophilia.org

Monthly. Electronic newsletter informs the community on current medical breakthroughs, blood safety, advocacy updates, industry information, community news.

HemAware

National Hemophilia Foundation
www.hemophilia.org

Bimonthly. Newsletter of largest US hemophilia nonprofit. Articles on bleeding disorder medical research and treatment; articles for families; reports on community events.

Bloodstone Magazine

Accredo's Hemophilia Health Services
www.HemophiliaHealth.com

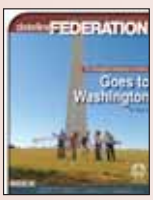
Semi-annual. Articles on living with hemophilia; profiles of families and people; Q&A and news.

Factor Nine News

Coalition for Hemophilia B
www.coalitionforhemophiliab.org

Quarterly. Brief newsletter features latest news and treatment for hemophilia B; community events.

Dateline Federation



Hemophilia Federation of America (HFA)
www.hemophiliafed.org

Quarterly. News magazine of second largest national hemophilia nonprofit. Healthcare information 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 from home healthcare company for hemophilia patients features patient profiles, news, new products and services.

Wyeth Lifelines

Wyeth Pharmaceuticals
www.hemophiliavillage.com
Hard copy or e-newsletter

Bimonthly. Information about hemophilia treatment; tips for living an active life; inspirational stories from people living with hemophilia; latest programs and services from Wyeth.

Post Script Informer

Patient Services, Inc. (PSI)
www.uneedpsi.org

Quarterly. Newsletter of nonprofit that helps people with certain chronic illnesses or conditions locate suitable health insurance coverage and access ways to satisfy expensive co-payments. Up-to-date information on insurance changes for people with chronic disorders.

Voices Uninhibited

Novo Nordisk Inc.
www.novonordisk-us.com/biopharm

Quarterly. First newsletter devoted solely to the inhibitor community that provides treatment information, events, patient stories, Q&A, new resources.

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 Magazine

Plasma Protein Therapeutics Association (PPTA)
www.pptaglobal.org

Quarterly. Information about the global plasma protein therapeutics industry. Includes interviews with key leaders; guest 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. Newsletter of Save One Life, a non-profit founded by Laurie Kelley, which provides individual child sponsorships to children with bleeding disorders in impoverished countries.

TFY

Baxter BioScience
www.thereforyou.com

Quarterly. Inspirational stories about families with hemophilia; product information from Baxter BioScience.

WEB-BASED PROGRAMS

GameFaces™

CSL Behring
www.GameFaces.com

Encourages physical activity by providing kids with customized physical challenges based on age, bleeding disorder severity, current level of physical activity. Child chooses a GameFaces™ character and logs on daily to track his physical activity progress.

CD, DVD & VIDEO

Hemophilia in Pictures

World Federation of Hemophilia, 2005
www.wfh.org
English, Spanish, French, Arabic, Russian, Chinese;
Web module, PDF or CD only

Pictorial guide to hemophilia for health-care workers, parents, patients. Reflects the multicultural diversity of the global hemophilia community. Useful for teaching people with low literacy levels. Includes teaching notes.

The Gift of Life

Plasma Protein Therapeutics Association
www.pptaglobal.org
English; Spanish subtitles

How plasma protein therapy is created, from plasma donor to patient, from vein to vein. Hear from plasma donors,physicians, consumers; learn about the complex development of plasma protein therapies and the industry's commitment to safety, quality, innovation.

Function of FVIII at the Site of a Bleeding Joint

Bayer HealthCare
www.kogenatefs.com

Patient-friendly CD illustrates and explains the role of factor VIII in repairing a bleed. Describes clot formation and the role of the factor VIII molecule. Describes an adult patient and the role the molecule plays in his life.

A Bright Future (series)

Inalex Communications
www.inalex.com

DVD series about living with hemophilia. *The Hemophilia Diagnosis* includes parents' testimonials on how they felt and coped, inspiring new parents to overcome fear and doubt and better handle hemophilia. Includes *The Extended Family* and *Teaching the Educators*. Sponsored by Baxter BioScience.

ORDERING INFORMATION

Accredo's Hemophilia Health Services
201 Great Circle Rd.
Nashville, TN 37228
(800) 800-6606
www.HemophiliaHealth.com

Baxter BioScience
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

BioRX
5800 Creek Road
Cincinnati, OH 45242
(866) 44-BIORX
www.biorx.net

CSL Behring
Choice Support Center
1020 First Avenue
King of Prussia, PA 19406
(888) 508-6978
www.helixatefs.com

Coalition for Hemophilia B
825 Third Avenue, Suite 226
New York, NY 10022
(212) 520-8272
www.coalitionforhemophiliab.org

Committee of Ten Thousand
236 Massachusetts Ave. NE
609
Washington, DC 20002-4971
(800) 488-2688
www.cott1.org

Cook Children's Medical Center
801 Seventh Avenue
Fort Worth, TX 76104-2796
susanz@cookchildrens.org

Coram Hemophilia Services
6 Spring Mill Drive
Malvern, PA 19355
(888) HEMO-789
www.coramhemophilia.com

Factor Support Network
900 Avenida Acaso, Suite A
Camarillo, CA 93012-8749
(877) FSN-4-YOU
www.factorsupport.com

Hemophilia Association, Inc.
4001 North 24th Street
Phoenix, AZ 85016
(602) 955-3947
www.hemophiliaz.org
www.naccho.com

Hemophilia Federation of America (HFA)
1405 West Pinhook, Suite 101
Lafayette, LA 70503
(800) 230-9797
www.hemophiliafed.org

Inalex Communications
38 East Ridgewood Ave #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

Novo Nordisk Inc.
100 College Road West
Princeton, NJ 08540
(609) 987-5800
www.novonordisk-us.com/biopharm

Patient Services, Inc. (PSI)
PO Box 1602
Midlothian, VA 23113
www.uneedpsi.org

Plasma Protein Therapeutics Association (PPTA)
147 Old Solomons Island Road
Suite 100
Annapolis, MD 21401
(800) UPDATE-U
www.patientnotificationsystem.org

Save One Life
PO Box 922
Byfield, MA 01922
(978) 352-7652
www.SaveOneLife.net

World Federation of Hemophilia (WFH)
1425 Réne Lévesque
Boulevard West, Suite 1010
Montreal, Quebec H3G 1T7
Canada
(514) 875-7944
www.wfh.org

Wyeth Pharmaceuticals
500 Arcola Road
Collegeville, PA 19426
(888) 999-2349
www.hemophiliavillage.com

Manufacturer

Longer-Acting FVIIa?

Bayer HealthCare has started phase I clinical testing of the recombinant factor VIIa protein acquired from Maxygen.

Source: "Bayer expands hemophilia franchise," Ron Leuty, *San Francisco Business Times*, October 24, 2008

Breaking News: Pfizer to Buy Wyeth

Pfizer Inc. will pay about $68 billion for Wyeth, according to the two pharmaceutical companies' announcement on January 26. New York-based Pfizer, which also has operations in New Jersey, expects the cash-and-stock deal to close by the end of 2009.

Source: www.njbiz.com

Global

Project SHARE Donates 3.7 Million IUs

Project SHARE, the humanitarian program of LA Kelley Communications, donated over 3.7 million IUs to more than 30 countries in 2008. Operational support in 2008 was provided by Acreedo's Hemophilia Health Services, ASD Healthcare, Bayer HealthCare, Baxter BioScience, CSL Behring, Grifols USA, New England BioLabs, and Novo Nordisk. Most factor donations are unwanted or unused product from HTCs, specialty pharmacies, and individuals.

For information: www.kelleycom.com

India: On the Road to Independence

India has committed to building five world-class blood banks at a cost of $95.5 million. These facilities will have the capacity to process nearly 300,000 units of blood a year, and the Chennai plant will have a plasma fractionation unit to produce coagulation factor concentrates for hemophilia patients.

Source: *IBPN*, January 2009

China's First HTC

On January 11, 2009, The Institute of Hematology and Hospital of Blood Diseases of Chinese Academy of Medical Sciences began operating a hemophilia treatment center in Tianjin City – first of its kind in China. The center will provide prophylaxis for patients up to age 18, and free recombinant factor VIII for some impoverished patients. China plans to build 40 HTCs in 30 cities in the next five years. Of the 100,000 people with hemophilia in China, fewer than 5% receive proper treatment.

Source: www.shihua.com.cn and www.tradingmarkets.com

Home Care

Recombi Closes

Recombi, a specialty pharmacy in Westlake Village, California, that focused on providing services to hemophilia patients, has closed its doors. As of this writing, the website is still accessible.

For information: www.recombi.com

Nonprofit

Hemophilia Federation of America Annual Meeting

The HFA 2009 Annual Educational Symposium will be held March 13–14 at the Marriot East Indianapolis, Indiana. This year's theme is "On the Right Track," and the program hopes to create a strong, unified voice of community and self-advocacy.

To register: www.hemophiliafed.org/site33.php

Michigan Hemophilia Foundation Trains Youth Advocates

MHF hosted CSL Behring's *Raise Your Voice!* for Michigan youths at a teen retreat on October 25–26, 2008. The program offers training and tools to encourage teens to share their perspectives and experiences in public policy discussions, become partners with government, and effect change. Representative Mike Simpson, vice chair of the Health Policy Committee, Michigan House of Representatives, delivered the keynote speech. He shared his personal story about running for office, presented an overview of lawmaking, and encouraged youths to vote and become self-advocates.

For information: CSL Behring *Public Policy Newsletter*, Policy Impact – US, Fall/Winter 2008, www.cslbehring.com

Medical

Study Suggests Single Dose Enough to Treat Joint Bleeds in Inhibitor Patients

Recently published research suggests that a single dose of rFVIIa efficiently stops hemorrhaging, alleviates pain, and improves mobility in joints while avoiding the need for additional medications to stem bleeding. The findings from these studies, designed primarily to measure product efficacy and safety, showed that a single dose of rFVIIa is comparable to repeat dosing. Study funded in part by Novo Nordisk.

For information: "Single-dose Recombinant Activated Factor VII for the Treatment of Joint Bleeds in Hemophilia Patients with Inhibitors," *Clinical Advances in Hematology & Oncology*, August 2008

Transitions... continued from page 6

you from performing essential job functions or that you would pose a risk of injury to yourself or others.

As you can see, the interview process can become a game of semantics. The bottom line? Be prepared. Have a response ready if the subject of hemophilia surfaces. Worst-case scenario? You're not prepared for the question, and you're caught like a deer in headlights.

When In Doubt, Seek Help

The subject of discrimination in the hiring process involves complex legal issues. If you think you're a victim of discrimination, seek legal assistance and consider filing a claim with the Equal Employment Opportunity Commission (EEOC).

Bear in mind that there are time limitations for filing claims, and that legal action far from guarantees a satisfactory outcome. Obtaining representation is difficult, and according to Beth Sufian, only 3% of ADA cases are won by the employee.

If you decide to pursue legal remedies, the Bleeding Disorders Legal Information Hotline is a sound place to start. The toll-free number is (800) 520-6154.

There's no way to predict if the subject of your hemophilia will arise during a job interview. In any case, you should be prepared to address it. Handling the issue with poise could end up landing you the job.

Richard's Review... continued from page 3

coughs, he is likely to cough blood. Sometimes he passes it in his urine, which leads them to believe the internal tissues have frayed…The poor child bumped his arm against a baggage rack when his train carriage lurched… and was laid up for weeks…What should be a bruise for another child, is an incapacitation for Prince Leopold."[1]

The romance of Georgie and Patrick was a bit cheesy for my taste, but the suspense kept my attention. Unfortunately the story is sometimes confusing, as chapters are narrated by various characters. Queen Victoria is inaccurately portrayed as too evil; she may have been eccentric, but that shouldn't be held against her. Still, I liked *A Flaw in the Blood* because the author did her research, and she acknowledges it in the Afterword, citing appropriate references and offering a genealogical pedigree of Albert and Victoria. Yet the idea that Victoria would use any means, even violence, to suppress information about the genetics of the royal family can only be presented due to lack of proof, not due to substantiated facts.

Hemophilia is adequately explained by *Flaw's* characters, although Leopold's bleeding at birth was fabricated for the novel. The first medical journal report on the royal hemophilia, published in 1868, noted that Leopold experienced more bruising than joint bleeds as an infant. Over time, the royal physicians have revealed the medical conditions of royal family members in a formal, diplomatic way to preserve the family's privacy.

I'm not sure how the hemophilia community will react to the novel's catchy title: to outsiders, the word *flaw* may seem appropriate, but to members of the hemophilia community, it may seem offensive.

1. *A Flaw in the Blood*, pp 182–3.

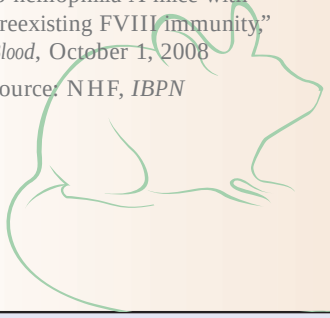
Science

New Gene Therapy: Transgenic Mice Express Factor VIII

Scientists at the Blood Center of Wisconsin's Blood Research Institute and the Medical College of Wisconsin have described a new way to genetically modify an experimental line of transgenic mice to express factor VIII. Scientists removed the bone marrow from mice, genetically modified the stem cells in it, and then reintroduced the marrow to elicit adequate production of factor VIII. In spite of the lack of factor VIII in the plasma of the mice, there was an improvement in clotting. More important, the bleeding was corrected in the presence of high inhibitory antibody titers introduced into the mice by infusion or by spleen cell transfer from recombinant mice. Research funded through an NHF grant.

For information: "Syngeneic transplantation of hematopoietic stem cells that are genetically modified to express factor VIII in platelets restores hemostasis to hemophilia A mice with preexisting FVIII immunity," *Blood*, October 1, 2008

Source: NHF, *IBPN*



Being Frank about Rank

The US spends $2.2 trillion, or 16% of GDP, on healthcare. This is the world's highest percentage, yet we rank 46th and 42nd, respectively, in life expectancy and infant mortality. Without adjustment, healthcare spending will double to over $4 trillion by 2016.

For information: "Don't Curb Your Enthusiasm Just Yet," Daniel Jacome, January 2, 2009, seekingalpha.com

Inhibitor Patients More Prone to Disability

Hemophilia A patients with a history of inhibitor antibodies tend toward increased physical impairment, when compared to hemophilia A patients without inhibitors (after controlling for age). These findings, from the Hemophilia and Thrombosis Research Society (HTRS) Registry, compared 333 patients with inhibitors to 251 patients with moderate to severe factor VIII deficiency, who never had inhibitors. Analysis of data partly supported by Novo Nordisk.

Source: *IBPN*, January 2009

Inbox... continued from page 2

When our four-year-old was diagnosed with severe hemophilia A at 18 months, we were inundated with information. *Raising a Child With Hemophilia* was truly the best resource I came across. Now with two boys with hemophilia, we feel more "seasoned" in the day-to-day trials and tribulations (though I'm certain we have plenty more to learn).
Ann Hodyl
Illinois

Our son Andrew is 13, with severe hemophilia A, and is doing well. Thank you for all your hard work to keep everyone informed in the hemophilia community. You are an inspiration to so many of us. We enjoy *PEN* and all the wonderful information inside it.
Al and Jan Shaw
Illinois

Thank you for all you do. May God continue blessing you all through the new year. Muchas gracias.
Rosa Maria Coles
President, Hemophilia Outreach
Texas

Project SHARE

As we enter the new year, I entreat you to remember that everyone at Project SHARE made it possible for a young man to complete his first semester of college. Most important, please remember that a boy in Africa is alive thanks to you. I wish you a Happy New Year and may God bless you bountifully.
Kofi Agyekum
Ghana

I am writing to thank the LA Kelley Communications staff who gave me a great helping hand. You were not indifferent to a patient with hemophilia far away in Uzbekistan, and twice helped me when I was in critical condition.

It is impossible to find this medicine in our country; it is not available in drug stores, and we receive no government assistance. Considerable numbers of patients die of blood loss, and some become permanently handicapped. My right leg bone has been deformed from hemorrhaging in the joints. I cannot bend or straighten it, and it's hard to sit down.
Dilmurod Poshokhadjaev
Uzbekistan

It's tough to lead a life with a chronic condition without proper medicine. It is sad that we cannot save many lives because of lack of medication. Thanks to you who generously help us in our urgent need. We are always grateful.
Parimal Debnath
Bangladesh

As financial coordinator for an HTC, it really makes me feel better than I ever thought it would to [donate] near-expired factor!
Tom A.
Massachusetts

I have no words to say thank you to everyone who helped us support a young man undergoing lifesaving leg amputation surgery. NovoSeven, donated locally, covered five days post-surgery, while FEIBA arrived in time to cover another seven days. It was heartening to see him walking again. He will soon have an artificial limb. I will work on clearing his inhibitors in the next few months so that he can be treated with factor VIII again.
Dr. Tahir Shamsi
Pakistan

Thank you so much for the shipment you made for my sons Ernest, Everest and Elvis. I am very happy God is using Project SHARE to restore life to my sons. I do not know what I would have done without you. I don't know how to thank you. I will only pray for long life for you and Project SHARE.
Gladys Njoku
Nigeria

Dulguun and his mother were really excited and thankful that you were able to share some factor with them. Thank you and Project SHARE for all your help and kindness.
Jeremy Walker
Kentucky

Thank you and the people who donated such valuable drugs to patients in need in China. I tell everyone who receives a donation that it came from America.
Delin Kong
China

Thank you for the thank-you card regarding the factor donation from Joanne Wombolt, Jonathan Wadleigh's widow. I know that she will be grateful to know just how his factor was utilized to help others. Thank you for the wonderful ministry that you provide to those in need in the global hemophilia community. My best to you all at LA Kelley Communications and Project SHARE. Keep up the great work.
John P. Rider, COTT
Massachusetts

Thank you so much for the factor donation. On behalf of patients and for myself, I want to express my deep thanks to the staff of Project SHARE, who always consider us and have invaluable charity.
Chean Sophal, MD
Phnom Penh, Cambodia

Thanks so much for all your help in getting this factor to someone who can use it. I hated the idea of throwing it away.
Donna S.
Connecticut

Thank you again for your kindness and generosity in providing four-year-old Ron David Torres his lifesaving doses of factor IX. His family was very happy and relieved. As a result, Ron is now out of ICU and recovering in a regular pediatric unit. The family hopes that he will recover fast and be able to go home soon.

I praise God for your ministry. Project SHARE works unselfishly for the benefit of those who cannot advocate for themselves. Although I do not personally know this child, I have become very attached to him, always praying for him and keeping his picture in my Bible. You are a lifesaver. Please continue your invaluable labor of love, and extend my appreciation to your donors.
Carlos M. Salazar
California

Thank you once again for your assistance. Really, you save the lives of people. All the parents of the patients join me in telling you thanks a lot.
Dr. N'Zore
Ivory Coast, Africa

inbox

THANKS FROM THE BOTTOM of my heart for the lifesaving medicines donated to me, due to which I am able to live again. In fact, I had no hope that my treatment was possible because I know how expensive and difficult it is to get factor concentrates. I was so excited to know that Project SHARE was sending medicine for me. In the meantime, I used plasma and factors from Nepal Hemophilia Society in the Bir Hospital. I can only guess what would have happened if your support had not arrived in time. I wish for the progress of your lifesaving organization.
Sita Ram Shestha
Nepal

THANK YOU VERY MUCH for the card and photo! It was a nice surprise to see the young man who is benefitting from our factor donation and your great work. May the new year bring more luck for good works.
Cliff Haas
Massachusetts

MY UNCLE DEEPAK PHADKE brought me the factor VIII medicine which you kindly donated. I have problems with bleeding and joint swelling. Dr. Apte, hematologist and consultant for the Hemophilia Society of Maharashtra (Pune) gives me medical treatment. This factor VIII you sent will be very useful. Thank you so much.
Ketan Phadke
India

THANK YOU SO MUCH FOR sending factor VIII for my son, Abraham. I really appreciate it. May our dear Lord continue to bless Project SHARE! May you continue helping less fortunate people around the globe.
Marietta Charvet
Philippines

GREAT WORK BY LA KELLEY Communications, who are trying to save the lives of those children of the creator of the universe who are suffering from a bleeding disease. I appreciate your sincere efforts in order to serve humanity. May God almighty bestow his choicest blessings in abundance on you.
Priyanka Roopa Rawatindia
India

THANK YOU VERY MUCH for coming to the Philippines. You have done a great job in helping those with hemophilia and other bleeding disorders in the developing world. Your organization's work has truly changed and impacted lives of countless families. God bless you!
Andrea Trinidad-Echavez
Philippines

MY FRIEND, MIKKO GONZAGA, told me that his parents, Reynaldo and Elsa Gonzaga, met you [in October in the Philippines]. They told me that you gave them the factor IX concentrates, and they want to again thank you. I want to personally thank you for giving those concentrates to my friend just when he needed it. Mikko is a very special friend for me, and as much as possible, I don't want to see him in deep pain.
Ronwaldo Reyes
Philippines

HOW I WISH I COULD THANK you in person for all the help you have extended to us, especially my son. Project SHARE saved my son's life. We are almost drained. Honestly, as a public school teacher in the Philippines, my salary is not even enough to buy one vial of factor VIII concentrate. I want my son to go back to college and then find a job so that he can support himself later. I hope I'll be able to realize my dream of seeing my son realize his dreams.

I always tell my son to be strong and have faith in God, to accept what he is, and to try his best to make the most of what he is.

I might break into tears if I related to you all the hardships that Angelo has undergone. God is really good; He did not take my son. He gave him a second chance. Project SHARE and Father Don Kill will always remain in our hearts. God bless you for all that you are doing, especially for those with hemophilia in the Philippines.
Gloria Cuevas
Philippines

WE THANK GOD, PROJECT SHARE, and all those people who continuously support Project SHARE to help those with hemophilia around the world. Miracles do happen!
Joey Aranda
Philippines

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