

# Parent Empowerment Newsletter

## The 2005 PEN Bleeding Disorders Resource Guide

### BOOKS

#### Raising a Child With Hemophilia: A Practical Guide for Parents



Kelley, Lauren A. 3rd ed. 1999. 398 pp. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833.

Toll-free (800) 297-7977 [www.kelleycom.com](http://www.kelleycom.com)

Sponsored by ZLB Behring. ZLB Choice Member Support Center (888) 508-6978 [www.zlbbehring.com](http://www.zlbbehring.com)

Available in English and Spanish.

**FREE**

Practical medical, child development and consumer information about hemophilia, and stories from parents. Written by a parent of a child with hemophilia.

#### Success as a Hemophilia Leader



Kelley, Lauren A. 2004. 269 pp. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833.

Toll-free (800) 297-7977 [www.kelleycom.com](http://www.kelleycom.com)

**FREE** to qualified Hemophilia Leaders.

A guidebook to creating, managing and growing a grass-roots hemophilia organization. Explores creating a vision and mission,

forming a board, fundraising, producing a newsletter, programming, establishing an office, and working with a medical advisory board. Offers excellent advice on creating an organization or improving an existing one. Made possible by a grant from Talecris Biotherapeutics, Inc.

#### Teach Your Child About Hemophilia: From Preschool to Adolescence



Kelley, Lauren A. 2005. 152 pp. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833. Toll-free (800) 297-7977 [www.kelleycom.com](http://www.kelleycom.com)

Sponsored by and also available through ZLB Behring, ZLB Choice Support Center (888) 508-6978 [www.zlbbehring.com](http://www.zlbbehring.com)

**FREE**

Explains how to teach your child about hemophilia with methods, words and concepts appropriate to each developmental stage. Offers ideas on correctly teaching preschoolers, school-age children and teens about hemophilia, genetics, joint bleeds and infusions. Interviews with children illustrate different developmental stages. Includes new chapter on children's understanding of ports and prophylaxis. Appendices show how to conduct your own interview with your child. For parents and clinicians.

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Sherrell Portrait Design

**S**UMMERTIME IS HERE, AND SO is your summer reading list! It doesn't contain blockbusters like *The Da Vinci Code*, but it's back by popular demand: We are pleased to provide our *Resource Guide* for the bleeding disorders community in this issue of *PEN*. A wealth of educational materials—from books to newsletters, from CD ROMS to DVDs—is available for all ages to meet the many needs of the hemophilia community. Best of all,

these resources are *free* to patients and families. Some of the materials we feature have been valuable mainstays for years; others are brand new. We've whittled down our list to include the items we think will most interest parents and patients—educational resources that can make a direct, positive impact on your life.

In this issue of *PEN* we also introduce a new column. *Storm Watch* will keep you updated with current information, significant happenings and landmark events that are changing the way the hemophilia industry is managed in the US. The last three issues of *PEN* became catalysts that had everyone talking, and *Storm Watch* picks up where they left off. Insurance reimbursement changes are impacting our community, so stay informed by reading Mike Russo's summary of the ways that PBMs may influence personal hemophilia care. We've learned that approximately 80% of families don't know what a PBM is, but they *need* to know.

Read our annual report on Project SHARE<sup>SM</sup>. Last year we donated over \$5 million worth of factor, free of charge, to families with hemophilia in the developing world. Thanks to you—parents, homecare companies, HTCs and pharmaceutical manufacturers—lives have been saved, and pain alleviated for those often-forgotten families far from us. Thanks to everyone who has helped us achieve goals and touch lives.

## letters

### Readers respond to our three-part series on the business of hemophilia

Thank you for the wonderful service you provide to the bleeding disorders community! The three-part series "Hemophilia, Incorporated" (*PEN*, Nov. 2004), "The Coming Storm" (*PEN*, Feb. 2005) and "Taking Center Stage" (*PEN*, May 2005) was informative, revealing and somewhat frightening. I began reading at the mailbox! My hat is off to you!

**Shirley Wilson-Oslund**  
NuFACTOR

*continued on page 17*

## PARENT EMPOWERMENT NEWSLETTER AUGUST 2005

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

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

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

**LA Kelley  Communications**

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### Correction

In "Speaking the PBM Language" (*PEN*, May 2005), the statement "the pharmacy benefit often has a lifetime cap of \$1 or \$2 million" needs further clarification. There are different kinds of lifetime maximums (or caps) when considering the benefits that an insurance policy provides. There are overall policy caps, medical benefit caps, and pharmacy benefit caps. These can each be lifetime limits or annual limits. Historically, the hemophilia community has been concerned with the lifetime maximums on either the medical benefit or the overall policy. As policies have changed, many in the community have seen their lifetime maximums eliminated or extended to \$5 million or higher. But a few policies have started to institute other kinds of caps, such as a \$5,000 annual pharmacy cap. As a specialty pharmacy benefit emerges, we are likely to see a new cap on biological products.

# Don't Let Bureaucrats Limit Your Healthcare

In 1988 when our son Dwight, who has severe hemophilia, was four years old, Medicaid decided not to pay for the new heat-treated factor concentrates. It was considered an unnecessary expense. Our hematologist was concerned about the newly emerging virus and would prescribe only heat-treated products for Dwight.

While the US government debated the merit of additional costs versus safety, and while widespread cases of HIV emerged daily in the hemophilia community, we ran out of heat-treated factor. Our homecare company had to request an emergency supply from the American Red Cross, good for only a few days of treatment. Living from one week to the next, wondering if heat-treated factor would be available, was scary for us. Just three years earlier my father, who had severe hemophilia, had died of AIDS. Finally, due to overwhelming pressure from the hemophilia community, Medicaid approved heat-treated factor. Thanks to the high standards maintained by our hematologist and our homecare company, Dwight remains HIV-free.

When Dwight was in elementary school, another issue surfaced: Medicaid coverage for hemophilia treatment center visits. The Tennessee State Medicaid program, Tenn Care, felt that HTC visits were an unnecessary expense. I called our local physician's office daily to see if the state had approved a visit to the HTC. After a few weeks of no approval, the office gave me the hotline number at Tenn Care. I called the hotline and talked with a representative. To my shock, the Tenn Care representative admitted that he had no idea what hemophilia was or why it was so important for my son to go to an HTC! I gave a quick five-minute educational speech on hemophilia and my son's visit was instantly approved. The incident left me shaken, as I realized that my son's healthcare coverage depended on people who had no understanding of hemophilia.

In Dwight's senior year of high school, Tenn Care required that patients see a doctor only within their particular geographic area. Since we lived in a rural mountainous area, two and one-half hours away from our HTC, the HTC was not approved. I immediately called the Tenn Care hotline to protest. I spent days on the phone. I soon learned that leaving a message was fruitless—no one ever called back. Calling first thing in the morning meant being put on hold and waiting for hours. Sometimes, I was cut off suddenly and had to call all over again. After spending a month calling and faxing to get approval to use our HTC, I was informed that my petition was denied. I immediately appealed the decision and called my state representative and senator for help. Tenn Care then informed me that I would be granted a phone hearing with a judge to decide my case. The week of the hearing I got a phone call from a Tenn Care representative who advised me to drop the charges since I didn't stand a chance of winning approval.

She laughed at me when I refused to drop the charges. Her phone call left me shaken and full of doubts about the advisability of challenging the state. I'm not an aggressive person and I suffered severe headaches from the stress, but I refused to back down in the fight for my son's health.

During my telephone hearing, a Tenn Care representative cross-questioned me. She tried to imply that I was a stubborn mother who was not willing to work with Tenn Care. Another representative chimed in: the hearing was unnecessary, and Tenn Care could find plenty of qualified physicians in my geographic section to take care of my son. Tenn Care's physician testified that any doctor who passed the state board could treat hemophilia; he implied that I was an overwrought mother needlessly alarmed by my son's disorder. Our HTC nurse, present as a witness, helped to refute these opinions by informing the judge that simply studying a couple of paragraphs in a medical textbook didn't provide sufficient knowledge to treat hemophilia. I mentioned the time when I had taken Dwight to the emergency room for an infusion, and the doctor wouldn't even come into the room. He refused to treat my son, and told the staff nurse that he knew nothing about hemophilia.

To everyone's amazement, I won the case! Once the judge understood what hemophilia was, he ruled that Dwight could be treated by any hematologist specifically trained in hemophilia—anywhere in the state. Although I had been informed again and again that challenging the state was useless, I am proof that it is possible to challenge bureaucracy and preserve our healthcare standards.

Don't let bureaucrats limit your healthcare. As parents and patients, we must stay informed to ensure that our freedom of choice is not taken away. We must educate others, and advocate for our right to factor safety and sufficient insurance coverage on a regular basis. Sadly, the payers do not always understand hemophilia, and decisions are made solely to lower costs. As we unite, we can keep the hard-won goals that have been attained over the past years: product safety and the right to choose what is best for us individually within the hemophilia community. 🍷



Dorcas Walker is a freelance writer who lives in Jamestown, Tennessee. She is the author of *To Say Good-bye*, and is currently working on a biography about raising a son and daughter with hemophilia. For more information visit her website at [dorcasannettewalker.com](http://dorcasannettewalker.com) or e-mail her at [dorcaswalker@yahoo.com](mailto:dorcaswalker@yahoo.com).

## Annual Report 2004



PROJECT  
**SHARE**

*It's time to give back.*

*"I feel better because of the medicine you sent to me. I thank God that He worked in your hearts and that you are close to me. This gives me confidence and hope. I am special, and I am happy the way I am. Thank you."*

*~ Eduard, age 14, Romania*

### Introduction

Project SHARE<sup>SM</sup> (Supplying Hemophilia Aid and Relief Everywhere) is a humanitarian program devoted solely to donating life-saving antihemophilic factor (AHF) to the hemophilia community in developing countries.

Founded in 2002, Project SHARE is the world's first humanitarian hemophilia program to partner with corporations to ship medicine to patients who do not qualify for assistance from any other source. With Project SHARE, millions of units of factor that would be destroyed are able to reach deserving people with hemophilia.

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

### Summary and Accomplishments

- Donated **5,043,281** IUs of factor (est. value: \$5 million), a **62% increase** from 2003. Notable shipments include:
  - 1,000,000 IUs to the Nicaraguan Red Cross, supplying all patients' needs for an entire year.
  - 39,100 IUs of factor IX to 14-year-old Fernando C. Ecuador for life-saving surgery after a head bleed.
  - 60,000 IUs of factor VIII to 26-year-old Galo V. of the Philippines for the removal of a tumor.
  - 24,577 IUs of factor VIII to 28-year-old Mohammad W. of Pakistan for a life-threatening bleed.
  - Sent over \$1,000 in donated clothing and generic medicine to St. Vincent and the Grenadines following the devastation of Hurricane Ivan.
  - 23,000 IUs of factor VIII to Iraq to help doctors reestablish hemophilia care.
- Established a partnership with **International Medical Equipment Collaborative** (IMEC) to store ancillary and durable medical equipment (DME) donations, allowing us to close our storage area for an immediate savings of over \$1,600 and an ongoing savings of thousands more.
- Emailed 52 **weekly updates** on factor donations to WFH, SHARE board members, and other interested parties.
- Expanded Project SHARE's outreach to **37 countries**, including **5 new** recipients (in bold):

- |                      |                |                                |
|----------------------|----------------|--------------------------------|
| ■ Afghanistan        | ■ El Salvador  | ■ Pakistan                     |
| ■ Algeria            | ■ Haiti        | ■ <b>Peru</b>                  |
| ■ Armenia            | ■ Honduras     | ■ Philippines                  |
| ■ Bahamas            | ■ India        | ■ Romania                      |
| ■ Bangladesh         | ■ Indonesia    | ■ Russia                       |
| ■ Belize             | ■ <b>Iraq</b>  | ■ Serbia & Montenegro          |
| ■ Bolivia            | ■ Jamaica      | ■ St. Vincent & the Grenadines |
| ■ Bosnia             | ■ Kazakhstan   | ■ <b>Trinidad &amp; Tobago</b> |
| ■ China              | ■ <b>Kenya</b> | ■ Ukraine                      |
| ■ Colombia           | ■ Mexico       | ■ Vietnam                      |
| ■ Dominican Republic | ■ Morocco      | ■ Zimbabwe                     |
| ■ Ecuador            | ■ Nepal        |                                |
| ■ Egypt              | ■ Nicaragua    |                                |



## Source of Factor Donations

Project SHARE accepts donations of unwanted, in-date factor from all reputable sources. Our main sources of donations include US individuals, HTC's, NHF chapters and hemophilia nonprofit organizations.

Project SHARE does not actively seek donations from factor manufacturers, which normally are donated to the World Federation of Hemophilia (WFH). Our intent is to recover excess or unwanted factor that would otherwise be destroyed. We accept any assay size, to within days of expiration, in shipments of one bottle or up to hundreds of bottles.

## Where We Have Helped



### Russia

Project SHARE couriers factor to Matvey L. and other patients in hard-to-reach areas like Siberia.



### Nicaragua

Project SHARE donated 1 million IUs of factor VIII and IX to Nicaragua, enough to supply the entire country for a year!



### Zimbabwe

Project SHARE is one of just two factor donors to Zimbabwe—a country enduring extreme political and economic unrest.



### Philippines

Project SHARE paid for 16-year-old Dodong T.'s first clinical checkup where he was diagnosed with hemophilia, and provided factor for his first infusion.



### Bangladesh

Parimal D. of the Hemophilia Society of Bangladesh has factor VIII deficiency. He facilitates requests and shipments between Project SHARE and others.



### Indonesia

Michael D. sends handwritten thank-you notes for the factor he receives from Project SHARE.

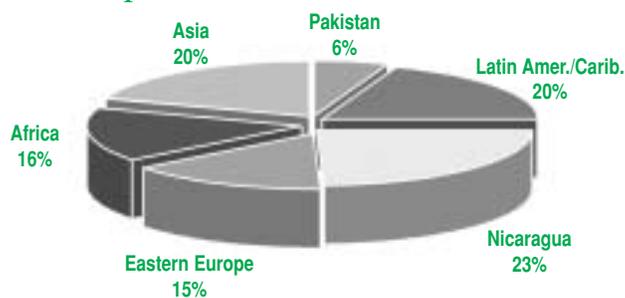
## Ancillary Supply Donations

A new partnership with medical equipment shipping organization **International Medical Equipment Collaborative** (IMEC) allows Project SHARE to concentrate on what we do best—shipping factor! IMEC has ample storage space and allows Project SHARE to access ancillary medical supplies as needed, so donations unused by Project SHARE will not be wasted.

To donate non-factor products, call or email IMEC directly to set up the best shipping location and method.

IMEC (978) 388-5522 • [snoon@imecamerica.org](mailto:snoon@imecamerica.org)

## Factor Recipients 2004



Total IUs donated: 5,043,281

## In Gratitude

Project SHARE exists only through the support of our generous corporate partners. We would like to thank the following companies:

- Bayer HealthCare
- Baxter BioScience
- Hemophilia Health Services
- Novo Nordisk Pharmaceuticals
- ZLB Behring

We give special thanks to New England Biolabs for its continued funding and management of our shipments, and to S.T.A.R. Children Relief for its help in Romania. Thanks to all individuals who donated factor to Project SHARE, especially those who donated in memory of a loved one.

## Our Vision

To provide life-saving factor donations as a major US shipper, and to offer expert consultation on the delivery of humanitarian aid to hemophilia patients in the developing world.

## Our Mission

- Collect unwanted antihemophilic factor (AHF).
- Transport donated AHF to developing countries.
- Attract patients to treatment centers.
- Support camps, surgeries and physical therapy.
- Alleviate pain and save lives.
- Encourage the US hemophilia community to give.

### Project SHARE

c/o LA Kelley Communications, Inc.  
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Please see our website for more information about our policies, operations and funding.

by Michael Russo



The Bruckner Group

# When Cost-Cutting Cuts Into Clinical Decision-Making

**P**harmacy Benefit Managers (PBMs) are making inroads in hemophilia care by becoming either providers of factor concentrate or owners of the companies that provide concentrate. PBMs are poised to make sweeping changes in the way factor is reimbursed. Originally, PBMs were designed to reduce the overall burden of pharmaceutical expenses for the health insurers and employers with whom they contract, without affecting patient care—that is, without recommending or controlling the type, brand or assay of a drug that a patient might receive. But during the 1990s as PBM competition heated up, PBMs identified and rolled out new ways to offer cost savings. These new ways have encroached on the clinical decision-making that typically is largely determined by an individual patient’s physician. PBMs are not entirely unqualified to venture into clinical decisions. Their clinical analyses leverage teams of healthcare professionals and large amounts of clinical data to help guide their clinical policies. But, as some families with hemophilia have experienced, PBM policies that govern whole populations of patients do not always apply to individual cases.

PBMs often appear to stay clear of direct clinical decisions by offering an array of options, many of which are not actually practical financial choices for most patients. Still, PBMs can and do influence clinical decisions through these initiatives:

**1. Hefty copayments.** A PBM may leave you (and your doctor) no practical option but to comply with its factor brand preferences as dictated by the PBM formulary’s copayment system. If you choose

to exercise the option of obtaining a non-preferred factor brand, your formulary may require you to pay a hefty price, perhaps even the full cost of the drug.

**2. Limited brand choice.** A PBM may prefer a particular factor brand, not because it’s clinically superior or equivalent to its nearest competition, but because it’s comparatively cheaper. PBMs may engage in deals with manufacturers that provide manufacturers with a preferential status in exchange for lower prices. This tactic might save money in the short term, but has a real effect on brand choice, the incentive to create innovative factor products, and the supply safety net offered by the availability of multiple products.

**3. Specific restrictions.** The following three types of formulary policies interfere with a physician’s clinical authority and a patient’s freedom to make choices. The fact that patients often have the option of “violating” these rules by paying for the entire prescription cost themselves is irrelevant when drugs become prohibitively expensive for average people.

**Prior authorizations:** Demanding that physicians fill out additional paperwork to obtain a PBM’s prior authorization to determine whether it will cover a specific therapy for a particular patient.

**Step programs:** Insisting that a particular therapy or brand be tried first, and fail, before a PBM will cover a physician’s prescription for another therapy.

**Utilization limits:** Enforcing limits on the dosage or frequency that a physician prescribes for a patient by refusing to pay for additional utilization.

**4. Mail-order preference.** For the same copayment, PBMs allow patients to obtain a 90-day supply by mail, but only a 30-day supply from a retail pharmacy. This drives patients to use the mail-order service, saving the PBM money and possibly improving patient compliance by creating a more automated service with fewer refills. But PBMs also know that automation of the prescription process eliminates some patient involvement and erodes the potential for patients to feel empowered to take control of their drug regimen.

Work with your physician or hemophilia treatment center to determine whether your healthcare policy uses PBMs. Find out if the PBMs are encroaching on medical decisions made by your physician. Cutting healthcare costs is important and necessary, but not at the expense of the prescribed treatment regimen that will ensure a high quality of life for your child with hemophilia.

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Michael Russo is a partner at The Bruckner Group (BGI), a strategy and research firm serving the healthcare industry. Michael is a recognized expert in helping stakeholders—manufacturers, payers and patients—preserve and defend their interests in the emerging value- and outcomes-based healthcare system. To comment on this article, contact Michael at [mrusso@brucknergroupp.com](mailto:mrusso@brucknergroupp.com). Learn more about BGI by visiting [www.brucknergroupp.com](http://www.brucknergroupp.com).

## Revolutionary Longer-Lasting Factor

Bayer HealthCare (Biological Products Division) has received FDA permission to begin Phase I clinical trials of its longer-acting Kogenate<sup>®</sup>, the first factor VIII product of its kind to be granted FDA permission for use in hemophilia clinical trials. The product, which uses PEGylated liposome technology licensed from Zilip-Pharma, could produce a major breakthrough in hemophilia treatment based on a longer time of activity. This improvement could result in weekly or even less frequent prophylactic infusions.

Contact: [www.kogenatfs.com](http://www.kogenatfs.com)

Source: Bayer press release

## Wyeth Announces 9th Year of Product Donation to Camps



Wyeth continues its ongoing support of the hemophilia community by donating a supply of both ReFacto<sup>®</sup> and BeneFIX<sup>®</sup> to US hemophilia summer camps for the ninth consecutive year. In 2004, Wyeth supplied 24 camps with donated products. Wyeth is also the exclusive sponsor of the North American Camping Conference of Hemophilia Organizations (NACCHO), conducted by the Hemophilia Association, Inc. of Arizona.



## Inalex Communications Workshops: Goal-Setting for Life

Inalex Communications is offering a two-day goal setting teleconference for men in the bleeding disorders community seeking effective tools to set and achieve personal and professional goals. In a supportive environment, participants will learn practical techniques and have direct practice in setting powerful, inspiring and achievable goals. Part 1 of the two-part conference will be held on October 18, 2005, and Part 2 on November 15, 2005. Speakers include Robert Berkley and Joseph Caronna. Register for these and other workshops and teleconferences beginning the first day of the month for that month's conference. There are three ways to register: 1) Sign on to [www.inalex.com](http://www.inalex.com), click on the "Teleconference" button, then click the register icon. 2) Email [joe\\_caronna@Inalex.com](mailto:joe_caronna@Inalex.com). 3) Call toll-free (866) 802-0304.

## Another PBM Buys a Hemophilia Homecare Company

On July 21, 2005, the PBM Express Scripts announced an agreement to acquire the specialty pharmacy Priority Healthcare for \$1.3 billion. With the addition of Priority, CuraScript (Express Scripts' specialty pharmacy subsidiary) will become one of the nation's largest specialty pharmacy and distribution

companies, with over \$3 billion in annual revenues. CuraScript's broad specialty pharmacy product line includes hemophilia.

Contact: David Myers, Vice President  
Investor Relations (314) 702-7556  
[investor.relations@express-scripts.com](mailto:investor.relations@express-scripts.com)

## PBM Pairs with Hemophilia Homecare Company

June 27, 2005: Curative Health Services, Inc., announced a strategic alliance with PharmaCare Management Services, Inc., CVS Corporation's pharmacy benefit management company. The agreement makes Curative the preferred provider for specialty home infusion services for PharmaCare's customer base, including factor products for bleeding disorders.

Source: Curative press release

Contact: Sean Mahoney  
(603) 888-1500  
[smahoney@curativehealth.com](mailto:smahoney@curativehealth.com)

For more information on PBMs and hemophilia, see "Taking Center Stage: How PBMs are positioned to make or break the level of hemophilia care in America," *PEN*, May 2005.

## Increase to HTC Funding Unlikely

June 24, 2005: the US House of Representatives passed the 2006 Labor, Health and Human Services (HHS) and Education Appropriations bill by a vote of 250-15. The bill now moves to the Senate. The bill provides \$633 million less than last year. It includes a cut of \$295 million in the Centers for Disease Control (CDC) budget, and a cut of \$24 million in the Maternal and Child Health Block (MCHB) Grant. The CDC and MCHB are the primary

sources of government funding for US hemophilia treatment centers. The bill did not include the increase requested by NHF for HTC funding.

Contact: [www.hemophilia.org/News/legislative/lu\\_06\\_25\\_05.htm](http://www.hemophilia.org/News/legislative/lu_06_25_05.htm)  
Source: NHF

## Wyeth Free Trial Prescription Program 2005

Through a trial program, Wyeth is giving patients and healthcare professionals the opportunity to gain experience with a free trial of ReFacto<sup>®</sup> and the new ReFacto R2 Kit. Introduced in November 2004, the ReFacto R2 Kit is the first needleless reconstitution device with a prefilled diluent syringe for hemophilia. Patients who receive their healthcare from Medicare or Medicaid and hematologists not associated with a hemophilia treatment center are eligible to participate in the program.



Contact: [www.hemophiliavillage.com](http://www.hemophiliavillage.com)  
Source: Wyeth press release

## BINDERS

### First Step



The National Hemophilia Foundation, 116 West 32nd Street, 11th Floor, New York, NY 10001. (212) 328-3700 (800) 42-HANDI [www.hemophilia.org](http://www.hemophilia.org)

**FREE** with paid NHF membership.

Resource guide for parents and families of children newly diagnosed with bleeding disorders.

Contains information about NHF programs, hemophilia, von Willebrand Disease, treatments, childcare, parenting, healthcare, scientific and medical issues.

### The Consumer's Guide to Hemophilia and von Willebrand Disease Products



2004. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833. Toll-free (800) 297-7977 [www.kelleycom.com](http://www.kelleycom.com)

Sponsored by Factor Support Network, 900 Avenida Acaso, Suite A, Camarillo, CA 93012-8749. Toll-free (877) FSN-4-YOU [www.factorsupport.com](http://www.factorsupport.com) or [RandyDeSantis@factorsupport.com](mailto:RandyDeSantis@factorsupport.com)

**FREE**

A comparative guide to all factor concentrate products and specialty products for the bleeding disorders community; concisely examines all relevant information for consumers. Factor VIII, factor IX, factor IX complex and inhibitor products are color coded and easy to cross-reference. Binder also can be used as a stand for flip-chart style teaching.

## BOOKLETS

### Empower Yourself About Hemophilia



Kelley, Lauren A. 2004. 40pp. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833. Toll-free (800) 297-7977 [www.kelleycom.com](http://www.kelleycom.com)

*Available in English and Spanish.*

**FREE**

For families of children newly diagnosed with hemophilia. Includes goal-setting methods, and ways to change your perception of hemophilia and take charge of your life. Cartoon illustrations of "before" and "after" situations offer concrete methods to regain control during the rocky first year of hemophilia.

### Living with Hemophilia (series)



2005. Hemophilia Health Services, 6820 Charlotte Pike, Nashville, TN 37209-4234. (800) 800-6606 [www.HemophiliaHealth.com](http://www.HemophiliaHealth.com)

*Available after November 2005.*

**FREE**

Series covers events and information needed for different life stages: 0-12 months, 1-5 years, 6-11 years, 12-18 years, 19-50 years, and 50+ years.

### Your Child's Hemophilia (series)

2001. ZLB Behring, 1020 First Avenue, King of Prussia, PA 19406. ZLB Behring Choice Support Center (888) 508-6978 [www.zlbbehring.com](http://www.zlbbehring.com)

**FREE**

Three-part series for parents about what to expect during different phases of children's development. Series includes:

*Your Child's Hemophilia: What to Expect During Infancy*

*Your Child's Hemophilia: What to Expect During the School Age Years*

*Hemophilia: The Young Adult Years*

### Dental Care Series



2001. ZLB Behring, 1020 First Avenue, King of Prussia, PA 19406. ZLB Behring Choice Support Center (888) 508-6978 [www.zlbbehring.com](http://www.zlbbehring.com)

**FREE**

Four-part series on dental care, primarily for people and families with hemophilia A, hemophilia B and VWD. Series includes:

*Dental Care for Infants, Toddlers, and Preschoolers With Bleeding Disorders*

*Dental Care for Children With Bleeding Disorders: Ages 5 to 10*

*Dental Care for Adolescents With Bleeding Disorders: Ages 11 to 18*

*Dental Care for Adults With Bleeding Disorders*

## PERIODICALS

### Parent Empowerment Newsletter (PEN)



LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833. Toll-free (800) 297-7977  
www.kelleycom.com

**FREE** to patients, families, HTC's, hemophilia nonprofit organizations, and corporate partners of LA Kelley Communications. \$20.95 yearly (hard copy) or \$12.95 yearly (PDF) for other subscribers.

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

### Hemophilia: An Internet Resource Guide for Patients



2004. 39 pp. Wyeth Pharmaceuticals, 500 Arcola Road, Collegeville, PA 19426. (800) 944-1433 www.hemophiliavillage.com

**FREE**

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



### Living with Hemophilia B

Wyeth Pharmaceuticals, 500 Arcola Road, Collegeville, PA 19426. (800) 944-1433  
www.hemophiliavillage.com

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



### A Family Guide to Hemophilia B

2001. ZLB Behring, 1020 First Avenue, King of Prussia, PA 19406. ZLB Behring Choice Support Center (888) 508-6978  
www.zlbbehring.com

**FREE**

Discusses the unique challenges that a family faces when living with hemophilia B. Read about treatments and recent advances. Easy-to-understand dosing tools and exercise guides help you grow stronger. See how to self-infuse with easy-to-follow directions.

### HemAware



The National Hemophilia Foundation, 116 West 32nd Street, 11th Floor, New York, NY 10001. (212) 328-3700 (800) 42-HANDI www.hemophilia.org

**FREE** with paid NHF membership.

*Quarterly.* Articles on hemophilia medical research and treatment in areas of social work, physical therapy, orthopedics and dental nursing. Articles for families; community event information.

### The Common Factor



Committee of Ten Thousand (COTT), 236 Massachusetts Avenue, NE, Suite 609, Washington, D.C. 20002-4971. John P. Rider (800) 582-3803 or Dave Cavenaugh (800) 488-2688

*Biannual.* Topics include medical updates and lobbying efforts. COTT is a national advocacy organization for people with hemophilia and HIV/AIDS, and affected family and friends.

### Bloodstone Magazine



24 pp. Hemophilia Health Services, 6820 Charlotte Pike, Nashville, TN 37209-4234. (800) 800-6606  
www.HemophiliaHealth.com

**FREE**

*Quarterly.* Covers news specific to the bleeding disorders community; focuses on people living beyond their bleeding disorders. Includes "Adventures of Welligan Hugsley" series for children.

### Factor Nine News



Coalition for Hemophilia B, 225 West 34th Street, Suite 710, New York, NY 10012. (212) 554-6898 www.boygenius.com/cfb  
Hemob@ix.netcom.com

**FREE**

*Quarterly.* Brief newsletter features latest news and treatment for hemophilia B. From nonprofit organization dedicated to improving quality of life for people with hemophilia B by supporting research and education, and liaison with the pharmaceutical industry.

## Dateline Federation



Hemophilia Federation of America, 1405 W. Pinhook Rd., Suite 101, Lafayette, LA 70503. (800) 230-9797 [www.hemophiliafed.org](http://www.hemophiliafed.org)

### FREE

*Quarterly.* Healthcare information about bleeding disorders; government and healthcare events, educational programs, family assistance programs and upcoming events.

## The Infusion Inquirer



Hemophilia Options, 1410 Heriford Rd., Columbia, MO 65202. [www.hemophiliaoptions.com](http://www.hemophiliaoptions.com) (866) 436-4376

### FREE

*Quarterly.* For patients with bleeding disorders, and case managers, physicians and treatment centers. Includes calendar of local and national events, insurance tips, safety articles and treatment information.



## VIDEOS, DVDS, CD ROMS

### Infusion Tracker2

NuFACTOR, 41093B County Center Drive, Temecula, CA 92591. (800) 323-6832 [www.nufactor.com](http://www.nufactor.com)

### FREE

Consumer software helps patients record, analyze, visualize and report bleed and infusion histories. Allows patients to print and email reports to healthcare providers. Helps identify target joints, track effectiveness of prophylaxis schedule, recognize seasonal bleed patterns and record lot numbers permanently. For Windows 98 Second Edition and newer systems.

### The Winning Spirit

Delaware Chapter of NHF, 222 South Easton Road, Suite 107, Glenside, PA 19038. (215) 885-6500

### FREE

What new parents should expect from hemophilia: initial feelings after the diagnosis, developmental stages, what happens inside during a bleed, factor therapy, sports and activities, and keeping life normal. 20 minutes.



### Joint Health CD-ROM

Baxter BioScience, One Baxter Parkway, Deerfield, IL 60015. [www.hemophiliagalaxy.com](http://www.hemophiliagalaxy.com)

Guide that teaches how joints work, the benefits of exercise, sticking with a treatment plan and more. Tips and advice from patients and healthcare professionals.



### Function of FVIII at the Site of Bleeding

Bayer Corporation, Biological Products, 400 Morgan Lane West Haven, CT 06516-4175. [www.kogenatefs.com](http://www.kogenatefs.com)

### FREE

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



## BOOKS AND GAMES FOR CHILDREN

### What is Hemophilia? (series)

Kelley, Lauren A. 1995. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833. Toll-free (800) 297-7977 [www.kelleycom.com](http://www.kelleycom.com)

Sponsored by and also available through ZLB Behring, ZLB Behring Choice Support Center (888) 508-6978 [www.zlbbehring.com](http://www.zlbbehring.com)

*Available in English and Spanish.*

### FREE

Developmentally arranged series explaining hemophilia to children using language and concepts appropriate for three age levels: preschool, school-age, adolescent. Each book covers the same topics in educationally and cognitively different ways. Contains "Note to Parents" for each age level.

#### Level 1: Joshua, Knight of the Red Snake



Empowering story about a preschooler with hemophilia. Illustrated large-text format. Ends on a note of joy and confidence to empower children. Ages 3-7.

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



A humorous story about Tony, who must explain hemophilia to his fourth grade classmates. Includes glossary for children. Ages 7-11.

#### Level 3: Tell Them the Facts!



Question-and-answer book on hemophilia for pre-adolescents and adolescents. Material on genetics divided into two sections: ages 11-14 and 14-16. Also for teachers, parents of newly diagnosed children. Includes glossary.

### Must You Always Be a Boy?



Kelley, Lauren A. 1991. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833. Toll-free (800) 297-7977 [www.kelleycom.com](http://www.kelleycom.com)

Sponsored by and also available through ZLB Behring, ZLB Behring Choice Support Center (888) 508-6978 [www.zlbbehring.com](http://www.zlbbehring.com)

### FREE

Four rhyming tales explore adult reactions to bleeds, overprotective parents, sibling rivalry and classroom bullies. Illustrated. Ages 3-8.

### Alexis: The Prince Who Had Hemophilia

Kelley, Lauren A. 1992. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833. Toll-free (800) 297-7977 [www.kelleycom.com](http://www.kelleycom.com)

Sponsored by and also available through ZLB Behring, ZLB Behring Choice Support Center (888) 508-6978 [www.zlbbehring.com](http://www.zlbbehring.com)

*Available in English and Spanish.*

### FREE

True story of Alexis, youngest child of Russian Tsar Nicholas II, and how his hemophilia influenced events in Russia ultimately leading to the Russian revolution. Ages 8 and older.



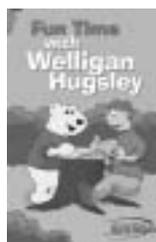
### Hemophilia Logic



Horbacz, Diane. 2005. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833. Toll-free (800) 297-7977 [www.kelleycom.com](http://www.kelleycom.com)

### FREE

Sherlock Bones guides children through activity book about hemophilia, body functions, independence, treatment and self-esteem with colorful mazes, matching, glyphs, games and puzzles. Ages 7-12.



### Fun Time with Welligan Hugsley

Hemophilia Health Services. 2004. 52 pp. Hemophilia Health Services, 6820 Charlotte Pike, Nashville, TN 37209-4234. (800) 800-6606 [www.HemophiliaHealth.com](http://www.HemophiliaHealth.com)

### FREE

Teaches children about hemophilia through creative characters and fun activities. Topics include the infusion process, hemophilia camp, dental care, exercise and safety.

### Factor Fun!

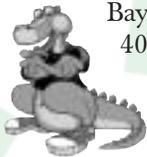


Horbacz, Diane. 2001. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833. Toll-free (800) 297-7977 [www.kelleycom.com](http://www.kelleycom.com)

### FREE

Activity book teaches about hemophilia and self-esteem with colorful mazes, matching, glyphs and counting. Ages 4-7.

**The Kogee Club** (ages 7 and under) and  
**The Kojo Club** (ages 8–12)



Bayer Corporation, Biological Products,  
400 Morgan Lane West Haven, CT 06516-4175.  
www.kogenatefs.com

**FREE**

Friendly dinosaurs Kogee and Kojo teach children about hemophilia, how to live quality lives, make smart choices and take control of their disorder. Club members receive newsletters, birthday cards and holiday cards with fun facts on living a healthy lifestyle.

**Infusion Time**



Horbacz, Diane. 2004. Hemophilia Health Services,  
45 Route 46 East, Suite 609, PO Box 2011, Pine  
Brook, NJ 07058. (800) 549-2654  
www.HemophiliaHealth.com

Sponsored by Bayer HealthCare.

*Available in English. Spanish available November 2005.*

**FREE**

Interactive book teaches children the steps of an infusion through a port. Rhymes and tactile features make learning fun. Filled with teaching tips for parents to promote confidence and build self-esteem.

**My Brother is Getting a New Port**



Horbacz, Diane. 2004. Hemophilia Health Services,  
45 Route 46 East, Suite 609, PO Box 2011, Pine  
Brook, NJ 07058. (800) 549-2654  
www.HemophiliaHealth.com

Sponsored by Bayer HealthCare.

**FREE**

Written through the eyes of an older brother who supports his little brother through each step of the hospital experience as he prepares for port surgery.

**Learn About Hemophilia**



Hemophilia Health Services, 45 Route 46 East,  
Suite 609, PO Box 2011, Pine Brook, NJ 07058.  
(800) 549-2654 www.HemophiliaHealth.com

**FREE**

Dom the Domino guides coloring book about hemophilia. Teaches about bleeds, types of hemophilia, how blood clots and basic genetics. Accompanies *Learn About Hemophilia* CD-Rom.

**Diane Dino's Dilemma**

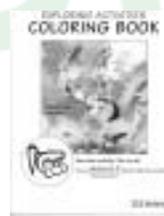


2001. ZLB Behring, 1020 First Avenue, King  
of Prussia, PA 19406. ZLB Behring Choice  
Support Center (888) 508-6978  
www.zlbbehring.com

**FREE**

Storybook about a little dinosaur with VWD who explains the disorder in simple terms. Illustrated. Ages 5–9.

**Diane Dino's Exploring Activities Kit**



2001. ZLB Behring, 1020 First Avenue, King  
of Prussia, PA 19406. ZLB Behring Choice  
Support Center (888) 508-6978  
www.zlbbehring.com

**FREE**

Coloring book and paint kit companion to  
*Diane Dino's Dilemma*. Features Diane Dino,  
her friends and favorite activities. Ages 3 and older.

**If You Wear a MedicAlert®**



Horbacz, Diane. 2004. Hemophilia Health Services,  
45 Route 46 East, Suite 609, PO Box 2011, Pine  
Brook, NJ 07058. (800) 549-2654  
www.HemophiliaHealth.com

Sponsored by Bayer HealthCare.

*Available in English. Spanish available in November 2005.*

**FREE**

Addresses the challenges children on prophylaxis face when communicating with peers about hemophilia. As two young baseball teammates chat, repetition of key words helps foster communication skills.

**My Infusion Wooden Peg Puzzle**



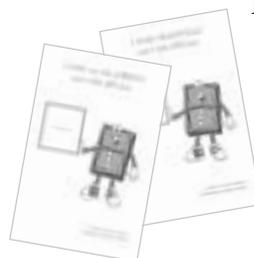
Hemophilia Health Services, 45 Route 46  
East, Suite 609, PO Box 2011, Pine Brook,  
NJ 07058. (800) 549-2654  
www.HemophiliaHealth.com

Sponsored by Bayer HealthCare.

**FREE**

Education tool enables parents to introduce hemophilia infusion concepts to very young children. Helps develop fine motor skills and dexterity while focusing on language development regarding infusion items.

**I Have Hemophilia and I am Special and  
I Have vWD and I am Special**



Horbacz, Diane. 2005. Hemophilia  
Health Services, 45 Route 46 East,  
Suite 609, PO Box 2011, Pine Brook,  
NJ 07058. (800) 549-2654  
www.HemophiliaHealth.com

Sponsored by Bayer HealthCare.

*Available in English and Spanish.*

**FREE**

Offers young children ways to effectively communicate with peers about hemophilia and related bleeding disorders. Fill in your child's name throughout this personalized book to make your child the focus.

## CD ROMS AND VIDEOS FOR CHILDREN

### Inside a Bleeding Joint



Bayer Corporation, Biological Products, 400 Morgan Lane, West Haven, CT 06516-4175. [www.bayerbiologicals.com](http://www.bayerbiologicals.com)

**FREE**

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

### Learn About Hemophilia



Hemophilia Health Services, 45 Route 46 East, Suite 609, PO Box 2011, Pine Brook, NJ 07058. (800) 549-2654

[www.HemophiliaHealth.com](http://www.HemophiliaHealth.com)

**FREE**

Dom the Domino guides a computer tutorial about hemophilia. Teaches about bleeds, types of hemophilia, how blood clots and basic genetics. Accompanies *Learn About Hemophilia* coloring book. PC and Mac compatible.

### Every Step of the Way



Bayer Corporation, Biological Products, 400 Morgan Lane West Haven, CT 06516-4175. [www.kogenatefs.com](http://www.kogenatefs.com)

**FREE**

Animated character "Factor 8" connects with Jimmy, who has factor VIII deficiency, in an online chat room. Factor 8 guides Jimmy through the factor VIII manufacturing process, including virtual tour of the state-of-the-art Berkeley Facility. Translates the highly technical manufacturing processes into an entertaining, straightforward step-by-step overview.

## PERIODICALS FOR CHILDREN

### Lil' Factors

Hemophilia Health Services  
45 Route 46 East, Suite 609,  
PO Box 2011, Pine Brook, NJ 07058.  
(800) 549-2654 [www.HemophiliaHealth.com](http://www.HemophiliaHealth.com)

**FREE**

*Quarterly.* Periodical helps children understand hemophilia and VWD. Features "Karing for Kids" activities, Dom the Domino, and articles by and about children with bleeding disorders.



## KITS

### School Preparedness Program and Kit

Coram Hemophilia Services, 6 Spring Mill Drive, Malvern, PA 19355. (800) 992-4091 (ext. 3377) [schoolprep@coramhemophilia.com](mailto:schoolprep@coramhemophilia.com)

Available through participating HTC's.

First-of-its-kind kit contains variety of tools and resources to help parents plan ahead for a safe and rewarding school experience. Program offers free presentations and staff support designed to educate school staff and students about hemophilia, and foster vital communication among physicians, HTC's, families and schools.



### Patient Starter Kit

Baxter BioScience, One Baxter Parkway, Deerfield, IL 60015. [www.hemophiliagalaxy.com](http://www.hemophiliagalaxy.com)

Available only through HTC's.

**FREE**

Includes video featuring families of children with hemophilia, information booklet, and letters to school and employers. For new parents.

### Venous Access Toolkit

Baxter BioScience, One Baxter Parkway, Deerfield, IL 60015. [www.hemophiliagalaxy.com](http://www.hemophiliagalaxy.com)

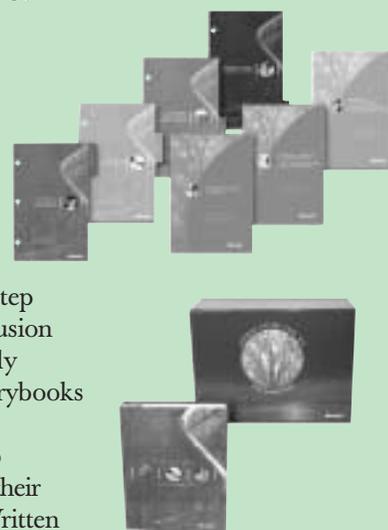
Available only through HTC's.

**FREE**

Tool kit includes tabbed sections dealing with every aspect of learning about, choosing, transitioning and monitoring various venous access methods.

Includes step-by-step guide to self-infusion and beautifully illustrated storybooks for children beginning to learn about their treatment. Written in straightforward, patient-friendly style.

Components may be available for patients to take home.



## PROGRAMS

### Inalex Communications Workshops for Men

Inalex Communications,  
38 East Ridgewood Ave #244,  
Ridgewood, NJ, 07450.

(201) 493-1399 Toll-free (866) 802-0304  
www.inalex.com or Joe\_caronna@inalex.com



#### FREE

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



### North American Camping Conference of Hemophilia Organizations (NACCHO)

Hemophilia Association, Inc., 4001  
North 24th Street, Phoenix, AZ 85016.  
(602) 955-3947 Toll-free (888) 754-7017  
www.hemophiliaz.org or  
Wyeth Pharmaceuticals at  
www.hemophiliavillage.com

Funded by an unrestricted educational grant from Wyeth. Created and hosted by the Hemophilia Association, Inc. of Arizona.

#### FREE

NACCHO is a weekend workshop created for those responsible for planning, organizing and operating a bleeding disorder summer camp. Attendees include camp counselors, camp directors, infirmary staff, fundraisers, activities leaders and camp committee members. Nationally known presenters share useful camp resources and techniques, explore camp programs and activities, and facilitate networking and problem solving. Attendees can exchange resource materials with other camps, meet with NHF representatives, pick up new ideas and share their own. *Next NACCHO: February 2006.*

### Living With Hemophilia: Speaker's Bureau

Wyeth Pharmaceuticals, 500 Arcola Road, Collegeville, PA 19426. (800) 944-1433 www.hemophiliavillage.com

#### FREE

Wyeth supports speakers who visit HTC's and local hemophilia organizations to discuss topics related to hemophilia and Wyeth products. Topics include basic facts about hemophilia, review of treatment options, day-to-day challenges, and financial aspects of living with hemophilia. Interested organizations can contact their local Wyeth representatives or call the Hemophilia Hotline at (888) 999-2349.

### Parents Empowering Parents (PEP)

Funded with an unrestricted educational grant by Bayer since 1995. For information about bringing PEP to your HTC:

(212) 229-8476 www.PEPprogram.org or e-mail  
cmiller@ccapr.com



#### FREE

Innovative peer-to-peer skills program introduces parents to tools to help handle the realities of raising a child with a bleeding disorder. PEP is presented to parents by parents of children with bleeding disorders in tandem with HTC social workers and nurses.

### Mission: Transition

Hemophilia Options, 1410 Heriford Rd., Columbia, MO 65202. (866) 436-4376 www.hemophiliaoptions.com

Program for teens with hemophilia or other bleeding disorder. Assists the HTC by helping young adults increase awareness of their transition needs. Program includes infusion techniques, career planning, healthy lifestyle discussion, practice pharmacy calls for ordering factor, and scholarship opportunities. Administered by the team at Hemophilia Options.

#### FREE

### Families Supporting Families

Hemophilia Options, 1410 Heriford Rd., Columbia, MO 65202. (866) 436-4376 www.hemophiliaoptions.com

#### FREE

Mentoring program for families provides communication and shared support through the knowledge of experienced families. Offers the chance to attend local or national events and receive important educational materials.

### Gettin' in the Game<sup>SM</sup>



ZLB Behring, 1020 First Avenue, King of Prussia, PA 19406. ZLB Behring Choice Support Center (888) 508-6978  
[www.zlbbehring.com](http://www.zlbbehring.com)

#### FREE

Encourages kids with bleeding disorders to exercise, play sports and be physically active.

Exercise can help people with bleeding disorders build stronger muscles and joints, and improve venous access. Sports and exercise build self-confidence, teach teamwork, and create a sense of community. Offers local events where children and their families can learn sports tips, participate in appropriate exercises and warm-ups, and meet other kids with bleeding disorders. Contact your HTC or local NHF chapter.

### The National Hemophilia Foundation-ZLB Behring Junior National Championship

Contact [www.zlbbehring.com](http://www.zlbbehring.com)

#### FREE

Encourages kids with bleeding disorders to be active and stay fit by participating in four baseball and golf regional competitions. Competitions include clinics, art programs, group exercises and awards. Four regional winners in golf and baseball receive a free trip for themselves and two accompanying adults to Orlando, Florida to compete against other regional winners in the final round of the NHF-ZLB Behring Junior National Championship on October 8, 2005.

### The Patient Notification System (PNS)

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

#### FREE

Confidential 24-hour communication system provides information on plasma-derived and recombinant therapy withdrawals and recalls. The system was created to provide consumers with a single, convenient source for up-to-date information. Developed by producers and distributors of plasma therapies with direct input from consumers. Registered patients receive automatic updates of product recalls and withdrawals. Administered by the Plasma Protein Therapeutics Association (PPTA).



### Karing for Kids: Innovative Learning

Hemophilia Health Services, 45 Route 46 East, Suite 609,

PO Box 2011, Pine Brook, NJ 07058. (800) 549-2654  
[www.HemophiliaHealth.com](http://www.HemophiliaHealth.com)

#### FREE

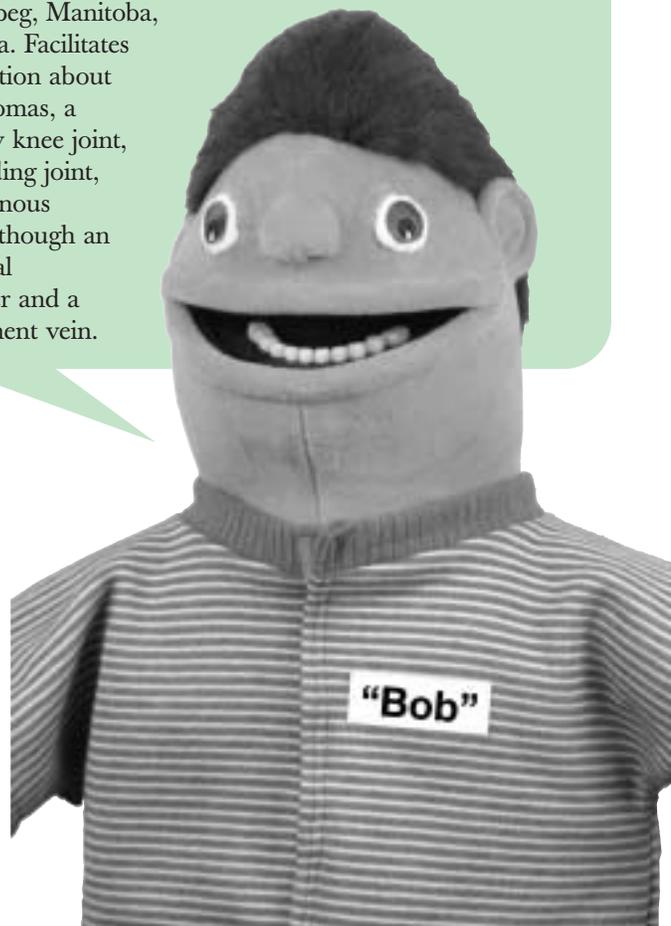
Series of interactive workshops and presentations helps children with bleeding disorders and their families gain knowledge, confidence and control in managing hemophilia. Includes *Kids' Workshops* for parents and children, *Hemophilia for Preschoolers*, *My Amazing Blood* for school-age, *Junior Scientist* for teens. Offers educational resources and PARENTLine<sup>TM</sup> toll-free number for advice on parenting issues.

### Puppets as Teachers in Hemophilia (PATH)

Wyeth Pharmaceuticals, 500 Arcola Road, Collegeville, PA 19426. (800) 944-1433  
[www.hemophiliavillage.com](http://www.hemophiliavillage.com)

Available through HTCs only.

PATH helps healthcare professionals teach children with hemophilia about their disorder using a specially designed puppet. The Hemophilia Training Puppet was developed in conjunction with Patient Puppets, Inc., Winnipeg, Manitoba, Canada. Facilitates instruction about hematomas, a healthy knee joint, a bleeding joint, and venous access through an external catheter and a prominent vein.



## FOR VON WILLEBRAND DISEASE

### Von Willebrand Disease: A Guide for Patients and Families



Paper, Renée, R.N. with Kelley, Lauren A. 2002. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833. Toll-free (800) 297-7977 [www.kelleycom.com](http://www.kelleycom.com)

Sponsored by and also available through ZLB Behring, ZLB Behring Choice Member Support Center (888) 508-6978 [www.zlbbehring.com](http://www.zlbbehring.com)

#### FREE

The world's first book on the world's most commonly inherited bleeding disorder. Covers learning to cope with VWD, inheritance, the medical system, treatment, women's issues and health insurance. Includes a complete resource guide and real-life stories.



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

2001. ZLB Behring, 1020 First Avenue, King of Prussia, PA 19406. ZLB Behring Choice Support Center (888) 508-6978 [www.zlbbehring.com](http://www.zlbbehring.com)

#### FREE

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

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

2001. ZLB Behring, 1020 First Avenue, King of Prussia, PA 19406. ZLB Behring Choice Support Center (888) 508-6978 [www.zlbbehring.com](http://www.zlbbehring.com)

#### FREE



Companion pieces about Type 1, Type 2A, Type 2B, Type 3 VWD, and VWD in women. Each piece may be ordered separately, and describes a particular type of VWD, symptoms and treatment.

### Von Willebrand Disease: A Guide for Patients and Families

2005. Hemophilia Health Services, 6820 Charlotte Pike, Nashville, TN 37209-4234. (800) 800-6606 [www.HemophiliaHealth.com](http://www.HemophiliaHealth.com)

Available after November 2005.

#### FREE

Booklet contains an overview of VWD, types, inheritance patterns, diagnosis and treatment.

## THERAPEUTIC PRODUCTS

### Cryo/Cuff™

Aircast, Inc., 92 River Road, Summit, NJ 07901. (800) 526-8785 or (908) 273-6349; Fax (800) 457-4221 or (908) 273-1060 [www.aircast.com](http://www.aircast.com) [USInq@aircast.com](mailto:USInq@aircast.com)

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

Cryo/Cuff and Pediatric Knee/Elbow Cryo/Cuff are specifically designed for children's injuries. Can be ordered as a single cuff or with a cooler and tube assembly. Detachable cooler allows for uninterrupted treatment. AutoChill® System is an accessory to the Cryo/Cuff, automatically exchanging the water between cooler and cuff and eliminating the need for manual water recycling. Cuffs are available for adults and children, for ankle, back/hip/rib, calf, elbow, foot, hand/wrist, knee, shoulder and thigh.



### Kneetogs™

Bee's Knees, 224 Burntside Drive, Golden Valley, MN 55422. Toll-free (888) 377-4511 Fax (888) 377-2106 [www.beeskneeskids.com](http://www.beeskneeskids.com)

[sales@beeskneeskids.com](mailto:sales@beeskneeskids.com)

\$14.99 per pair.



Specially-designed kneepads protect comfortably and look fashionable. Kneetogs' exclusive Sentinel Microcell™ is a patented, closed-cell foam that provides 50% more shock absorption than urethane foams used in other toddler knee pads. Absorbs almost no water; naturally hypo-allergenic and anti-bacterial. Helps keep bumps, bruises and joint bleeds to a minimum. Available in three fun designs. Hand or machine washable. ®

I don't want your readers to place all PBMs into the same category as organizations that will limit choice. Later this summer, it is anticipated that Accredo Health Group, of which Hemophilia Health Services is a division, will be owned and operated as a subsidiary of Medco, a national Pharmacy Benefit Manager.

Medco recognizes the excellence of Hemophilia Health Services FactorCare® program and the services we provide, including our collaborations with HTC's and physicians for the bleeding disorders community and their caregivers. Since our founding, our commitment has been, and will always be, to clinicians and their patients. We will remain an advocate of choice, education and support, while continuing to deliver the same high quality care the community and clinicians have come to expect.

**Ken Trader**  
VP Sales & Marketing,  
Hemophilia Health Services

The Lone Star Chapter applauds [Laurie Kelley's] efforts to help people with bleeding disorders understand how the hemophilia business is structured and operates.

**Debbie de la Riva**  
Executive Director, Lone Star  
Chapter of the NHF

The most recent issues of *PEN* have been invaluable educational tools in the present struggles faced by the clotting disorders community. *PEN* provides information, knowledge and empowerment, and should be mandatory reading for all who are affected.

**Donald D. Akers**  
Hemophilia Federation of  
America, New Iberia  
LOUISIANA

Ez and I are delighted with *PEN* on the subject [of reimbursement]. It's been a long time coming, and the articles have been clear, informative and beautifully balanced.

**Ziva Mann**  
MASSACHUSETTS

I'd like to know whether any lobbying is going on for the manufacturers to lower their prices. It seems that homecare companies are taking the hit in reimbursement, while the manufacturers are not. This is a topic that is not being addressed. The burden of lower reimbursement should be shared by all, not just by the homecare companies.

**Homecare company employee**  
*name withheld*

*PEN* is a great publication. The May issue was very good. You might wish to reconsider your target readership. I am a patient with severe hemophilia A. The insurance issues affect all patients and families of patients. *PEN* should reach a broader audience than just parents of children with hemophilia.

An important issue for me and many other patients is the lifetime cap. Unfortunately, NHF is slow to address this essential issue. Another issue is state legislation to enact a patient bill of rights. New Jersey has such a law. In Pennsylvania, we have just had a law passed in the House of Representatives. We used the New Jersey law as a model, and added other issues important to Pennsylvania residents. You're doing a great job of informing your readership about vital issues.

**George Levy**  
Member of the Board of Directors  
of the Delaware Valley Chapter  
PENNSYLVANIA

My company just changed insurance to Aetna and I was informed that Aetna is a PBM. I printed out "The Coming Storm" and shared it with

others in my office. There is now a big concern about people suffering from other chronic diseases or conditions.

The PBM issue is huge when it affects you. I can't use my homecare company anymore. As a result, I am taking a new job at a company that has the insurance I need for my son. I realize that this is a little radical, but the position is with a company where I would like to work.

I realize that we are like Chicken Little telling people the sky is falling; but the general public, and people with hemophilia in particular, need to be made aware of the PBM trend. After attending [Laurie Kelley's] talk about "The Coming Storm" in Seattle, and after some more research, I now understand what PBMs are, and what they will and won't do for you. They are a great money-saving opportunity for employers. I can see in the near future that they will limit not only the quantity of factor, but the quality: they will say that people with AIDS don't need the highest quality since they have already been compromised. These are potentially alarming problems.

I don't think you can say too much or give too strong a warning. The PBM presentation at my company almost made me a believer that this would be in my best interest—until I called my homecare company and was told I wouldn't be able to use their services with Aetna. I was also told that all factor would have to go through my doctor and through Aetna, and that Aetna would monitor my factor quantity. Aetna hasn't asked for infusion records, but I can see this happening soon.

The biggest problem faced by families with hemophilia is ignorance. You provide the right messages to protect us from ourselves. All factor providers should be distributing your message to their consumers.

**John Filicetti**  
WASHINGTON



I enjoyed “Taking Center Stage.” Having been involved with the community that reads and needs *PEN*, I feel that parents need to be educated about just how bad things could become, both financially and emotionally, with PBMs. As a community member who has been involved for the last 20 years—from living with this disease on a daily basis to taking up the fight on a legislative level—I feel strongly that some PBMs are intent on taking away choice of homecare companies and choice of products. Through my vast experience, I never saw the “savings” created by volume purchasing being shared with consumers. The question “How will this affect the bleeding disorder community?” is never asked. I also know that some in PBM management truly believe that co-infected people with hemophilia should be put back on monoclonal products specifically for cost containment. I was looking for a tone [in *PEN*] that would have been more critical of these entities.

**Edward M. Burke**  
**Hemophilia Advocate**

Thank you for such a great magazine! We have met some very good friends through *PEN*. Our twelve-year-old son has hemophilia. Through *PEN*, we met another family whose son was born on the same day. We live across the US from each other, but have been in contact, exchanging letters, notes and emails, for nearly eleven years. We are in Ohio and they are in California. Maybe someday we will meet!

We have several concerns in our lives now. The number one issue is insurance. At age twelve, our son has maxed out on my insurance at \$2.5 million. We now have him on my husband’s insurance for another \$2 million. We hope it can last longer this time. After that, I guess one of us will change jobs. It just doesn’t seem right to work so hard while the healthcare community is eating up our son’s insurance.

When we were close to maxing out on my insurance, our homecare company took us all out to dinner. In front of our son, the representative told us that we were almost out of insurance. We had no idea we were that close. I thought my husband and I were going to be sick! The rep told us we had several options: use my husband’s insurance; I could get a different job; or get divorced—our low income would make our son eligible for financial assistance. Our son heard all of this. How devastating! Needless to say, after switching insurance companies, we negotiated with another homecare company to get our son’s factor. The price was much better, too!

Thank you again for a wonderful publication. It has helped me many times over the years.

**Karen Bishop**  
**OHIO**

I found “Taking Center Stage” very helpful in understanding PBMs. Good information was presented. We have the insurance coverage we need for our son’s factor and supplies through Express Scripts. However, with rising insurance costs, I am concerned that this could change in the near future. I have one point of contention: we are encouraged to monitor medical costs, or how much we are charged for services provided. However, our insurance company will not supply us with information concerning how much it is charged for factor, and tells us that its contract with Express Scripts is private. When our son’s factor was billed under our basic medical plan, we received an explanation of benefits (EOB). We don’t get that now—just a statement showing the amount of our copay. I could call my husband’s employer to see what is being billed, but I don’t want to call attention to the high cost of our son’s medical care.

Recently, my husband brought home a company letter discussing the rising cost of insurance coverage, and mentioning that several employees have extraordinary medical expenses. I guess that our son falls into that category. Right now we don’t pay for our insurance coverage, but that could become a reality. My husband will retire in about eight years at age 66. I’m hoping his company doesn’t push early retirement as our son has his senior year of high school and college to finish.

Thanks so much for the wonderful work that you and the staff at *PEN* do!

**Kim Beard**  
**PENNSYLVANIA**

Thank you for always being on the forefront of issues in the hemophilia community. Your articles are always educational, thought provoking and empowering.

I would love to see more about how we, as insurance subscribers, can help make changes in the way insurance companies dictate our care. I am very concerned about the rising cost of our insurance premiums and the dwindling amount of care that we receive in exchange for these elevated premiums. How can we be more proactive? Do we have the right to demand change from our “big” corporate insurance companies?

**Janet Harty**  
**MASSACHUSETTS**

**Editor’s note:** *First, become educated about every aspect of your personal insurance and meet with your insurance company. Know the name of the product you use, and its price. Keep careful logs: how much of your cap have you*

used? Use the checklist from the November issue of PEN to guide you. Then, call your local hemophilia organization, the New England Hemophilia Association. NEHA has just formed an advocacy committee and is looking for volunteers to help advocate for insurance change at the state level.

My son Patrick is in veterinary school. When he applied to St. George's University, they offered insurance that actually covered hemophilia treatment. We were excited because Patrick was turning 25 in June, and would be discontinued from my insurance. Three weeks before Patrick's birthday, our homecare company called to say that there was a problem: the new insurance covers hemophilia but not injectables. We had already discussed this issue with the new insurance company, and were assured that with a doctor's letter of necessity, it wouldn't be a problem. Wrong!

When I called our insurance representative, she said she was upset that *she* had been given the wrong information. I spent three weeks calling everyone I could think of. I called our state representative, senators—anyone who would listen. On some days, I told our story six times and at the end of the day I was either crying or swearing! Where can a young man with hemophilia get affordable insurance for his chronic illness?

I have my insurance with our city, which finally arranged to keep Patrick on my insurance from his birthday until the turnover insurance date. The price is high. I also called our local NHF chapter, which suggested we call Patient Services, Inc. in Virginia. PSI is now helping with insurance premiums. Patrick can stay on the city's insurance for only two years. He still has more than three years left of school, so we are not out of the woods.

I'm very angry at a country that can spend so much on war and space exploration, and not enough on preserving healthcare for hardworking people who already suffer from illness. Where is everyone getting their insurance, and how are they paying for it? I'd like to know!

**Beverly Sullivan**  
MASSACHUSETTS

We have had problems with the brands of factor that require a lot of diluent and large syringes. Many times we have lost the vein part way through the infusion. We began to dread infusions. Even though Garrett was supposed to be on prophylaxis, we treated only when absolutely necessary. Our doctor suggested a low-volume brand which, when reconstituted, fits in a small syringe even though it is over 2,000 units. This has made infusions bearable again. If we had to use a large-volume brand approved by our insurance company, I'm sure it would eventually affect Garrett's view of hemophilia, as well as his health. We would be devastated!

**Susan Shawley**  
PENNSYLVANIA

In 2000 you helped match us with an adoption agency to bring a little Korean boy with hemophilia, now named Michael Paul, into our family. Our older son, Thomas Pat, now 15 and an Eagle scout, always enjoyed your books. Recently Michael Paul read your book *Joshua, Knight of the Red Snake*. He too enjoys it. Thank you for writing about hemophilia. Thanks for helping us find Michael Paul! Thanks for all you do for the hemophilia families around the world.

You do a great job keeping us informed, educated and alert. Keep up your good work!

**Tom and Kathy Kuklish**  
VIRGINIA

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