

Parent Empowerment Newsletter

HEMOPHILIA TREATMENT CENTERS:

Are They Up to the Challenge?

by Paul Clement

For more than 30 years, hemophilia treatment centers (HTCs) have set the standard of care for the treatment of bleeding disorders. But HTCs must cope with chronic under-funding. And they must adapt to many variables: the constantly changing health insurance industry; changing federal mandates; funding fluctuations in federal and state healthcare programs; and flat funding from federal agencies, such as the Maternal Child Health Bureau (MCHB) and the Centers for Disease Control and Prevention (CDC). HTCs also have to deal with shortages of physicians trained in bleeding disorders. Somehow, HTCs have managed to survive. Yet recent and ongoing changes in the insurance industry, additional federal mandates, a burgeoning bleeding disorders population, and looming physician shortages all present new challenges, requiring HTCs to adapt at a rapid pace. Any HTCs unable to adapt may lose patients or revenue sources, forcing them to reduce services or face the prospect of closing.

The Birth of the HTC

Today, HTCs provide *comprehensive care*, a team approach to treating all aspects of hemophilia. This concept was pioneered by a few hospitals in the United Kingdom and the US in the late 1950s and early 1960s. In 1962, for example, at Orthopaedic Hospital in Los Angeles, Dr. Shelby Dietrich used seed money from a federal grant to pull together a multi-specialty team that

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As the cost of providing care at HTCs escalates, taking a bigger bite out of the host hospital's general budget, HTCs are under increasing pressure from their hospitals to "pull their own weight" or face a reduction in services—or even closure.



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Sherrell Portrait Design

With all the talk about the changing hemophilia industry—which I’ve compared to a thunderstorm on our horizon—what’s happening to the centers of excellence that provide medical care for our children? What is the fate of hemophilia treatment centers (HTCs) in a whirlwind of slashed drug budgets, consolidated factor providers, powerful homecare businesses, and increasingly

independent hemophilia patients? Do HTCs stand a chance of survival as the storm relentlessly bears down?

Paul Clement looks intensely at this question, and traces the evolution of HTCs from innovative medical comprehensive care centers to key players in the \$2 billion factor marketplace. He examines the challenges—from pricing issues to payer policies—now facing the HTCs that function as factor providers. He reveals the irony in which HTCs are caught: the ones that sell factor find it more challenging, and the ones that don’t sell factor may be forced to enter the market. Like every entity involved in the business of hemophilia, HTCs will need to revisit and revise their revenue strategies to preserve the care they so admirably developed and deliver.

But the pressure is on. In *As I See It*, “Desperate Measures for Desperate Times” offers insights into just how much the pressure to win patients may affect the ethics of those who serve us. This anonymous author reminds us that our children are worth a lot of money to those who sell factor, from homecare company representatives to even our own HTC staff. Be wary of anyone who uses guilt, blame, or personal relationships to win your business.

The articles in this issue of *PEN* are hard-hitting and thought provoking—and draw conclusions that most of us are uncomfortable considering. But they force us to think of ourselves as more than passive patients. We are consumers in a constantly changing marketplace. Be a smart consumer—my consistent mantra for 16 years—and read this issue carefully, to preserve your right to choice on your terms, and to preserve your standard of care.

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letters

JUST WANT TO LET YOU KNOW HOW MUCH I APPRECIATED your presentation (“The Current Storm”) on June 11 at the Hemophilia Foundation of Illinois’ annual meeting. It was not only clear and informative, but you engaged everyone in the audience. People can really sense your concern and passion in safeguarding this issue.



Elizabeth Fung, SW
Children’s Memorial Hospital
ILLINOIS

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Desperate Measures for Desperate Times: *When 340Bs and Homecare Companies Cross the Line*

As the insurance battle to lower healthcare costs heats up across the country, patients may become pawns to factor providers scrambling to prevent desertions from their camps. Specifically, I mean 340B programs—HTCs that sell factor—and specialty pharmacies, sometimes referred to as homecare companies. By turning patients into pawns, these providers may cross the line: ignoring what's best for the patient, and even going beyond what's ethical and lawful.

Last year, I was invited to attend a hemophilia clinic at an HTC that is also a 340B program. I observed patients meeting with various comprehensive team members. One team member stood out. She had a pharmacy technician title, and was one of the staff members each patient was required to meet behind closed doors—although I could hear her through the door. Listening, I learned that this pharmacy technician was a representative of the factor distribution program for the HTC. She was very persuasive with these patients, laying guilt on them about using the 340B program instead of their current homecare company as a factor provider. I heard her say, “You don't want to see this HTC go away because of no funding, do you?”

I learned of a 16-year-old inhibitor patient who was being serviced by a 340B program. His family moved to another state, and the new state's Medicaid program requires an in-state pharmacy to dispense factor. Yet to keep him on the 340B's service, this patient's HTC decided to ship the drug to his aunt, who still lived in the original state, and ask her to drive it across state borders to deliver it to her nephew.

I received a letter from the mother of a patient, stating that she had been threatened by her HTC: If she did not get her son's factor from the HTC, her son would not be allowed to attend hemophilia camp.

Patients as pawns? This isn't just a tactic of some 340B programs. Currently, most homecare companies are hiring “customer service reps” or “patient advocates.” These employees either have hemophilia and know many families

and patients personally in the community, or work as customer reps and establish rapport through strong interpersonal relationships with patients. Like the Pied Piper, some of these homecare reps encourage patients to follow them personally, regardless of whether it's in the best interest of the patient. When the rep switches jobs and moves to another homecare company, he or she encourages patients to follow to the new company, and sign on as new customers.

For the patient, this decision is based on a manipulated personal relationship, not on whether the new homecare company is the best strategic choice. The only one who directly benefits is the customer rep, as he or she gains in employment—greater salary, more perks—at the expense of true customer service.

The pressure to increase patient base is fierce. I know of several homecare companies that ask for a prospective employee's patient list before hiring him or her as a customer rep, and then estimate the amount of revenue generated by each patient that the prospective employee can bring to the company. Many homecare customer reps are unqualified to be working in the homecare field; they have no business, sales or pharmacy experience. They have no credentials other than the ability to woo patients as customers. With each patient representing, on average, about \$100,000 in annual revenues, who needs credentials?

Guilt. Fear. Threats. Manipulation. These are the desperate measures that some factor providers sink to in an increasingly competitive environment. Don't let yourself be a pawn in someone else's struggle to survive. Ask questions before allowing anyone to switch your service or cajole you into using theirs. Speak to your local hemophilia organization, or to other parents—anyone with no financial ties to your decision about where you'll get your factor. Your child is more than a dollar sign. He is a child who deserves to have good healthcare come first. ☺

The author, who wishes to remain anonymous, is an employee of a specialty pharmacy and has 15 years' experience in customer service and management.



by Paul Clement

Controlling Bleeds with Inhibitors: *Your Two Basic Choices*



Inhibitor Insights is a PEN
column sponsored by
Novo Nordisk, Inc.

Inhibitors are antibodies that target infused factor as a foreign protein, and inactivate it. Inhibitors greatly complicate the treatment of bleeds in people with hemophilia because they prevent most or even all of infused factor from playing its role in the formation of fibrin, which is needed to make a clot.

So what factor products can be used by people with inhibitors? Currently, there are two popular products: FEIBA®VH and NovoSeven®. FEIBA is a plasma-derived product and NovoSeven is a recombinant product. Both work, in different ways, by eliminating the need for factor VIII or factor IX.

For people with inhibitors, the selection of an appropriate factor concentrate depends on two things: 1) the level of inhibitors, and 2) how the inhibitor level responds to exposure to factor. Inhibitor levels are measured in *Bethesda Units* (BU), sometimes called *Bethesda Titer*. People with an inhibitor titer of less than 5 BU, and whose inhibitor level remains below 5 BU upon exposure to factor, are called “low responders.” People whose inhibitor titer rises above 5 BU upon exposure to factor are called “high responders.” For those using recombinant factor, more than half of new cases of inhibitors are low responders. Of these inhibitor cases, about a third spontaneously disappear after a few weeks or months—these are known as *transient inhibitors*. For those using plasma-derived factor, more than 80% are high responders. High-responding inhibitors are usually permanent, unless they can be eradicated by specialized treatment programs.

Of the two types of inhibitors, low responders are easier to treat. Bleeds in low responders can often be controlled with frequent high doses of factor VIII or IX (depending on the type of hemophilia). Usually, two to three times the normal dose is sufficient. One or two high doses of factor may also successfully control a bleed in high responders whose inhibitor titer has dropped to less than 5 BU following a lack of exposure to factor for several months to years. But this treatment is a “one-time shot” because exposure to factor stimulates the immune system to produce additional inhibitors, making the factor useless for another several months to years.

Which factor products should be used for high responders with high-titer inhibitors? Normal factor concentrates are useless in the presence of high-titer, high-responding inhibitors. Why? Because inhibitors neutralize virtually all of the infused



factor, regardless of the amount infused. The preferred method of treatment in this case is a *bypassing agent*. Bypassing agents work by skipping the “missing” factor (the one the inhibitor attacks), and then moving on to the next level of the clotting cascade. Some types of bypassing agents do this by combining mixtures of several clotting factors that are already “activated,” and stand ready to activate the next clotting factor in the clotting cascade. The most commonly used product of this type is Baxter’s FEIBA. FEIBA is classified as an *activated prothrombin complex concentrate* (APCC), also known as *anti-inhibitor coagulant complex* (AICC). FEIBA contains activated forms of clotting factors II (prothrombin), VII, IX and X. APCCs have been used successfully to treat bleeding in people with inhibitors for more than thirty years. But these products have several drawbacks. They are short-acting, and contain small amounts of factor VIII and larger amounts of factor IX, which can stimulate the formation of inhibitors to factor VIII or IX. Frequent infusions of bypassing agents may cause certain clotting factor levels to rise, increasing the risk of a dangerous and sometimes fatal side effect called *disseminated intravascular coagulation* (DIC), in which unwanted clotting occurs throughout the body.

Another kind of bypassing agent is Novo Nordisk’s NovoSeven, a recombinant factor VIIa that uses an entirely different route in the coagulation pathway. NovoSeven has several advantages over APCCs. It contains no clotting factor other than rVIIa, so it doesn’t stimulate formation of inhibitors. It operates primarily at the site of injury, and rarely causes DIC or other dangerous side effects associated with bypassing agents. And because it is not produced from blood plasma, it avoids blood-borne viral infections. On the other hand, NovoSeven has a half-life of only about two hours, requiring frequent infusions—and it’s expensive. NovoSeven may be used in conjunction with APCCs like FEIBA. It is the product of choice for people with factor IX inhibitors and allergic reactions to APCCs. NovoSeven can also be used in conjunction with antifibrinolytic drugs such as Amicar®, which helps retain clots. When used with APCCs, Amicar increases the risk of unwanted clotting.

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by Julia Quigley Long

To Give is To Receive

I'll never forget something I read in a money management book years ago: If you find yourself down on your luck financially, pick a charity and donate. Somehow, the author insisted, if you give to others at a time when you feel most vulnerable, good fortune will come back to you in spades.

I liked that idea very much, but the logic escaped me. How could giving when you can least afford it make you richer? After working with Project SHARE for just a few months, I began to understand what the author meant. I oversee the influx and outflow of millions of units of factor, just as a bank does with money. But at any given moment, I may have only a few hundred units—or even nothing—to distribute to the many people with hemophilia throughout the world. Everything depends on the donations that come in.

More than once, I've received requests for large quantities of factor to send to a patient, leaving me temporarily "penniless" in an emergency. In a recent memorable example, a teenaged boy in Mongolia needed many units of factor VIII for a life-threatening emergency. Sending all the factor he needed would have wiped out the entire Project SHARE supply, at a time when our flow of incoming donations was barely a trickle. We were faced with a dilemma: send all of our factor VIII to this one patient, or hold on to it for potential requests? We decided to send all of it immediately to Mongolia. Medicine sitting in our refrigerator wasn't helping anyone, although I knew that the next request might arrive moments after the factor left our office.

Indeed, the phone did ring within days of our shipping the factor. But it wasn't a request—it was a patient who wanted to know how he could donate a large amount of factor VIII. And he had almost the exact number of units that we had just shipped! Our supply was replenished and, even more important, a young man's life was saved.

Chief Seattle of the native American Suquamish and Duwamish tribes said, "Humankind has not woven the web of life. We are but one thread within it. Whatever we do to the web, we do to ourselves. All things are bound together. All things are connected." Maybe chance isn't as random as it seems. Maybe, in a world full of complexity, a sim-

ple good deed quietly generates more good deeds. What seems like a modest gift when you can least afford it—money to a charitable organization, compassion to the wilted soul of a stranger, or factor donated to a poor child halfway across the globe—can actually be the catalyst to dramatically improve a person's life. And that modest gift can create ripples that eventually find their way back to you. I now understand what the author of the money management book meant: Wealth shared creates more wealth; and goodness shared creates more goodness, even when—perhaps especially when—you think you have no wealth or goodness left

to give. ☺

Nathaniel, Rafael and Michael Strachan (left to right) of the Bahamas benefit from the many generous donations received by Project SHARE.





National Hemophilia Foundation

by Glenn Mones

Facing New Challenges as a **United Community**

The National Hemophilia Foundation (NHF) has long described its mission as resting on three pillars: education, advocacy and research. Although the middle pillar of advocacy is not new, in recent times

NHF has reinforced advocacy in response to some of the pressing challenges now faced by the bleeding disorders community.

In March 2005, Dr. Alan Kinniburgh, NHF's newly arrived CEO, created a new Department of Public Policy and asked me to lead it. For three years prior, I had served as NHF's director of communications and marketing, and as editor of *HemAware* magazine, so I had learned a great deal about the challenges the community faced in maintaining access to high-quality care. Although I had found my previous assignment very rewarding, here was an opportunity to have an even greater impact on the foundation's mission.

While many of the challenges the community faces today can be grouped under the broad heading "access to care," the reality is that most challenges come down to access to reimbursement; or, more simply said, how all this really expensive care gets paid for. Those who pay for medical care, whether private (employers and insurance companies) or public (government-sponsored Medicaid and Medicare programs), are dealing with skyrocketing healthcare costs and searching daily for ways to cut them. Although not the only target, hemophilia is seen by some as a prime—and perhaps easy—target because of the high individual cost and small number of individuals affected. For example, last year Pennsylvania tried to restrict people on Medicaid to only one or two clotting factor products by means of a preferred drug list (PDL)—something no state had done previously. NHF worked closely with the two state chapters, with industry, and with other groups in the community to conduct a unified, broad-based grassroots and media campaign that explained to government officials and the public why restricting access to

treatment was harmful and wrong. In the end, the Pennsylvania state government relented and included all products.

Unfortunately, the battle does not end in Pennsylvania. Many states have either submitted or are considering changes to their Medicaid programs under the provisions of the Deficit Reduction Act. These changes may include increases in premiums and copayments, annual caps on payments, limitations on coverage, and many more. Furthermore, threats to coverage are not limited to Medicaid, but extend also to Medicare and private insurance. Regarding Medicare, a new lower formula for reimbursement means that some providers of clotting factor may be less interested in serving Medicare. Providers may also be compelled to demand the 20% copayment that many consumers cannot afford. A coalition of community organizations, including NHF, Hemophilia Federation of America (HFA), Committee of Ten Thousand (COTT), and representatives of industry, has been working to address this problem by seeking federal legislation that would guarantee across-the-board consumer access to supplemental "Medigap" policies to cover these payments. On the private insurance front, the same organizations and individuals successfully fought the recent "Enzi Bill," which would have allowed the creation of substandard insurance policies that would circumvent state regulation, broadening the divide between "healthier Americans" and those with significant healthcare needs.

The bottom line is that as a community, we are facing significant challenges that cannot be ignored. However, if we join together as a community, develop strategies that make the most sense, and then pursue those strategies as a united community that speaks with one voice, we can go a long way toward preserving access to the high-quality medical care that everyone needs and deserves. ☺

Glenn Mones is vice president for Public Policy at the National Hemophilia Foundation. He can be reached by email at gmones@hemophilia.org.

Inhibitor Insights... continued from page 4

Treating bleeding episodes in the presence of inhibitors is always a challenge. Currently, none of the products used to treat bleeds in people with inhibitors is as effective as treating bleeds with pure factor VIII or IX in people without inhibitors. As a result, people with inhibitors tend to bleed for a longer time. This increases the risk of joint damage (arthropathy), life-threatening hemorrhages, and possible side effects from treatment. For a lucky 60% to 80% of people with factor VIII inhibitors, immune tolerance therapy can successfully "retrain" the immune system to accept factor as a natural protein in the body, and to stop producing inhibitors. But for an unlucky few, nothing except

NovoSeven seems to work. Today, physicians have an arsenal of treatment options at their disposal to fight inhibitors, with FEIBA and NovoSeven being the first line of defense. To take advantage of this arsenal, people with inhibitors should always be seen at an HTC, where physicians have the expertise to properly treat their bleeds. The future of inhibitor treatment looks bright. Research into the causes and treatment of inhibitors is at an all-time high; and new, more effective products, including some with longer half-lives, are in the pipeline. ☺

Ed. note: This article discusses only the most common factor concentrates used in the treatment of inhibitors.

provided care for people with hemophilia. This team included two pediatricians, an internist, a part-time orthopedic surgeon, a physiotherapist, a nurse, a social worker, a vocational counselor and a secretary. The center's reputation grew nationally, and many Americans with hemophilia came in for treatments and consultations.

One was Louis Friedland, then president of the National Hemophilia Foundation (NHF). In the early 1970s, he brought his son with hemophilia to Orthopaedic Hospital for treatment. Friedland was so impressed with the center that in 1973 he initiated a two-year NHF campaign to establish a nationwide network of hemophilia comprehensive care centers. As a result, Congress passed Public Law 94-63 on July 29, 1975, authorizing federal funding to establish a national network of comprehensive HTC. The following year, \$3 million was appropriated to fund 26 HTCs, greatly expanding access to comprehensive care for patients with bleeding disorders.

The HTC Philosophy

Why has this multi-disciplinary approach proved so successful? Comprehensive care means addressing all the needs of a person with a bleeding disorder: physical, emotional, psychological, educational, financial and vocational. The composition of HTC treatment teams and standards of care are regularly reviewed and updated by bleeding disorders medical experts on the NHF's Medical and Scientific Advisory Council (MASAC). MASAC periodically publishes a detailed outline of comprehensive care standards, including services that HTCs should provide. A recent recommendation identifies seven "core team" members of an HTC comprehensive care team, and another seven "extended team" members.¹ The core team includes a program coordinator, hemophilia nurse coordinator, medical director, physical therapist, psychosocial professional, case manager and secretary. The extended team includes a coagulation laboratory director, pharmacist, dentist, genetics counselor, orthopedist, obstetrician/gynecologist, and other specialists such as HIV/infectious disease experts and nutritionists. An HTC team not only provides specialty care, but can also act as a resource for family physicians and dentists who treat people with bleeding disorders. Comprehensive care is aimed at *preventive* care, rather than treating complications after they have occurred. It also incorporates intensive patient and family education.

HTCs have greatly improved the quality of life for people with bleeding disorders by helping them to be more independent and productive, with fewer complications. By preventing many of the costly, debilitating complications of bleeding disorders, HTC comprehensive care has proved highly cost-effective over the long term.

Financial Challenges

Bleeding disorder specialists universally agree that HTC comprehensive care represents the standard for people with bleeding disorders. Yet the continued success of HTCs is not assured. Many challenges threaten them—but the most serious is financial pressure.

In the early years, virtually all HTCs struggled financially. Few hemophilia patients in the 1960s and early 1970s had health insurance: because of disabling joint damage, few people with hemophilia held jobs. Few, if any, state or federal programs existed to cover the cost of medical care for people with hemophilia. And for those patients lucky enough to have insurance, few policies covered blood products. Funding improved in the 1970s, when private health insurance began covering blood products, and some states introduced taxpayer-funded assistance programs to cover blood products and medical care for uninsured or inadequately insured children and adults. Still, funding for HTCs remained tight.

The \$3 million allocated by Congress in 1976 was desperately needed by fledgling HTCs. Initially, funds were distributed directly to the HTCs by what is now called the MCHB, a division of the US Health Resources and Services Administration (HSRA). In the early 1980s, the HSRA developed a network of twelve regional HTC "grantees," and gave them general grant oversight responsibilities, including identifying and responding to regional needs for developing new HTCs. Instead of funding each HTC directly, the MCHB eventually shifted the responsibility of determining regional grant allocations to these regional grantees. The initial federal funding was critical, but limited—enough to fund only a nurse at a small center, or a few mid-level employees at a large one.² These grants were never intended to fully finance the HTCs. Rather, they were considered seed money, intended to show that the comprehensive care model was effective. It was expected that the cost of running an HTC would eventually be incorporated into the existing healthcare system.

Regrettably, federal funding for HTCs has languished. Funds haven't kept pace with the increasing number of HTCs, or with the increasing cost of providing and coordinating care for the many people infected by HIV and hepatitis. According to Judith Baker, MSHA, regional administrative director of the Federal HTC Region IX, at UCLA in Los Angeles, MCHB and CDC grant funding has essentially remained flat for ten years, at approximately \$12.1 million per year. During this time, Baker says, the number of patients with bleeding disorders in Region IX has grown by about 85%—due primarily to new diagnoses of patients with von Willebrand disease. Adjusting for inflation, this \$12.1 million is approximately the same level of funding as the \$3

Seven "core team" members of an HTC comprehensive care team: program coordinator, hemophilia nurse coordinator, medical director, physical therapist, psychosocial professional, case manager and secretary.

¹MASAC Recommendation #132, *Standards and Criteria for the Care of Persons with Congenital Bleeding Disorders*, March 24, 2002.

www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=57&contentid=220

²Carol Kasper, MD, *A Brief History of Hemophilia Center at Orthopaedic Hospital, Los Angeles*, 2004. www.carolkasper.com/Historical/historyHTC2004.pdf

million allocated by Congress in 1976. But instead of being distributed to just 26 HTC, funding is now shared among 141 HTCs, including public health, education and monitoring services required by the MCHB and CDC and provided by the 12 regional grantees. In effect, this represents a *decrease* in funding of over 80%. In 2001, the New York State Hemophilia Advisory Panel reported that federal funding for HTCs represented about 11% of annual HTC budgets nationwide (this percentage is much lower for HTCs selling factor through the federal drug discount 340B program).^{3, 4}

Although federal funding has never accounted for a large percentage of HTC budgets, federal support has still been critical to the survival of HTCs. Unfortunately, this support has been eroded by flat funding and inflation. The cost of delivering medical care over the last three decades has far exceeded the rate of inflation. And the cost of improved factor products has risen five to ten times, further eroding HTC budgets and their ability to provide services and education, and provide factor to poor patients.⁵ As the cost of providing care at HTCs escalates, taking a bigger bite out of the host hospital's general budget, HTCs are under increasing pressure from their hospitals to "pull their own weight" or face a reduction in services, or even closure.

Increasing financial pressures have forced many HTCs to raise revenue by selling factor to patients through the 340B Drug Pricing Program, a federal discount program. The revenue earned by HTCs operating a 340B factor sales program has relieved some financial pressure, allowing them to stay in business and even expand services. The day may be approaching when HTCs not currently selling factor are forced to do so.

The 340B Program

Section 340B of the Public Health Service Act (PHS) portion of the Veteran's Health Care Act was enacted in 1992. It requires pharmaceutical manufacturers who participate in Medicaid programs to provide discounted prices on covered outpatient drugs purchased by specified government-supported facilities, known as "covered entities." The discounted price is called *PHS pricing* or *340B pricing*. Covered entities can then resell the drugs to their patients at a markup, keeping the profits to help support services and programs. HTCs qualify as covered entities because they receive federal funding from the MCHB.

The 340B discount is the average manufacturer price (AMP) reduced by a minimum rebate percentage of 15.1% for brand-name prescription drugs, and 11% for generic and over-the-counter drugs. The 340B discount is a ceiling price that manufacturers can charge, and is about 49% of average wholesale price (AWP). AWP is sometimes called the "sticker price" of a drug, and only cash-paying customers or those without a drug benefit in their medical insurance plan pay this price. But most insurance companies pay the AMP, which is 20% to 40% less than AWP.⁶

The 340B law places restrictions on 340B operations: covered entities, like participating HTCs, can sell prescription drugs only to their patients. They can't sell factor to other parties, such as homecare companies (an illegal practice known as "diversion"). And HTCs can't force their patients to purchase factor from them—participation in the 340B



³"Hemophilia Treatment in New York State: Status Report and Recommendations." The New York State Department of Health, Hemophilia Advisory Panel, Richard A Lipton, MD, Chairman, Third Edition, 2001. www.wadsworth.org/labcert/blood_tissue/hemo/hemo1.pdf

⁴Baker, J.R., Crudder, S.O., et al., "A Model for a Regional System of Care to Promote the Health and Well-Being of People with Rare Chronic Genetic Disorders." *American Journal of Public Health*, November 2005, 95:1910-1917. www.hemophiliaregion9.org/Baker.pdf

⁵Evatt B. L., "The Natural Evolution Of Haemophilia Care: Developing And Sustaining Comprehensive Care Globally." *Haemophilia* (2006), 12, (Suppl. 3), 13-21. www.blackwell-synergy.com/doi/pdf/10.1111/j.1365-2516.2006.01256.x

⁶See *Drug Pricing Glossary* at the Public Hospital Pharmacy Coalition (PHPC) for a comprehensive list of pharmaceutical terms and their definitions. www.phpcrx.org/Drug%20Pricing%20Glossary,%20revised.doc

program is voluntary. HTC's are required to notify patients that they can choose to purchase factor through a homecare company or specialty pharmacy.

The MCHB also restricts the way HTC's use 340B program revenues. Most HTC's use this revenue to support their clinical programs, and to provide essential services such as nursing, physical therapy, social services, training programs for new hematologists, outreach and education, and medical care and factor for poor patients. The operation of the 340B program itself may consume a lot of program revenue with expenses like purchasing factor, personnel costs for filling prescriptions, packaging, delivery to clients, billing and managing inventory.

Contracting Specialized 340B Services

The 340B program was intended to give HTC's the ability to maintain and grow the services they offer patients, without relying on additional funds from the federal government. As of January 2005, 72 of the 141 federally-funded HTC's have 340B programs—only about half. If HTC's are hurting for funds, why haven't more HTC's applied to participate in the 340B program?

One reason is that most physicians, nurses and social workers aren't business people. They're medical experts. Running a 340B program requires a pharmacy. And it means working with insurance payers, drawing up contracts, managing billing, collections, inventory control and distribution—not to mention financial reporting and marketing. An HTC needs startup capital—perhaps several million dollars—to purchase enough factor inventory to start. Some HTC's may consider all this too overwhelming. And some HTC's, along with watchdog groups like the Committee of Ten Thousand (COTT), see factor sales by HTC's as a potential conflict of interest.

To make up for a lack of experience or resources, HTC's can contract outside specialty pharmacies to distribute the factor. They can also contract out, for a fee, other aspects of running the program. One California management organization, Red Chip Enterprises, provides 340B management services and expertise to help HTC's avoid hiring extra staff or developing in-house expertise. Red Chip also works with both in-house and contract pharmacies, and does payer marketing to help HTC's compete for patients in their geographic areas.

The Truth About 340B Profits

So how much money can an HTC make by operating a 340B factor sales program? For a large 340B program, potentially millions. The profit depends on three things: 1) the total number of units of factor sold, 2) the markup of the final price of factor, and 3) the operating costs of running the 340B program.

These markups and profits vary widely and are hard to pin down. A report from the US Office of the Inspector General (OIG)⁷ revealed that in a sampling of six anonymous 340B HTC's, price markups for factor ranged from 15% to 40%. For three of the HTC's reviewed, revenue surpassed \$2 million per year. Still, the OIG report may not reflect the



For a list of HTC's in the US, go to www.cdc.gov/ncbddd/hbd/htc_list.htm

finances of most HTC's. Four of the six centers studied have "large" 340B programs, meaning they sell more than ten million units of factor per year. HTC's just starting a 340B program would make only a fraction of that.

Do patients reap the benefits of the 340B discount by accessing lower factor prices at their HTC? Although federal law stipulates the ceiling price that a manufacturer can charge a 340B entity, it doesn't specify selling prices for drugs sold to consumers. In other words, HTC's are free to charge whatever they want—and some charge the same prices that homecare companies charge. In the eyes of consumers, HTC's should ideally sell factor at a significantly reduced cost, keeping a modest portion of the income to support and expand HTC services, and passing on significant savings to their patients. This would benefit patients with lifetime caps, who might extend their insurance coverage for at least an extra two to three years.

Yet some HTC's don't seem to operate as consumers might expect. Are HTC's that charge high markups on factor ignoring the best interests of their patients? Not necessarily. When setting the sales price for factor, HTC's must consider many issues. Typically, HTC's using contract pharmacies or contract management services have higher costs than HTC's using in-house pharmacies and personnel. But this isn't always true: HTC's serving many Medicaid patients, and purchasing factor for them through the 340B program, receive only a \$3 to \$4 dispensing fee—not enough to cover the cost of providing the service. Some HTC's serve many poor, uninsured patients, whose medical services and factor aren't reimbursed and must be covered by 340B program income or by the hosting hospital. HTC's just starting a 340B program, and those with few patients enrolled, have a smaller patient base over which to spread the cost of running the program. The result? A higher markup on factor.

Not All 340B Programs Are Equal

It's almost impossible to make useful comparisons among 340B programs. HTC's and their 340B programs vary widely, and much of their data is confidential. We can only hope that HTC's, even those with high markups, are trying to do the greatest good for the greatest number of patients.

Still, any program that generates revenue has the potential for abuse. The OIG found that the parent company of one HTC controlled the disposition of 340B revenues, and inappropriately billed the program for inflated pharmacy costs, carrying costs and corporate overhead. This same HTC also over-billed Medicaid by \$613,000 in a single year! How? By purchasing factor for its Medicaid patients at 340B prices, and then billing Medicaid at the cost of the factor plus a 37%

⁷Review of Hemophilia Treatment Centers' Disposition of Program Income and Patient Choice for Factor Provider for Calendar Year 2000 (A-03-01-00350). Department of Health and Human Services Office of Inspector General — AUDIT. <http://oig.hhs.gov/oas/reports/region3/30100350.htm>

What's the Difference?

Major Factor Providers for Bleeding Disorder Patients

- **Hemophilia Treatment Centers (HTCs)**
Operate 340B programs
- **Home Infusion Companies ("homecare companies")**
Provide home nursing services; may sell factor
- **Specialty Pharmacies**
Focus on high-cost therapies for chronic diseases; may directly provide or subcontract nursing services
- **Pharmacy Benefit Managers (PBMs)**
Private third parties that manage drug benefits; sell drugs through networks of retail pharmacies or via mail order

markup. In reality, the HTC was allowed to bill Medicaid only at the acquisition cost plus a small dispensing fee, which amounted to \$3.65 per prescription in that state—hardly a 37% markup. In its report, OIG attributed these abuses to lax oversight of 340B programs by the MCHB, and determined that the “MCHB did not have sufficient controls over the grantees that subcontract with HTCs to ensure program funds are used for their intended purposes and to further program objectives.”

Most HTCs share control of the disposition of 340B revenues with their hospitals, and make joint decisions on how to spend the funds. Judith Baker notes that some HTCs have formed committees with consumer representatives to advise the HTC and hospital on the best ways to spend the revenue.

Educating Payers

To stay financially solvent, all an HTC has to do is offer a 340B program, right? For the near future, the answer is yes. But market forces may eventually limit the ability of HTCs to recruit bleeding disorder patients for their 340B programs. The cost of providing healthcare continues to spiral upward, and healthcare providers are under constant pressure from payers to contain costs. Health Maintenance Organizations (HMOs) and other Managed Care Organizations (MCOs), which include Preferred Provider Organizations (PPOs) and Point of Service Organizations (POSs), have been attempting to hold down costs by keeping patients in-network and preventing them from seeking healthcare outside the network, where the MCOs have no control. Out-of-network organizations include HTCs. Healthcare providers are also

attempting to control the cost of pharmaceuticals, especially the exploding number of biological drugs like factor concentrates. The overall cost of these drugs is increasing at three times the rate of conventional drug costs.

So far, HTCs have succeeded in educating payers about the long-term benefits of HTCs for their patients. Notes Steve Yamaguchi, president of Red Chip Enterprises, who does payer marketing and education for HTCs, “Payers understand the concept of *centers of excellence*.” They realize that it’s cost-effective over the long term, and in the best interests of patient health, to allow patients to receive comprehensive care at an HTC. “Our goal is to educate payers about the services an HTC can provide *before* a patient is lost,” Yamaguchi explains, “which may be a new way for HTCs to look at their business.” This trend is highlighted by Derek Robertson of the Hemophilia Alliance, a consortium of 48 HTCs with 340B programs. “In the past,” says Robertson, “HTCs responded [by educating payers] retroactively, after losing patients. Now there is an understanding that HTCs must be proactive.”

Perversely, HTCs have been victims of their own success, and must now educate their own patients about the benefits of HTCs. Why? Gone are the days when people with severe hemophilia spent extended time each year in the hospital at the HTC, receiving treatments for bleeds and follow-up physical therapy to rehabilitate joints. Indeed, today many teenagers on prophylaxis have never spent the night in a hospital because of a bleed. And many of the 60% of our nation’s 18,000 people with hemophilia that HTCs claim as patients are seen only for an annual checkup. Many people with hemophilia today often feel that they don’t really need the HTC. Yet research proves otherwise. When a person with hemophilia suffers from a severe bleed, traumatic injury or other complications, the care he receives outside the HTC is often substandard compared to typical HTC care. Research published by the CDC⁸ found a 40% reduction in the risk of death and a 40% reduction in bleed-related hospitalizations among men who used an HTC at least once in the three-year study period.

New Drugs Create Skyrocketing Costs

Rising drug costs will profoundly impact the number of patients who purchase factor through 340B programs, as payers increasingly turn to pharmacy benefit managers (PBMs) and specialty pharmacies as a way of reducing costs. PBMs are private third parties that manage drug benefits for large groups of people, such as enrollees in an insurance plan or employees of a self-insured company. By negotiating both discounts from participating pharmacies and rebates from preferred manufacturers, PBM customers (payers) typically pay less than a drug’s AMP. PBMs also own or work with specialty pharmacies. Specialty pharmacies are primarily distinguished from other pharmacies by the kinds of drugs they offer. Most drugs handled by specialty pharmacies are injectable or infusion therapies. And many are biological drugs or *biologics*—drugs produced by living cells that have

⁸Soucie, J.M., Nuss, R., Evatt, B., et al. “Mortality among Males with Hemophilia: Relations with Source of Medical Care.” *Blood* 2000; 96: 437–42.
www.bloodjournal.org/cgi/reprint/96/2/437

been modified by recombinant DNA technology to secrete a specific drug or protein, such as recombinant clotting factor concentrate. The use of specialty pharmacies has increased over the past ten years, chiefly because the new biologics require expensive and complex inventory control procedures that are beyond the capabilities of most retail pharmacies.

Biologics are also fueling the double-digit increases in drug prices. In 1995, only 29 biologics were on the market. Today, more than 300 biologics are available, with more than 800 in development. The cost of these drugs is expected to grow from \$55 billion in 2005 to over \$90 billion by 2009. That's 28% of all pharmacy spending, up from 19% in 2005. Yet only 3% to 5% of all patients are using these drugs.⁹ According to a 2006 report by Express Scripts¹⁰, the third largest PBM in the nation, spending on drugs to treat hemophilia increased by 25% in 2005, largely due to an increase in dosage units dispensed per prescription. Annual treatment for hemophilia costs about \$100,000 per patient.

Both PBMs and specialty pharmacies can use their purchasing power to secure rebates from preferred manufacturers and buy drugs at a discount. So they generally save money for both the payer and consumer. This makes them attractive as factor providers for consumers. But to help lower costs for payers, PBMs and specialty pharmacies employ some strategies that are unpopular with the hemophilia community. For example, some PBMs restrict the drug choices available to the consumer and physician. The concept of formulary management¹¹ may be excellent—but only when applied to drugs that are chemical compounds (as opposed to biologics), and when the cheaper, generic form of the drug is identical to the name brand form. But there are no generic forms of biological drugs. And formulary decisions are often made on the basis of price alone, ignoring the fact that different people respond differently to different factor brands, and that switching products may induce inhibitors in a small percentage of people.

PBMs often require that drugs be purchased only through their own specialty pharmacies. This policy is forcing homecare companies to redefine themselves as “disease management companies” so they can continue selling their services to payers and maintain a niche presence in the marketplace. Otherwise, they risk being squeezed out of business. Homecare companies also face direct competition from specialty pharmacies that are trying to stay competitive by offering more services, including disease management, eliminating the need for separate homecare services. The same trend is affecting HTCs: Although a patient may get permission to use an HTC, he may not have the option of buying factor there. Every year, HTC factor sales slowly lose revenue to PBMs and specialty pharmacies. And as more payers turn to PBMs and specialty pharmacies to control costs, the loss of revenue from HTC 340B programs is sure to accelerate.

Adapting to the Changing Healthcare Climate

If 340B programs can sell factor at lower prices because of the federal discount, why wouldn't PBMs want their patients to access 340B pricing to save money?

Greg Hamilton is vice president of the hemophilia program at CuraScript, Inc., the specialty pharmacy owned by Express Scripts. According to Hamilton, PBMs offer the best price to payers who agree to use the PBM's specialty pharmacies *exclusively*. Although payers may save a little money on a few patients who purchase factor from a 340B program, this would cost them significantly more overall than an exclusive contract with the specialty pharmacies. Why? Without an exclusive contract, the payer would be paying higher prices on all the drugs for its other patients. Having many individual contracts means the payer might not save much by reimbursing factor through a 340B program. In addition, the PBM would lose control over access to patient data. PBMs and specialty pharmacies can track purchases of any drug in real time—payers can see which drugs in which quantities have been purchased, and can find the drugs in the distribution pipeline. Some of this data is unavailable to the PBM, specialty pharmacy and payer when factor is purchased through a 340B program. Payers want this data to examine ways to further control spiraling costs.

What's the future for HTCs in this rapidly changing healthcare industry? HTCs currently operating 340B programs will probably see their revenues slowly decrease, as they lose factor sales to PBMs and specialty pharmacies. Faced with flat federal funding and increasing federal mandates, HTCs currently not offering 340B programs may be forced to start them to remain financially solvent. Homecare companies are likely to be squeezed out of business or purchased by PBMs. The lone survivors will probably reinvent themselves as disease management companies, and have access to smaller pools of patients.

HTCs and their comprehensive care model have been highly successful, and have proved the standard of care for treating bleeding disorders. As the awareness and diagnosis of bleeding disorders increases, especially in women, the mission of HTCs will become even more critical. HTCs have adapted and will continue to adapt, even as medical cost-cutting pressures of the marketplace continue. If HTCs cannot or will not adapt, they will close. ☺

Paul Clement is a high school science teacher and contributing editor of *PEN*. Mr. Clement has a BS in biology and MA in science education from California State Polytechnic University. He lives in Southern California with his wife Linda and children Erika (21) and Brett (19), who has severe hemophilia A.

⁹“Specialty Biotech Drug Spending Skyrockets.” Wed., Jun 7, 2006. <http://today.reuters.com/stocks/QuoteCompanyNewsArticle.aspx?view=PR&symbol=ESRX.O&storyID=50087+07-Jun-2006+PRN>

¹⁰*Express Scripts Specialty Drug Trend Report 2005*. June 2006. www.express-scripts.com/ourcompany/news/industryreports/

¹¹A “formulary” is a preferred list of drugs that typically limits the number and choice of drugs available within a therapeutic class for purposes of drug purchasing, dispensing and/or reimbursement. A government body, third-party insurer or health plan, or an institution may compile a formulary. (Adapted from the Health Resources and Services Administration (HRSA), www.hrsa.gov/opa/glossary.htm)

New Study Concludes Two Factor VIII Products Comparable

Wyeth conducted a study of 17 patients at eight HTC's to compare the pharmacokinetics of two different recombinant factor VIII products: ReFacto® (produced by Wyeth) and Advate (produced by Baxter). Several measures were examined in the study, including peak plasma concentrations, *in vivo* recovery, incremental recovery, and terminal half-life. This study compared the pharmacokinetics of both products and found them bioequivalent.

For more information:
Christopher Garland
Wyeth Pharmaceuticals
484-865-6323

Bayer Hemophilia AWARDS PROGRAM (BHAP) 2006

Five US physicians were among the 26 healthcare professionals from around the world who were recognized for their work to advance the state of hemophilia care. Four years ago, Bayer created BHAP to support basic and clinical research and education in hemophilia, hoping to move toward the next generation of care for people living with hemophilia. Today BHAP is one of the leading sources of hemophilia research funding. Each year, recipients are awarded a total of \$2.75 million in grants to pursue research projects.

Bayer's Longer Acting Kogenate® INITIAL RESULTS

Weekly infusions may some day become a reality, even for those with severe hemophilia A, suggest data from Bayer's two early-stage clinical trials. An experimental factor VIII replacement product called BAY 79-4980 was developed in partnership with Recoly N.V. This product is a unique combination of recombinant factor VIII and proprietary synthetic polyethylene glycol (PEG)-coated liposomes.

The first phase I safety and pharmacokinetics trials show that the pharmacokinetic properties of BAY 79-4980 appeared comparable to those of Kogenate® FS. The second trial evaluated the protection from bleeding provided. Patients treated with BAY 79-4980 went an average of 13.3 days without experiencing a bleed, compared to 7.2 days following a Kogenate® FS infusion.

For more information: Sreejit Mohan
510-705-5477
sreejit.mohan.b@bayer.com

Baxter's NEW 2,000 IUs Dosage for Advate

A new ultra-high dosage strength vial makes it easier for people requiring higher doses to administer Advate by reducing both the infusion volume of drug solution and the storage space. Advate is now the only factor VIII therapy to offer people with hemophilia A in the US

five different dosage strengths: 250, 500, 1000, 1500 and 2000 IU. More than one billion units of Advate have been distributed since the product's debut in 2004.

For more information:
Alyssa Bleiberg, Porter Novelli
212-601-8102

ZLB Behring Foundation Awards

The ZLB Behring Foundation for Research and Advancement of Patient Health, a nonprofit organization, has awarded funding for programs designed to benefit the bleeding disorder community. Nine recipients accepted awards. The grants support a range of initiatives, from supporting and educating specific patient populations to researching the genetic aspects of hemophilia. Since its inception in 2001, the ZLB Behring Foundation has awarded millions of dollars in grants to the bleeding disorder community. Recipients include:

- **Hemophilia Federation of America (HFA)** to support efforts to educate women on the signs and symptoms of bleeding disorders.
- **Dr. Barbara Konkle of the University of Pennsylvania** to research the pattern of von Willebrand factor (vWF) antigen fluctuation during pregnancy and post-partum in patients with von Willebrand Disease (VWD).
- **Inalex Communications** for "Healthy Father-Son Relationships," a weekend retreat.

For more information:
www.zlbbehringfoundation.com

Novo Nordisk ANNOUNCES New Scholarships!

Three new scholarships are available for the bleeding disorder community:

Professor Ulla Hedner Scholarship

For high school seniors and college or vocational students with hemophilia and inhibitors.

SevenSECURE K-12 Edu-Grants

K-12th grade tutoring for students with hemophilia and inhibitors.

SevenSECURE Adult Education Grants

For adults over age 23, to be used for training to help improve careers or transition to new ones.

For more information:
SevenSECURE
1-877-NOVO-777
SevenSECURE@rxcrossroads.com

Wyeth Introduces Hemophilia Rapid Response Service

Wyeth's new program helps hemophilia patients in pilot areas of the country get emergency access 24/7 to ReFacto® (recombinant factor VIII) and BeneFIX® (recombinant factor IX). Wyeth is the first company to provide such a program, which will supply 2,500 hospitals via a network of 25 pharmacies located across the country. Hospitals will receive the product usually within three hours of placing a call to the Rapid Response Service's toll-free number.

For more information:
Wyeth Hemophilia Hotline
 888-999-2349

Come to the NHF's 58th Annual Meeting!

Philadelphia, PA
October 12-14, 2006
Philadelphia Marriott Downtown

Join other families, individuals, advocates, the NHF, medical experts and industry representatives to learn more about the latest treatments and therapies.

Register now at
www.hemophilia.org or
 call 1-800-42-HANDI

Insurance "Storm" Skirmish... A Success!

The NHF led the hemophilia community to oppose legislation in the Senate that was potentially harmful to patients with hemophilia. Numerous calls and letters from our community resulted in the May 11 defeat of S. 1955, the Health Insurance Marketplace Modernization Act (HIMMA), introduced by Sen. Michael Enzi (R-WY). The bill was designed to broaden access to health-care coverage for employees of small businesses; but as written, HIMMA might have wiped out important consumer protections and created a class of insurance policies offering inadequate coverage at a high cost. The NHF will continue to monitor this type of legislation and keep the community informed of new developments.

For more information: Glenn Mones, NHF
gmones@hemophilia.org
www.hemophilia.org

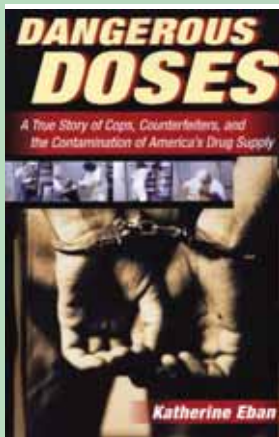
New ER Awareness Campaign

On June 21, Factor Foundation kicked off FactorFirst®, its new emergency room campaign. FactorFirst targets ER staff by promoting education, awareness, and immediate treatment of hemophilia patients' needs in the ER. Factor Foundation marked the event by presenting Jackson Memorial Hospital in Miami with a poster stressing the need to immediately address hemophilia patient bleeds in the ER.

For more information: Ed Burke, chair, Factor Foundation of America
 866-843-3362



homecare



Read This Book!

An updated version of *Dangerous Doses: A True Story of Cops, Counterfeiters and the Contamination of America's Drug Supply* by Katherine Eban was published in May. This book is must reading for all health-care consumers—particularly hemophilia patients and factor providers. Check out the conclusion, which notes certain factor providers who are now in jail for illegally diverting factor products. NuFACTOR

has a limited supply of free copies of *Dangerous Doses* for *PEN* readers. For your free copy, please email your request with your full name and mailing address to Sean Hubbert at shubbert@nufactor.com.

DANGEROUS DOSES

IT IS QUITE REMARKABLE HOW MUCH you and your work have been a part of our lives. Zak's favorite bedtime book right now is *Must You Always be a Boy?*

We recently had our NHF fundraising walk, which was a tremendous show of community. All of the senior members of the nursery school were there, along with Zak's teachers, gym coach, music teacher, and so many nursery school families, as well as three other families with hemophilia. Besides fundraising, the walk had some additional benefits. Several moms told me that they spoke to their children for the first time about hemophilia. Parents felt comfortable asking me honest questions, like "Does my child have to play differently with Zak?" And Zak, for the first time, talked to other kids about hemophilia. One child was talking to his mother about the "red snake" that Zak wears—they read *Joshua, Knight of the Red Snake* in class!

 Melissa Penn
NEW YORK

THANK YOU FOR THE EXCELLENT and caring work of your organization, which provides tremendous assistance to the hemophilia community.

 Valentina Cannell
MASSACHUSETTS

YOU DO A GREAT JOB GIVING THE hemophilia community useful information. I have used more information from you than from any other source. What a change from years ago, when you were not present in the hemophilia community. Prior to your company, there was no information sent to parents unless you searched for it—which was almost impossible. You get rave reviews from our family.

 Nancy Rasch
OHIO

WE ABSOLUTELY LOVED THE ARTICLE and photos you printed about my son Mark and The Red Nose Club [*PEN*, May 2006]. It was more than spectacular! It far exceeded my expectations. I sent a copy to our friend in Scottsdale, who is a dear friend of Patch Adams. The two men have "clowned" together in hospitals in Russia and China. I asked our friend to forward a copy of the article to Dr. Adams, as I'm sure he will be very pleased to read it and know he was the inspiration for The Red Nose Club. The students were thrilled to see themselves in your publication. Thank you for all that you do. We appreciate the newsletters and other information that you send to us.

 Susan Phillips
ARIZONA

Storm Watch

I THINK *PEN* IS A WONDERFUL publication. Working in the health-care industry myself, I found some of the articles about the changing role of the pharma industry and insurance payers truly eye-opening.

 Nikhil Gadre,
Market Analyst
NEW JERSEY


"Living with Inhibitors" (May 2006)

THE ARTICLE IS GREAT! THANK YOU so much for taking the lead in bringing inhibitor families together. You really are a blessing to our community and an inspiration to me personally.

 Kerry Fatula
PENNSYLVANIA

THANKS, AS ALWAYS, FOR HIGHLIGHTING the interesting and important issue of inhibitors in *PEN*.

I do have a concern about your editorial note. You encouraged families to call *PEN* so that you could link them with families and companies to welcome and educate them. I'm concerned that the roles of the HTC and chapters were omitted from this suggestion. While manufacturers do provide a great deal of educational material to the families, we believe that the educational link between the HTC and families is critical, as both work together to plan for the care of the individual with hemophilia. I also encourage networking at the chapter level to link to families for support and education.

 Jan Kuhn, RN
Central Virginia Center
for Coagulation Disorders

I WOULD LIKE TO EXPRESS A VERY heartfelt thank you, and also say it's about time someone in the hemophilia community finally has realized what a challenge inhibitors are, and how they are adversely affecting so many.

My son was born with hemophilia A 12 years ago, and was diagnosed with a high-titer inhibitor when he was six months old. He has never tolerized to factor. Six years ago, I started writing articles to try to get the community to realize the problems faced by some people with inhibitors. I was shunned by much of the community; people acted like I was actually making up these stories. Someone told me, "Hemophilia can't possibly be that bad." When I took my son to hemophilia conferences, mothers accused me of being over-protective and "forcing my son to be in a wheelchair."

I served on the board of my local hemophilia chapter, but resigned after I was treated as an alarmist

who tried to make hemophilia much worse than it really was. I have tried to advocate for more activities to include hemophilia patients in chapter events. For example, our chapter hosts field hockey, rock climbing, and aggressive basketball as events for children during informational meetings. Our chapter's hemophilia camp cannot accommodate my son because he is in a wheelchair. It was a big shock to realize that patients with hemophilia have been split into two groups: those with inhibitors and those without. It reminded me of the terrible days of the HIV controversy within the NHF and the local chapters. In frustration, I have almost completely withdrawn from the hemophilia community. I now devote much of my time to the Arthritis Foundation and United Cerebral Palsy. These organizations have been much more useful to me and my son than hemophilia organizations.

I hope that your newsletter and the articles you have presented will be the first step in raising the awareness of this aspect of hemophilia within the hemophilia organizations and, most important, with hemophilia patients and families. All is not well for many of us. A lot of work still needs to be done in this area.



Debbie Porter
CALIFORNIA

Project SHARE

WE HOPE YOU CAN USE THIS donation of stuffed animals for your trips overseas. Thanks for all you do for children around the world. We're blessed in the US. As a parent of Benjamin, age four, who has severe hemophilia B, I think of our blessings regularly. As a family, we believe that we must be active in the bleeding disorder community for ourselves and



Benjamin, age four, donates to Project SHARE.

the future, but the learning curve is steep! I hope this small box of goodies can brighten someone's day.



Name withheld
WISCONSIN

I ADMIRE HOW MUCH YOU ARE reaching out to make a difference in the lives of people with hemophilia, and I had to do the same. I read your books to my children all the time. They are six and four, so it is hard for them to understand what their baby brother has. Through your books, they have a clear understanding of what really happens in the lives of hemophiliacs. I thank you as a mother! You are truly an inspiration!

I would like to know how I can find out how other countries are getting factor products. I am most interested in getting information about Jordan, because that is where I am from. Who do you think is the best contact for me? I would like to know how they are funded; and if they do receive American aid, I'd like to know how can I find out who to contact here in US to ask questions about this matter. I would deeply appreciate any information you may have.



Rania Salem
OHIO

Ed. note: Information was sent to Ms. Salem to help her in her search.

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