

Parent Empowerment Newsletter

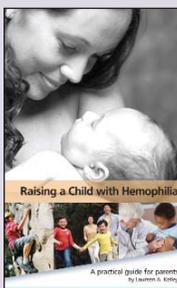
PEN's Biannual

BLEEDING DISORDERS RESOURCE GUIDE

BY ZORAIDA ROSADO

2007

BOOKS



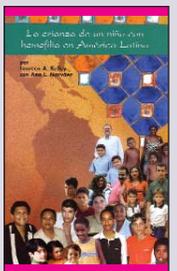
Raising a Child With Hemophilia: A Practical Guide for Parents

Kelley, Lauren A., 2007
(available fall 2007)
LA Kelley Communications, Inc.
www.kelleycom.com



The fourth edition of the world's first parenting book about hemophilia written by a parent of a child with hemophilia.

Practical, easy-to-understand information on medical treatment, genetic transmission, child development stages, consumer issues, school, sports. Includes stories and advice from experienced parents, compiled from interviews with more than 180 families. Sponsored by and available through CSL Behring (www.cslbehring.com).



Raising a Child With Hemophilia in Latin America

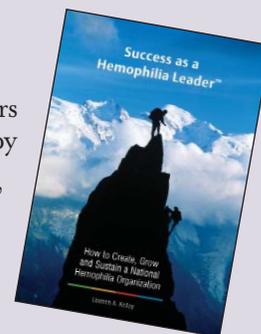
Kelley, Lauren A. with Narváz, Ana L., 2006
LA Kelley Communications, Inc.
www.kelleycom.com
English (PDF only), Spanish or Portuguese

The first book about hemophilia in Latin

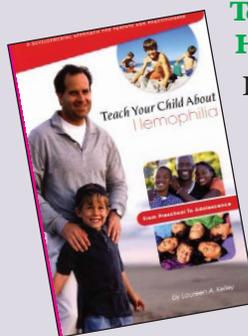
America. Based on interviews with dozens of families and patients in five countries, covering widely diverse areas. Written from parents' point of view by a parent of a child with hemophilia. Topics include differences in hemophilia treatment, genetics, transmission, family dynamics, government policies, being a smart consumer, medical complications. Sponsored by Baxter BioScience (www.hemophiliagalaxy.com).

Success as a Hemophilia Leader

Kelley, Lauren A., 2004
LA Kelley Communications, Inc.
www.kelleycom.com
Free to qualified Hemophilia Leaders
English CD format; Spanish hard copy



The world's first guide to founding, managing and growing a grassroots hemophilia organization. Explores creating a vision and mission, forming a board, fundraising, producing a newsletter, programming, establishing an office, and working with a medical advisory board. Offers valuable advice on creating an organization or improving an existing one. Sponsored by Talecris Biotherapeutics, Inc. (www.talecris.com).



Teach Your Child About Hemophilia

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

In-depth exploration of the way children think and how they 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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- 7 Richard's Review: The Blood Doctor

**All listed resources are free, although some restrictions may apply.
Visit the publishers' websites to register and learn more.**

LA Kelley Communications, Inc.



Sherrell Portrait Design

Every two years, *PEN* publishes something unique: a list of dozens of free resources to help you learn about bleeding disorders. Patients, families, medical staff, nonprofit employees, volunteers, pharmaceutical and home care representatives, even the international community—all consider this one of the most helpful issues we publish. Please read this special feature carefully, and call or email to order the free resources that can help you *today!*

With this issue we inaugurate *Transitions*, a new column that speaks to the younger generation in our community, born after 1985, who are now coming of age. They are the fortunate ones who didn't have to struggle with blood-borne diseases; they reaped the benefits of what happened to our older brothers, those born before this watershed year. My son Tommy is one of the younger generation, and in this first column, I share my thoughts and advice as he strikes out on his own.

You'll read some great commentaries in this issue. In *Homefront*, Ziva Mann relates her hilarious but poignant tale of power struggles with her son, Shai. In *As I See It*, Dennis Penning reminds us of the importance of being informed. Paul Clement gives us the nuts and bolts of pain management for acute situations in *Inhibitor Insights*. And Richard Atwood shares an excellent novel that includes hemophilia and will make a great summer read!

Finally, we say goodbye to a good friend and colleague, Kyle Callahan, president of Hemophilia Health Services, who is retiring. I met Kyle almost 17 years ago, and was awed at his rise to presidency of the largest hemophilia home care in the country. Even more inspiring to me, Kyle has remained the same approachable, compassionate person he always was. He has been our partner with Project SHARE, and even he doesn't realize the impact of his help on hundreds of lives around the world. Currently through Save One Life, Kyle sponsors two children with hemophilia in Belize and Romania, who rely on him for financial aid. As he accepts an early retirement, we wish him well and thank him for so many years of dedicated service. ☺

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inbox

"Switched!" *PEN*, May 2007

THE MAY ISSUE IS OUTSTANDING. THANK you again for showing us what's going on. The [graphic of] three PBM ships and their passenger lists is a very good way of looking at the big picture of providers. The providers on the passenger lists are not always telling consumers this up front. Also, thanks to those who share their stories about being forced to switch. The more we talk about these problems, the more likely we are to get

what we deserve. We should not have to stand by helpless while insurance companies

become total dictators. I really like reading HemaBlog™ as well. Thanks, Laurie, for posting from around the world.

Tom Albright, *Arkansas*

Ed. note: Read HemaBlog online every Monday morning at www.kelleycom.com/blog/.

JUST A NOTE TO LET YOU KNOW THAT I read the May issue twice. It was just so good. Wonderful, really. Keep up the outstanding work.

Elena Bostick, *Executive Director Hemophilia Association of New Jersey*

I'd like to note one correction to your article. HTC's get approximately \$5 million (not billion) of the \$6-plus million from the CDC. I wish it were billion; then no one would be doing 340B!

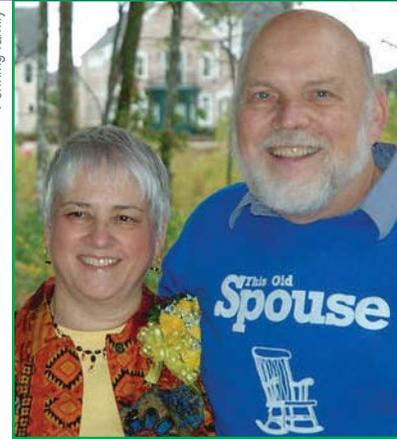
Derek Robertson, *MBA, JD, Maryland*

I WONDERED WHY, AND HOW, PBMS AND insurance companies have so much authority and/or power to do the switching. Can automobile insurance companies dictate the brand of parts that I buy to replace those damaged in an auto accident? Can they dictate the car "doctor" who diagnoses and treats the "patient" (the car)? Then it came to me: Health insurance

BY DENNIS PENNING

The Value of BEING INFORMED

Penning family



Dennis Penning and wife Kieran

THERE IS AN OLD SAW: WHAT YOU DON'T know won't hurt you. Some in the bleeding disorders community use this as a coping skill when overwhelmed with information, especially when a hemophilia diagnosis is completely unexpected, as it is in one-third of new cases. And only so much new information can be absorbed at one time. Still, there is great value in learning as much as you can about this disorder, both when the diagnosis is new and throughout your life and your child's life. While the basics will not change, your understanding will evolve, especially as the science, insurance situations and available resources evolve.

For example, there is great value in keeping updated about the science of hemophilia. Remember, at one time medical science thought there was only one kind of hemophilia, factor VIII deficiency; only in 1952 was factor IX identified. Now, gene therapy is being researched, new factor delivery modes are being studied, and new scientific questions are being considered all the time in hemophilia.

As the insurance industry changes, the financial impact of being informed can be significant. Many of us think we understand how our insurance policy works, for example, until faced with a situation that, after the fact, is not what we'd assumed. Occasionally, families assume that since their factor is paid for by their insurance, everything is fine. They then stop reading and staying informed. Later, they discover

their factor was billed to their regular insurance, not to a separately funded pharmacy plan. Sometimes the factor supplier even knows that another source of payment exists, but chooses not to point that out. Some in our community lost out on the opportunity to receive HIV compensation simply because they couldn't be located. These people decided not to be connected to the community, so no one knew how to reach them or, in some cases, that they even existed.

You don't need to absorb everything new at once. Excellent print materials are available to review at your pace, and new materials are produced constantly. Access these resources through national advocacy organizations, such as the National Hemophilia Foundation and Hemophilia Federation of America; local member organizations; and private companies like LA Kelley Communications or your home healthcare company. Most information is free, but you can purchase some, like *The Hemophilia Handbook* from Hemophilia of Georgia. Most information is in print, although the Canadian Hemophilia Society's *Guide for Families* is available online in English and French. You can download Spanish resources at the World Federation of Hemophilia website. Explore other internet resources, such as email support groups for bleeding disorders. If you don't have a computer at home, your local library may provide internet access. There is significant value in staying

informed, even for those who don't bleed often, if they at least visit their local HTC for information and updates.

We must be vigilant, continue to learn as much as we can, and stay in touch with the community. Throughout this edition of *PEN*, you'll find resources of great value. Use them. Keep in touch with your HTC and local bleeding disorders organization. Let them know when you move or change your phone or email. Our community is small, but our impact can be felt if we stay connected, for we bring value to each other as much as the resources we need bring value to us. ☺

Dennis Penning is clinical service coordinator for the Hemophilia Foundation of Illinois, which he joined in 1991. Dennis, who is fluent in Spanish, has extensive experience in public health and education. Thrombophilia and hemophilia are in his family. He and his wife, Kieran, and their daughter Alyssa have served as a volunteer foster family for Healing the Children. Alyssa has seven siblings from Colombia, Dominican Republic, Guatemala, India and Nigeria who are part of the family.

companies get their authority and power from the health insurance contract between the *insurance company* and the *purchaser of the contract*, who is not necessarily the insured. Unless the patient is buying his own insurance (under contract), the purchaser of the contract (and insurance policy) is the employer or some other entity. I wonder if insurance companies have the power to switch us to a different doctor. I wonder if the people in *PEN* with the horror stories were able to have a lawyer look at the contract under which they were covered.

Jim Olszowka, *Illinois*

As I See It, *PEN*, May 2007

I COULDN'T BELIEVE HOW I COULD RELATE to Jeff Mueller's story ["A Letter to Aetna: What Were You Thinking?"]. We, too, were switched from HHS to ASP without a choice. We encountered similar problems with their shipments, including billing errors, which were likely a result of their high staff turnover. I would like to know if Jeff's policy is an HMO. If so, he should not be billed the \$35 copay. ASP erroneously tried to bill me a few times for copays and balances due. I was told by Aetna Member Services that factor orders like ours are not to be billed to the

pharmacy benefit, but should be billed against the medical benefit. Therefore, they had to credit my account. Please share this information with Jeff or any others dealing with a similar situation. They may be able to save a lot of money through account reconciliation.

Susan Gaede-Tackett, *Florida*

In General...

I RECEIVED THE STRANGEST LETTER IN THE mail today, and I wonder if this has happened to anyone before. The letter is from Ingenix Subrogation Services. My son Dustin was in the ER on January 31

continued on page 5

BY PAUL CLEMENT



Easing the Pain of Inhibitors: Acute Pain

first in a two-part series

PAIN NORMALLY ALERTS US TO AN INJURY, OR TELLS US THAT something's wrong in our bodies. Pain that lasts only hours or days while the body is healing is called *acute* pain. People with hemophilia often have acute pain during a muscle or joint bleed. People with inhibitors must deal with acute pain just like everyone, but may face other, special pain issues. Ongoing pain in inhibitor patients, usually caused by joint damage, is called *chronic* pain. Often destructive and debilitating, chronic pain lasts six months or more.

People with hemophilia often suffer acute pain from a muscle or joint bleed. The key to limiting the damage and pain of such bleeds is to treat *immediately* with the appropriate clotting factor concentrate. When treated immediately, most people with hemophilia can resolve bleeds with a single infusion, often feel little residual pain, and get back to a normal routine soon after the infusion.

Alas, this isn't the case for most people with inhibitors. Bypassing agents, often used in treating inhibitors, are less effective than pure factor concentrates. As a result, bleeding lasts longer. Additional blood in a joint or muscle causes more pain and sets the stage for further complications. Residual blood left in a joint after a bleed inflames the lining of the joint (*synovium*) and attacks the joint's cartilage. Repeated bleeds into the same joint cause chronic inflammation of the synovium. This results in a thickening of the membrane and stimulates the growth of additional blood vessels, a condition known as *synovitis*. The additional blood vessels in the synovial membrane bleed more frequently, causing a *target joint* that bleeds repeatedly and often spontaneously. This vicious cycle can sometimes be interrupted by a surgical procedure called a *synovectomy*, in which the inflamed synovium is removed surgically or the blood vessels in the membrane are destroyed with chemicals or radioactive isotopes. If not stopped, repeated bleeds into a joint will destroy the joint cartilage, causing *hemophilic arthropathy*, a painful arthritic condition. Once a joint has progressed to this stage, pain is chronic. Although the pain can be managed, the only "cure" for hemophilic arthropathy is joint replacement or fusion (surgical immobilization) of the joint.

In addition to factor concentrates or bypassing agents to control bleeds, people with inhibitors should faithfully use "adjunct" or additional therapies, such as RICE, to help control bleeding and speed healing. RICE stands for Rest, Ice, Compression and Elevation.¹

What about controlling the pain? The approaches to treating acute and chronic pain differ markedly, yet many physicians are not well educated about the appropriate management of acute versus chronic pain. Unfortunately, chronic pain among people with hemophilia is under-diagnosed and under-treated, leaving many to suffer. Given today's improved knowledge of pain, and the improved pain treatments currently available, no one should have to live with intolerable pain.

Most physicians, familiar with controlling acute pain, usually have no qualms about prescribing necessary pain medications. And many people with hemophilia self-medicate with over-the-counter (OTC) pain medications. What kinds of medications are used to treat acute pain? Pain medicine is often divided into three groups:

1. *Non-opioids*, including non-steroidal anti-inflammatory drugs (NSAIDs) and acetaminophen.
2. *Opioids* (also called narcotics), such as hydrocodone and morphine.
3. *Adjuvant analgesics*, a loose term for many medications, including some antidepressants and anticonvulsants, originally used to treat conditions other than pain, but now also used to help relieve specific types of pain.

Drugs with no direct pain-relieving properties may also be prescribed as part of a pain management plan. These include medications to treat insomnia, anxiety, depression and muscle spasms. They can significantly aid in the overall pain management of some patients. Opioids and adjuvant analgesics are usually reserved for chronic pain and intense, acute pain.

Non-opioids are the drugs of choice for acute pain. In one study, 196 people with hemophilia were surveyed on how they experience and treat pain.² Approximately 34% of respondents used acetaminophen (Tylenol®) to treat pain, and approximately 39% used NSAIDs. Acetaminophen is most often recommended for treating pain in people with hemophilia because unlike NSAIDs, it does not affect the blood's clotting ability. Acetaminophen is also relatively safe, although high doses (more than 3,000 milligrams in 24 hours) may cause liver damage—a particular concern for people who are also infected with hepatitis C.

To treat pain, many people with hemophilia use NSAIDs because unlike acetaminophen, they have an anti-inflammatory effect. This is in spite of the fact that NSAIDs can inhibit the blood's ability to clot by inhibiting platelet adhesion. NSAIDs can also cause gastrointestinal bleeding and ulcers, and can negatively

¹ For more information on RICE, visit www.novoseven-us.com/patient_hemophilia/managing_RecognizingBleed.aspx or www.hemophilialgalaxy.com/patients/managing/joint/bleeds.html

² Sponsored by Novo Nordisk Inc. and four HTC's, a collaborative study was conducted by the Munson Medical Center in Traverse City, Michigan, and the Henry Ford Health System in Detroit. Witkop, M; Lambing, A; HemAware Clinician "Pain Assessment," *HemAware*, May/June 2007; 12 91. To join in a pain study currently underway, with results to be published in December 2007, visit www.henryford.com/painstudy

affect the kidneys and liver. NSAIDs are a diverse group of drugs that affect the function of two enzymes in the blood: cyclooxygenase-1 and cyclooxygenase-2 (COX-1 and COX-2). COX-1 is found in blood platelets and COX-2 is found at sites of inflammation. These enzymes affect the function of compounds in the blood called *prostaglandins*. Prostaglandins help blood platelets become sticky and adhere to each other to help form a blood clot; they protect the stomach lining from the effects of stomach acid; and they are produced at sites of injury or inflammation and allow pain receptors in the surrounding area to become more sensitive to pain.

NSAIDs include the OTC pain medications aspirin, ibuprofen, naproxen and ketoprofen. Many other NSAIDs are available by prescription only. No two NSAIDs work exactly the same way. Each has slightly different side effects, and each lasts for a different length of time. Unlike opioids, all NSAIDs have a limitation called a “dose ceiling.” This means that taking doses above the ceiling dose significantly increases the risk of serious side effects, such as kidney failure or gastrointestinal bleeding, which can be life-threatening.

Aspirin (acetylsalicylic acid or ASA) is the oldest NSAID, introduced in 1899. Aspirin is an effective analgesic, but should never be used by anyone with hemophilia because it forms an irreversible chemical bond with COX-1, preventing platelets from adhering to form a platelet plug—the first step in the blood-clotting process. This inhibition of platelet adhesion lasts for the life of the platelet, about seven to ten days. A person with hemophilia who takes aspirin risks gastrointestinal bleeding and uncontrolled bleeding because the platelets are unable to form a platelet plug. Aspirin is found in dozens of OTC medications, including many that are not for pain. If you have a bleeding disorder, carefully check the package of any OTC medication for the presence of acetylsalicylic acid or ASA.

³ www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=57&contentid=175

Ketorolac (a prescription-only NSAID, brand name Toradol) is also a potent platelet inhibitor, often causes intestinal bleeding, and should not be used by anyone with hemophilia.

Many people with hemophilia use low-dose ibuprofen to treat pain and inflammation. Ibuprofen also inhibits platelet activation, but much less so than aspirin; and the inhibition is short-term, about four hours. While taking ibuprofen, people with hemophilia may report no excessive bleeding problems, but they should *not* take it when a bleed is in progress. High-dose ibuprofen (600 or 800 mg tablets) are prescription-only medications and should be used only under a doctor’s direct supervision. And of course, it should go without saying that no one should take another person’s prescription pain medication!

A different class of NSAIDs, the selective COX-2 inhibitors, or *coxibs*, were marketed only a few years ago. They were developed to reduce the risk of ulcers caused by other NSAIDs. By targeting only COX-2 and not COX-1, these drugs theoretically shouldn’t affect platelet activation, like other NSAIDs, or cause gastrointestinal bleeding. But National Hemophilia Foundation’s Medical and Scientific Advisory Council recommendation #162³ reports incidents of bleeding in some individuals, and recommends using COX-2 inhibitors at the lowest effective dose, for short duration. Currently, only one selective COX-2 inhibitor, celecoxib (brand name Celebrex[®]), is still available. The other two COX-2 inhibitors, rofecoxib (Vioxx[®]) and valdecoxib (Bextra[®]), were voluntarily pulled from the market in 2005 due to increased risk of heart attack and stroke among people who took the drugs.

Treating acute pain is almost always manageable with OTC or prescription pain medications. But treating chronic pain is a different animal. Managing debilitating, chronic pain usually requires opioids plus non-opioid analgesics, as well as several non-drug adjunct therapies. Controlling chronic pain is the topic of our next *Inhibitor Insights*. ☺

Inbox... continued from page 3

after we thought he had broken his finger playing touch football. Pacificare HMO ordered an investigation of this claim. The paperwork from Ingenix [includes] a questionnaire about the injury: how it happened, who is at fault, is there a police report, etc. The paperwork states, “This information will help to determine if Pacificare can be reimbursed by some other insurer, organization, or responsible person associated with the accident.” I called Pacificare to ask about this and was told, “Sometimes these reports just go out. Just call and work it out with Ingenix.” I called Ingenix and apparently, any time a claim is put through on my policy for over \$500, there will now be an investigation into it.

Has anyone heard of this before? This is the first time we’ve gotten a letter like this in the 14 years we have been with Pacificare.

Pattie Huerta, California

Ed. note: Your insurance company may hope that it might be able to share payment and costs with another insurance agency, for example, one that provides workers’ compensation. Of course, since he’s a child, Dustin does not have workers’ compensation; but as PacifiCare stated, these things are automatically generated. It’s pretty normal to get these communications. Don’t be alarmed by the term “an investigation.” Just report what happened, and you should be fine. PacifiCare will probably drop the investigation when they realize Dustin is only a child.

Ever since we translated *Raising a Child With Hemophilia* into Japanese and posted selections from it on our “Club Haemophilia” website in June 2002, it has been by far the most popular page on this site. Your book is probably the most educational and well-written insight into what it is actually like to raise a child with hemophilia.

Kelly Lausen, Director
NovoSeven Business Unit
Novo Nordisk Pharma, Ltd. Japan

Read about Laurie Kelley’s visit to Japan at www.kelleycom.com/blog
Visit Novo Nordisk’s “Club Haemophilia” at www.clubhaemophilia.jp

Project SHARE

The first donation of factor from Project SHARE arrived at Zewditu Hospital yesterday. My family and I are very grateful to all of you who determined to help our children. God bless you for your humanitarian help.

Tadesse Belay, Ethiopia ☺

Thank you very much for this new donation, which helped us get out of a very difficult situation regarding two patients who required surgical intervention. It is so wonderful to have such generous friends to help us constantly in times when, unfortunately, the resources which should be available for our little patients, are not.

Prof. Margit Serban, MD, PhD, Romania ☺

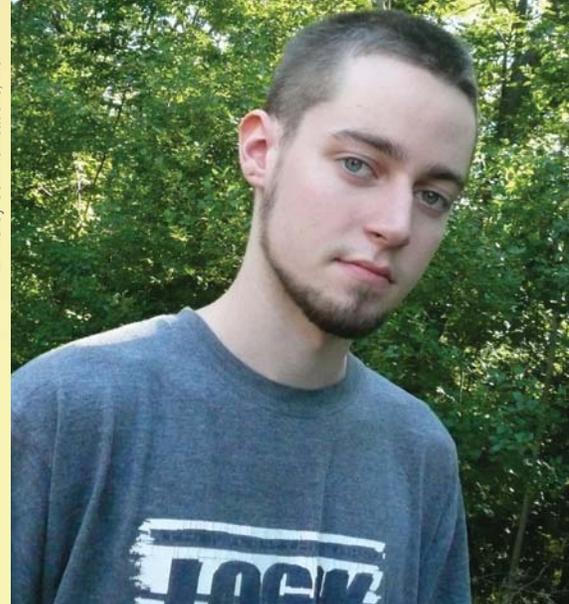
BY LAURIE KELLEY



Transitions is a PEN column sponsored by Baxter BioScience

From Chrysalis to Freedom

L.A. Kelley Communications, Inc.



Independence Day: On the brink of adulthood

I LIKE TO BRAG THAT I AM THE PROUD mom of a wonderful son who is about to turn 20. But I'm also the proud mom of a butterfly—so to speak.

One fall day in 1994, a friend brought us a chrysalis he had found while hunting in the Maine woods. Looking like a miniature sleeping bag, the delicate, pale green, tightly wrapped object stubbornly gripped a milkweed branch by only a thread. We decided to observe the hatching of the monarch butterfly that we hoped would develop within. I propped the branch between two glasses so the chrysalis could hang comfortably, while Tommy and Tara, only seven and four, eagerly watched. "I'm so *happy!*" little Tara gushed.

There is excitement in watching a creature morph into a completely new being, entering the world from its safe haven—especially when you are responsible for its safety. We're doing this now with our son, who is ready to embark on his own adult life.

Tommy is leaving in September to attend the University of Massachusetts. It's time. He's been attending community college to wet his feet, and living at home, gritting his teeth politely when we remind him to drive slowly, phone us when he's late, and order his factor. Now he's ready not only to try a larger school, a more demanding schedule and more serious study—he's attending the music program—but also to get an apartment. To sum it up: He's flying the coop. Or cocoon.

Even when the monarch develops right under your nose, you can't really see it. You can only hope to catch sight of the butterfly as it emerges from the chrysalis. But you know it's developing. And while my son developed right under my nose, it's hard to recall how and when it all happened.

Maybe it's a cliché to say the time went by so fast, *but it did*. Did I prepare my son for the "real" world? Is he ready to take full responsibility for his hemophilia? Did I follow my own advice from my own books? So many thoughts flow through my head when the clock is ticking. I think, He can't possibly be ready to live independently when he still can't remember to close his car windows before it rains. He *needs* us.

Yes and no: He doesn't need to be dependent on us anymore. But, as Tommy gets ready to leave home, we've found that he does need us to assemble a checklist for him. As parents, we all take for granted that our young men know what to do, but there's a lot to remember. And for most of us, up until now we have done it all for them. We've invested years of our time and emotions in nurturing the fragile beauty of a child into the strong character of a man; naturally, we want to continue to protect his life. How to keep our son safe when he leaves, without intruding on his new-found independence?

Whether he is off to college or just moving out, here's a list of basic things your son should know, to live independently, responsibly, safely and maturely. He should:

Know how to order factor. Tommy has been ordering his own factor for the past year, and he's developed a strong relationship with his home care rep. The rep helps Tommy with dosing, number of vials, logging bleeds, insurance, updating his prescription... and the latest iPod downloads.

Enter phone numbers and emails of all doctors in cell and internet accounts. I made a chart showing all the doctors' numbers and email addresses, and when Tommy should

visit them. Family doctor, routine illnesses. HTC at least once a year, or more often if a specific bleed is troublesome. ER for emergencies only, or for after-clinic hours.

Remember the dentist. Easily overlooked, but very important. Your son needs to visit the dentist every six months. Program it into his computer, cell phone or calendar. Have the dentist's office call to remind him.

Know his insurance policy. Review *Storm Log*¹ with your son. At the very least, complete the magnet in the kit and stick it somewhere obvious. Remind him to carry his insurance card. He should know the name of his insurance company and policy number, and know that he may be asked for a copay. Tell him when he needs to get a referral to make sure he's covered by his policy.

Locate the nearest ER. Don't wait for an accident to start looking! He needs to learn to go to the ER if it's the middle of the night or if the campus health clinic or HTC isn't open.

Visit the campus health clinic. If he's attending college, have him drop off some simple brochures and books on hemophilia and introduce himself. Perhaps he can store some factor at the clinic as backup.

Wear MedicAlert® or keep a wallet card. Tommy doesn't like to wear medic ID jewelry. That's fine, as long as he always carries his wallet card.

Take factor along when traveling

continued on page 18

¹ Order *Storm Log* from Baxter BioScience at www.hemophiliagalaxy.com

BY RICHARD J. ATWOOD

*The Blood Doctor*Barbara Vine, 2002, New York, NY:
Shaye Areheart Books. 369 pages.

Describing a biography he's planning to write, lead character Martin A. Nanther announces in *The Blood Doctor's* first sentence, "Blood is going to be its theme."

In Vine's novel, Martin is the fourth Lord Nanther, a 44-year-old Londoner who contemplates writing the biography of his great-grandfather, Henry Alexander Nanther. Henry, the first Lord Nanther, was a physician with a specialty in blood, especially hemophilia. He became Physician-in-Ordinary, or medical consultant to the royal family; and he was Queen Victoria's consultant on hemophilia. After reading Henry's journals and interviewing extended family members, Martin Nanther discovers that his great-grandfather married a hemophilia carrier, a descendant of the Swiss Tenna¹ pedigree. He also discovers that his American cousin, a physician conducting gene therapy trials on hemophilia at the University of Pennsylvania, has mild factor VIII deficiency. While conducting his biographical research, Martin Nanther has to deal with complex personal challenges: his wife's infertility, and various organizational changes in the House of Lords.

The Blood Doctor so successfully incorporates medicine, history and politics that the reader easily forgets that this is fiction. As in many of Vine's novels, the story is not so much a mystery as a puzzle in which important bits of information are gradually gleaned, piece by piece. The recurring theme of blood is exemplified by its dual role—as the conductor of an inherited title, and the transmitter of hereditary disease. To assist the reader, Vine includes three pages of the Nanthers' diagrammed family tree, as well as detailed descriptions of hemophilia and its treatment over the past 200 years. The fatal flaw in this novel is that the Swiss Tenna pedigree was factor IX deficient, while the Nanther men with hemophilia are factor VIII deficient! The award-winning author writes mysteries under her own name, Ruth Rendell, and also writes novels using her pen name, Barbara Vine. 🌀

¹ The Swiss Tenna, one of the oldest and largest hemophilia families ever described, are named after the village in the upper Rhone valley where they lived for about seven centuries. A German-speaking family founded Tenna in the 14th century, and they remained isolated by language and geography, so the hemophilia gene that appeared around 1650 did not migrate. This group, who called themselves "bluters," was first described in medical literature in 1837 and has been extensively studied since then.

BY ZIVA MANN

THE SHARP EDGE
of Power

SOME MONTHS AGO, FIVE-YEAR-OLD SHAI decided to turn two. Mind you, this wasn't the first time he'd turned two, so he is rather good at it. And this wasn't just the Terrible Twos, this was Two with a Vengeance. This was Two as Two wishes it could be. This was Two with *Words*.

No! I won't do it!

You aren't listening to me!

I am not going to hear another word you say!

I'm going to go and have some quiet time, now!

"Ah," I said to him wisely, secretly at a loss. "Off you go, then."

Two. The terrible, glorious urge of Two to take control of the world, to achieve its desires. The passion and fury of—heaven help us—Two. For the next month, Shai dug in his heels: He didn't want to go to school, where he created masterworks with paper and wood. He dawdled on his way to gymnastics, where he was in love with the little girl in the shiny purple leotard. He argued vehemently about everything, even on the way to the grocery store, where the fish guy held out lobsters close enough to touch. Oddly, the one thing Shai didn't argue about was factor.

We were astonished, but grateful. It was smooth sailing on the venipuncture seas, and factor was a peaceful, cooperative moment in our otherwise turbulent days. Until one day when Shai turned to me and said, "I want to do my own factor."

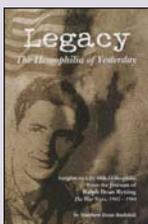
Um, no. Shai has a history of lousy veins: hard to find, quick to hide, rolling and disappearing altogether. All his expert pediatric IV nurses rated his veins "seven out of ten, where ten is really, really hard, on a good day." Plus—and let's emphasize this fact—he's *five*. Behaving like two, but five years old according to the calendar. So, *no*. Still, I let him call his nurses to tell them of his ambition. The nurse on call praised Shai for his desire, but privately told me not to get his hopes up. Shai glowed, and I quietly waited for him to forget about the idea.

The phase went on, and only got nastier. Shai argued about everything and worked hard to control each small moment, each little event around him. Things finally came to a head when he started barking orders at Akiva, his 20-month-old brother. Infuriated, exasperated, and seriously considering putting Shai up as an item on eBay (*One child, slightly used, reasonably complex*), I said, "Fine. You can try infusing a banana."

I drew a branching vein on a banana, took a fresh butterfly needle from a box of factor, pulled out an alcohol wipe and a piece of gauze. I walked Shai through the steps: *First, set out your supplies. Then, get your grasp on the banana, holding it firmly but not squishing it. Picked your spot? Now, clean the spot, dry the spot, and hold the needle, so. Good. Steady now, angle down and flatten out. In!* Half an hour later, Shai was still practicing—focused, quiet. In fact, the rest of the day was relaxed and almost dreamlike after the chaos that had preceded the banana. I put down my copy of *So, You're Desperately Trying to Get Your Child To Listen?* and listened to the quiet. An idea was born.

A few days later, a nurse visited our home. She helped Shai with his banana-poking, and then she looked at him. "You've got a good vein there," she said. "Do you want to do your factor with me?" He gulped, wriggled, and agreed. Brave lady, brave child. The nurse guided him through the tourniquet, alcohol wipe and gauze, then guided and aimed the needle. And let go. Miracle of miracles, Shai hit his mark, blood filled the tubing, and he carefully pushed the factor through.

There were a few repeat performances after that, but nothing really reliable—he is five, you know, with all the flightiness and determination that comes with that age. But the defiance and need for control faded a bit, along with my thoughts of an eBay listing. Shai had looked for control in his world, and when we put a needle in his hand, he'd found it. 🌀



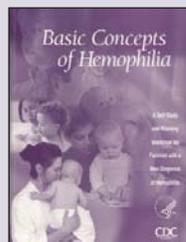
Legacy: The Hemophilia of Yesterday

Barkdull, Matthew Dean, 2006
LA Kelley Communications, Inc.
www.kelleycom.com

A teen with a passion for writing begins a journal in 1942, during World War II. What mysterious illness plagues him? The wartime journal of Ralph Dean Rytting is possibly 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 his life. Sponsored by and available through Bayer HealthCare (www.kogenatefs.com) and Hemophilia Health Services (www.hemophiliahealth.com).

Hemophilia in Pictures

World Federation of Hemophilia (WFH), 2005
www.wfh.org
English, Spanish, French, Polish or Estonian; PDF or CD only
Pictorial guide to hemophilia for healthcare workers, parents and patients reflects the multicultural diversity of the global hemophilia community. Useful for teaching people with low literacy levels. Includes teaching notes.



Basic Concepts of Hemophilia

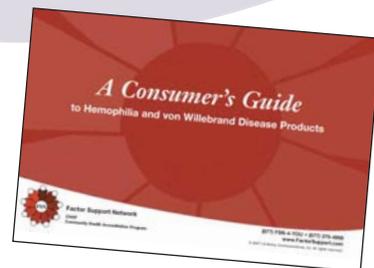
Butler, Regina; Crudder, Sally O.; Riske, Brenda; Toal, Susan, 2001
Available from NHF at www.hemophilia.org
Large-format workbook on hemophilia basics for parents of children, adolescents and young adults with hemophilia. Intended for use as part of an educational program with HTC staff. Funded by Centers for Disease Control and Prevention.

BINDERS

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

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

Comparative, concise guide to all factor concentrate and specialty products for the bleeding disorders community; lists all relevant information for consumers. Factor VIII, factor IX, factor IX complex and inhibitor products are color-coded and easy to cross-reference. Binder can be inverted as a stand for flip-chart style teaching. Sponsored by Factor Support Network (www.factorsupport.com).



BOOKLETS

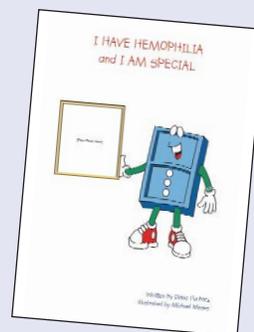
Empower Yourself About Hemophilia

Kelley, Lauren A., 2004
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. Cartoon "before" and "after" illustrations offer concrete methods of regaining control during the rocky first year of hemophilia. Sponsored by Grifols USA (www.grifolsusa.com).

I Have Hemophilia and I Am Special

Horbacz, Diane, 2005
Hemophilia Health Services
www.FactorCare.com
English or Spanish
Helps children learn hemophilia basics as they personalize the information inside. Ages 3-7. Sponsored by Bayer HealthCare (www.kogenatefs.com).

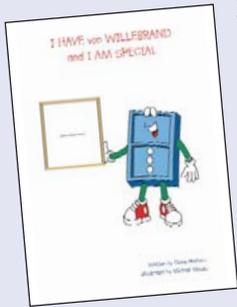


Living with Hemophilia (series)

2006
Hemophilia Health Services
www.FactorCare.com

Series of educational booklets covering events and information for different life stages: 0-12 months, 1-5 years, 6-11 years, 12-18 years, adult.





I Have von Willebrand and I Am Special

Horbacz, Diane, 2005
Hemophilia Health Services
www.FactorCare.com

Booklet helps children learn von Willebrand Disease basics as they personalize the information inside. Ages 3–7. Sponsored by Bayer HealthCare (www.kogenatefs.com).

Your Child's Hemophilia (series)

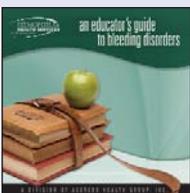
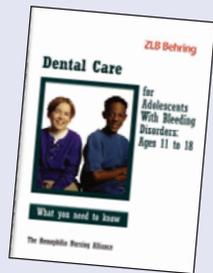
2001
CSL Behring Choice Support Center
www.cslbehring.com

Three-part series for parents about what to expect during different phases of children's development. Includes *Your Child's Hemophilia: What to Expect During Infancy*; *Your Child's Hemophilia: What to Expect During the School Age Years*; *Hemophilia: The Young Adult Years*.

Dental Care (series)

2005
CSL Behring Choice Support Center
www.cslbehring.com

Four-part series on dental care, primarily for people and families with hemophilia A, hemophilia B, VWD. Includes *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*.



An Educator's Guide to Bleeding Disorders

Hemophilia Health Services, 2007
www.FactorCare.com

Gives educators a general overview and answers common questions about having a child with a bleeding disorder in the classroom. Reviews how to recognize bleeds; provides a contact list.

B2B Speaking from Experience

2006
The Coalition for Hemophilia B
www.coalitionforhemophiliab.org

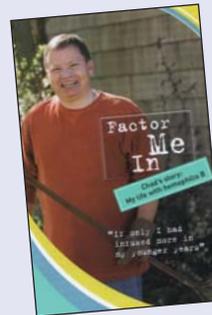
Colorful booklet for adults and teens shares personal experiences of factor IX deficient patients. Developed using

recommendations from Wyeth Consumer Advisory Board. User-friendly, packed with information designed to reach people already living successfully with hemophilia B.

B2B Speaking from Experience: A Guide for Mature Adults

2007
The Coalition for Hemophilia B
www.coalitionforhemophiliab.org

Latest installment in the B2B series provides mature adults with helpful knowledge to make informed life decisions and remain healthy today and in the years ahead. Sponsored by Wyeth Pharmaceuticals (www.hemophiliavillage.com).



Factor Me In: Chad's Story—My Life with Hemophilia

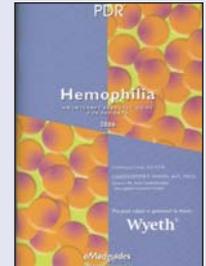
Wyeth Pharmaceuticals
www.hemophiliavillage.com

A man with hemophilia B discusses the importance of preserving joint health.

Hemophilia: An Internet Resource Guide

Wyeth Pharmaceuticals
www.hemophiliavillage.com

Review of hemophilia, the internet, and how to research hemophilia information through websites devoted to hemophilia.



Living with Hemophilia B

Wyeth Pharmaceuticals
www.hemophiliavillage.com

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

A Family Guide to Hemophilia B

2005
CSL Behring Choice Support Center
www.cslbehring.com

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

booklets

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 and objective style. Empowers parents and patients as educated consumers.



HemAware

National Hemophilia Foundation
www.hemophilia.org

Quarterly. Newsletter of largest hemophilia nonprofit in US. Articles on bleeding disorder medical research and treatment in areas of social work, physical therapy, orthopedics, dental nursing. Articles for families; community events.

Bloodstone Magazine

Hemophilia Health Services
www.FactorCare.com

Quarterly. Magazine of largest hemophilia home healthcare company. Bleeding disorder information covers news, insurance, Q&A, treatment, psychosocial issues, cartoon strip. Presents positive view of living with hemophilia.



Factor Nine News

The Coalition for Hemophilia B
www.coalitionforhemophiliab.org

Quarterly. Brief newsletter of nonprofit organization 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 and healthcare events, innovative programs, upcoming events.



Quest

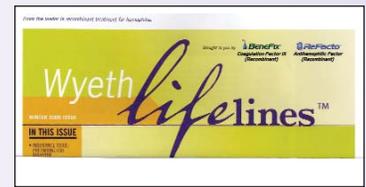
Coram Hemophilia Services
www.coramhemophilia.com
quest@coramhemophilia.com

Quarterly. Newsletter features patient profiles, news, and new products and services from this home healthcare company for hemophilia patients.

Wyeth Lifelines

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

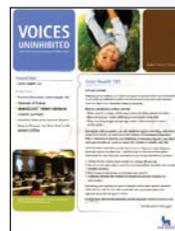
Three times yearly. Newsletter includes helpful information about hemophilia treatment and tips for living an active life, including inspirational stories from people living with hemophilia. Describes latest programs and services available from Wyeth.



Post Script Informer

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

Quarterly. Newsletter of Patient Services, Inc., nonprofit organization that specializes in providing temporary insurance coverage to those with chronic medical conditions who face loss of insurance. Provides 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.

VIDEOS, DVDS, CD ROMS



Infusion Tracker 2

NuFACTOR
www.nufactor.com
PC format

Software program helps patients record, analyze and visualize bleeding episodes for selected range of dates, on color-coded map of the body. Helps patients identify target joints, track prophylaxis schedule effectiveness, learn seasonal bleeding patterns, document factor usage, record lot numbers permanently, review statistics, print usage reports.

Function of FVIII at the Site of a Bleeding Joint

Bayer HealthCare
www.kogenatefs.com
CD

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

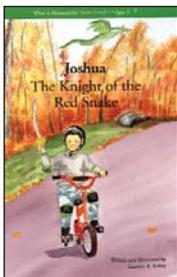


BOOKS FOR CHILDREN

What is Hemophilia? (series)

Kelley, Lauren A., 1995
 LA Kelley Communications, Inc.
www.kelleycom.com
 English or 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. Contains "Note to Parents" for each age level. Sponsored by and available through CSL Behring (www.cslbehring.com).

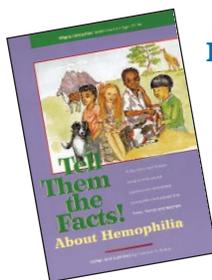
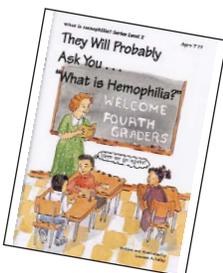


Level 1: Joshua, Knight of the Red Snake (Ages 3-7)

Empowering story about preschooler with hemophilia. Illustrated large-text format. Ends on a note of joy and confidence to empower children.

Level 2: They'll Probably Ask You "What is Hemophilia?" (Ages 7-11)

Humorous story about Tony, who must explain hemophilia to his fourth-grade classmates. Includes glossary for children.



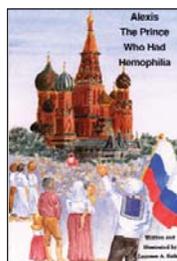
Level 3: Tell Them the Facts! (Ages 11-16)

Question-and-answer 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.

Must You Always Be a Boy?

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

Four rhyming tales explore adult reactions to bleeds, overprotective parents, sibling rivalry, classroom bullies. Illustrated. Ages 3-8. Sponsored by and available through CSL Behring (www.cslbehring.com).



Alexis: The Prince Who Had Hemophilia

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

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

The Winning Spirit

1993
 Delaware Chapter of NHF
www.hemophiliasupport.org
 VHS (20 minutes)

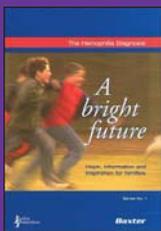
Excellent introduction to hemophilia describes what new parents should expect: initial feelings after the diagnosis, developmental stages, what happens inside during a bleed, factor therapy, sports, activities, keeping life normal.



Joint Health Educational Primer

Baxter BioScience
www.thereforeyou.com
 CD or VHS

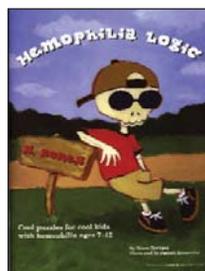
Interactive educational tool highlights the importance of healthy joints.



A Bright Future

Inalex Communications
www.inalex.com
 DVD

Brief introduction to the impact of a hemophilia diagnosis on new families. Includes testimonials from parents: how they felt and coped with the diagnosis. Inspires new parents to overcome fear and doubt, and to better handle hemophilia. Sponsored by Baxter BioScience (www.hemophiliagalaxy.com).



Hemophilia Logic

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

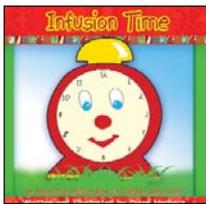
Sherlock Bones guides children through activity book about hemophilia, body functions, independence, treatment and self-esteem with colorful mazes, matching, glyphs, games, puzzles. Ages 7-13. Sponsored through a grant from Factor Foundation of America (www.factorfoundation) and Wyeth (www.hemophiliavillage.com).

Factor Fun!

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

Activity book teaches about hemophilia, safety and self-esteem with colorful mazes, matching, glyphs, counting. Illustrated. Each activity arranged by color-coded topic. Ages 4-7. Sponsored by Hemophilia Health Services (www.FactorCare.com).





Infusion Time

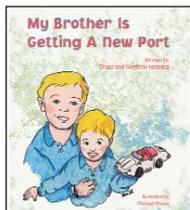
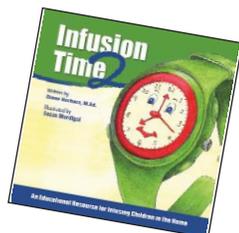
Horbacz, Diane, 2004
Hemophilia Health Services
www.FactorCare.com

Interactive book helps children with ports understand the infusion process. Rhymes and tactile features make learning about infusion fun. Ages 3–11. Sponsored by Bayer HealthCare (www.kogenatefs.com). *Publication is being updated and will be available fourth quarter 2007.*

Infusion Time 2

Horbacz, Diane, 2006
Hemophilia Health Services
www.FactorCare.com

Interactive book helps children who infuse using venous access learn the infusion process. Rhyming scheme makes information easy to remember. Age 3 and older. Sponsored by Bayer HealthCare (www.kogenatefs.com).



My Brother is Getting a New Port!

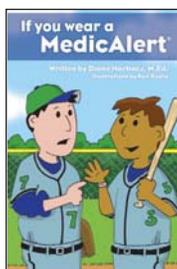
Horbacz, Diane, 2000
Hemophilia Health Services
www.FactorCare.com
English or Spanish

Story of a boy living with hemophilia who has a port. He helps prepare his younger brother with hemophilia for port surgery. Ages 3–11. Sponsored by Bayer HealthCare (www.kogenatefs.com).

Diane Dino's Dilemma

Shapiro, Jane, 1996
CSL Behring Choice Support Center
www.cslbehring.com

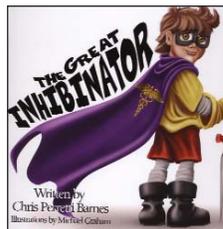
Colorful storybook features a dinosaur with von Willebrand Disease. Topics include definitions, doctor visits, sports, blood clotting, treatment. Ages 7–11.



If You Wear a MedicAlert

Horbacz, Diane, 2006
Hemophilia Health Services
www.FactorCare.com
English or Spanish

Addresses the challenges faced by children on prophylaxis when talking to their peers about hemophilia. As two young baseball teammates chat, key communicative words are repeated, helping to foster communication skills. Ages 5–11. Sponsored by Bayer HealthCare (www.kogenatefs.com).



The Great Inhibinator

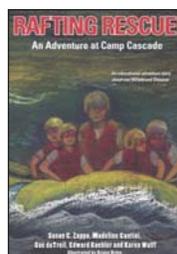
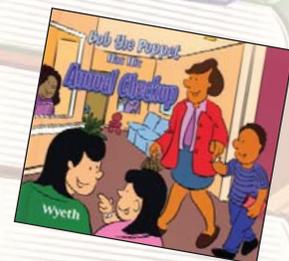
Perretti Barnes, Chris, 2006
BioRX
www.biorx.net

Hardcover book about Nate, a boy who discovers he has an inhibitor. Colorfully illustrated story centers on creating a Halloween costume. 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 series of hardcover books should open discussions between parents and children about clinic visits and hemophilia. In *Bob the Puppet Has His Annual Checkup*, Bob visits an HTC to get a routine physical. In *Bob the Puppet Goes to School*, Bob attends a new school and talks about hemophilia. Ages 4–7.

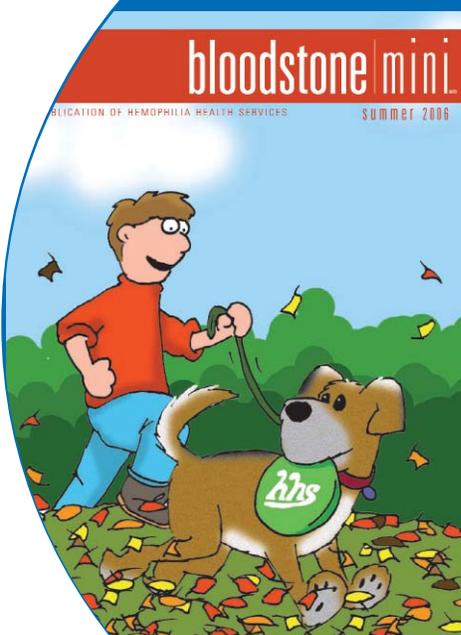


Rafting Rescue!

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

Chapter book about adventures at camp and how to handle and treat VWD. Ages 10–16.

PERIODICALS FOR CHILDREN



Bloodstone Mini

Hemophilia Health Services
www.FactorCare.com

Word games, puzzles, activities and articles cover hemophilia and health basics. Features friendly bear Welligan Hugsley and Imagination Forest Friends. Ages 6–12.

for children

GAMES FOR CHILDREN



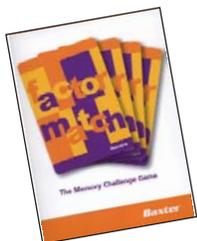
Wooden Peg Puzzle

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



A stack of illustrated cards about hemophilia, with duplicate illustrations, creates a memory card game that helps 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. Can be played as matching game or used as flash cards.



FactorQuest

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

Action/adventure video game designed for kids with bleeding disorders. Challenges kids to learn about their bleeding disorder, master its treatment, and "evolve" to independence. In the game's debut episode, "Cavern of Bones," players face one of the most common challenges of bleeding disorders: maintaining healthy joints.

CD ROMS & VIDEOS FOR CHILDREN



Inside a Bleeding Joint

Bayer HealthCare
www.kogenatefs.com
English or Spanish; DVD

A child describes hemophilia and its symptoms. Details how joints work, joint bleeds and damage, self-infusion, and the importance of detecting bleeds early. For children, schools, summer camps. Animated.

Every Step of the Way

Bayer HealthCare
www.kogenatefs.com
CD

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 highly technical manufacturing processes into an entertaining, straightforward, step-by-step overview.



KITS

Wyeth Self-Infusion Training Kit

Wyeth Pharmaceuticals
www.hemophiliavillage.com
Available through HTC's

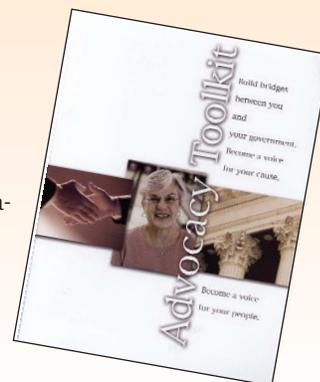
Synthetic hand and elbow model allows practice of infusion techniques. Includes replaceable skin and veins for people to practice inserting a butterfly needle and infusing clotting factor; infusion mat, tourniquet, butterfly needles, biohazard disposal container; sample ReFacto R2 Kits to practice product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



Advocacy Toolkit

Bayer HealthCare
www.kogenatefs.com
Limited copies

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. Brief but comprehensive, easy-to-read, colorful, insightful toolkit suggests strategies to help the bleeding disorders community protect against threats to factor coverage.



Kits from Baxter

Baxter BioScience
www.thereforyou.com
Available through HTC's

Flight Gear, The Hemophilia Starter Kit

Helps newly diagnosed hemophilia patients and families understand care and management of hemophilia. Includes brochures, treatment log entry forms, evaluation checklists.

kits

Home Infusion Kit

Helps caregivers who are starting their child's factor replacement at home. Designed with a fun racecar theme, filled with educational activities, step-by-step guides, infusion logs, infusion CD/DVD, emergency contact card.



Venous Access Toolkit

Features tabbed sections dealing with every aspect of learning about, choosing, transitioning, and monitoring various venous access methods. Includes step-by-step guide to self-infusion and beautifully illustrated storybooks for children beginning to learn about their treatment. Written in straightforward, patient-friendly style. Components may be available for patients to take home.



Self-Infusion Kit

For patients who are ready to self-infuse. Convenient drawstring bag provides tools for factor replacement.

Includes step-by-step instructions, bleeding/infusion log, tools to use at infusion time, and more.



School Toolkit

Collection of educational components designed to inform school personnel about hemophilia and the challenges of the student with hemophilia. Provides specific guidelines for emergencies; PE activities and emergency contact information;

flipchart for school presentations; fact sheets with team members' responsibilities; worksheets to track treatment plans.

PROGRAMS

First Step

National Hemophilia Foundation
www.hemophilia.org

Program for new parents and families of children with bleeding disorders. Almost entirely

composed of local parents working in conjunction with a professional team that includes local hemophilia organization and HTC representatives. First Step provides small meetings, educational resources from the community, "Train the Trainer" program, mentoring with experienced parents.

Facts First

Baxter BioScience
www.hemophilagalaxy.com



Educational series of programs for hemophilia patients and families, hosted by a chapter or

HTC. Provides knowledgeable speakers: local physicians, national advocates, industry experts. Addresses issues of importance to hemophilia community; helps create camaraderie among families through engaging events.

Karing for Kids™: Innovative Learning



Hemophilia Health Services
www.FactorCare.com

Through interactive workshops held across the country and educational resources geared for children, program helps children with hemophilia and their families gain confidence and control in managing hemophilia. Directed by Diane Horbacz, MA, MEd.

The PEP Program (Parents Empowering Parents)



www.pepprogram.org
Available at selected US HTCs

Peer-to-peer skills program helps parents improve parenting skills, understanding and confidence. Topics include therapeutic relationships, response to bleeding episodes, behavior management, discipline, self-esteem. Team presentations by parents of children with bleeding disorders, social worker and nurse offer peer support and professional expertise. Funded by Bayer HealthCare (www.kogenatefs.com).

School Preparedness Program

Coram Hemophilia Services
www.coramhemophilia.com

National school preparedness program helps parents of children with hemophilia set the stage for a safe, happy, rewarding educational experience. Through a series of educational presentations, families and HTC staff learn how to educate school personnel and students about hemophilia: what it is, how it feels, how it's treated, and how schools should respond. Families receive additional tools and educational materials to make preparing for school easier.

Inalex Communications Workshops for Men



Inalex Communications
www.inalex.com

Workshops and teleconferences for men in the bleeding disorders community offer education and direct community support. Classes are designed to empower men to deepen their relationships and better deal with the anxiety, frustration, stress and anger of living with a bleeding disorder. Life and executive coaches, social workers, PhD instructors, and bleeding disorders community leaders conduct sessions.



Gettin' in the GameSM

CSL Behring Choice Support Center
www.cslbehring.com
Available through HTC's or local NHF chapters

Encourages kids with bleeding disorders to exercise, play sports and be physically active. Exercise can help build stronger muscles and joints, and improve venous access. Sports and exercise build self-confidence, teach teamwork, and create a sense of community. Offers local events where children and families can learn sports tips, participate in appropriate 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 HTC's

Helps healthcare professionals teach children with hemophilia about their disorder using specially designed puppet.

Hemophilia Training Puppet was developed in conjunction with Patient Puppets, Inc., Winnipeg, Manitoba, Canada. Facilitates instruction about hematomas, a healthy knee joint, a bleeding joint, and venous access through an external catheter and prominent vein.



Dads in Action

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

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

A.C.C.E.S.S. Program

www.hemophiliahealth.com

Advocacy program helps people with bleeding disorders navigate available state and federal programs. All information is kept confidential. Sponsored by Hemophilia Health Services (www.hemophiliahealth.com).

Coram Community Conference Calls

Coram Hemophilia Services
www.coramhemophilia.com

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

Knights' Crossing

Baxter BioScience
www.thereforyou.com

Fun, activity-based learning program encourages and challenges young people in physical, emotional and social development. Ages 10-15.



CEO

Baxter BioScience
www.thereforyou.com



Full day of career planning and learning about financial independence. Participants take two popular career assessments online and then apply the results during professionally facilitated interactive activities. Ages 15-20.

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 HTC's 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.

Hemophilia University

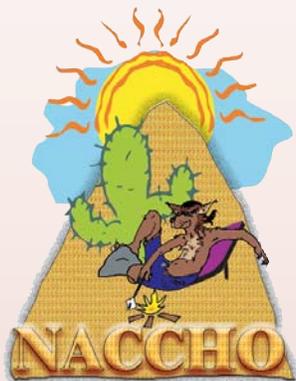
Bayer HealthCare
www.livingwithhemophilia.com

Designed to support nurses, social workers, pharmacists and physicians by offering teleconferences for earning continuing education credits. Supported by an educational grant from Bayer HealthCare to the University of Nebraska.

North American Camping Conference of Hemophilia Organizations (NACCHO)

Hemophilia Association, Inc.
www.hemophiliaz.org
www.naccho.com

Annual workshop brings together experts in camping, to teach planning, organizing and operating a bleeding disorder summer camp. Nationally known presenters share useful camp resources and techniques; explore camp programs and activities; facilitate networking and problem solving. Sponsored by Wyeth Pharmaceuticals (www.hemophilivillage.com).



Patient Notification System (PNS)

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

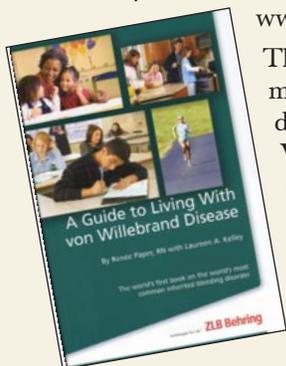
Confidential 24-hour communication system provides information on plasma-derived and recombinant therapy withdrawals and recalls. Registered patients receive automatic updates of product recalls and withdrawals.

programs

FOR VON WILLEBRAND DISEASE PATIENTS AND PARENTS

A Guide to Living With von Willebrand Disease

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



The world's first book on the world's most commonly inherited bleeding disorder. Covers learning to cope with VWD, inheritance, the medical system, treatment, women's issues, health insurance. Includes complete resource guide and real-life stories. Sponsored by and available through CSL Behring (www.cslbehring.com).

THERAPEUTIC PRODUCTS

Cryo/Cuff™

DJO, Inc.
www.djortho.com
Cryo/Cuffs are orthopedic devices that provide the therapeutic benefits of controlled compression to minimize hemarthrosis and swelling, and cold to minimize pain. Anatomically designed to provide maximum coverage to injured area.



QR™ Powder

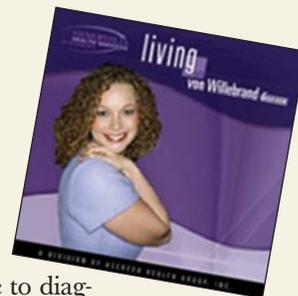
Biolife, LLC
www.biolife.com
QR Powder works independently of the blood's clotting process to help stop bleeding of minor external cuts, skin tears, nosebleeds and puncture wounds. The powder is non-toxic, does not cause allergic reactions, and does not react with other medications. Use only on wounds covered with blood. Available at all drugstores. Also available as UrgentQR™ and NosebleedQR™.



Living with von Willebrand Disease

2007
Hemophilia Health Services
www.FactorCare.com

Comprehensive booklet covers everything from general understanding of von Willebrand Disease to diagnosis, transmission and treatment options.



von Willebrand Disease (VWD): A Patient's Guide to Understanding

2005
CSL Behring Choice Support Center
www.cslbehring.com

Easy-to-read booklet about VWD symptoms, testing, diagnosis and treatment.

Ordering Information

To order the bleeding disorder resources listed in this issue, please contact companies and organizations at the following addresses:

A.C.C.E.S.S. Program

4710 Eisenhower Blvd.
Suite E 3
Tampa, FL 33634
(888) 700-7010
www.hemophiliahealth.com

Bayer HealthCare

400 Morgan Lane
West Haven, CT 06516-4175
(888) 606-3780
www.kogenatefs.com

Baxter BioScience

One Baxter Parkway
Deerfield, IL 60015
(800) 423-2090
www.hemophiliagalaxy.com

Biolife, LLC

1235 Tallevast Rd.
Sarasota, FL 34243
(800) 722-7559
www.biolife.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.cslbehring.com

The Coalition for Hemophilia B

825 Third Avenue, Suite 226
New York, NY 10122
(212) 520-8272
www.coalitionforhemophiliab.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
quest@coramhemophilia.com

DJO, Inc.

1430 Decision Street
Vista, CA 92081
(800) 321-9549
www.djortho.com

Delaware Chapter of NHF

222 South Easton Road, Suite 122
Glenside, PA 19038
(215) 885-6500
www.hemophiliasupport.org

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

Hemophilia Health Services

6820 Charlotte Pike
Nashville, TN 37209
(800) 800-6606
www.hemophiliahealth.com
www.FactorCare.com

Inalex Communications

38 East Ridgewood Ave #244
Ridgewood, NJ, 07450
(866) 802-0304
www.inalex.com

LA Kelley Communications, Inc.

68 East Main Street, Suite 102
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

NuFACTOR

41093 County Center Drive, Suite B
Temecula, CA 92591
(800) 323-6832
www.nufactor.com

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

World Federation of Hemophilia

1425 René Lévesque Boulevard West
Suite 1010
Montreal, Quebec H3G 1T7
Canada
(514) 875-7944
www.wfh.org

Wyeth Pharmaceuticals

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

overnight. This has been a tough issue for us. Some teens go through a denial phase where avoiding infusions is a sign of manhood, apparently. But we are over that now... I think.

Infuse at the first sign of a bleed.

Obvious? You'd think by age 20, young people would know this, but it happens: They wait. They're busy. They're studying. They're on a date. They're with their friends...

Keep plenty of factor in the refrigerator.

Your son can have it shipped to his dorm or apartment. Check to be sure the neighborhood is safe to leave factor on a doorstep or in a hallway. Does the dorm have a front desk with a student receptionist? Who will get the factor if your son is not there?

Go through Hemophilia 101 again. Don't assume he knows everything just because he lives with the disorder. Quiz him. Use the resources in this issue of *PEN* to help him review hemophilia one more time.

Wear seat belts. Don't speed. Practice safe sex. Don't drink and drive. Don't use drugs. This is the long mantra repeated by parents shepherding teens into adulthood, but it bears constant repetition, discussion, and sometimes arguments.

Call your mother. OK, I threw that one in solely for me.

Our beautiful chrysalis eventually burst. I had been staring at it, awaiting the butterfly's birth, admiring the now translucent cocoon and shimmering gold beads that appeared on its rim. Then the phone rang. Two seconds later, I looked back, and there was a gorgeous, brilliant orange monarch butterfly, flexing its damp wings, clinging to the deflated cocoon. The breathtaking transformation happened while I was *right there*. And I missed it.

We kept the monarch for two days and finally, sadly, knew we must free it. Monarchs must migrate to breed and feed; they are the only insects capable of transatlantic flight. Yet to us, the butterfly seemed as reluctant to leave as we were to let it go. As we set it aloft, I worried about this beautiful, delicate being. It's an unsafe world, but freedom involves inherent risks. I could only watch the butterfly soar away. With Tommy, I can do more: I can help ensure as much safety as possible, while allowing him to soar freely through what could be some of the best years of his life.

Tommy has begun packing. Despite some parental apprehension, I want to gush like Tara, I am so *happy*. He's developing just as he should, and spreading his wings is as natural for him now as breathing. It's time. ☺

Pharma

NIH Gives EpiVax Grant for Hemophilia Study

EpiVax, a developer of second-generation vaccines and biotherapeutic agents, has received a \$528,313 grant to help develop a new treatment for hemophilia, to see whether a reengineered factor VIII avoids an antibody response. Research will be conducted in collaboration with Dr. David Scott at the University of Maryland and Dr. Ed Forman at Hasbro Children's Hospital.

To learn more:
www.epivax.com



Novo Nordisk and Neose: Longer-Acting Factor VIIa

Novo Nordisk Inc. has initiated a phase I clinical trial of GlycoPEGylated factor VIIa, a long-acting version of NovoSeven®. The trial will assess the safety and pharmacokinetics of GlycoPEGylated factor VIIa in healthy volunteers. GlycoPEGylated factor VIIa is being developed by Novo Nordisk under a license agreement with Neose.

To learn more:
www.novonordisk-us.com

New VWD Product on Horizon

Octapharma, a Swiss-based company that specializes in plasma products, completed US clinical trials of Wilate, a new von Willebrand/factor VIII concentrate. Wilate is not currently available in the US. Octapharma is also developing a B-domain deleted recombinant factor VIII product.

To learn more:
www.octapharma.com

BeneFix® Enhanced

Wyeth's recombinant factor IX product, BeneFIX, will soon have more patient-friendly enhancements: the ability to reduce the final infusion volume of BeneFIX by up to 75%; a needleless reconstitution kit, the BeneFIX R2 Kit; a new 2,000 IU vial.

To learn more:
www.hemophiliavillage.com

New IU Size for Kogenate FS®

Bayer HealthCare announced a new 2,000 IU vial size as part of the Kogenate line of products. It comes with new "Grab & Go" small packaging, including BIO-SET® reconstitution system integrated with Kogenate FS; prefilled diluent syringe; BD Safety-Lok® butterfly infusion set; alcohol swabs, cotton pad, latex-free bandage.

To learn more:
www.kogenatefs.com

CSL Behring Foundation Awards Ten Grants Totaling \$487,000

The CSL Behring Foundation for Research and Advancement of Patient Health has awarded more than \$487,000 in funding for programs designed to benefit the bleeding disorders community. The grants will support a range of initiatives, including research

projects and programs developed to educate and support patients. The foundation awards grants twice yearly, and in this cycle, ten US organizations received awards.

To learn more:
www.csلبehringfoundation.com

Nonprofit



NHF 59th Annual Meeting!

Come to the National Hemophilia Foundation Annual Meeting in Orlando, Florida, November 1-3, 2007.

To learn more:
Sonia Roger, Education Department, NHF
116 West 32nd Street, 11th Floor, New York, NY 10001
(800) 42-HANDI
sroger@hemophilia.org

nonprofit

Home Care

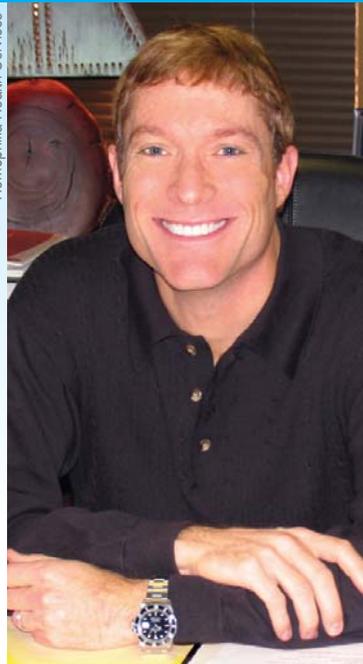
HHS President and Project SHARE Colleague Retires

Hemophilia Health Services announces the retirement of President Kyle Callahan, a person with hemophilia who is also the son of HHS founder Diane Martz. Kyle has been a competent and inspiring leader, and a generous patron of the US hemophilia community. Readers may not be aware that Kyle is the driving force behind a huge international effort to help those with hemophilia in the developing world. For more than ten

years, HHS has provided factor to Project SHARE to assist hundreds of patients with bleeding disorders who may never have received treatment. The impact on patients' lives thanks to Kyle's efforts can't be overstated. Kyle has helped save and improve lives, and given hope to hundreds. We wish him well in his retirement and thank him for all his dedication and assistance.

To learn more:
www.hemophiliahealth.com

Hemophilia Health Services



Walgreens to Acquire OptionCare

Walgreens announced on July 2 that it will buy OptionCare in an agreement estimated at \$850 million. OptionCare is based in Buffalo Grove, Illinois, and provides specialty pharmacy and home infusion services, including hemophilia. This acquisition is the latest in the continuing pattern of large PBMs and pharmacies purchasing smaller ones to consolidate business, as payers seek to lower reimbursement costs of specialty pharmacies.

To learn more: www.walgreens.com

PEN gratefully acknowledges our corporate sponsors

Baxter

800-423-2862
www.hemophiliagalaxy.com
Baxter's website for hemophilia families



Bayer HealthCare
Biological Products Division

Customer Service
800-243-4153
Reimbursement HELpline
800-288-8374
www.kogenatefs.com



800-800-6606
www.HemophiliaHealth.com
info@hemophiliahealth.com



novo nordisk®
800-727-6500
www.novoseven.com

Wyeth®

888-999-2349
www.hemophiliavillage.com

CSL Behring

888-508-6978
www.csلبehring.com

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Georgetown, MA 01833 USA

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www.kelleycom.com

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factor deficiency type and severity

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