May 2007 • Volume 17 • Issue 2
Parent Empowerment Newsletter

Switched!

How Hemophilia Patients are Losing the War on Home Care Choice

BY LAURIE KELLEY

Faulkner Fotography

Forced to switch:
Lana Hannaman of Tennessee.

Lana Hannaman was surprised to receive a letter from her insurance company in early December. Her son Bradley, the letter stated, would be switched from his current factor provider, Caremark, to CuraScript.[1] Both Caremark and CuraScript are major players in the factor distribution market. The letter provided no options and no choices, and requested no feedback. "I didn't inquire about the switch," Lana explains, "because the letter was pretty much like I didn't have a choice in the matter." But the switch, which occurred on January 1, made Lana uncomfortable. Nine-year-old Brad had used only Caremark's services since birth. Would this new company provide the same level of service for his hemophilia care?

Lana's situation is far from unique. It's just one example of how insurance reforms are impacting families with hemophilia across the country. Families are discovering that payers have been switching factor providers at alarming rates, in many subtle and not-so-subtle ways. After a switch, some hemophilia families are left with profound changes in their level of care, which can negatively affect lifetime caps, the home infusion process, and family finances.

Welcome to the new hemophilia market of 2007. The "Coming Storm" is now the Current Storm, and it's blown into the homes of hundreds of families, battering them with increasingly inflexible insurance policies. "I've been a part of this industry for twenty years, and I've never witnessed anything like this before," remarks Nancy Diaz, reimbursement specialist at Matrix Health Group, a factor provider. Insurance changes threaten our choice and power as consumers. What's your risk of being suddenly switched? How might a switch affect your child's care?

Medicaid Sets the Course

Factor provider switching occurs as health insurers–payers[2]–gain more control over consumer healthcare spending. There's no question that hemophilia is one of the most expensive chronic disorders to treat, with the range of average costs estimated at $100,000 to over $500,000 annually.

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[1] CuraScript is owned by PBM giant Express Scripts.
[2] Payers include private companies like BlueCross BlueShield and Aetna, and public programs like Medicaid and Medicare.

inside PEN

welcome

Sherrell Portrait Design

My son Tommy, 19, is off to college in September. Anticipating Tommy's departure from under our protective wing, I deeply appreciate the role of Stan, his homecare rep. Stan now calls Tommy's cell phone directly to take his order, chatting with him about rock bands, movies, and life in general. When Tommy leaves home, Stan will provide a vital link by calling Tommy man-to-man to remind him of his healthcare needs. I'm grateful for their relationship because I think Tommy finds it more acceptable for a business rep than a mother to phone a budding rock star.

These are the kinds of relationships being threatened by the current insurance cost-cutting frenzy in America. For over two years, we've been warning the hemophilia community about the massive changes rolling in, and how they might affect us all. The changes are hitting close to home now, as you'll read in "*Switched!* How Hemophilia Patients are Losing the Home Care War." You might be at risk of losing your cozy relationship with your current home care rep, as your insurer desperately makes better deals with other home care companies–or even buys its own specialty pharmacy to lower overall medical costs. You might be switched to a factor provider who has no experience with hemophilia. Learn how insurers are forcing hemophilia families to switch factor providers, and how this can enhance or endanger your healthcare.

Personal stories, like Jeff Mueller's in *As I See It*, highlight the effect of insurance change on hemophilia families. In *Homefront*, Ziva Mann shares the lighter side of everyday life with hemophilia, and explains how stories can reveal more than just the punch line. In *Inhibitor Insights*, Paul Clement reveals the fascinating scientific story of fibrinolysis, the "other half" of the blood-clotting process. Paul tells us why we need to know about this often overlooked process.

Finally, the newswires are red-hot with stories–new technologies, new legislation, enhanced products… You'll find all the information condensed in *News Notes* and *Storm Watch*. There's a lot to absorb, so please read on, and stay informed. As we totter on the edge of massive change, 2007 is shaping up as one of the most exciting years ever in hemophilia.

Read HemaBlog™ published every Monday: www.kelleycom.com/blog

PARENT EMPOWERMENT NEWSLETTER MAY 2007

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I LIKED YOUR INSURANCE ARTICLE A GREAT DEAL. ["YOUR 2007 Insurance Primer," *PEN*, Feb 2007] It was clear and detailed, and gave excellent suggestions for handling insurance. In fact, I picked up a few tips about how to be a watchdog for my own health insurance! Congrats on a really excellent primer for parents.

Steve Humes, MPH
Regional Coordinator, Region IV
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AS ALWAYS, I APPRECIATE RECEIVING *PEN*. I THOUGHT I WAS THE only one concerned about the potential hostile takeover at Caremark, and you of course are right on top of the story. ["Monstrous Acquisition of Factor Providers Looming," *PEN*, Feb 2007] I have provided a link to a copy of a letter sent out to shareholders, which is very distressing. One might see this as a media opportunity to discuss the potential negative effect with a segment of our population: "Express Scripts Mails Letter to Caremark Stockholders," Financial News, Yahoo! http://biz.yahoo.com/prnews/070201/nyth087.html?.v=76

In your *Welcome* column, you list several actions for the reader, including contact with NHF. May I gently remind you that HFA is also an important source of information and communication, especially in the area of advocacy.

Barbara Chang, board member
Hemophilia Federation of America

BY JEFF MUELLER

A LETTER TO AETNA: *What Were You Thinking?*

To the Customer Service Department Manager:[1]

In June 2005 I received a letter notifying me that Aetna would no longer be covering Hemophilia Health Services, our current pharmaceutical provider, as an in-network provider. The letter stated that the change would take effect *in three days*.

I called Aetna and spoke with Jane[2], a pediatric hematology nurse with over ten years' direct experience in hemophilia. My options? Stay with HHS and pay about $3,200 out-of-pocket per year, or switch to Aetna Specialty Pharmacy (ASP) and have a copay of $35 per month. We were forced to choose the second option.

Jane surprised us by suggesting that my son Alex use a less expensive and equally effective recombinant factor product, but she was unable to provide a brand name. We kept our original brand, which was to be delivered immediately after ASP received the prescription from our hematologist.

Our factor arrived three days later—without heparin, saline, or Huber needles. I spoke to another Aetna case manager, who informed me that there was no order for heparin and saline. When I questioned him further, he found the order written below the factor order. He apologized for the inconvenience, and informed me that ASP was out of Huber needles but would ship them as soon as possible.

The supplies arrived a few days later: 22-gauge straight needles and half of the necessary heparin and saline. Again I spoke with Jane, who was as frustrated as I was. She told me that the people who processed the orders were nonmedical, "right off the street," and were being trained as they worked. Jane reassured me that everything would work out and that she would get the supplies sent immediately. The rest of the supplies arrived soon after.

A few days later, I received a call from ASP's billing department, asking for $950. I told Jane that I wouldn't pay a cent until this issue was resolved. Jane looked over the bill, found the error, and said it would be resolved as soon as possible. It took nearly a week to fix, and our final copay was $45. I called ASP and asked Jane why our copay included an extra $10. "Because they sent out two shipments of heparin and saline." I reminded her that this was ASP's error, and she agreed to have the amount adjusted.

The next month, I got a call from ASP. My new case manager was Josh; Jane had left ASP. Josh was unable to locate my file and had to obtain Alex's demographic data, insurance information, and supply needs *again*.

A few days later, I received Alex's supplies, again with half the heparin and saline. I called Josh. The missing supplies arrived a few days later. At the end of the month, I got a bill for the $45 copay and called Josh. Was this higher copay due to the double shipping again? Josh said he would look into it and eventually removed the extra $10 charge.

Next month? Same thing: half the heparin and saline. I called Josh to ask why I was receiving only half my order again. He didn't know. The following day, ASP called me to take my order. I refused to give consent for shipment, and said that the order should have been filled correctly the first time. I asked for the caller's name, department, operator ID, or extension. She refused to give me any information, and she insisted that I give consent for shipment. I asked to speak with her manager, and she refused. I was irate—professional, but irate. In the end, I told her never to call again. I said I would be calling my case manager immediately to report her.

Josh was completely surprised to hear of my experience. He insisted that no department would contact me, but said that since I was unable to obtain a name or department, he couldn't help me. I informed Josh that ASP's shipping practices were either incompetent or fraudulent, and that I would be reporting ASP to the Colorado district attorney. Josh assured me that this was an isolated incident, and he would do his utmost to resolve the issue. At the end of the month, I received my correct $35 copay invoice.

Mueller family

Jeff Mueller with son Alex.

From that point, everything seemed to be working well. My only complaint was that although we had a prescription for L.M.X. 4® (topical anesthetic), because Alex is allergic to EMLA®, ASP would not send it to us. I was told that L.M.X. 4 was too expensive, and they sent nothing at all.

On December 1, ASP called to request our order. On December 2, Martina called from ASP billing to say that I needed to send my copay of $950 before supplies could be shipped. I told her this was Aetna's error, and she should verify it with the case manager. She replied that I should call the case manager myself and pay the bill. I reminded her that it was *her* job, not mine, to resolve billing discrepancies. She refused to ship out Alex's supplies until the issue was resolved. I told her that it was against the law to refuse medical

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[1] This article is an edited version of an actual letter sent to Aetna in 2005. See Aetna's response on page 16. [2] The names of all Aetna employees have been changed for this article.

BY PAUL CLEMENT

FIBRINOLYSIS: *The "other half" of hemostasis*

Do a Google search for "hemostasis" and you'll likely get this definition: "the process of halting bleeding" or "the arrest of bleeding." But this describes only half of the process of hemostasis. The other half is *fibrinolysis*[1], which is the breakdown and absorption or elimination of blood clots. Although often overlooked, fibrinolysis–and being able to inhibit fibrinolysis to retain blood clots–is important for anyone with a bleeding disorder, especially for those with inhibitors.

In the February issue of *PEN*, we looked at the first half of hemostasis: *coagulation*, or the halting of bleeding and the formation of a blood clot. Coagulation involves three steps and ends with the formation of a fibrin clot. Most people with bleeding disorders quickly become familiar with this clotting process, but they tend not to think much about fibrinolysis, the other half of hemostasis.

A Delicate Balance:
Coagulation and Fibrinolysis

So what happens to the clot after it's formed? Externally, a "scab" forms on the skin when the clot is exposed to air and allowed to dry out. Many people associate all blood clots with scabs, which generally stay in place until the injury is healed. But internally, this isn't the case. Almost as soon as the clotting cascade kicks into action to produce fibrin, feedback loops within the cascade start to shut down fibrin production. Why? To prevent the clot from continuing to grow and eventually blocking off blood flow. While these feedback loops are working, fibrinolysis begins its job of trimming back fibrin fibers, so unnecessary parts of the clot can be dissolved. In fact, when a blood clot is formed, the seeds of its own destruction are woven into the clot itself.

To dissolve a blood clot, the fibrin fibers in the clot must be "cut." What cuts the fibers? It's the job of an enzyme called *plasmin*. In its inactive form, plasmin is known as *plasminogen*. As a fibrin clot forms, plasminogen circulating in the blood attaches itself to the fibrin and becomes incorporated into the clot. When "plasminogen activators"[2] are released by the cells of the injured blood vessel, the plasminogen is activated to form plasmin. The plasmin starts cutting fibrin fibers, and fibrinolysis begins. As a result, the blood clot is in a constant state of flux: a delicate balance that allows the clot to continually reform as the tissues beneath it heal.

Like the clotting cascade, fibrinolysis has multiple feedback loops that keep it under control. Fibrinolysis is regulated chiefly by "plasminogen activator inhibitors" and "plasmin inhibitors," which are released by the cells of the injured blood vessel and by platelets. These special inhibitors inactivate both the plasminogen activators and the plasmin. The result? Fibrinolysis slows or stops, helping to maintain the delicate balance known as hemostasis.

Antifibrinolytic Drugs:
Keeping the Clot

Some parents of children with bleeding disorders find their child's pillow blood-stained after a tooth falls out, or after a nosebleed that's hard to stop even with clotting factor or DDAVP. Bleeds in the mouth and nose are often difficult to stop because mucous membranes secrete large quantities of plasminogen activators and little or no plasminogen activator inhibitors. This favors fibrinolysis and the rapid breakdown of clots, making it hard to retain clots. Along with rapid fibrinolysis, the mechanical actions of eating, drinking, and probing tongues can easily dislodge clots in the mouth. Clots in the nose are dislodged by nose blowing and probing fingers.

When bleeds in the mouth and nose are hard to stop, physicians may advise parents to use an antifibrinolytic drug to slow fibrinolysis and help maintain the clot. In the US, two of these drugs are commonly used by people with bleeding disorders to help retain clots: *epsilon aminocaproic acid*, sold under the brand name Amicar®, and *tranexamic acid*, sold under the brand name Cyklokapron®. Amicar is available in elixir, tablet and injectable forms.[3] Cyklokapron is available in tablet and injectable forms.[4] Both drugs bind to plasminogen, preventing it from binding to fibrin; and in turn, preventing the activation of plasminogen to plasmin by plasminogen activators. Cyklokapron is about ten times more potent than Amicar and has a longer half-life.

Unfortunately, antifibrinolytic drugs are often used incorrectly. One of the most common errors is to use the drug without factor replacement or DDAVP. Amicar helps inhibit fibrinolysis–it does *not* help to form a clot. Without a strong clot in place, Amicar is useless. Some people mistakenly take only one dose of the drug and expect to see lasting results, when the drug is meant to be taken hourly.

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[1] *Lysis* is from the Greek word meaning to break down or separate. [2] Tissue plasminogen activator and urokinase.
[3] See Xanodyne Pharmaceuticals: www.xanodyne.com [4] See Pfizer, Inc.: www.pfizer.com

PROJECT SHARE

It's time to give back.

Annual Report 2006

Thanks for giving me hope.

~ Kurt P., Jamaica

Project SHARE (Supplying Hemophilia Aid and Relief) is a humanitarian program devoted solely to donating lifesaving antihemophilic factor to the bleeding disorders community in developing countries.

Founded in 2002, Project SHARE is the world's first private humanitarian hemophilia program to partner with corporations to ship medicine to patients who do not qualify for assistance from any other source. Thanks to Project SHARE, millions of dollars worth of factor that would be destroyed is able to reach impoverished people with bleeding disorders. Project SHARE saves lives.

Project SHARE donations help attract rural patients to treatment centers for care. Donations also encourage patients to create hemophilia societies where none exist. Project SHARE serves as a central advisory agency for HTCs, hemophilia nonprofits, home care agencies, and patients seeking information about donating factor overseas.

SOURCES OF FACTOR DONATIONS

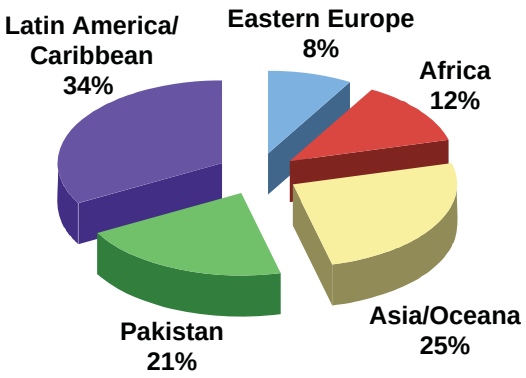
Project SHARE accepts donations of unwanted, in-date factor from all reputable sources. Our main sources of donations include specialty pharmacies and home care companies, US individuals, HTCs, and hemophilia nonprofit organizations.

Project SHARE does not actively seek donations from factor manufacturers, who normally donate to the World Federation of Hemophilia. Our goal is to recover excess or unwanted factor that would otherwise be destroyed. We accept any number of vials, in any assay size, within days of expiration.

ACCOMPLISHMENTS

- Donated more than **9.7 million IUs** of factor (estimated value: $9.7 million), including:
  - ➞ A first-ever donation to Mongolia to save the life of a 15-year-old boy with a head bleed.
  - ➞ Over 1.5 million IUs of factor within seven days of expiration.
  - ➞ 70,000 IUs of factor to allow corrective foot surgery for 14-year-old Peter D. of Belize.
  - ➞ Almost 500,000 IUs of short-dated factor to Armenia and Romania.
  - ➞ Over 1.5 million short-dated IUs of factor to Nicaragua.
  - ➞ Over 1.6 million short-dated IUs of factor to Pakistan.
  - ➞ Over 500,000 IUs of factor to Zimbabwe; the largest donation they've received in two years.
- Sponsored **first-ever clinic** visits for six boys in the Philippines to receive proper hemophilia diagnoses.
- Supplied factor for the first **summer camp** in Romania and the eighth annual camp in the Dominican Republic.
- Provided guidance for the **official founding** of the Ghana Haemophilia Society.
- Emailed **52 weekly updates** on all factor donations to our board of directors, World Federation of Hemophilia, and other interested parties.
- Enhanced Project SHARE's visibility with **feature newspaper articles** in *The Springfield Republican* and *The Boston Globe*.
- Expanded Project SHARE's outreach to **45 countries**, including **five new recipients**.

FACTOR RECIPIENTS 2006



For the complete Project SHARE 2006 Annual Report, visit www.kelleycom.com/projshare.html

Mandatory Health Insurance Moves

California Governor Arnold Schwarzenegger wants to extend medical coverage to almost all of the 6.5 million uninsured in the nation's largest state. Massachusetts passed a law last year requiring everyone to be medically insured. Maine and Vermont have also moved to guarantee healthcare coverage. The idea behind this legislation is that all state citizens must have health insurance, just as car owners must carry insurance.

Source: Newsweek, January 22, 2007.

Community Pharmacy Fairness Act Introduced

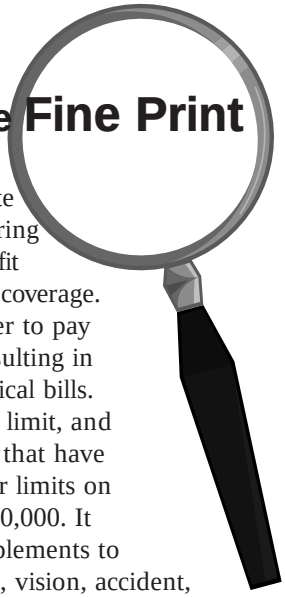
Independent community pharmacies are supporting legislation that would give them leverage against take-it-or-leave-it payer contracts. House Resolution 971 would allow independent pharmacies, defined as pharmacies not owned or operated by a publicly traded company, the same leverage that much larger chains enjoy when negotiating Medicare Part D and other third-party contracts. Introduced by Anthony Weiner (D-New York) and Jerry Moran (R-Kansas), the bill is intended "to ensure and foster continued patient safety and quality of care by making the antitrust laws apply to negotiations between groups of independent pharmacies and health plans and health insurance issuers (including health plans under Parts C and D of the Medicare program) in the same manner as such laws apply to protected activities under the National Labor Relations Act."

The National Community Pharmacists Association (NCPA), which was integral in creating the legislation, asserts that H.R. 971 levels the playing field and expands patient access and *choices of providers*.

For more information: www.house.gov

Source: Hemophilia Foundation of Illinois.

Be Forewarned: Read the Fine Print



Good news for people with chronic disorders: The Insurance and Real Estate Committee approved a House bill requiring large-print, boldface text on limited-benefit policies that don't provide comprehensive coverage. Limited policies often leave the consumer to pay for costs exceeding the policy's limit, resulting in thousands of dollars of unexpected medical bills. The House bill does not set a minimum limit, and its requirements would apply to policies that have aggregate limits of less than $100,000; or limits on each service or condition of less than $20,000. It would also apply to policies sold as supplements to regular medical insurance, and to dental, vision, accident, disability, hospital indemnity, specific disease, and credit insurance policies.

Source: Diane Levick, *The Courant*, March 15, 2007.
www.courant.com/business

A Behemoth is Born

Caremark Rx, Inc., located in Nashville, Tennesee, is the nation's second-largest PBM. Caremark Rx has recently approved a $27 billion takeover by CVS. Read this carefully: *Caremark has been sold*. The acquisition has created a behemoth with the power to define, redefine, and direct the nation's pharmacy distribution system. CVS/Caremark will have combined sales of more than $80 billion and rank among the top 20 Fortune 500 companies. Express Scripts, the number three PBM in the country, attempted a hostile takeover of Caremark in 2006. What will Express Scripts do next? Chad Brand of Seeking Alpha, a web-based provider of stock market opinions and analyses, suggests that Express Scripts might have its eye on Medco, number one PBM and owner of HHS.

It can't be stressed more strongly: Hemophilia patients must follow the rapidly changing acquisitions to know where their health benefits and service will originate, how this will affect their treatment and care, and where their health dollars will be going. For now, it looks like a lot of healthcare dollars are going to Wall Street.

Source: Various newswires.

Colorado Discriminating Against Hemophilia Patients?

The cost of healthcare has caused double-digit annual increases in premiums for several years in Colorado, and everyone realizes that costs must be contained. But hemophilia patients in Colorado no longer want to be penalized for having a chronic disorder.

Since 2003, legislation has allowed insurers to charge higher premiums, by up to 10%, to employers who have employees with high medical costs, like those associated with chronic disorders. Insurers are allowed to offer healthy groups a 25% discount. Should the chronically ill pay more for insurance?

Colorado lawmakers have introduced a bill to repeal this law. Proponents of the 2003 law say that health-based discounts draw healthier people into the pool, which lowers rates for everyone. Opponents say that people shouldn't be penalized for health conditions, and that the current system benefits only insurance companies, not consumers.

Source: Amy Fletcher, *The Denver Business Journal*, March 19, 2007.
http://denver.bizjournals.com/denver/stories/2007/03/19/daily9.html

BY ZIVA MANN

The Stories We Tell

Few things are as powerful as stories. Stories about heroes and villains illustrate good and evil. Stories about love and grit show us that affection and courage exist. In a less dramatic way, stories about doctor visits and managing bleeds not only teach us how to handle such situations, but make those situations familiar, even comfortable. Reading these stories, we learn: I did it, they did it, anyone can do it. We build our understanding of the world with narrative, and some stories are even true. Like this one…

One autumn day, I took Shai to visit a friend who had just gotten a brand new toy garbage truck, complete with opening and closing compactor. Shai was vibrating with excitement.

The play date started out well. The other mom had paled at inviting a kid with hemophilia over, but she decided to give it a try. We moms sat in the kitchen, drinking coffee and feeding the babies while the bigger kids wreaked havoc across the hall. Watching Shai jump off her couch, the mom relaxed. "Okay," I could hear her thinking, "maybe he's not so different. Maybe this could work."

I smiled at her and accepted the teething biscuit she offered Akiva, who gnawed on it enthusiastically. Five minutes later, Akiva was vomiting, covered in hives, and exhibiting signs of early anaphylaxis.[1] We called 911. The mother's calm unraveled, and her son panicked. The ambulance was stuck in traffic. A firefighter arrived to keep us company while we waited, alert for respiratory distress in Akiva and hysteria in me. Shai, relaxed, was asking questions about the fire truck.

"Shai," I said, "do you want to ask your friend if he wants to go see the fire truck?" Thoughtfully, Shai said, "Okay, but I'll have to go slowly, because my knee hurts." Stupidly, I stared at him. Knee? Hurts? *Now???*

Of course, now. Or was it really hurting? I thought about stories, which help us understand our reality, but also let us rewrite it. Sometimes we tell stories about how we *wish* the world worked. Which kind of story was Shai telling me?

It's hard to say. After Akiva was born, Shai complained of pain in his target joint, and limped–sometimes theatrically–to remind us that even with a new baby in the house, *he* should be the center of attention.

I was torn. If I cross-examined Shai about each symptom, I risked teaching him not to bother telling us about the early sensations of a bleed, perhaps thinking that suspicious adults wouldn't believe him if he did. Could I afford to do that?

No. After consulting with our HTC, we decided to offer him respect, in case the bleed was real. If it wasn't, we would at least respect the emotion driving Shai's storytelling. We would invite him into the decision-making process: *Your knee hurts? Let's see if ice helps. How does it feel now?* And we would give him the attention he needed. Occasionally, that was enough. He'd sit with the ice pack, and we'd spend time with him, building together a happy ending to his drama.

As for the play date, the mom stopped me recently to tell me a story about the day of Akiva's allergic reaction. It was a story in which I was calmer than I'd really been and shown more grace than I'd ever actually mustered. Clearly, it was the story that she needed to tell. Meanwhile, we'd had our own happy ending: a confused ER doctor who walked into our room while I was infusing Shai with Akiva nearby. "I was told my patient was an infant," she said. "Which one needs treatment?" I looked up and said, "Tell you what–you deal with that one, and I'll handle this one. They're double-teaming us today." I winked at Shai, who grinned back at me. Shai and I were going to co-write the ending to this story, and that alone made it triumphant.

[1] Anaphylaxis is a life-threatening allergic reaction.

BY RICHARD J. ATWOOD

NEW Column

PEN **welcomes new columnist Richard Atwood, MA, MPH. Richard lives in Winston-Salem, North Carolina, where he worked for 17 years at the Hemophilia Treatment Center at Wake Forest University. Currently he serves on the board of Hemophilia of North Carolina. His background in anthropology and public health gives him a broad perspective on bleeding disorders. Richard owns a mountain home in Transylvania County, North Carolina: an appropriate place, he notes, for someone interested in blood.**

Bleeding Hearts

Ian Rankin, 1994, *Bleeding Hearts*. New York, NY: Little, Brown and Company. 378 pages. Available through Amazon.com.

Michael Weston, known as Demolition Man or D-Man, as well as several aliases, is a professional assassin in his mid-30s who happens to have mild hemophilia. When he targets a female TV journalist in London, the police are informed. Michael barely escapes capture by having an ambulance remove a bleeding patient with hemophilia from the crime scene. Pursued by the English police force, a drug-abusing private detective from New York, and various shady characters from a religious cult, Michael travels from London to Scotland with the daughter of a slain gun dealer. Then, moving on to the Pacific Northwest, Michael tries to discover his employer's identity and learn why his assassin plot was exposed.

In this crime thriller, hemophilia is explained several times by a hematologist. Michael mentions his hemophilia paraphernalia–his "works"–and the need to carry an identity card. The usefulness of a national register is discussed, and the reader learns that the police and military won't recruit people with hemophilia. *Bleeding Hearts* augments descriptions of bloody corpses and gun shot fatalities with information about hemophilia and bleeding problems. In one scene, a hematologist confirms that being a professional assassin is not an appropriate career choice for someone with hemophilia–or for anyone else.

"Hemophiliacs don't bleed faster than other people," explains Michael, "we just don't stop once we've started. I was a mild case, but even so there was only so much clotting my body could do for me." In his role as assassin, Michael targets his victims' hearts, commenting, "In my line of work bleeding hearts *are* the business."

Since the book's original English publication in 1994 and subsequent American publication in 2006, airport security has changed: carrying guns, knives, and illegal drugs on commercial airplanes is no longer possible.

In his acknowledgments, Rankin thanks The Haemophilia Society, the national nonprofit that serves people with bleeding disorders, located in London. The award-winning best-selling author lives with his family in Edinburgh, Scotland.

Inhibitor Insights... continued from page 4

Antifibrinolytics may also create unwanted side effects. Never use them if you're experiencing a kidney bleed. They prevent the kidney from breaking down clots, which may result in blockage and possible kidney damage. People with inhibitors, who are taking activated prothrombin-complex concentrates such as FEIBA®, may also be at risk of unwanted clotting. FEIBA's product insert, revised in 2003, states, "It is, however, recommended not to use antifibrinolytics until 12 hours after the administration of FEIBA VH AICC." In situations like this, it's better to avoid the risk of unwanted clotting by using the antifibrinolytic drug as a mouthwash. If you're bleeding from a lost or pulled tooth, soak a gauze pad with the antifibrinolytic drug, and use it as a compress. Patients have reported excellent results from using a 5% solution of Cyklokapron as a mouthwash every two hours.[5] Amicar can also be used as a mouthwash, but you may need to use it more frequently due to its lower potency. Check your HTC's protocol for using Amicar as a mouthwash. If you are taking an antifibrinolytic drug orally, and having trouble keeping a blood clot in place in your mouth, using the drug as a mouthwash should increase its effectiveness, since little of it enters the saliva from the bloodstream.

Antifibrinolytics are a useful addition to factor replacement therapy and/or DDAVP. They help retain clots on mucous membranes in the mouth and nose. They're useful in treating *menorrhagia*, or excessive menstrual bleeding. And they can help reduce factor usage. To be a better-informed consumer, know the basics of fibrinolysis, and the uses and risks of antifibrinolytic drugs. You'll be able to treat bleeds more effectively.

[5] Sindet-Pedersen, S, "Distribution of tranexamic acid to plasma and saliva after oral administration and mouth rinsing: a pharmacokinetic study." *Journal of Clinical Pharmacology*, 1987; 27; 1005. http://jcp.sagepub.com/cgi/reprint/27/12/1005.pdf?ck=nck [6] Using an antifibrinolytic drug as a mouthwash is not approved by the FDA and is considered an "off label" use of these drugs.

Switched!... continued from cover

In "The Coming Storm" [*PEN*, Feb 2005] we explained that payers are struggling, in a variety of ways, to reimburse a dazzling array of high-cost biological (injectable) products for various chronic disorders, including hemophilia. One cost-containment method used by payers is to reimburse all the biological products needed by their insured patients from *one factor provider only*. This allows stronger negotiation for lower prices, and streamlines paperwork. Theoretically, payers can negotiate lower prices on products in return for giving all their business to one company.

The hemophilia community has seen this happen in the Medicaid arena.[3] The total cost of biological products has skyrocketed over the past ten years, and physicians have been prescribing more of these products for patients with chronic disorders and diseases. Yet Medicaid budgets have not increased by even a fraction of this sharp rise. States are required by law to balance their budgets, and Medicaid consumes on average about 20% of a state's budget.[4]

To contain Medicaid costs, some states turned to a single factor provider strategy. Medicaid hemophilia patients in Arizona now get all their factor from one HTC, regardless of whether they use that HTC for medical services. In February, Alabama Medicaid notified its patients that all factor and supplies must be ordered from the 340B program, unless their home care company would be willing to comply with greatly reduced reimbursement rates. Says hemophilia patient Andrew Savage, "The new rates are

[3] Medicaid is state and federally funded program that provides medical coverage for needy and low-income people.

[4] In his State of the State speech to the Florida legislature in March 2005, Governor Jeb Bush called for a transformation of Medicaid, and said it was unsustainable in its current form. In October 2005, the Bush administration approved a sweeping Medicaid plan for Florida: one that limits spending for many of the state's 2.2 million beneficiaries, and gives private health plans new freedom to limit benefits. The Florida program, likely to be a model for many other states, shifts from traditional Medicaid to a "defined contribution" plan, under which the state sets a ceiling on spending for each recipient. Source: *The New York Times*, October 19, 2006.

NEW Column

commentary

BY KAYLA ROGERS

Kayla Rogers

Gen X: *Narcissistic or Nurturing?*

According to the Corporation for National and Community Service, 3.3 million college students volunteer annually. The figure represents 30.2% of college students, surpassing the 28.6% of adults who volunteer. This surprised me, because college students are so often stereotyped as self-centered and spoiled, eager to spend "daddy's money." Fueling that stereotype is a recent scholarly report, published last year in a new book by Jean Twenge, PhD.[1] Researchers at San Diego University found college students more self-centered and narcissistic than those of previous generations.

While these findings may be true, they overshadow the 30.2% of students who are selfless, compassionate, and community oriented. I am one of them. I'm a senior at Saint Mary's College in Notre Dame, Indiana. Throughout my four years there, I have been volunteering at the college and in the South Bend community. Volunteering gives me a feeling of self-worth, pride and purpose, because I know I'm making an impact on the lives of others. I started volunteering in 2004 at a Title One school after learning that many elementary school children needed tutors. Every Monday and Wednesday, I drove a group of Saint Mary's volunteer students with me to tutor at the school in downtown South Bend. On our drives back to campus, we talked about how we were making a difference in the children's lives, and how great a feeling that was.

Almost all of my friends have also volunteered since freshman year. They participate in activities such as tutoring, running food drives, and serving on student government community service boards. We all commit approximately two to four hours of volunteer time every week. Although these hours may seem minimal, they represent enough time to make a significant impact.

Because I enjoyed volunteering, I decided to apply for summer internships in the nonprofit sector. Last summer, I interned at the Western Pennsylvania Chapter of the National Hemophilia Foundation. I learned how to write grants, organize the Annual Boat Cruise, and market the chapter's mission statement to local Pittsburgh businesses. By doing this, I was able not only to help people within the hemophilia community, but also to educate Pittsburgh businesses on how they, too, can give back.

Even though college students are often seen as narcissistic and self-centered, many of us still lend our time to helping others. Actually, there isn't one woman I know at Saint Mary's who has *not* volunteered some of her time. Volunteering doesn't necessarily mean giving up all your free time. Even running in a 5K road race–something a student might do anyway–can raise money for a local food bank, for example. I believe that college students know that volunteerism is needed and have made a conscious effort to improve their communities. We may be self-centered; but some of us at least are trying to give back to the communities where we live, perhaps even help the very communities that made us this way.

Kayla Rogers is a 21-year-old senior at Saint Mary's College, majoring in communications. She has regularly volunteered since high school. Kayla's father had hemophilia and died in 1985. After graduation in May, Kayla looks forward to continuing her volunteer work and becoming more involved with the hemophilia community.

[1] Twenge, Jean M., PhD, *Generation Me: Why Today's Young Americans Are More Confident, Assertive, Entitled—and More Miserable Than Ever Before.* New York: Simon and Schuster, 2006.

at or below the cost of the product for most home care companies, and will effectively force most, if not all, to discontinue service to Alabama Medicaid recipients. Alabama Medicaid has offered no appeal process." In Florida, Medicaid wants patients to get their factor from one of two specialty pharmacies: Caremark or CuraScript.

As predicted in *PEN*, private payers closely observed the Medicaid arena and want to use similar strategies. Many hemophilia families now find themselves suddenly switched to a completely different factor provider *without their consent*.

Limited–or no–choice of factor provider: good or bad? It depends. Lowering costs is good overall, but limited choice may be bad for some individuals, and for our community.

Choice has become sacred to the hemophilia community, following the HIV epidemic of the 1980s and the frightening recombinant factor shortage in 2002. Because the biological distribution system is uneven and at times unfair in the US, choice of factor provider seems crucial to ensure the best care and a plentiful supply of products. Factor provider switching is a tactic of widespread cost containment, which could deprive hemophilia consumers of the choice they desire. The era has come when choice is being trumped by need. But the needs conflict: Insurance companies need to cut costs, while hemophilia families need specific services and products, uncompromised.

The Dwindling Field: Cost Impacts Home Care

For-profit home infusion and specialty pharmacy companies directly service people with chronic disorders. They purchase fragile biological products and ship them directly to patients' homes. Many companies are experts at "disease management," the insurance term for administering and monitoring all aspects of treating bleeding disorders. Disease management involves helping the patient handle lifetime caps and insurance paperwork. It also means providing correct assay sizes, product choice, product disposal, home infusion, and 24-hour expertise. If a patient has a particular medical requirement–a certain assay size or infusion needle gauge–the company can meet that individual need. Approximately 70% of patients on hemophilia home care obtain their factor through specialty pharmacies, and are at risk of being switched.

Hemophilia has been highly profitable–especially for home care companies and specialty pharmacies–but it was often overlooked by payers, who blindly reimbursed the price of factor. Not so anymore. Since 2004, payers have done an about-face: They are now questioning every aspect of specialty pharmacy home delivery and disease management. As payers fight lower reimbursed prices, sizable home care profits are shrinking. The owners of many smaller home care and specialty pharmacy companies have sold their businesses to larger ones, further reducing choice for consumers. In the last two years, as specialty pharmacies have consolidated, we've witnessed an alarming acceleration of acquisitions. What's left? Fewer, larger, and more powerful factor providers who dominate the field (see graphic on next page).

One winner in the cost-cutting war is a new player in the hemophilia market: pharmacy benefit managers (PBMs). PBMs were originally hired by employers to help negotiate lower prices in the pharmacy benefit for their employees' insurance plans. Seeing the lucrative contracts, PBMs entered the hemophilia field by purchasing specialty pharmacies–and became the sellers that they were hired to manage. Since 2004, PBMs have become a dominant force in the hemophilia community. How dominant? Caremark and Medco, two of America's top five PBMs, now own the largest hemophilia specialty pharmacies, servicing thousands with hemophilia. Like single heiresses waiting to be courted, specialty pharmacies attracted rich PBM suitors. And now, PBMs are eyeing each other. In March, rival PBM Express Scripts failed to win the hand of Caremark, despite a bid of *$27 billion*.[5] Instead, Caremark was acquired by northeast retailer CVS, creating yet another new union that will spawn even more changes.

Switching Scenarios: Where Do You Fit In?

Having your factor provider switched without your knowledge is a shock. Hemophilia patients are accustomed to exerting some control over their chronic disorder. But is *all* switching bad? No. And in this era of cost cutting, hemophilia consumers may have to live with some switching and some sacrifices. If you're switched, the most important thing is your new company–*do they know hemophilia?* Can they manage your disorder and deliver the product and services you need, at a price your healthcare budget can afford?

If you are switched, you may fall under one of these three scenarios:

- Switched from an experienced factor provider to an experienced factor provider.
- Switched from an inexperienced factor provider to an experienced factor provider.
- Switched from an experienced factor provider to an inexperienced factor provider.

1. Switched from an experienced factor provider to an experienced factor provider.

This might involve being switched from Caremark to Hemophilia Health Services, or vice versa. These are the two largest specialty pharmacies, both highly experienced. It might also mean being switched from a larger specialty pharmacy to a smaller one like Factor Support Network or NuFACTOR, both experts in hemophilia management and factor delivery. Or you might be switched from smaller to larger. Either way, you *will* get your factor, and most likely in the correct assay sizes, with appropriate ancillaries, in a timely way, at comparable prices.

Lana Hannaman was switched from Caremark to CuraScript. Both are large factor providers with disease management expertise. The new price per unit of factor was comparable; but unfortunately, both Lana and her son Brad were attached to their Caremark representative, with whom they had a long and positive relationship. Brad had to get used to a

[5] See *Storm Watch*, page 6.

new rep, and Lana hopes they will develop the same rapport. This is a minor casualty of switching, an inconvenience that families need to accept.

2. Switched from an inexperienced factor provider to an experienced factor provider.

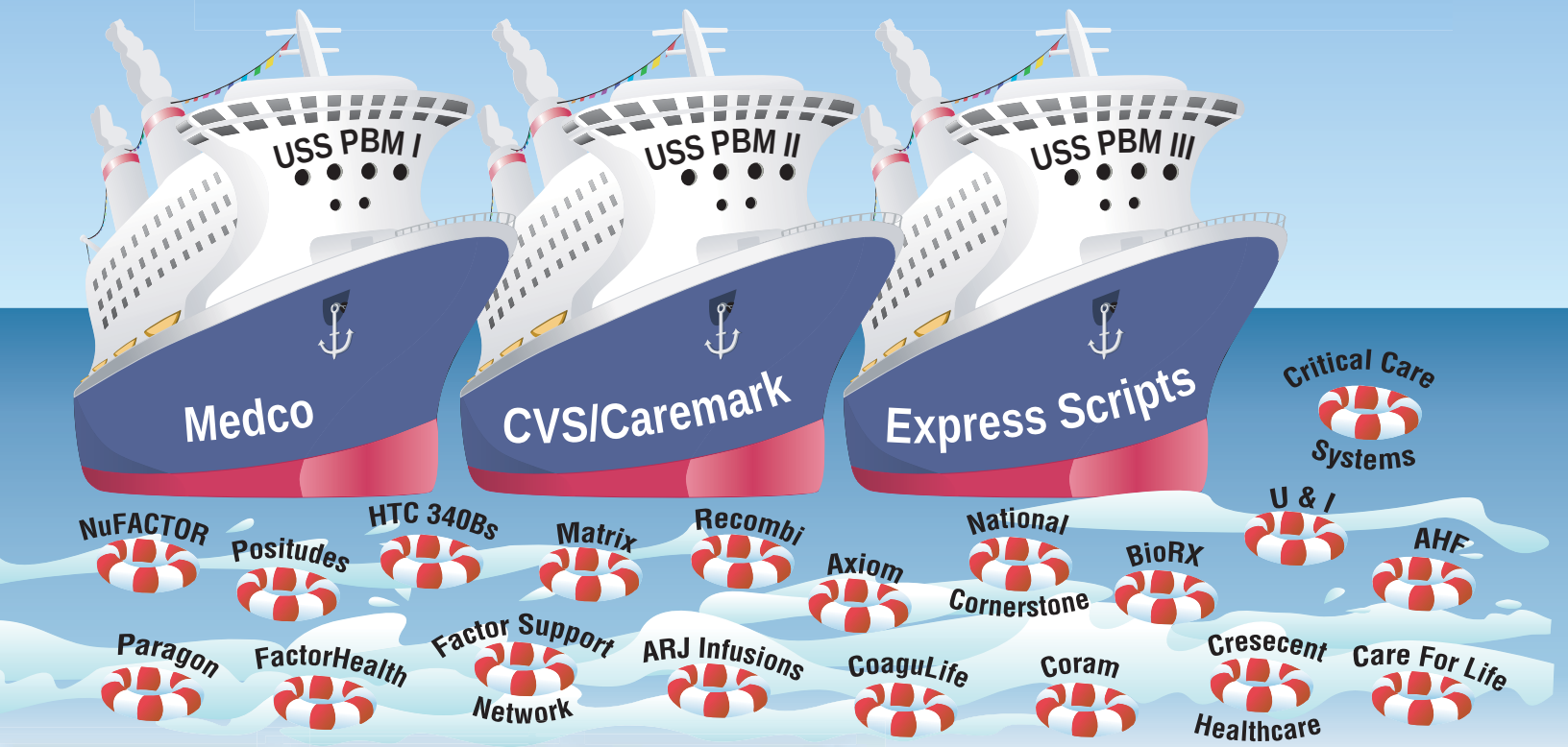
This is a blessing in disguise. If you have poor service, mismatched assay sizes, or must leave home to pick up your factor, you'll enjoy getting the right product in the right sizes delivered to your door overnight, with 24-hour customer service and educational literature or programs.

3. Switched from an experienced factor provider to an inexperienced factor provider.

This is your worst nightmare come true.

It happened to Dana Kuhn, who has hemophilia A and is founder of Patient Services, Inc., which helps patients with chronic disorders keep their insurance premiums. When his

Home Care Acquisitions: *More Power, Less Choice?*



Medco
PASSENGER LIST
- Accredo
  - Hemophilia Health Services
    - Nova Factor
    - Alpha Therapeutics
    - HRA
    - BioPartners
    - Gentiva Specialty Ph

CVS/Caremark
PASSENGER LIST
- CTS
- Choice Source
- AdvancePCS
- ProCare

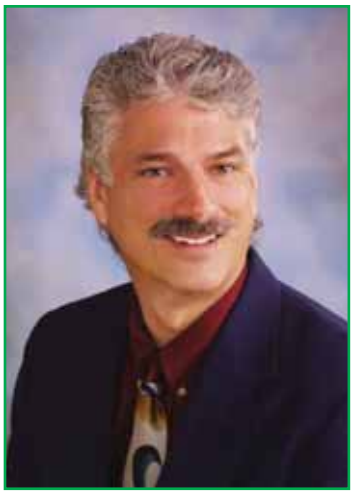
Express Scripts
PASSENGER LIST
- CuraScript
  - Priority
    - HOSS

Critical Care Systems
PASSENGER LIST
- Millennium
- Infinity
- Critical Care
- Medcare
- OptCare Plus
- AllCare
- eBioCare
- Apex
- Hemophilia Access
- Curative

Waves of Change: Acquisitions in the hemophilia business have created a few dominant factor providers and left numerous smaller ones in their wake. The nation's two largest PBMs, Medco and CVS/Caremark, have the largest share of the factor distribution market. They have significant clout to contract with insurance companies, who now compete by acquiring or creating their own specialty pharmacies. These dramatic changes threaten the survival of many independent specialty pharmacies and home care companies that offer choice of provider, employ many hemophilia patients, and give funds to the community.

Note: Each "Passenger List" details the factor provider acquisitions that helped create the larger companies. Critical Care Systems, while not a PBM, has a huge "passenger list." It has acquired at least ten other companies with hemophilia patients.

PSI



Protested switch: Dana Kuhn of PSI.

employer changed insurance plans, Dana was required to use a preferred network pharmacy. He contested the switch, but was assured by his insurance carrier that the pharmacy was well informed about servicing hemophilia patients.

The pharmacy's managed care guidelines quickly revealed its lack of knowledge. "They were treating hemophilia literally 'by the book,'" says Dana. "The 'book' says I should stop bleeding with 1,500 units, although I respond to 2,000 units. They also lacked a 24-hour delivery policy and did not understand why one was necessary."

Elyse McGuire is the mother of nine-year-old Tommy, who has hemophilia A. Two years ago, the McGuires were suddenly switched to another factor provider, and found that their new home care company had little or no experience with hemophilia. "The home nurses didn't know how to mix factor," Elyse said in disbelief. One rep even suggested that the McGuires consider switching to a plasma-derived product, which would be easier to obtain in case of a shortage. This medical ignorance pushed Elyse to fight the switch. The McGuires were given a six-month extension to continue using their previous home care company while the situation was investigated.

McGuire family

Tommy McGuire: Home healthcare nurses didn't know how to mix his factor.

Pat DeRatto is the former executive director of the United Virginia Chapter of the National Hemophilia Foundation (NHF), and now an employee with a home care company. She explains, "My son has just been switched to a PBM through Anthem. We must use the prescription plan through PrecisionRx. A call to PrecisionRx left me quite concerned: 'Do you supply needles and syringes?' 'I don't know. I guess when you get your shipment, we'll find out. If they aren't there, just go the store and buy them.' 'Do you provide sharps containers?' 'Yes, but you have to dispose of them yourself. I'm sure you can just throw them in the trash.' 'How do you ship?' 'UPS, no signature required.' 'How much of my son's product do you keep in inventory at any given time?' 'Oh, we always have plenty, at least 9,000 units at all times.' Nine thousand? Are they *for real*?"

So not all switches are equal. The most dangerous switch happens when you're assigned to a factor provider who is inexperienced with hemophilia. And even when you are switched to an experienced provider, if you can no longer order factor through your hemophilia treatment center (HTC), that creates another tragic consequence. Then your HTC suffers, too.

How Switching Affects HTCs

Switching is particularly hard on HTCs that sell factor and participate in the 340B program.[6] According to Derek Robertson, executive director of The Hemophilia Alliance, a consortium of 340B HTCs, "Patients have been moved off the 340B program to an affiliate of the health plan, or to another home care company not of their choosing. Choice of provider is being impacted by third-party payers, and we need to focus on who the providers are in order to make sure that the ones who are chosen are acting in the best interest of the patient." Standards of service have slipped, Robertson adds, "because many of the new providers are not accustomed to working with this population. Special instructions on orders often fail to be heeded."

HTCs are being hit hard by two concurrent economic constraints. First, every year, an individual HTC's slice of the $3 billion pie (originally allocated by Congress three decades ago[7]) gets smaller and smaller, as inflation and cost of factor increase dramatically. Second, some HTCs are being pressured by hospital administration to encourage patients to obtain factor through their 340B program, to generate income for the HTC and hospital. Factor sales become a revenue source to fund hemophilia nurses and programs.

You're unlikely to be switched from one 340B to another 340B. But you might be switched from your HTC's 340B program, where your dollars can help the HTC, to a large home care company or specialty pharmacy. This happened to Kelley Buchanan. "Our insurance is through Continental Airlines, which uses BlueCross BlueShield of Texas. We were

[6] In 1992, Congress passed the Veterans Health Care Act (VHCA), which established section 340B of the Public Health Service Act. The PHS Act allows the lowest manufacturer purchase prices on prescription outpatient drugs for certain federally funded entities and public hospitals that treat a disproportionate share of Medicaid and Medicare patients. The intent of Congress was to "... enable these entities to stretch scarce Federal resources as far as possible, reaching more eligible patients and providing more comprehensive services." (H.R. Rpt.102-384, 102nd Cong., 2d Sess., pt. 2, at 12 [1992]). These covered entities serve special groups of patients, typically the uninsured or low income, those facing catastrophic medical costs, or those who are underserved in the healthcare of certain diseases, such as AIDS. Federally funded covered entities named in the VHCA include community health centers, black lung clinics, family planning centers, Native Hawaiian Health Centers, and HTCs that receive grants from the Maternal and Child Health Bureau (MCHB). [7] Carol Kasper, MD, *A Brief History of Hemophilia Center at Orthopaedic Hospital, Los Angeles*, 2004. www.carolkasper.com/Historical/historyHTC2004.pdf

Buchanan family

Kelley Buchanan: "We could no longer get factor through our 340B program."

told that we could no longer get factor through Gulf States Pharmacy, our 340B program. We have to get factor from CuraScript. CuraScript has been nice, but we didn't have a choice, and I wonder if factor is more expensive through them."

Ellen Kachalsky, a social worker for the Henry Ford Hospital's Adult Hemophilia Treatment Center in Detroit, Michigan, agrees that cost-cutting pressure is chipping away at care. "Healthcare insurers are continually attempting to cut costs by limiting what they pay, thus minimizing profit. Also, Medicare, Medicaid and other state programs do not reimburse cost, but set specific reimbursement amounts. Medicare and Medicaid reimbursements rarely or barely cover the acquisition cost of drugs." If switching causes 340B programs to lose patients with private insurance, they could be left with patients whose reimbursements don't cover costs. The result? HTC revenues will plummet.

Nancy Diaz agrees. "The 340Bs are being threatened. If they are not contracted with the insurance plan, they will be shut out as factor providers. Since they purchase factor at PHS pricing rates, which are lower than what anyone else gets, they could compete financially and offer lower factor prices for insurers and patients." But insurers don't seem to be biting. Why?

Nancy Diaz

Nancy Diaz of Matrix Health Group: "Being switched… it's really about *control*."

Is the Goal *Really* to Lower Cost?

Supposedly, switching factor providers is all about cost: lowering reimbursed prices on factor by finding a factor provider competitor who can offer it for less. But what happens when you're switched to a factor provider with *higher* per-unit costs? Is there a hidden agenda?

Derek Robertson notes that sometimes, lower per-unit price is *not* the reason that an insurer chooses particular home care companies or specialty pharmacies. They're chosen for the package deals they offer: bundled services for asthma or diabetes patients, or increased efficiency in tracking product usage. More bang for the insurer's buck, not necessarily better services for the hemophilia patient–and not necessarily lower prices.

Nancy Diaz speculates further: "Being switched is *not* about cost containment. It's being disguised as cost containment, but it's really about *control*. A few big players have been upset about sharing the revenue pie, and they've figured out a way to bring everything in-house."

Gaining control is the goal of many players in the hemophilia market. More control means bigger market share, increased revenues, higher profits, and greater pricing power. One way to gain control is to acquire other companies. Large home care companies have purchased smaller ones. The big PBMs have been buying both large and small specialty pharmacies, amassing many patients, and building negotiating strength with insurers. The per-unit factor price for one patient becomes small potatoes when compared with the cost of billions of dollars for all the products covered by an insurance plan. The specific needs of one family may not be considered important by a massive PBM, especially when it isn't well versed in hemophilia.

Ziva Mann of Cambridge, Massachusetts, faced a switch that didn't make sense to her in terms of cost. "My husband's company announced that rising healthcare costs were forcing them to make changes in specialty pharmacies." Ziva learned that her family would soon be forced to switch home care companies–not a smart option, she thought, especially as the new company's factor prices were much higher. She couldn't understand why the insurer would make this choice. Was it ignorance, or a closed-door deal? A powerful specialty pharmacy can be persuasive to an employer and insurance company, offering package deals and bundled services at the expense of individual families' needs.

Another way insurers gain control is simply by owning their own specialty pharmacy and forcing their patients to use it. Insurers can then charge their own prices with no third-party negotiation. This tactic has snowballed in the last two years. Aetna Specialty Pharmacy, CIGNA's TelDrug, and Anthem Wellpoint's PrecisionRx are all examples of insurer specialty pharmacies. "These are measures by the insurance companies to cut cost," notes Ken Trader, vice president of HHS. But they are also ways to consolidate power. The insurers not only dictate factor provider, services to cover, and price, but they also directly reap factor revenues; and they offer little, if any, support to the community or the advancement of therapy management.

Ellis Sulser

Ellis Sulser: A switch robbed him of choice and forced him to pay more for factor.

Ellis Sulser is a person with hemophilia who also owns Factor Support Network, a specialty pharmacy. "I've been able to purchase factor at a low price for a long time, which extends my $5 million lifetime cap. In March 2007, BlueCross, our company insurance carrier, told us we were no longer able to use any pharmacy we wanted. We *had* to use PrecisionRx, their in-house pharmacy. PrecisionRx then farms out its disease management to ChroniMed, which is owned by

PrecisionRx." What Ellis learned shocked him: This disease management company was charging almost $.60 *more* per unit for his brand of factor than the price he'd been paying through the company he owns.

The irony is not lost on Ellis. Not only is he paying more for factor, he says, "I can't even buy factor from the specialty pharmacy I own."

Just *Whose* Costs Are Reduced?

Even assuming that switching to another factor provider will lower your per-unit prices and preserve your cap (and your employer's premiums), you may be hit hard in another way: larger copays.

"My insurance removed the option of using the major medical portion of our plan that includes home care companies," says Pat DeRatto of Virginia. "Now everything must go through the prescription portion, along with a $50 copay for each shipment, which did not apply to the major medical portion."

Kathleen and Dwight George, who also live in Virginia, have eight children, including three with hemophilia who are still on their parents' insurance. One child also has type 1 diabetes. As in Pat's case, the Georges' insurance carrier, Anthem, designated PrecisionRx as the family's factor provider. But unlike Pat, Kathleen thinks that so far, Precision Rx seems knowledgeable and willing to learn about hemophilia, "at least on the phone," she quickly adds. But the switch will cost the Georges $600 in monthly copays. "Are other families going through this?" asks Kathleen. "What have other families done? I already work three jobs and home school our four youngest."

Why should you be alert to higher copays when switched? Copays are another cost-cutting tactic of payers. Copays make you think twice about whether you really need a certain service or medication—whether you must dash off to the emergency room with a bee sting or sunburn, or order extra sleeping pills or more antibiotics. The insurance companies don't want to reimburse for questionable doctor visits or unnecessary drugs. But for families with chronic disorders, who cannot negotiate when they need their medication, copays become crushing penalties for being born with a medical condition. This is when cost cutting goes too far.

What Parents and Patients Can Do

Consumers often feel like the rope in a four-way tug-of-war between the old factor provider, the new provider, the HTC, and the insurance provider. Everyone says they want what's best for the patient, but in truth, all eyes are on the revenues that factor usage briskly rings up.

How can you best protect choice, insurance coverage, and personal healthcare control in the switching war? Arm yourself with knowledge about hemophilia and facts about the factor providers involved. Then, challenge your insurance company and negotiate directly. To help prepare, learn from the successes of these parents and patients:

Tell them your needs. Kathleen George fought back out of desperation. "I was partially successful in convincing PrecisionRx that the monthly copay of $600 was too much for any family to bear. They agreed to waive the first script's copay, but not the entire monthly copay. The company is working with us to make payments that fit better into our budget."

Educate factor providers. Dana Kuhn achieved success by educating the provider. "They eventually initiated a 24-hour delivery policy—after a few persuasive talks," he admits. "I believed the new service would be seamless, unhindered in management and delivery. It wasn't at first, but after I educated the new providers and informed them of my needs, things got better."

Get the facts. Susan Moore, mother of a young man with hemophilia and now a representative with Matrix Health Group, believes that success in maintaining choice boils down to parent and patient knowledge—and imparting that knowledge ferociously. "Years ago, I chose an insurance plan that allowed choice of home care company," she recalls. "I chose Company A. About two months into the policy, I was told that Company X would be servicing my son. When I explained that I already had service from Company A, Company X became belligerent and insisted that I had to use them. I immediately phoned my insurance provider. While an investigation ensued, I researched Company X and learned that they knew nothing about hemophilia. I used this information to plead my case. It took about two months, but in the end, my choice prevailed."

Joshua Moore

Susan Moore: "In the end, my choice prevailed."

Know per-unit prices and compare. When Ziva Mann faced a switch, although it was to an experienced provider, she demonstrated that this would cost the insurer more per unit. "We researched prices and sent our insurer a description of what each home care company provided, including a price comparison. The proposed switch would raise our factor costs from $1.03 to $1.59 per unit. Our insurer eventually conceded that we could stay with our current provider."

Propose a compromise. Last year, Delphine and Anthony Martin were switched to a large PBM, Medco, from a small hemophilia home care company, Medfusion Rx. Their Medfusion rep also had hemophilia and spent one-on-one time coaching them through medical difficulties. Struggling with a newborn, Delphine was unhappy about losing this close contact. And the Medco reps who spoke with her didn't seem to know much about hemophilia. Eventually, Delphine learned that Medco owns HHS, an experienced specialty pharmacy, which assigned her a qualified rep. She presented her needs and wishes to her insurance company. "Since we spoke to HHS, all is set. Now HHS contracts with Medfusion Rx's nurse, who visits us at home, so it's a happy medium."

Question decisions. Andrea, an Ohio mother of a toddler with hemophilia, was upset when her insurance company told her that she would be switched to a different home care company. "Why?" she asked her insurer. She was told that the switch

Photo by Becky

Proposed a compromise: Delphine and Anthony Martin, with son Tristan.

was in the interest of maintaining cost and other pharmacy services, some of which were "educational." Andrea didn't need educating; she knew a lot about hemophilia. She pressed her insurer to explain, but got no answers. So Andrea continued with her current factor provider, and the insurer has continued to reimburse.

Contact your state legislator. Ellis Sulser advises calling your state legislator and describing your situation. "Some insurance companies are going to the state insurance commissioner and saying, 'Hemophilia is costing us a ton, and we have to raise rates.' Yet *these* are the companies who aren't charging the best price or using the lowest-price specialty pharmacy!" He continues, "The insurance commissioner unwittingly grants their request, rates go up, employers pay more, and patients' lifetime caps get eaten. We need to inform the insurance commissioner and ask, 'Is this legal? Are you being told what's really happening?'"

Ask your state hemophilia organization for support. You're lucky if you live in states like Pennsylvania or New Jersey, where the local hemophilia organization fiercely protects the rights of people with hemophilia. Your local organization's leaders and advocates may be able to help you prepare or defend your case to your insurer, and can provide up-to-date information on insurance law changes. They can also put you in touch with other families who are having the same problems with the same insurance carrier–remember, a solitary voice is often weaker, which works to the advantage of the insurer. Together, you and other insured families can protest as a team.

Speak to your current factor provider. "We try to arm our clients," says Ken Trader of HHS, some of whose patients have been switched without consent. "We offer talking points and a series of questions that they can discuss with their employers or insurance companies, enabling them to advocate for themselves. We often get our clients back during open enrollment." Elyse McGuire took such an opportunity: "Just this past month, I had a chance to switch home care companies to a local one that handles only hemophilia."

Kathleen George was switched to an unskilled specialty pharmacy, but made the best of it. She reports, "PrecisionRx established a Bleeding Disorders Solutions team, in direct response to the issues that Pat DeRatto, other families and I raised. They now have a proactive nurse who is learning about hemophilia, and customer service reps who are now trained in filling our scripts."

Susan Moore fought a switch. She reflects, "What finally convinced the insurance company, I think, was that I was knowledgeable and articulate in stating my son's needs. I was able to show that a switch would be dangerous, a liability. It truly does pay to understand your son's medical needs, and to speak the language of the insurance companies." Delphine Martin warns parents to make the issues of insurance and switching paramount: "Not knowing is dangerous to our son Tristan."

From Choice to Compromise

Switching is symptomatic of the changing hemophilia industry; there's no going back. The industry has changed permanently, and families will need to compromise on some aspects of care. Being switched from your current factor provider to another experienced factor provider is irritating, but you will still receive good care. Being switched to an inexperienced factor provider is nonnegotiable.

Ann Rogers, executive director of the Delaware Valley Chapter of NHF, believes, "We need a national summit of stakeholders, everyone who is involved in bleeding disorders–consumers, HTCs, home care companies, hematologists, nurse clinicians, social workers, and others involved in our care. The focus of this summit should be on finding solutions together to the problems facing our families, and deciding what is specifically needed to correct them." Ann emphasizes that consumers should focus on *need* rather than choice.

Glenn Mones, vice president of public policy for NHF, agrees. "NHF avoids talking about choice, along with terms like 'preference' and 'what consumers want.' Instead, we talk about what consumers need." Why has NHF taken this stand? "Payers have made it clear that they are not interested in anyone's particular preference. The only thing they will even consider besides cost is that which is medically necessary to maintain life and health–period. If we can show medically and scientifically that a patient needs a certain drug or service, they will try to pay as little as they can for it, but they will cover it. If we cannot demonstrate medical necessity for something, it's out."

Ellis Sulser believes that insurance cuts and consolidation of control won't be the end of the changes. "Once insurers succeed at dictating factor provider, what's to stop them from dictating what product you will buy? It's happening to some people right now."

Nancy Diaz predicts that specialty pharmacy acquisitions will continue. "Eventually, the larger companies will be the only place where hemophilia patients can get their factor. I'm afraid this will become a monopoly, with the larger companies calling all the shots." She notes that the smaller home care companies employ many people with hemophilia, who need the jobs to get factor. With increased acquisitions, these families with hemophilia may lose jobs and insurance coverage.

Some patients now focus on whether needs are being met, rather than trying to preserve choice based on entitlement. Lana Hannaman eventually grew to appreciate her new service. "I like CuraScript. They do always send me an EOB, and they have good service." But Lana may be in the minority for now, as switching remains a constant plague on our community, at least in the short term.

Annie T.[8] is one hemophilia parent who has already had enough. "I was switched at least three times in 30 days, from one home care company to the next, without our consent. It's affecting our insurance billing, referrals, prescription refills—everything. My boys are down to one dosage correction each, and we have *no* idea who to call to get a refill. It's ridiculous. Every time I turn around, another company is calling me to welcome me to their service. There *has* to be some kind of regulation to stop this madness."

Written with the research assistance of John Lanzon.

Laureen A. Kelley is president of LA Kelley Communications, Inc., author of ten books on hemophilia, and the mother of a 19-year-old with hemophilia. When her husband's employer changed insurance companies in 2005, the Kelleys were offered a choice of three specialty pharmacies. Three days later, they were told that they had to use the insurer's preferred company. Laurie refused, and then demanded that her payer explain its directive. When the payer couldn't explain, the Kelleys were granted their request to use their own preferred company of the three original choices, which offered the same prices but better services than the insurer's preferred company.

[8] This is a pseudonym.

As I See It... continued from page 3

treatment based on the inability to pay. Within 30 minutes, Martina called back and said that everything was taken care of, and the supplies were on the way. I told her that I was leaving ASP on January 1. She informed me that I owed $90, and that my payment would close the account. I made the payment.

On January 25, I received an erroneous bill from ASP for $371.68. I contacted ASP and spoke with Alain, a customer service representative. He transferred me to another rep, Shelley. She said she would send an email to the reimbursement department, which would contact me within 24 hours.

On Monday, January 30, I called ASP again. I spoke to Rachel, who informed me that Aetna had not taken any of the funds I had previously paid. I informed her that the payments were debited from my account. She told me that I needed to speak directly with the reimbursement department. When I asked her to transfer me, she said she couldn't, and told me they would contact me. I explained that Shelley told me the same thing on January 26, but no one had contacted me. Rachel said that she could do nothing else until the case was resolved. When I asked to speak with a supervisor, Rachel told me that they were all in meetings and would be tied up until the following day. She suggested that I call Aetna's Member Service Center, since ASP has nothing to do with patient billing; billing was generated by Aetna and not ASP. She hung up before I could reply.

I called Aetna's Member Service Center and was told that all patient bills were generated by ASP, and that all that the service center could do was review my EOB.

Within 20 minutes, I got a call from Tina, who identified herself as a manager with ASP's reimbursement department. She explained that Aetna prorates its copays: If ASP shipped only half of the supplies, then Aetna would prorate my copay for half of the amount. "If this is true," I asked, "then why was I billed $90 in September when I received a full shipment? Why was my copay not $35?" Tina put me on hold, and after ten minutes, she told me that it was because ASP had shipped out five medications in September, so the copay reflected the quantity shipped. But I had received saline, heparin and factor; how did she come up with five? She told me that in addition to the heparin and saline, three different types of factor were sent. I told her that the factor brand was the same—the only difference was the number of units. She told me that this was how Aetna billed its patients. I then referenced my statement, noting that in June, the exact same products were sent out correctly and my copay was $35.84 instead of $90. I asked her to explain the inconsistencies, but she couldn't. She said that she was not a supervisor, and she'd have to forward my case to her supervisor. She hung up before I could reply.

It appears to me that every Aetna customer service representative I contacted was uninformed about hemophilia and uninformed about Aetna's services, and tried any excuse to quell my concerns. I am completely frustrated with Aetna, which appears to be incompetent and possibly fraudulent. Due to Aetna's lack of professionalism and knowledge regarding hemophilia, I have returned to HHS. It's a huge relief to know that my son is receiving the quality of care he deserves.

Jeff Mueller has five children, including ten-year-old Alex, who has severe hemophilia A. An EMT for 16 years, Jeff is currently studying to become a pediatric hematologist.

From Walt Cherniak, Aetna spokesperson, on April 11, 2007: "Aetna's commitment to its members' health and well-being led Aetna to create Aetna Specialty Pharmacy (ASP) in 2005. The unfortunate issue described above happened nearly two years ago during our startup. It was promptly resolved at that time. Since then, we are proud to say that ASP has dispensed hundreds of thousands of prescriptions with a 99.99% dispensing accuracy rate. We're also pleased to report that our customer satisfaction rate was over 91% last year."

Camp Little Oak

New Summer Camp for Girls with Bleeding Disorders!

Camp Little Oak is a sleep-away camp in upstate New York for girls, ages 8–17, with bleeding disorders, their siblings, or carriers. Join us August 20–25 for six days of fun in a safe, caring environment, with 24-hour HTC nurse coverage. Enjoy campfires, canoeing, camaraderie, swimming and sisterhood!

Do you know a girl who would like to go to camp? Do you want to volunteer as a counselor? Donations are also appreciated.

For more information:
Bob Graham, camp director
bobgraham04@msn.com
Camp Little Oak
205 Riverside Drive
Johnson City, NY 13790

Know Your NHF Board

NHF

New NHF chair
Ray Stanhope

The National Hemophilia Foundation has a new board, and welcomes Ray Stanhope as chair. Stanhope, who has hemophilia, is former vice chair, former vice president of chapter affairs, and former president of NHF. He also served as treasurer and president of the Greater Houston Chapter of NHF. Additional new officers are Michael O'Connor, vice chair; Brian K. Andrew, treasurer; and Eileen F. Bostwick, PhD, secretary. Newly elected NHF board members are Stephen Bender, Phillip Blomquist and Thomas Truncale, MD.

For more information:
www.hemophilia.org/NHFWeb/MainPgs/

Travel Grants *available for* NHF 59th Annual Meeting!

NHF is offering a limited number of travel grants for first-time attendees at the Annual Meeting, Orlando, Florida, November 1–3, 2007. Those unable to attend due to financial constraints will be especially considered for assistance. Application deadline: June 29, 2007.

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

news notes

Longer-Acting Recombinant Factor IX Researched

Wyeth Pharmaceuticals announced two new research collaborations to discover, develop, manufacture and market novel biopharmaceutical products to treat hemophilia. Research partnerships with Nautilus Biotech (Evry, France) and MediVas, LLC (San Diego, California), will employ a patented technology that slows the degradation of factor IX in the body, which should extend the half-life of recombinant factor IX therapies. If successful, a new product with an extended half-life might allow patients to reduce the number and frequency of treatments.

For more information:
Gerald Burr, Wyeth
(484) 865-5428

BeneFix® Enhancements

Wyeth announced FDA approval of BeneFix enhancements on March 26:

- BeneFix R2 Kit with Prefilled Diluent Syringe: a syringe prefilled with diluent, a vial adapter, and a single-use vial of BeneFix.
- Low Diluent Volume in a Prefilled Syringe: lowest infusion volume of hemophilia B therapies when similar IU dosages are infused.
- 2000 IU Vial: the largest unit dosage vial offered for hemophilia B treatment.

For more information:
Douglas Petkus, Wyeth
(973) 660-5218

Source: Wyeth press release.

Baxter Researches Longer-Acting Factor

Results of testing in a mouse model of hemophilia A suggest that Baxter's proprietary, longer-acting form of recombinant factor VIII may double or triple the half-life of the circulating factor VIII. Results were presented at the American Society of Hematology in Orlando, Florida. Baxter plans to conduct additional preclinical research before this modified protein will be available for clinical evaluation.

Source: IBPN, January 2007.
www.marketingresearchbureau.com

New VWD Website

CSL Behring has launched a new educational and promotional website dedicated to the needs of von Willebrand disease patients and caregivers. Visit the new website at www.HumateP.com.

Source: IBPN, March 2007.
www.marketingresearchbureau.com

Alphanate®
Good for VWD Treatment

Grifols received FDA approval to market its Alphanate human plasma-based anti-hemophilic factor/von Willebrand factor concentrate for the treatment of von Willebrand disease in patients undergoing surgery or other invasive procedures, when desmopressin is ineffective or contraindicated. The product is not indicated for use in patients with severe type 3 VWD who are undergoing major surgery.

Source: IBPN, February 2007. www.marketingresearchbureau.com

New Diluent Size for Humate-P®

CSL Behring announced that Humate-P is now available with a smaller-sized diluent, containing 50% less in all assay sizes. This means that patients can spend less time receiving their infusions. Vial and package sizes are also smaller, taking up less storage space. Humate-P is the only factor concentrate approved by the FDA for use in treating adult and pediatric patients who experience spontaneous and trauma-induced bleeding episodes in severe VWD, and in mild or moderate VWD where the use of desmopressin is known or suspected to be inadequate.

Source: IBPN, February 2007. www.marketingresearchbureau.com

Inhibitor Education Summits 2007

Inhibitor Education Summits, sponsored by Novo Nordisk, are designed to connect, inspire, educate and empower people in the inhibitor community. On-site childcare is provided. Travel and lodging assistance may be available through NHF to cover expenses.

May 18–19 Nashville, TN

July 20–21 San Diego, CA

October 5–6 Dallas, TX

For more information:
www.inhibitorsummits.org
(888) 706-6867

Sounds Like...
Factor IX Gene Therapy?

Pain Therapeutics, Inc., has licensed new technology to treat hemophilia. Originally developed by researchers at Stanford University School of Medicine, the patented technology proposes to replace daily or weekly factor replacement therapy with a *single, lasting procedure* that promotes normal blood coagulation. The key is to insert a healthy copy of the human gene for factor IX into the cells of a hemophilia patient. Production of persistent, normal levels of factor IX may cure the patient. This method of gene integration does *not* rely on viral vectors. In a preclinical experiment, this technology resulted in robust, persistent, normal levels of factor IX in mice. The FDA has not yet evaluated the merits, safety or efficacy of this treatment.

For more information:
www.paintrials.com
Christi Waarich,
senior manager,
investor relations
Pain Therapeutics, Inc.
(650) 825-3324
cwaarich@paintrials.com

Source: www.redorbit.com/news/display/?id=878068

Non-intravenous Treatment for Hemophilia

Baxter and Jerini (Berlin, Germany) are partners in developing a non-intravenous treatment for hemophilia disorders. Jerini will research programs aimed at "novel approaches to creating new therapies," although specifics were not disclosed. The collaboration was initiated in 2001. The partners are using Jerini's proprietary "Peptides-to-Drugs" (P2D) technology to develop a new therapeutic injectable and oral compounds targeting hemophilia disorders.

Source: IBPN, March 2007. www.marketingresearchbureau.com

Transgenic Animals to Make Recombinant Factor VIIa

GTC Biotherapeutics, Inc. (Framingham, MA) and LFB Biotechnologies (Paris, France) will collaborate on developing hemophilia products using recombinant plasma proteins and monoclonal antibodies. Their first collaborative product is a recombinant human factor VIIa (rhFVIIa) therapy. The rhFVIIa will be developed from the milk of GTC's transgenic rabbits. Transgenic animals, such as cows and rabbits, are produced using externally introduced genes designed to trigger the production of specific human proteins in their milk. These proteins are then purified for therapeutic uses, such as treating patients with bleeding disorders.

Source: America's Blood Centers Newsletter, October 6, 2006.

Ambitious New Biotech Company Promises Hemophilia Products

New, privately held Inspiration Biopharmaceuticals (San Diego, California) has announced plans to initiate phase I clinical trials of its proprietary intravenous recombinant factor IX concentrate this summer. The product is prepared using a proprietary cell line that seeks to produce higher yields at lower cost than existing manufacturing processes. To address a wider hemophilia and coagulation disorders market, Inspiration has applied its high-yield technology to factor VIIa, and also intends to produce a factor VIII product. A second product in early-stage development is a non-injectable factor IX product intended for prophylactic use.

Source: Company promotional letter.

Grifols Prepares New LA Facility

Grifols announced its new "MiniFrac" facility, providing additional plasma fractionation capacity by up to 700,000 liters. The Los Angeles facility was part of Grifols' initial acquisition from Mitsubishi Pharma, which divested its Alpha Therapeutics unit in July 2003. Completed by Alpha in 1999, the MiniFrac was never validated or approved by the FDA. It will be fully operational in about two years, when validation and approval are complete. Over the past four years, Grifols has invested over $300 million in US production and logistics facilities, product licenses, and dedicated plasma collection operations.

Source: IBPN, March 2007.
www.marketingresearchbureau.com

community news

World's First Book on Inhibitors

This year, Laurie Kelley will begin researching and writing *Raising a Child With Inhibitors™*, the world's first parenting book about inhibitors. Funded with an unrestricted grant from Novo Nordisk, the book will cover all aspects of inhibitors, from diagnosis to teen years, from medical to psychosocial, in language that parents can understand. You'll find lots of practical information, advice, resources, and actual stories from families.

Are you the parent of a child with an inhibitor? A patient with an inhibitor? Laurie would love to hear your story. The collective stories of real people dealing with inhibitors day-by-day will form the backbone of the book. Laurie's goal is to directly address what parents want and need to know, based on information provided by parents, patients and medical professionals.

Please contact Laurie Kelley at laurie@kelleycom.com or (800) 249-7977.

Limits Sought on Conflict of Interest: Doctors and Drug Money

The US Food and Drug Administration moved to bar scientists from serving as advisers to the FDA if they have financial ties to drug and medical-device companies exceeding $50,000.

According to Diedtra Henderson of *The Boston Globe*, congressional critics and consumer advocates have long sought to restrict the role of scientists who receive funding from drug companies and medical-device makers from FDA decisions that directly affect those firms' products. Specifically, the new regulations would cover doctors and researchers who received in the previous 12 months more than $50,000 in consulting fees or research grants from drug and device companies with a financial stake in the FDA's ultimate decision.

Adapted from Diedtra Henderson, *The Boston Globe*, March 22, 2007.

HemaBlog™ Bite

No Wonder There's No Money For Factor

Just some food for thought, while we all contemplate our diminishing choices over healthcare. I read this in the latest *Time* magazine:

$100 billion: Amount that the new budget proposed by President Bush would save over five years by trimming Medicaid and Medicare costs.

$100 billion: Additional funding Bush is seeking for Iraq and Afghanistan for fiscal 2008, on top of $70 billion already requested this year.

Very slick: Juxtaposing the two figures makes you naturally ask, Why is Medicaid—and factor—being targeted for cost cuts and limited choice? To fund this war? The answers are never so clear-cut. And yet off the top of my head, I can think of 12 families with hemophilia who are suffering due to increasingly limited healthcare coverage in their states. We have elections coming up in November 2008; candidates are already announcing their entry into the race. It will be great to get a dialogue going now on how our federal and state budgets are being used, and use our right and power to vote, to protect our healthcare dollars. Be ready for 2008, and read up on the candidates now. Will their decisions about how to end his war in turn impact healthcare budgets?

Posted Sunday, February 11, 2007. Send your comments to www.kelleycom.com/blog/

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