February 2008 • Volume 18 • Issue 1

Parent Empowerment Newsletter

When You Lose Your Health Insurance

BY LAURIE KELLEY

As the New Year rolls in, anxiety about healthcare coverage for hemophilia families is at an all-time high. The government and insurance companies continue their crusade to cut costs, and employers may make it tougher for employees to find adequate coverage. In an economy reeling from subprime lending collapse and massive debt, jobs may be more difficult to find. And an entire post-HIV generation is preparing to graduate from college–but finding itself without insurance. Now more than ever, it's vital for every person with hemophilia, every family, and every graduating student to understand: **You need some kind of insurance to obtain factor.** This article will help you find that coverage.

For a family with hemophilia, one of the most frightening scenarios is the loss of health insurance. You can lose your health insurance when…

- you change jobs or companies
- you resign from a company or are laid off
- you depend on, and then lose, your spouse's insurance
- you reach your lifetime cap
- your employer cancels your insurance coverage

Depending on the policy, your child can lose the insurance he receives through you when…

- he turns 18 or 19 and is not a college student
- he finishes college
- he is a college student and turns 24

Many parents live in fear of losing their insurance, particularly when the local economy is depressed, jobs seem threatened, or the family depends on a single insurance policy. Some parents remain stuck in unsatisfying jobs because they fear that switching jobs will lead to losing their insurance. Often, both spouses must work to ensure adequate coverage.

It's possible to maintain adequate insurance, even when you change jobs to improve your career or move to another state for a new job. But such moves must be carefully planned.

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Excerpted from *Raising a Child With Hemophilia: A Practical Guide for Parents*, 4th edition

inside PEN

welcome

Sherrell Portrait Design

While the presidential candidates are stumping to sound-bite promises of "change" and "hope," millions of Americans are facing change, but not much hope. Persistent insurance cost-cutting measures continue to warp the outline of American healthcare. For those of us with hemophilia, home care switching may be our number-one worry. In this issue, find out what to do when things seem hopeless. Our feature article guides you through the steps to recovery when you lose your insurance. And *Storm Watch* tracks the involuntary switching that many states currently face from Blue Cross Blue Shield franchises.

Want to put life into perspective while wrestling with payer problems? Read about hemophilia care in Zimbabwe and my visit there just two months ago. At least we have factor—no one in America goes without that. Zimbabweans with hemophilia suffer on all levels, in a country that was once heralded as a model for Africa. Through our own Project SHARE℠, we are offering aid to keep hope alive. Read more about my trip on HemaBlog™, updated every Monday morning, at www.kelleycom.com/blog.

Ziva Mann offers comic relief with her testament to New Year's resolutions in *Homefront*, giving us a peek at the crazy life of a family with hemophilia. Speaking of crazy, check out tattoos in *Transitions*—that is, check out Tommy's tattoo. Learn how they're created, what they mean, and how best to handle the subject with your transitioning child. In *Inhibitor Insights*, be inspired by Paul Clements' look at the remarkable Huerta family of California. The Huertas refused to accept the medical community's passivity in the face of an inhibitor, and with tenacity and hope, overcame tremendous challenges.

Finally, we say goodbye to my good friend and co-author, community advocate Renée Paper. Renée passed away on November 7 at age 49. Her death prompted accolades, letters of grief, and condolences from around the world. Napoleon once defined a leader as a "giver of hope." In a world of change, Renée was undoubtedly a leader.

PARENT EMPOWERMENT NEWSLETTER FEBRUARY 2008

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Funding provided through generous grants from our corporate sponsors (page 19)

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inbox

THANK YOU SO MUCH FOR SENDING YOUR LITERATURE. MY father had hemophilia B, which made 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 that have been 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 for educating us.

Susan Francis
Florida

I AM A MOTHER OF TWO BOYS WITH SEVERE HEMOPHILIA, ages 10 years and 21 months. I am also an RN with a small home care company that provides excellent service. We have an insurance dilemma. Our company's insurance provider, Blue Cross Blue Shield, is switching to a single provider for hemophilia care. This provider is a large company that, in my eyes, is inadequate. I don't agree with single-source providers, as that limits our choice as patients. And while this company may look great on paper, I would consider its expertise in hemophilia care for patients in my area dubious. As a registered nurse, I usually need only our factor and supplies, but who knows? I have a toddler who can be

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BY MONICA GRUHER

The Making of a Gentleman

Player of the Year:
Ben Gruher

I stood on the cart path, watching the little blond-haired boy in the red, white and blue cap stride across the putting green, remove his cap in traditional PGA style, and shake his opponent's hand with a smile, saying, "Nice game." My son Ben took second place that day, succumbing to defeat after a two-hole playoff. Not so long ago, this might have resulted in a teary ending. Such a small action–removing his cap and congratulating the winner–I might not even have noticed, except for the slow but continual changes taking place. My boy, who at age three began to hitting wiffle balls with plastic clubs around the yard, is becoming a little gentleman at age eight.

I was planning to title this piece "The Making of a Champion," until I realized what I really have on my hands. Yes, my son is becoming a winner, but the evidence of his transformation is not the collection of trophies and medals displayed in his room. It's the kind of person I see developing before my eyes. A boy that I will, in the not-so-distant future, call a man. With confidence, I now accept invitations for him, at age eight, to play in foursomes with adults. He keeps up the pace, knows the lingo, and completely comprehends and practices the rules and protocol of the game–like don't walk across someone's line on the putting green!

It seems that golf demands a certain type of behavior or you don't last long. Good manners, control over your language, and a "gentlemanly" demeanor are as important as your score–if not more so. Tournament play definitely requires these protocols, even in children. I have now met many youngsters and young adults who play golf. Every one of these young people has impressed me. It's easy to see how the requirements and expectations of golf have influenced and developed their characters.

As a mom, I like the dress codes for courses and tournaments–again the gentlemanly influence. Gone are the T-shirts and jean shorts; they're replaced by collared polo shirts, neatly tucked in, khaki shorts, and... no, not the dreaded… *belt*! My son's petite size two saddleshoe-style golf shoes, and his ball cap with the attached ball marker, complete the look. Recently, I even noticed that he didn't offer resistance to the suit jacket I required him to wear to a wedding.

In golf, there are no participation trophies. You place, or you go home empty-handed until the next tournament. This is a learning process for life: to be a gracious "non-winner" by the tender age of eight; to cultivate the strength of head needed to strategize and gain mental toughness; and to develop the strength of heart to be a gracious winner.

Oh yeah, by the way, he has hemophilia. Severe factor VIII deficiency. Could there be a safer sport from a physical standpoint? How lucky I feel: I don't have to worry about a head injury or continual joint problems. Once, the built-up adrenalin and stress of a two-hole tie playoff produced a fairly severe nosebleed as we walked up to accept the first-place medal. But fortunately, this is the worst that has happened. Given the inherent vulnerability of having a bleeding disorder, participating in golf at any skill level builds confidence and self-esteem, which a chronic health problem can sometimes damage.

Although golf is often perceived as an expensive sport, we've found it no more expensive than many other sports. The "First Tee Program" at our local course focuses on kids in our metro area. It offers low-cost lessons and greens fees, and gives low-income grants.

Golf has been a godsend for us in providing a safe sport, but the making of our gentleman has truly been the blessing of all time. For parents looking for a path for their boy, I encourage you to follow this one.

Monica Gruher lives in Camas, Washington, with her husband Jim, son Benjamin, and daughter Jade (age three, also a golfer). She has been a mentor for mothers with newly diagnosed children, and hopes to continue her support and encouragement for other families with a hemophilia diagnosis. Ben was the 2006 NHF/CSL Behring Jr. National Golf Champion at age seven.

The First Tee Program is a national nonprofit available in 48 states at various golf courses. Its mission is to provide "young people of all backgrounds an opportunity to develop life-enhancing values such as confidence, perseverance, and judgment through golf and character education." Visit www.thefirsttee.org for more information.

BY PAUL CLEMENT

Dustin Huerta, *The Boy Scout Who Never Gives Up*

In February 1995, Pattie Huerta experienced an exceptionally difficult labor, and her obstetrician resorted to forceps and vacuum to deliver the new baby. Parents Pattie and Richard were sent home with their new baby, Dustin, just 12 hours after they had arrived at the hospital.

But something seemed wrong. The routine heel stick would not stop bleeding. The next morning brought a startling shock–Dustin's head was swollen and lopsided. As Pattie monitored Dustin, his head continued to swell. When Dustin became lethargic, his parents knew something was seriously wrong and rushed him to the emergency room. The ER physicians at first suspected shaken baby syndrome, but when Dustin's umbilical stump was accessed for a vein and kept bleeding, they suspected a bleeding disorder and ordered blood tests.

While in the ER, Dustin received several blood transfusions and fresh frozen plasma in an effort to control his bleeding. When he was four days old, the results of the blood tests showed that Dustin had hemophilia A. He was immediately given a dose of factor VIII concentrate. Now the bleeding from his heel stick and umbilical stump made sense. The vacuum and forceps had caused bleeding between his skull and scalp, causing his head to swell and distort. Dustin received several doses of factor and was released from the hospital when he was six days old.

Over the next few months, Dustin had several bleeds that didn't respond well to infused factor. Dustin bled from the infusion sites. After learning from NHF about inhibitors, Pattie asked her son's physician several times to have inhibitor tests done. The hematologist simply replied that Dustin didn't have an inhibitor, and refused to order a test. As a result, Dustin would suffer another severe bleed, with long-term consequences.

In April 1996, Pattie and Richard infused Dustin four times in two days for an ankle bleed, but with no effect. They took Dustin to the local hospital, where he endured 13 needlesticks before nurses could access a vein for infusion. The next day, at the site of an infusion in his right arm, Dustin's little elbow was swollen to six and one-half inches in diameter. The swelling spread, causing his hand to grow to several times its normal size. Blood then traveled up his arm and across his chest, causing his arm to swell, as Pattie describes it, "like the Michelin Man's."

Dustin's bleeding caused a dangerously high build-up of pressure within the sheath of connective tissue covering the arm muscles, known as the "compartment." The pressure eventually shut down blood flow within the muscle, a condition known as *acute compartment syndrome*. Acute compartment syndrome is a medical emergency. Without a supply of blood carrying essential nutrients and oxygen, muscle cells and nerve cells die. Without treatment, this can lead to paralysis, loss of limb, or death. Dustin's physician finally ordered an inhibitor test, which revealed a titer of 73 BU. Dustin was transferred from the local hospital to a medical center in Los Angeles, where a venous access device was implanted. A second inhibitor test showed the titer had risen to 135 BU.

By now the damage had been done. Pressure from the bleed had compressed the blood vessels in Dustin's arm so much that blood flow was reduced, and his arm was cold to the touch. The pressure also caused nerve damage–he lost sensation in his arm and hand, and was unable to move his arm. Dustin's paralysis caused multi-

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photos: Huerta family

Dustin's childhood hasn't been easy: Dustin with father Richard Huerta

PROJECT SHARE
It's time to give back.

ZIMBABWE: *Life on the Edge*

BY LAURIE KELLEY

When Zimbabwe gained independence from the UK in 1980, hopes were high. The small African nation, nestled between Zambia and South Africa, was regarded as the model for all African nations. Robert Mugabe, a teacher turned political reformist, became the country's first black president. He won kudos for doubling school enrollment, raising the minimum wage by 50%, offering free healthcare to the poor, and subsidizing prices. In his 1982 landmark book *The Africans*, David Lamb wrote that Mugabe had proved himself "perhaps the most capable leader in Africa."

How things have changed. With Mugabe still in power after 27 years, economic mismanagement, corruption and political terror have left Zimbabwe numb, like a traumatized child at the hands of an abusive father. The last white prime minister, Ian Smith, died just days before I arrived, and his fatalism about self rule in Zimbabwe seems to be fulfilled: the country is starved, dysfunctional, and fearful. Whites are leaving in droves and blacks suffer daily.

I visited Zimbabwe for ten days in fall 2007, my third trip to a country I admit I still love. I admire the lush countryside, the stunning beauty of Victoria Falls, the safaris, and above all, the gracious Zimbabweans, always polite and civil. But I was shocked to see the country's deterioration since 2001, when I attended our first hemophilia camp. The economy has collapsed by 50%. Inflation is rampant at 12,000%, the world's highest. Gas stations are empty, and banks are routinely closed. Unemployment has skyrocketed to 80%. Bread is mostly unavailable, in a country that used to be called Africa's Breadbasket.

Hemophilia care? Nonexistent. There are no hematologists in the country, except for one volunteer Cuban doctor, who is scheduled to leave in April. The only factor comes from Project SHARE and our partner, AmeriCares. I visited to assess needs, and I hardly knew where to begin. With my colleague Peter Dhlamini, who has hemophilia, I toured Harare, the capital, and Bulawayo, the second-largest city and Peter's home town. We met with doctors, the health ministry, patient groups, and influential people who might help us. Our goal was to resurrect the Zimbabwe Haemophilia Association (ZHA) and start a plan to get help.

Each day was a struggle. Where to get gas? How to exchange my dollars? (I paid $10 US for a glass of Coke one day; using the official exchange rate, you could go broke quickly.) Electricity shut down frequently. We ate only two meals a day because food was so hard to get. I shook my head, thinking ruefully about how many Americans will pledge to lose weight in 2008—here, you have no choice.

One night we visited Elton, a 17-year-old with severe hemophilia A. He lives on the outskirts of Harare on a red, dusty road. His house was dimly lit when we arrived, and mosquitoes constantly nipped our ankles. Elton, gangly and tall, has the worst case of synovitis I have ever seen. He told me his lower leg had gone numb from the swelling. His blood supply was being strangled, and he said he might lose his leg. Resigned, his family didn't bother to take him to the hospital. We immediately arranged to get Elton taken to Harare to see a surgeon or, better still, taken to South Africa, where they have better care. SHARE would pay all expenses.

By week's end, we had a clearer picture of how to begin helping in Zimbabwe. Project SHARE does a lot more than just dole out free factor. We use free factor as a tool—to get assessments, to get accountability; to get local hemophilia patients, doctors and health ministry officials working with us to improve long-term care. The health ministry was candid: It would be a long time before there would be money for factor. So it's up to us, the international hemophilia community, to care for our brothers in Africa. We will continue to ship factor. We will get care for Elton, and for anyone else who needs it. We'll buy two new refrigerators to store the factor, and buy a printer for the ZHA office. And best of all, we will hold a camp again in 2008 to provide medical care, factor, fun, and hope for a better future.

photos: LA Kelley Communications, Inc.

Day-to-day survival: vegetable seller in Harare

Fatalism: Laurie Kelley with Elton, who does not expect to get better

No factor for infection: Owen Kanozeya suffers in a hospital

Read about Laurie's trip on HemaBlog™ at www.kelleycom.com/blog

BY LAURIE KELLEY

The Wicked Switch of the West?

Home care switching has hit the hemophilia community hard in the past few months, and patients increasingly feel its sharp pinch. Insurers continue to negotiate new contracts with home care providers, and in some cases, even start their own specialty pharmacies to purchase and deliver factor. Hemophilia home care switching may no longer mean just being switched from one well-known provider to another; it may mean being switched to a new entity, one owned by an insurance company. At the forefront of the recent hemophilia switching wars is a specialty pharmacy called PrecisionRx Specialty Solutions, owned by WellPoint/Anthem. In July 2007, WellPoint/Anthem policyholders in Nevada, Colorado and California were notified that as of September 2007, they would be switched from their previous home care company to PrecisionRx, or to a local 340B entity. WellPoint/Anthem follows Aetna, Cigna, HealthNet, Kaiser, and other smaller plans that now own internally-integrated specialty pharmacies.[1]

"This issue has been creeping up on the bleeding disorders community for some time now," says Bill Jamison, a person with hemophilia from Harrisburg, Pennsylvania. "Choice is paramount to our wellbeing. WellPoint/Anthem is testing the waters and eliminating adequate [home care] choice for the consumer. The community must have choice to access expert care in treating this condition—not an insurance company that has absolutely no knowledge, experience or expertise in providing care to our very unique needs. Hemophilia care is not factor in a box."

"Hemophilia care is not factor in a box."

The switching has been followed by some hemophilia patients' complaints about services from these new entities (see "A Letter to Aetna," *PEN*, May 2007). WellPoint is quick to point out that whatever the problems, they aren't due to lack of knowledge or expertise: Wellpoint plans all have medical directors, case managers and pharmacy directors. PrecisionRx employs nurses, pharmacists, reimbursement specialists, and technicians trained in the specific needs of the bleeding disorders community. It also has a medical director with more than 40 years' experience in the bleeding disorders community.

Still, change isn't easy to make, or easy to take. And our community is reacting swiftly as the switching spreads eastward. Warned one town crier in the online chat group *Hemophilia Support*, "For those of you who have Anthem/Blue Cross in the states of Indiana, Kentucky, Missouri, Ohio, and Wisconsin… did you know that your in-network providers for your delivery of factor are going to change to either the 340B program at your HTC or the insurance-owned pharmacy PrecisionRx?"

Switching isn't happening only with PrecisionRx, of course. Chris Blair, president of Hemophilia and Bleeding Disorders of Alabama (HBDA), writes that Blue Cross Blue Shield of Alabama has also entered into a single-source provider, or exclusive, contract with a large healthcare company for patients in Alabama with hemophilia. Anyone in Alabama who is insured through BCBS, and whose factor provider is not the one selected by BCBS, will be transferred automatically to the new BCBS provider effective February 1, 2008.

Despite the articles and warnings previously sent to families,[2] the news still comes as a shock. And families still cling to what will soon be outmoded strategies. They express two fears:

1. Losing the long-term relationship they have with their current provider.
2. Poor service by the new home care company regarding assay management, delivery time, supplies, and knowledge about hemophilia.

Trust is built on long-term relationships. Sudden switching snaps apart the bond of trust between hemophilia families and home care; families want to keep the representative they knew, who understands their unique needs. But there is an added wrinkle. The hemophilia factor-provider industry is

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[1] Additionally, many insurance plans have developed an exclusive relationship with vendors for hemophilia care. For example, Coventry, IBC, Humana, and BCBS of Alabama all have exclusive carve-outs for hemophilia; some are with well-established and well-known hemophilia home care companies. [2] See "The Coming Storm," *PEN*, February 2005, and "PBMs Take Center Stage," *PEN*, May 2005.

BY ZIVA MANN

New Year's 2008 Resolutions

I blinked, and already there are Christmas trees on the curb. Where did 2007 go? I had such plans for 2007—but then again, I recall having plans for 2006. Sigh. Onwards we trudge, then. It's resolution time.

- I will get Shai to school on time. It's only 27 minutes away, so how hard could this be?

Note to self: Put little brother Akiva in car the night before.

- I will be more patient with lost gloves, forgotten (and moldy) lunchbags, and the seventeenth wail of "Muuuum, I'm huuuungry!"

Note to self: Pack more snacks in diaper bag. Consider a pack mule when diaper bag is full.

- I won't laugh when Shai limps theatrically, forgets, and then starts dancing to "Walk Like an Egyptian." Or at least, I'll laugh quietly. I will try not to roll my eyes noticeably when he says something hurts, but after considering the implications (factor? ice? rest?), decides that he feels just fine.

- I will remember to water the plants. And feed the fish.

Note to self: Failing the above, get better at hiding—or flushing—the evidence.

- I will thank my husband Ezra profusely and repeatedly for doing more than his share of morning infusions. An extra 20 minutes of sleep is wonderful.

Note to self: zzzzzzzzzzzzzzzzzzzz.

- I will file things. The Big Pile O' Paper is not (repeat, *not*) a filing system. I will file all the EOBs, the notes from arguing with people about the EOBs, the lists of lab results, my old factor log sheets.

Note to self: Develop filing system.

Note to self: Find place to put filing system. Use same methodology used to create extra hours in the day. Failing that, label a cardboard box INSURANCE 2008 and toss everything in there.

Note to self: Persuade self that a box is very, very different from a pile.

- I will remember that doing housework is less important than reading stories with my boys.

Note to self: Hire housekeeper.

Note to self: Get job to pay for housekeeper. Failing that, win lottery.

- I will learn about advocacy. I'm tired of fighting with our insurance company, and it gets worse every year. Is there something I can do to protect us?

Note to self: Call local NHF/HFA chapter and ask about advocacy. (Stephen King novel vs insurance battles? Insurance battles are far, far scarier.)

- I will go to bed before I drop in my tracks.

Note to self: Tasks before going to bed: clean up dinner dishes, laundry, make school lunch, set out tomorrow's school clothes, paperwork, put away toys, restock diaper bag, laundry, return phone calls, spend time with husband, email, blog, prep for morning factor infusion.

- I will eliminate some tasks.

Note to self: Which ones? Husband may have an opinion. Consult him.

- I will not be intimidated by the goals I've set for myself. Except that I am. Dang, that's a really long list.

Hmm. Maybe I should try and whittle this down. Okay, let's try again.

- I will learn to accept imperfection. The mittens will be lost, the lunchbag will contain something horrible and rotting, the gym is unlikely, and yes, I will probably roll my eyes from time to time. But maybe I could reduce the amount of horrified screeching?

- I will try to forgive mistakes—mine included. Because oh boy, are we going to make a lot.

Note to self: Find therapist. This rolling with the punches idea may be harder than I think. Do perfectionists ever roll?

Happy 2008, everybody! May your year bring joy, love and surmountable challenges. Oh, and a good filing system.

BY LAURIE KELLEY

Making Their Mark

Transitions is a *PEN* column sponsored by Baxter BioScience

Tommy learns Latin: *Honesty, Courage, Generosity, Beauty*

What does gene therapy have to do with tattoos?

The first hemophilia gene therapy trial, conducted in Boston in 1999, used *fibroblasts* as host cells for an implanted vector. The vector contained a gene that would produce factor VIII. Fibroblasts are dermal cells, lying beneath the epidermis. Unlike most other cells in the body, fibroblasts are long-lived and don't slough off like the outer skin layers. This makes them attractive cells for what we hoped was a permanent gene therapy.

Fibroblasts are also great for tattoos. Ink injected into fibroblasts stays in place, making tattoos permanent. The gene therapy didn't pan out, but tattoos are all the rage.

More than 20,000 tattoo parlors operate in our nation, according to *U.S. News & World Report.* A 2003 Harris Poll estimates that 36% of people aged 25–29 have one or more tattoos.[1] Chances are, your teen or young adult with hemophilia will consider getting a tattoo sometime.

But enough about statistics. Tommy came home just after Christmas to show me his gift to himself–a large tattoo on his left forearm of four Latin words in Old English script. **Pius**. **Animosus**. **Liberalis**. **Bellus**. Talk about mixed feelings: It's Latin! *It's a tattoo!* It's beautiful! *Is he crazy?*

Why a Tattoo?

For many parents, tattooing connotes rebellion, self-mutilation, conformity to peer pressure, or impulsiveness. Many teens and young adults see it differently. To them, tattooing means emerging autonomy and identity expression. Tattoos are fun, flirty and daring. I know one representative in the hemophilia pharmaceutical industry who sports a modest one, and an executive director of an NHF chapter who flaunts a large, colorful one.

Tommy has no adolescent angst; his tattoo is all about positive expression. Last year, he surprised us with a tattoo on his right deltoid: a vibrant green and gold shamrock. Hard to object when you're Irish. But this Latin one is more serious. It's big, it's black, it's on his forearm, and it's forever. As a contemporary musician, he feels this is appropriate "body art," as tattoos are now called.

If you have a transitioning teen with hemophilia who is considering a tattoo, please prepare him. Have the Tattoo Talk. Don't think you'll be planting ideas about getting one–because chances are, he'll think of it himself. When your child is transitioning, you need to help him make better decisions. For that, he needs to know your values and feelings on the subject, but he also needs good information.

Discuss the reasons your teen wants a tattoo. What message does he want to convey? What does the tattoo mean to him? How might he feel about it several years from now? Twenty years from now? Will he respect other people's feelings by avoiding racially, politically, sexually or religiously charged art? Can he handle the various reactions he'll get: Disgust? Shock? Admiration? Concern?

DOs and DON'Ts

Educate yourself and your young adult about the procedure, pain, follow-up care, and potential complications. In a nutshell, here are some things for you both to consider:

- Be sure your child is of legal age; in most states, this is 18.
- Call the hematologist first to discuss. Always infuse before tattooing.
- Be sure you child understands that tattoos are permanent. And remember, skin sags after age 45. As Robin Williams once said, that barbed-wire tattoo will look like a picket fence when you're 60!
- Choose a licensed shop and a qualified professional.
- Make sure the artist uses new or sterile equipment for each client.
- Try a temporary tattoo first, to see how friends, family–and you–react. Or try a small tattoo in an inconspicuous place.

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[1] Conducted online between July 14 and 20, 2003, by Harris Interactive® in a nationwide sample of 2,215 adults.

BY RICHARD J. ATWOOD

No Dueling Allowed!

A look at hemophilia in the early twentieth century

Diseases of the Kidneys and of the Spleen, Hemorrhagic Diseases
H. Senator and M. Litten, 1905
Philadelphia, PA: W.B. Saunders & Company
815 pages

Prince Alexis: In 1914, Russia had only 11 known individuals in seven hemophilia families

It's fascinating to examine the early twentieth century's view of hemophilia and its treatment, if only to appreciate the advanced treatment we enjoy today. In 1967, Robert K. Massie published *Nicholas and Alexandra*, his Pulitzer Prize-winning history of the last Russian tsarist family. Alexis, the tsarevich and heir to the throne, had hemophilia. Massie stressed the key role of hemophilia in shaping the course of events that led to the Bolshevik revolution. For contemporary medical insight, he cited Dr. M. Litten, who published *Hemorrhagic Diseases* in 1905, when Alexis was one year old. The combined work by Drs. Senator and Litten included a 95-page section on hemorrhagic diseases, where Litten summarized hemophilia ("Bleeders' Disease") in just 25 pages. At the time, hemophilia's prognosis was poor. Only 40% of those affected reached age eight, and just 11% lived to age 22, although the outlook slightly improved after puberty.

In the early twentieth century, hemophilia was known to be transmitted by female "conductors" to male "bleeders." It was also known that females could be affected, in a ratio of one woman to 13 men. Hemophilia's cause was not understood, although an unidentified bacterial infection was suspected; possible culprits even included psychic influences during pregnancy, and a susceptibility linked to anxiety. Ironically, hypotheses involving the vascular system and the blood itself had failed rigorous scientific examination. While scientists investigated the blood's reduced clotting ability, along with fibrin levels and the fragility of vessel walls, they reached no conclusions.

There was suggested treatment. A special diet cut out all beverages that "excite the vascular system" (alcohol, tea, coffee) and stressed bland, solid food with fresh vegetables. Seabathing was recommended, and cold dips followed by rubs. Life in the country was considered beneficial. Drugs used to treat hemophilia included chloride of iron, mineral acids, subacetate of lead, sulphate of magnesia, and sulphate of sodium.

Treatment for bleeds included tonic remedies, ergot, acetate of lead, hydrastis canadensis or opiates, and nitrate of silver. Mechanical treatment involved elevating the affected limb, local styptics such as chloride of iron, cautery, packing, rubber bandages, and compression.

Early hemophilia care also included some social rules:

- Playing with children should be supervised by an adult, and playthings should not inflict injury.
- The family physician should consult with the child's teacher about hemophilia symptoms.
- Children should not perform gymnastic exercises.
- Children should never be punished physically.
- Dueling is forbidden.
- People with hemophilia should avoid any profession or trade, including military service, with violent bodily exercise or exposure to slight injuries.
- Recommended employment: office work, drafting, or the "learned professions."
- Occupations to avoid: watch maker, engraver, wallpaper hanger, goldsmith, barber.

Expertise in care and treatment originated in areas where hemophilia was prevalent, and Germany furnished the majority of cases. In 1905, of a worldwide prevalence of 194 known hemophilia families and 630 people with hemophilia, 93 families and 258 individuals lived in Germany. Compare this to Russia, with only 11 individuals in seven hemophilia families.

Why did Massie choose to cite the Litten text on hemophilia in *Nicholas and Alexandra*? Possibly because it was readily available in its English translation and was published during Alexis's childhood. And probably because the more experienced German physicians presented the standard of hemophilia care in 1905. Interestingly, the Russian physicians may not have followed all of the German medical advice because of professional jealousy or national pride, as the Russian dislike of Germany at the time was well known. But regardless of treatment efforts, Alexis was assassinated by the Bolsheviks at age 14. He was perhaps the most famous person with hemophilia, and his life has been immortalized in many books and films.

For more on living with hemophilia in the early twentieth century, read *Legacy: The Hemophilia of Yesterday* by Matthew Dean Barkdull. To learn about the first known American family with hemophilia, read "The Appletons: America's 'First Family' With Hemophilia," by Richard J. Atwood and Sara P. Evangelos, *PEN*, November 2002. Order both resources through LA Kelley Communications at www.kelleycom.com.

In Memoriam: *Renée Paper*

With deep sadness we note the passing of our community's greatest advocate for people with von Willebrand Disease.

Renée Paper died November 7, at age 49, after an eight-week hospital stay following a fall. Renée had been on disability leave for the previous three years. She had just received an achievement award at NHF's 59th Annual Meeting in November, in recognition of her outstanding life achievement in helping others with bleeding disorders. People around the world knew Renée, as she traveled and lectured frequently prior to her disability. As many of you already know, after her gastric bypass surgery, Renée lost a tremendous amount of weight in a short time. She seemed to recover and was doing well, but then her health issues compounded. She had VWD and also battled hepatitis C, along with various other problems. Many of her friends stayed in touch by phone or by visiting her in Las Vegas over the past several years.

Renée was a personal friend, and also my co-author of *A Guide to Living With von Willebrand Disease*. She traveled with my family and me to Puerto Rico and the Dominican Republic on business. Renée and I gave presentations together in places as close as Connecticut and as far away as Australia. She was brilliant; she was fun-loving. She could be irreverent, yet compassionate. She loved animals, and one of her favorite gifts to her friends each New Year was to send a photo of herself with a different animal from different parts of the world: kissing a dolphin in the Caribbean, draping a boa constrictor around her neck in Mexico, nuzzling an alligator in New Orleans, atop a camel in the Canary Islands. Renée knew how to grab life by the horns and tame it, and she wanted others to do that, too, regardless of disorder or disability.

Renée was a certified critical care nurse with more than 20 years' experience in emergency nursing. She thrived in the midst of excitement and chaos with her typical take-charge personality. She served as a team member of several boards and committees for NHF, WFH, and other organizations. Renée founded Hemophilia Foundation of Nevada, bringing care and advocacy to hundreds. Nevada was an appropriate place for her to live, as her motto has always been "Just play the hand you're dealt."

After Renée's passing, messages poured in from around the world. Helen Campbell of the UK, from the MSN group *WomenwhoBleed*, wrote: "Renée has been a great inspiration to me personally (and to other women) in raising awareness and promoting advocacy within, and outside of, the bleeding disorders community regarding the issues surrounding women and their bleeding disorders. Her work has touched the lives of many both directly and indirectly. It is a great loss for the hemophilia communities and yet must be a greater loss for her family. Thank you, Renée. You made such a difference. From your acorns you saw great oaks grow, now the branches are reaching far and wide."

Parimal Debnath, Haemophilia Society of Bangladesh, wrote, "It's really sad news. My condolences for her family. May God rest her soul in eternal peace." Dr. Carol Kasper, renowned hematologist, emerita professor of medicine, University of Southern California, Orthopaedic Hospital, and Renée's close colleague and friend, best sums up Renée's legacy and memory:

> Renée Paper had a vision for Nevada, its own hemophilia foundation, its own hemophilia treatment center, and she made them happen. It wasn't easy. Renée was blessed with energy, enthusiasm and perseverance. She had a great ability to organize and to inspire. She also knew how to have fun. She was the life of the party! I remember driving with her down a country road in Ireland, in sheep country. Sheep strayed across the road. Renée stopped and shooed them off, and you have no idea how hard it is to shoo a sheep. We cleared a bit of road, drove on around a curve, and more sheep! We wound up in gales of laughter as we continued to shoo the sheep, and shoo and shoo.
>
> I am grateful to Dr. Jonathan Bernstein and nurse Becki Berkowitz, also Dr. Heather Allen, all of Las Vegas, who watched over Renée in her last illnesses, whenever Renée's spirit of independence would allow it. I shall remember her achievements, but the images of her exuberance and hilarity are foremost in my mind at this time. Her name will be remembered.

Renée is survived by her father, Harry Paper, of Encino, California. Harry expressed his deepest appreciation to all who were touched by Renée's work and took the time to write to him to share their thoughts, feelings and stories about Renée.

Good-bye to a tremendous leader, warm and loving human being, educator, visionary, and friend. There was ever only one Renée, and we will miss her.

Laurie Kelley and co-author Renée Paper, Boston, 2003

LA Kelley Communications, Inc.

> I was once offered a position that I really wanted, but I had to turn it down because of the insurance policy. Within three months, we were able to get my son covered under my wife's policy. So I accepted the job I had wanted, with the understanding that I would have to wait a year before my son was covered. To my dismay, we found out a year later that this could not be—after I had already changed jobs. The insurance industry has dictated that my wife must work forever.
>
> *—Ken Moffat, Ohio*

If you're lucky enough to be offered the job of a lifetime, first get written approval that you will be covered by your new employer's insurance. Make sure you get written answers to your questions concerning hemophilia, especially the new policy's pre-existing condition clause. Why do I stress *written*? Trust me: If you ever need to battle out a disagreement with your payer or employer through a mediator, or even in court, you'll need these written promises to support you legally. Try to have some savings on hand as a backup, in case the pre-existing condition clause requires a waiting period. Ask a reimbursement specialist about pharmaceutical companies' patient assistance programs, which sometimes grant free factor to needy families. Help is available–but first help yourself by getting prepared.

Even when you are prepared, sometimes the inevitable happens: You lose your insurance. What are your options?

Consolidated Omnibus Budget Reconciliation Act (COBRA)

If you lose your job or switch jobs, your first question should be, "Am I eligible for COBRA?"[1] The COBRA Act of 1985 was established to allow you to pay for continuing your insurance coverage, temporarily, at the group rate you received through your employer. COBRA applies only to certain qualifying events: when you lose your job, experience a reduction in hours, anticipate legal separation or divorce, or lose a spouse who has provided insurance.

Your employer[2] must notify its insurance plan administrator within 30 days of the date of the qualifying event. Within 14 days after this notification, the plan administrator must then notify you of your COBRA rights. You may elect COBRA coverage any time within 60 days after your insurance coverage terminates, or 60 days after the date you received notice from the plan administrator.

Drawbacks? Coverage through COBRA is expensive, although group coverage rates are lower than those of individual plans. You must pay the full premium and usual costs, such as deductible and copayments, on time. Missed or delayed payments result in immediate termination of your policy.

Advantages? COBRA lets you keep all the benefits and coverage you had before. You can use this extended coverage for 18 to 36 months, depending on your reason for eligibility. If you lose your job, you can continue coverage for only 18 months. Following divorce or separation, coverage is 36 months for the spouse and dependent child.[3]

Best of all, when you start a new job, you can be covered by your previous COBRA policy even when you begin a new insurance policy. If your new policy imposes a pre-existing condition clause or waiting period, you'll continue to be covered by your COBRA policy throughout the waiting period.

Public Assistance

What if you can't afford the expensive premiums and other payments associated with COBRA? You can work with your HTC social worker or reimbursement specialist to find assistance programs that help pay premiums and other costs. If you're unable to find such a program (like PSI; see p. 13), you may need to consider public assistance. Fortunately, all state governments have assistance programs for people facing medical expenses, and 33 states have specific hemophilia programs. Public assistance programs include Medicare,

[1] For COBRA information, call the Department of Labor hotline at 202-523-8784. Employers with more than 19 employees and a sponsored group program must allow the terminated employee to continue coverage through COBRA. However, the federal government is exempted from offering COBRA, so federal employees are not eligible for this continued coverage.
[2] Or your spouse's employer, if you are divorcing and you are dependent on your spouse's plan. [3] Under the new HIPAA rules (see *PEN*, February 2007), if a person is determined disabled within the first 60 days of COBRA coverage, he or she is allowed to purchase an additional 11 months beyond the usual 18-month coverage period. Family members of a disabled individual also qualify for the additional 11 months of coverage.

Medicaid, Supplemental Security Income (SSI), and Comprehensive Health Insurance Programs (CHIPs).

Medicare is a federal health insurance program for people over age 65 and people with disabilities or end-stage renal disease. Medicare's medical insurance covers only 80% of the cost of factor therapy, so all hemophilia patients should obtain a supplemental insurance policy that pays the additional 20% coinsurance. Because Medicare doesn't cover all health services, find out what's covered, and learn about any limits on hemophilia treatment. Medicare is divided into two parts. Part A covers hospital charges, and Part B covers physician-based services. Under Part B, Medicare covers all hemophilia factor products and reimburses you whether you use factor as an inpatient or outpatient.[4]

Medicaid is a state-run medical assistance program that pays medical bills for low-income families. The good news is that you will get full coverage for your factor. The bad news? To qualify for Medicaid, your annual income must be below a specified poverty limit, which varies state-to-state. To be eligible for continued assistance, you must keep your income low–often so low that many two-income families must return to one income and sacrifice many things they once enjoyed.[5]

> We have no insurance; we reached our $1 million cap. We had to apply for Medicaid and give up lucrative income in order to be eligible. It's really tough living under current income restrictions.
>
> *–Anonymous*

One SSI (see below) provision, 16-19-B, allows you to be eligible for continued Medicaid coverage even when you hold a job, as long as your adjusted income falls within certain approved levels. Since each state runs its own Medicaid program according to federal guidelines, coverage varies state-to-state. But all Medicaid programs offer choice of provider, as long as that provider accepts Medicaid patients. Ask your doctor or HTC if they accept Medicaid patients. If they don't, you may need to use public clinics, which normally lack specialized care for hemophilia.

Supplemental Security Income (SSI) and Social Security Disability Income (SSDI) are programs provided by Social Security. SSI pays monthly benefits to families with low incomes and limited assets that can be liquidated. Children with hemophilia may qualify for SSI if they meet the SSI definition of "disabled," and if their family's income and assets are low. SSDI is a social insurance program that offers Social Security tax benefits through your employer. If you are disabled, you can receive benefits based on your earnings.

Comprehensive Health Insurance Programs (CHIPs) are offered by most states. These are high-risk insurance pools for people who can't get insurance elsewhere. Under a CHIPs plan, you pay a premium that varies state-to-state, but it's generally lower than COBRA or individual policy premiums. You may have to pay a deductible, sometimes as much as $1,000.

Call to find out if your state offers CHIPs and exactly what is covered.[6] Usually, you are eligible if…

- you have had 18 months or more of previous coverage under a group health, government, or church plan
- you have had no lapse in coverage longer than 63 days
- you are not eligible for another group plan, Medicare, or Medicaid
- you do not have another source of health insurance
- you have used COBRA, and
- you were not dropped from your former plan due to nonpayment or fraud

State Children's Health Insurance Program (SCHIP) is offered in all states. SCHIP provides health insurance coverage to uninsured children under age 19 in families that meet certain financial guidelines. States may provide SCHIP coverage by expanding their existing Medicaid program, by creating a separate state program, or with a combination of both. The goal of SCHIP is to help children in working families with incomes too high to qualify for Medicaid, but too low to afford private family coverage. Although benefits vary state-to-state, children are usually eligible for regular checkups, immunizations, eyeglasses, doctor visits, prescription drug coverage, and hospital care. It's important for families to investigate the coverage options available in their states.[7]

If you still need assistance, and you don't qualify for the programs listed, check out other public programs that may help people with hemophilia pay for medical expenses or receive additional services.

Title V Children With Special Healthcare Needs Programs (CSHCNP). Each state has special programs under Title V government funding. Your state health department can supply more information about these programs. When you need instant, personalized advice on accessing state and federal assistance and entitlement programs, turn to

[4] In January 2006, the Medicare Modernization Act (MMA) became effective. The MMA does not change Part B coverage for factor products, but it does change how much your distributor will be reimbursed. In addition, the MMA will mandate prescription drug coverage for all Medicare recipients. [5] See the Centers for Medicare and Medicaid Services at www.cms.hhs.gov. [6] An excellent resource guide, *Comprehensive Health Insurance for High-Risk Individuals: A State-by-State Analysis*, can be purchased through Communicating for Agriculture at 218-739-3241. [7] For more information regarding eligibility and coverage, call 877-Kids-NOW or 877-543-7669.

No Insurance: *What Next?*

You can lose your insurance when you change jobs or companies, resign or are laid off, depend on and then lose your spouse's insurance due to divorce or death, reach your lifetime cap, or your employer cancels insurance coverage.

COBRA allows you to continue your insurance coverage after you've lost your job at the group rate you received through your employer, under certain conditions.

You may qualify for public assistance or entitlement programs. Medicare is a federal health insurance program for people over age 65 and people with disabilities or end-stage renal disease. Medicaid is a state-run medical assistance program that insures low-income families.

Along with public assistance programs, look into Social Security and Comprehensive Health Insurance for High-Risk Individuals.

PSI offers temporary free insurance premium coverage to qualified individuals, so you can stay insured while you work through insurance transition or loss.

There are many ways to get free factor: research trials, free trial programs, manufacturer coupon programs, and compassionate care services.

When insurance change threatens or occurs, contact your HTC social worker, local hemophilia chapter, or reimbursement specialist with your home care company or factor manufacturer.

Advocating for Chronic Conditions, Entitlements and Social Services (A.C.C.E.S.S.). This free service is funded by Hemophilia Health Services and offers in-depth information about public insurance from experienced hemophilia experts.[8]

Other Options for Obtaining Insurance and Factor

Some families may not qualify for public assistance but are threatened with the loss of insurance. The hemophilia community has special programs that can help cover insurance premiums or provide free factor. While it may take some juggling, frequent phone calls, and a lot of paperwork, you can use each of these programs to help fill the gaps in insurance.

Patient Services, Inc. (PSI). This nonprofit organization, founded by a person with hemophilia, is registered in all 50 states. PSI operates as a safety net to help maintain coverage while people with chronic disorders transition from one policy to another. It assists with premium payments for patients who can't afford them, and helps patients locate health insurance. PSI services are free.[9]

Research trials. Check with your HTC for new research studies that may offer free factor concentrate to study participants.

Free trial programs. To entice customers to switch products, factor manufacturers now offer free factor through special programs. Some programs require that you make a request through your HTC; others can ship product directly to you. Check all the manufacturers' websites to see if your factor manufacturer offers such a program. Supplies will be limited.

Coupon programs. Some manufacturers provide factor at no charge when you lose insurance, if you enroll in their coupon program while you are still insured. Some offer up to three years of free factor if you're a regular customer and have lost your insurance. This is a way to solicit customers and build brand loyalty. It's also a fabulous idea. Contact your manufacturer immediately to enroll in its program. But you must be registered *before you lose your insurance*. If you aren't registered now, please get registered!

Compassionate care programs. Pharmaceutical and home care companies sometimes offer compassionate care programs that provide free factor concentrate to families who can prove financial hardship. This is usually a one-time shipment. Your HTC social worker or nurse can help you with this resource, or you can visit the pharmaceutical websites directly. You can also call us at LA Kelley Communications, Inc.[10]

The entire hemophilia community–patients, HTC staff, home care companies, pharmaceutical companies–realizes that insurance is the foundation of good healthcare. Strive to maintain your current insurance, and know your options when you change insurance. If you lose insurance, be aware of the safety nets available to you. Preparation is your best hope for preventing a disastrous situation: no insurance and no options. The waters of hemophilia insurance are choppy, full of obstacles that can shipwreck you. Navigate these waters well with the help of all the resources listed here. An entire community is waiting to assist you.

[8] Contact A.C.C.E.S.S. at 800-999-LIFE. [9] Contact PSI at 800-366-7741. [10] Contact LA Kelley Communications, Inc., at 800-249-7977.

Inhibitor Insights... continued from page 4

"Boy Scouts... the best thing Dustin ever did."

ple problems. He gnawed his right index finger almost to the bone. He suffered bleeds because he was unable to stop himself with his right arm when he fell. Dustin underwent three years of physical therapy to regain the use of his right arm. Although he can now use it, he still lacks fine motor skills in his right hand, and simple tasks, such a tying a shoelace, are difficult.

To get the specialized medical care he needed, Dustin was switched to an HTC in Orange County, where he was started on Immune Tolerance Induction, with monthly infusions of IVIG, a product that maintains adequate antibody levels to prevent infections. At the beginning of treatment, Dustin's inhibitor titer was 185 BU, and it soon shot up to 800 BU. Fortunately for Dustin, the tolerization program was successful. Within a year, his titer dropped to zero.

Dustin's childhood hasn't been easy. He has suffered many complications of hemophilia. He has had two Broviacs® and two Port-a-Caths®. He's had four infected access devices that required surgical removal. One Port-a-Cath eroded through his skin, another clotted off several times, and a third developed a leak.

Now age 13, Dustin has arthritis in his ankles, knees, hips and elbows. His ankles are target joints, and he developed synovitis in both. In the winter, Dustin's ankles and knees are often so painful that he can't get out of bed. For four years, Dustin relied on a daily low dose of VIOXX® to reduce his pain and inflammation. When the drug was pulled from the US market in 2004, Dustin's ankle bled more frequently and became increasingly painful. Dustin had a radionuclide synovectomy performed on his left ankle. Due to the thickness of his synovium (his ankle was the size of a grapefruit), the synovectomy successfully removed only half the synovium. Seven months after his synovectomy, a cortisone injection in Dustin's ankle provided significant relief.

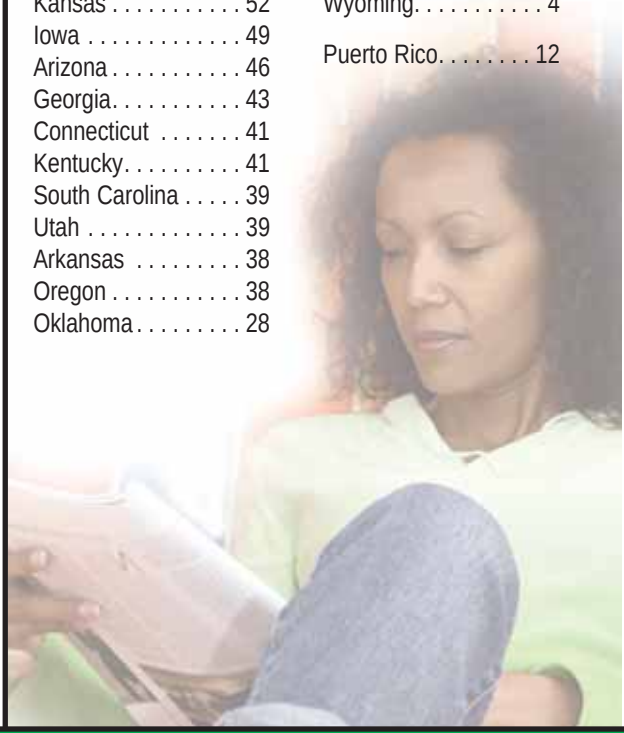
But life for Dustin is finally looking up. Getting tolerized to factor—and having the synovectomy and cortisone injection—has allowed him to go about his daily routine with only minor arthritic pain. Since the synovectomy, he's had far fewer bleeds in his left ankle. A little over a year ago, Dustin joined the Boy Scouts. He has participated in an eight-mile hike, four-mile backpacking trip, and 25-mile bicycle ride. Recently, Dustin went rock climbing with the scouts—no problems—and looks forward to enjoying future outings. Pattie says, "Joining the Boy Scouts is the best thing Dustin ever did." With proper care from educated parents and an excellent HTC, Dustin is finally living life to the fullest.

Who's Reading PEN?

We have many readers throughout the world, but who reads *PEN* here at home? Look below to see who's reading *PEN* in your neck of the woods. It's not surprising that our top readership mirrors the states with the biggest populations, but look at Maryland! Way to go! In 2008, help us reach more families by making it a point to share *PEN* with people in your state. How does your state measure up?

STATE	NUMBER OF READERS
California	218
Ohio	199
Pennsylvania	192
Texas	164
New York	153
Michigan	136
Florida	130
Massachusetts	125
Illinois	113
Indiana	86
Virginia	84
New Jersey	82
Minnesota	76
North Carolina	73
Missouri	71
Louisiana	67
Tennessee	67
Maryland	59
Washington	57
Wisconsin	57
Kansas	52
Iowa	49
Arizona	46
Georgia	43
Connecticut	41
Kentucky	41
South Carolina	39
Utah	39
Arkansas	38
Oregon	38
Oklahoma	28

STATE	NUMBER OF READERS
Colorado	27
Alabama	26
Nebraska	25
Maine	22
New Hampshire	22
Nevada	19
Idaho	16
New Mexico	16
West Virginia	14
Mississippi	13
North Dakota	13
Montana	11
Rhode Island	9
South Dakota	7
Delaware	6
Vermont	6
Alaska	5
District of Columbia (DC)	5
Hawaii	5
Wyoming	4
Puerto Rico	12



Transitions... continued from page 8

- Be sensitive to people's reactions: a tattoo carries a message.
- Removing a tattoo always leaves a scar.
- Research tattoo removal: laser treatment, dermabrasion, salabrasion, scarification. Painful, painful.
- *Never* put a girl's name on your body unless it is your mother's. (Or a guy's name. Just ask Angelina Jolie.)

Know the Health Risks

Tattooing requires repeated needle pricks that inject dye. This is done with a small machine. With every puncture, the needle inserts tiny ink droplets. The tattooing process may last from 20 minutes to several hours, depending on tattoo size. It may cause bleeding and swelling–a huge concern for someone with a bleeding disorder.

The Mayo Clinic says, "Getting a tattoo at an accredited professional tattoo parlor is relatively risk-free, but getting a tattoo still puts you at risk." What are the risks?

- serious infectious diseases, such as hepatitis C, hepatitis B, HIV or tetanus
- skin infections, such as impetigo
- dermatitis
- allergic reactions
- thick scars called *keloids*

A person with hemophilia should always consult a hematologist before getting a tattoo.

Take Care of the Tattoo

A tattoo is an open wound until it heals, usually within a week. During that time, your young adult must take care of it.

Here's how:

- Wash the tattoo an hour after application with warm, soapy water; pat dry with a clean towel. Do not rub the tattoo. Apply the antibacterial ointment given to you by the tattoo artist and cover the tattoo. Repeat this process daily for about a week.
- Try not to scratch it, although it will leak some fluids, become itchy and peel.
- Don't soak your tattoo while it heals. This means no swimming or baths.
- Don't expose your tattoo to direct sunlight while it heals. Use sunscreen when outdoors.
- Don't pick at scabs.
- Tattoos can get infected. If the skin around the tattooed area becomes very red, swollen or tender, see a doctor; you might need antibiotics.

Even when you try to talk him out of it, even when he takes proper precautions, shows good taste (can't go wrong with Latin, right?), and shares his zeal with you, you may still scratch your head and wonder, *why*? Why do they do it? *Possunt quia posse videntur*: They can because they think they can. Motto for the young, and for the young at heart.

Want to be Cutting-edge?

Use a Sharps Container–Correctly!

"Sharps container" is a generic name for any single-use hard container made for disposing of used medical needles and syringes. Proper disposal of needles and syringes is important—for you, and for those who take your trash. To prevent the potential spread of blood-borne diseases, and to avoid needlesticks, **do not** throw needles, syringes and sharps containers into household trash or recycling bins. Bring them to a drop-off site or hospital, or return them using a medical mail-back service.

Purchase sharps containers from a medical supply store, or call your home care company.

Bring a sharps container when traveling.

Do not put sharps containers in the garbage or with recyclables.

Put used syringes in a sharps container immediately.

Do not throw used syringes in the garbage.

Do not flush used syringes down the toilet or drop into storm drains.

Do not clip, bend or recap needles.

Keep needles away from children and pets.

Use a new needle every time you inject.

Get tested to learn your HIV/viral hepatitis status.

Never share needles or syringes.

Check out these sharps container mail-back services.
All provide a variety of container sizes and prepaid mailing cartons.

Medasend	800-200-3581	www.medasend.com
Sharps Compliance	800-772-5657	www.sharpsinc.com
Stericycle	800-355-8773	www.stericycle.com

Storm Watch... continued from page 6

unlike any other–it employs a large number of bleeding disorder patients and parents as representatives. Parents or patients who work for home care companies often purchase factor through their employer, providing the employer with a stream of revenue. These home care companies also contract with insurance companies to provide health coverage to their employees, regardless of whether they have hemophilia. But if the home care company's insurance provider switches suddenly to a competitor home care company as the plan's factor provider, this creates an awkward dilemma: Are hemophilia patients or parents, who are also home care reps, going to lose their jobs? Were they hired for their skills and contacts, or for their consumption of factor, which provides revenue?

Insurers will ask the same questions, since in some cases, the costs to employ a patient or even to waive a copay are passed through to the insurer. Are patient complaints about switching based solely on the fear of losing a unique long-term relationship, or more on the fear of losing revenue for the employer? Arguing about losing the long-term relationship with an empathetic rep may be a weak strategy once the insurer learns that the patient or parent earns his or her revenue from the home care provider.

Still, patients with no ties to industry are also being affected. Many advocates believe the battle is purely about choice. Tom Albright of Arkansas is furious that patients are being switched to PrecisionRx. In a letter to PrecisionRx, Tom wrote, "I like to have a choice in who my provider is. I believe I know my home care provider far better than Blue Cross ever will. What reason does Anthem/Blue Cross have for demanding its hemophilia patients use PrecisionRx? Is your company also going to tell patients what brand of factor they can get and how many doses they can receive at a time?"

Tom's concerns touch on another fear: Where will the switching end?[3] How much power do these companies have in our lives? WellPoint is an insurance giant, the largest publicly-traded, commercial health benefits company in the nation. It serves more than 34 million lives, and is an independent licensee of the Blue Cross and Blue Shield Association. One of every nine Americans is a member of a WellPoint health plan. The company wields considerable power. But at the current rate of mergers and acquisitions of home care and specialty pharmacies, the industry may indeed be left with only four or five providers, all powerful.

The second consumer concern is about lack of expertise–and how it will impact access to and delivery of product. This concern is more likely to get the insurer's attention, particularly if the insurer owns the specialty pharmacy. The best thing families and patients can do? Document every transaction, every phone call, and every delivery. Find out if the new company to which you are switched is truly incompetent or negligent. And check the per-unit cost. If you can show that it's less expensive to use your preferred company, you might have a case.

"We must accept that some change is inevitable." —Bob Robinson, HFI

The handwriting is on the wall. Home care switching is on the rise. Chris Blair writes, "If we do not work together to prevent this now, we will all ultimately be at the mercy of whichever healthcare company becomes the next potential low bidder selected to service our unique healthcare needs. We need to stand united in our efforts to keep from being controlled by insurers and their selection processes."

Bob Robinson, executive director of the Hemophilia Foundation of Illinois, is trying to preserve choice of home care, but concedes, "We must accept that some change is inevitable and that we are going to have to learn to compromise. There is just no way we can have 'our old way' anymore."

And Bill Jamison warns, "If this approach is successful for WellPoint/Athem, look for the other Big Blues to follow." He adds, "Our community must stand up and be heard or our choice of provider will go away. Educate, advocate and motivate yourself to stand up against this issue. Our lives depend on it."

Did You Know?

Starbucks spends more than $200 million annually to provide health insurance for its employees—more than it pays for its coffee beans.

New York Times Book Review, cited in *The Week*, Dec 28, 2007

[3] PrecisionRx has indicated that its open access to all hemophilia therapies will remain. It follows MASAC guidelines of a 2% +/- assay guarantee, and claims it will not mandate a formulary that eliminates choice of product or brand.

"Bloodstopper" — Herbal Relief?

Turkish scientists claim to have developed an herbal product that stops external bleeding in seconds. According to Professor İbrahim Haznedaroğlu of the hematology department, Hacettepe University, this product is not a medicine, although it has been licensed by the Turkish Ministry of Health. Currently available in ampule and spray forms, the liquid is intended for direct application to a wound. Scientists have not disclosed the names of the herbs used in the mixture.

For information: www.turkishdailynews.com.tr

NEW

Factor IX Products IN DEVELOPMENT

Inspiration Biopharmaceuticals has signed an agreement with Cook Pharmacia to develop its lead biologic therapy, an injectable recombinant factor IX. Founded in 2004, Inspiration Biopharmaceuticals focuses on revolutionizing hemophilia treatment in two ways: 1) developing lower-cost versions of existing intravenous recombinant therapies; and 2) developing non-invasive administration of therapies.

For information: www.inspirationbio.com

Humate-P No More Refrigeration

According to an FDA news release on October 19, 2007, Humate-P® can now be stored at room temperature. Almost all coagulation products can now be stored at room temperature.

For information:
see product insert or
www.cslbehring.com

More FIX Enhancements Studied

Baxter International has begun preclinical work on a genetically engineered product for bleeding in patients with hemophilia B. Nektar Therapeutics of San Carlos, California, and Baxter are working in partnership to create a more long-lasting treatment for hemophilia B. This is the second agreement between Nektar and Baxter. In September 2005, the two companies announced that they would work together to develop PEGylated, or longer-lasting, therapies for hemophilia A.

For information:
www.hemophilia galaxy.com

Noninjectable Factor IX?

Nastech Pharmaceutical Company, Inc., has begun a feasibility study with an undisclosed global leader in the production of plasma products. The study will examine the possibility of developing an alternative delivery method of factor IX without an injection.

For information:
www.nastech.com

Recombinant Factor IX Product Researched

GTC Biotherapeutics, Inc., of Framingham, Massachusetts, has purchased a license to develop a new recombinant factor IX product with ProGenetics LLC of Blacksburg, Virginia. Currently, the only existing recombinant factor IX product is BeneFIX®, made by Wyeth Pharmaceuticals of King of Prussia, Pennsylvania.

NEW

Helixate FS New 2000 IU Vials

CSL Behring's new, larger vial size of Helixate® FS reduces reconstitution time by eliminating the need to mix and pool multiple vials. This helps improves patient compliance and convenience. CSL Behring also introduces its new HeliTrax℠ system. The internet-based encrypted database is designed for professionals to track treatment. It includes a wireless, hand-held electronic diary for patients to log infusions and treatments with Helixate FS.

For information: www.cslbehring.com or 888-508-6978

Pharmaceutical

Home Care

NoseBudd Helps Stop NOSEBLEEDS

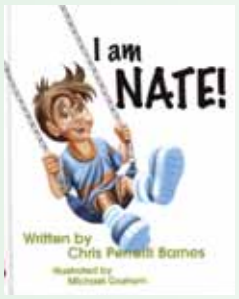
NoseBudd™ is a gel-pack that can be placed on the nose to stop bleeds, in combination with light pinching. Designed by a person with hemophilia.

For information: www.NoseBudd.com

Coram Community *Conference Calls*

Tired of emailing people or visiting chat rooms to talk about hemophilia? This program is a great way to stay in touch with others in the bleeding disorders community–live. The next conference call, sponsored by Bayer, is February 27, 2008, 7:00 pm EST. Featured guest is Nancy Roy, clinical nurse specialist at Palmetto Richland Health HTC in Columbia, South Carolina. Dial toll-free 866-213-1962 about five minutes before the call, then enter 2522783 when prompted.

NEW Children's Book on Hemophilia!



I am Nate tells the story of how hemophilia affects four-year-old Nate–and how it doesn't! Infusions are a weekly part of Nate's life, just like feeding his pets, dressing himself, and going to school. In his preschool class, Nate feels that he's "just like everyone else," and he looks forward to going to kindergarten. Written by Chris Perretti Barnes, mother of a child with hemophilia. Sponsored by Bayer and BioRx.

For information: www.biorx.com

Nonprofit

Advocate for Choice and Hemophilia Care!

NHF's Washington Days takes place on March 5 – 7, 2008, in Washington, DC. Join your community, and visit state senators and legislators to make them aware of our insurance problems. NHF credits last year's event with the increase in federal funding to the CDC's subsidization of HTCs, now at $18.2 billion a year.

For information: www.hemophilia.org

Factor IX Meeting

The Coalition for Hemophilia B, Inc., is hosting a one-day consumer symposium on Saturday, March 8, 2008, 9:30 am – 5 pm, at the Millennium Broadway Hotel in New York City. The NYC-based nonprofit provides information, education and support to people with hemophilia B and their families.

For information: 212-520-8272 or hemob@ix.netcom.com

HFA 2008 Meeting

Hemophilia Federation of America's 2008 Annual Educational Symposium will be held May 1 – 4, 2008, in Little Rock, Arkansas. The meeting brings together families, treaters, and businesses related to hemophilia for a weekend of education and fun.

For information: www.hemophiligfed.org

Bleeding Disorders HOTLINE *for Insurance Help*

Call toll-free 800-520-6154 with your questions about insurance changes, reforms, restrictions, and general information. Funded by Baxter, initiated by the Lone Star Chapter of NHF.

International

China: Lack of Plasma Blamed for Shortage of Hemophilia Treatments

Plasma supply in China dropped by about 50% in 2006 from the previous year. This led to reduced production of factor VIII by Chinese blood product companies. Total factor VIII production in 2006 was 48.9 million units, while production in 2007 was only 33.4 million units. In China, three pharmaceutical manufacturers produce clotting factor VIII: Shanghai RAAS Blood Products Co., Green Cross China Biotheological Co., and Hualan Biological Engineering in Henan Province.

Source: www.Xinhuanet.com

Medical

FDA Alert on Desmopressin

December 4, 2007: The FDA requested that manufacturers update the prescribing information for desmopressin to include important new information about severe hyponatremia and seizures. Desmopressin intranasal formulations are no longer indicated for the treatment of primary nocturnal enuresis. They should not be used in hyponatremic patients or patients with a history of hyponatremia. PNE treatment with desmopressin tablets should be interrupted during acute illnesses that may lead to fluid and/or electrolyte imbalance.

Inbox... continued from page 2

difficult to stick at times, especially if he were to have repeated treatments. I know this is happening to others, and I think that is horrible. And now I can't even use the company that I trust completely.

As the big home care companies get larger, they become more impersonal. They offer a phone call to someone who may have no idea about hemophilia, or an 800-number to a nurse across the country—instead of one who is actually in your area and has years of experience with bleeding disorders. I find that unacceptable for my children. We have made many phone calls to NHF, HFA, COTT, and others, but they all say they've gotten nowhere with private insurance companies.

My company is looking into other insurance companies as providers of our plan. But that takes time, and we may not get as good a policy, or the company may have limits, too. I would love to get involved on a national level to advocate for this. I plan to go to Washington Days this year, and have written to many of our local and national government officials about reform for healthcare and private insurances limiting our choices. Today it's our choice of provider, but eventually it will be our choice of medication or treatment. I lost my dad to HIV in 1990, and I refuse to let anything remotely like that affect my children.

Name withheld

KUDOS ON THE NOVEMBER 2007 ISSUE of *PEN*, especially the cover story "From Boys to Men: Nurturing Your Son with Hemophilia" by Ziva Mann. It is a must-read for all parents, caregivers and teachers of boys with hemophilia. I shared it with our extended family over the holidays and am taking it to our son's teachers tomorrow. Hope to see more from Ziva in the future!

Shanna Garcia
Texas

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