

Parent Empowerment Newsletter

Two Organizations, Two Visions

How the
NHF and HFA
Meet the Needs
of the American
Hemophilia
Community

by Denise D. Vermeulen

THE HEMOPHILIA COMMUNITY KNOWS ALL TOO WELL the challenges of managing a chronic illness. A diagnosis of hemophilia is often overwhelming — causing fear, confusion and depression. Yet many parents find that access to information and networking are key to overcoming the major obstacles that put a patient's life on hold. Personal contact and support from the hemophilia community are essential to reclaiming stability and control.

One of the first places parents turn for community support is to local and national hemophilia organizations. Your doctor may refer you to either a local hemophilia organization, or a national one—or both. You'll find educational and support programs, annual meetings, publications and websites offering knowledge that equates to power. These organizations provide a vital opportunity to network with caregivers, researchers and, most important, others with hemophilia. If you're new to hemophilia, where do you start to meet your community?

THE NATIONAL HEMOPHILIA FOUNDATION

Most parents are referred to the National Hemophilia Foundation (NHF) as a starting point. When Shari Bender learned that her daughter Rose had severe hemophilia, Rose was only nine months old. With no family history of hemophilia, and because the baby was a girl, the diagnosis was a shock. According to Bender, who lives with her family in Dix Hills, New York, only about a dozen girls in the US have hemophilia. Bender and her husband, Stephen, wasted no time seeking out information. An internet search for "hemophilia" provided their first contact with the NHF.

"When Rose was first diagnosed with hemophilia the NHF was our savior," explains Bender. "They're so responsive to the needs of the community." The Benders attended their first annual NHF meeting within months of Rose's diagnosis, gathered valuable information, and met a huge network of people. They've been attending annual meetings for the past five years.

continued on page 8

inside PEN

COVER STORY:

Two Organizations, Two Visions: How the NHF and HFA Meet the Needs of the American Hemophilia Community

- 3 As I See It: The Role of Industry
- 4 Insights: End to an Era of Giveaways?
- 6 Sharing Hope: Project SHARE™ extends a hand globally

welcome

Programs for parents of children with hemophilia abound in our community, but not all parents are aware of the many opportunities for support, aid and involvement.



In this issue of *PEN*, we present two hemophilia organizations. The National Hemophilia Foundation (NHF) is the oldest and largest in America. The Hemophilia Federation of America (HFA), created about eight years ago, is a grassroots organization. Why two national organizations? You'll see that they were formed for different reasons, and their missions differ; these differences are reflected in their programs and resource offerings. Get to know them and contact them. Find out how they can serve you. The NHF has a splendid, informative website with all kinds of information—from lobbying efforts to gene therapy to upcoming events. The HFA is ready to hear from you, and help you with insurance issues, or simply listen to your worries about raising a child with hemophilia.

Hemophilia organizations also exist on a local or state level. Some are affiliated with the NHF, the HFA, or both. Ray Makepeace, President of the Hemophilia Foundation of Minnesota and the Dakotas, offers an insightful look at potential conflict of interest and how to resolve it, from the point of view of a local chapter.

Lastly, check out *our* new program, Project SHARESM. Many of you know that I am deeply involved in working with the developing world. I visited Haiti for one week in early December, and I believe I am the first person from the international hemophilia community to visit and evaluate the situation there. It is bleak. There is no care, no factor, and a politically unstable regime, in a country about to explode with tension. The poverty is staggering. But there is hope. Through Project SHARE, we can impact the lives of children, like yours, who suffer. The message this quarter? **Get involved.** Improve your child's life, or the life of a child overseas. Visit our new website to learn more about SHARE and our other programs, and visit the NHF and HFA websites to learn more about their programs. Resources abound for us in America—take advantage of them! And after you do, think about sharing some of our bounty with those less fortunate.

PARENT EMPOWERMENT NEWSLETTER FEBRUARY 2003

<i>Editor-in-Chief</i> Laureen A. Kelley	<i>Managing Editor</i> Stephanie Allen	
<i>Contributing Editor</i> Paul Clement	<i>Editor</i> Sara P. Evangelos	<i>Layout Designer</i> Tracy Trunik
<i>General Manager</i> Pam Mosesian	<i>Administrative Assistant</i> Annie Schwechheimer	

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

PEN does not promote individual products or companies, and will use brand product names and company names pertaining only to news and education.

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68 East Main Street, Suite 102 • Georgetown, Massachusetts 01833 USA
978-352-7657 • 800-249-7977 • fax: 978-352-6254
info@kelleycom.com • www.kelleycom.com

Are you interested in submitting articles to *PEN*?

PEN is looking for medical professionals, advocates and consumers with good writing skills to submit articles. *PEN* pays \$800 for original feature articles, and \$50 for As I See It. For submission guidelines, contact us at info@kelleycom.com. *PEN* will work with authors on editing and content but cannot guarantee that submissions will be printed. Overseas authors welcome!

letters

About *PEN*, November 2002:

EXCELLENT ISSUE. I LIKED THE APPLETON FAMILY HISTORY. What and how preschoolers think was excellent.

Dr. Richard A. Lipton
LONG ISLAND JEWISH MEDICAL CENTER,
NEW HYDE PARK, NEW YORK

continued on page 5



THE ROLE OF INDUSTRY

Throughout
the decision
process, HFMD's
role is *not*
to make
recommendations
about which
products or
services
to use.

Since the Hemophilia Foundation of Minnesota and the Dakotas (HFMD) was founded over twelve years ago, and even predating this milestone, our community has had a partnership with the pharmaceutical and home health care industry ("Industry"). Key programs, such as hemophilia camps, our annual meeting, and family retreats, receive a major portion of funding from this partnership.

Not all of the funding required to meet our needs comes through Industry. We receive our contributions through member dues, voluntary donations from individuals, Community Health Charities of Minnesota, NHF, and other major fundraisers.

However, for our three major fundraising events (Annual Golf Tournament, Poinsettia Sale, Hearts of Hope Gala), Industry comes forward with assistance in planning, labor, marketing and participation. Without Industry contributions, we would not be able to conduct the growing and successful programs that we can now provide annually.

HFMD works directly for our bleeding disorders community, separate from the Industry. HFMD is protective of confidentiality. We do not share our member mailing list, names of affected individuals, or other private information with Industry. Now, this may sound like HFMD is acting as a protective 'shepherd' to the flock, while Industry, the 'wolf,' attempts to gain access by dressing in sheep's clothing.


That is not our intent. HFMD operates on behalf of the community. As a consumer, you make the ultimate decisions about which pharmaceuticals, pharmacy options, or home health care companies you use.

If you have a new family member diagnosed with a bleeding disorder, you may initially turn to your health care professional. Once a treatment plan is in place, you may then turn your attention to the long-term product coverage options.

For some families, product decisions are made with health care professionals. Others may make direct contact with a pharmaceutical or home care company. Still others may participate in our annual meeting, where patients can visit with Industry representatives.

Throughout the decision process, HFMD's role is *not* to make recommendations about which products or services to use. Our role is to assist in educating our community about the choices. As with every product or service you buy, Industry's goal is to gain your business and trust. Industry professionals I have met have a role to play for their company, and they will compete for your business. HFMD meets with Industry on a continual basis to ensure that an ethical relationship remains intact. From time to time we have conflict of interest concerns, but they are dealt with in an open manner.

Families or individuals make the final decisions about what is best for them. They can choose to access information and educational materials that offer choice. I give credit to those in the community who alter their choices to best fit their current situation.

Newer and safer products, newer and safer treatments, education and new ideas are part of the HFMD mission. These are also part of the Industry mission. I hope that our HFMD community continues to operate with this in mind. 

Adapted with permission from Veinline, the Newsletter of Hemophilia Foundation of Minnesota and the Dakotas, January 2003.

Ray Makepeace is President of the HFMD and father of three children, including one with severe von Willebrand disease. He works full-time in the Purchasing Group of Cummins Power Generation, Inc.



by Paul Clement

End to an Era of Giveaways?

Do you receive free services from your home care company? Beepers? Nursing services? Helmets and kneepads? Home care companies provide significant benefits to people with hemophilia. At a minimum, they offer prompt delivery of factor and ancillary supplies, often to your doorstep. Most home care companies also offer services such as home visits by nurses, educational materials, twenty-four hour pharmacy services, and insurance consultation. Your home care company may also provide **free** medical equipment—safety helmets, kneepads, MedicAlert® bracelets, tourniquets, cold packs, Cryo/Cuffs®, or factor carrying cases. This practice, however, may cease in the near future.

Last summer, the status quo was questioned. A home care company requested an “Advisory Opinion” from the Office of the Inspector General (OIG)* of the US Department of Health and Human Services (HHS). The home care company asked whether providing the parents of their pediatric hemophilia patients with free beepers and beeper service was a violation of the “prohibition against inducements to beneficiaries” section of the Social Security Act. In other words, is giving free beepers viewed as a way to get more business? The OIG’s response: The provision of goods or services valued at greater than \$10 per item, or totaling more than \$50 per patient per year, would be in violation.

Why? The OIG sees three problems: First, “freebies” may sway parents’ or patients’ decisions to choose the company that offers the **most free stuff**—and not necessarily the best service for their specific needs. Second, giving away free goods and services may promote **unfair competition**. Small home care companies may lack the financial padding of big companies, who have deep pockets and can afford the free goods or services.

Third, **quality of care** to patients may suffer. The race to offer valuable perks can increase the incentive to cheat on the quality of a Medicare item or service.

Does this mean that if you, a parent or patient, receive free goods or services, you are participating in something illegal? It’s not that simple. Technically, the Advisory Opinion applies only to the company that requested the opinion, and affects only beneficiaries of Medicare and certain state health care programs receiving federal funding, including Medicaid. But the home care industry is taking the Advisory Opinion as a warning that distribution of free goods and services totaling more than \$50 per year is not acceptable to the federal government.

Things are probably going to change. Since the opinion was issued on September 30, 2002, some home care companies have already begun revising their policies. One motivation for these companies is the risk of incurring **fines of up to \$10,000 per violation**, or even jail sentences. Some companies now may provide ancillary supplies and medical equipment only with a physician’s prescription and reimbursement by a

third-party insurer. It’s also likely that these home care company policy changes will affect *all* home care company hemophilia patients, not just those receiving Medicare and Medicaid.

What about items like pagers that are not reimbursed by a third-party insurer? It’s still possible for home care companies to provide ancillary supplies and medical equipment to consumers who need it. Funds—or the items themselves—could be **donated** to an independent nonprofit company that would then distribute them to families.

How will all of this affect you? **Call your home care company today**, and ask how it will interpret the OIG Advisory Opinion. Can your company recommend what to do if it can no longer provide beepers or helmets? Will loss of these items or services affect the price of your factor? Make a standby plan: contact your local hemophilia organization for assistance. There are programs in the community that offer safety equipment and beepers to families in need. The bottom line is that decisions being made at the federal level can and will affect you—so take action, call, ask questions, and get answers. 📞

* *The OIG is the investigatory and audit arm of the HHS, and works with the US Department of Justice to protect federal health care programs from waste, fraud and abuse.*

For the full text of **OIG Advisory Opinion 02-14**, visit the US Department of Health and Human Services website:
www.oig.hhs.gov/fraud/docs/advisoryopinions/2002/ao0214.pdf

ONCE AGAIN, *PEN* IS AN INTERESTING read, with lots of positives and practical articles. Our son will be interested in "College Step-by-Step."

I want to share our UK experience with factor VIII administration practice [As I See It, page 3]. For the past year, we have been encouraged to infuse using a 5 ml syringe of saline to flush out the last drop of factor VIII (Helixate® NexGen) from the butterfly tubing. It seems straightforward enough to leave a little air in the infusing syringe, allowing the syringe to be emptied down to the start of the butterfly tubing; then swap for the saline syringe, draw back to expel air, and flush through—to get that last drop out. Is there some reason that this practice is not used in the US?

Peter Robery
WEST MIDLANDS, UK

THE STORY OF THE APPLETON FAMILY was really interesting, and a little different from the material we usually publish in our newsletter. So I translated it into Finnish to publish in the Christmas issue of our society's newsletter, *Tiviste*.

Markku Toivainen
THE FINNISH HEMOPHILIA SOCIETY,
HELSINKI, FINLAND

One World: Aventis Behring Spearheads Educational Initiative to Improve Hemophilia Treatment in Developing Countries

Aventis Behring has launched "One World," a large-scale educational program to improve hemophilia treatment in the medical communities of developing countries. One World features eleven ongoing initiatives, including the following:

- 1. The Nurses Leadership Project and Aventis Behring Camp Support**
Selected nurses from developing countries receive the most current treatment information to apply at hemophilia centers with patients.
- 2. The Network Project**
A local leading physician and nurse travel to less developed, rural and remote areas of Argentina, Brazil, Mexico, Indonesia, Korea and Taiwan to educate local health practitioners and patients about the most effective treatment methods.
- 3. The Wall Library**
Aventis Behring translated and adapted several educational books for patients with hemophilia in many countries, including Turkey, Brazil, Mexico, Argentina, Taiwan, China, Korea and Indonesia. The books, displayed in an acrylic wall system, are available in selected hemophilia centers.
- 4. The Professional Skills Project**
Training program for people with hemophilia that teaches computer and language skills in preparation for employment.
- 5. The Physicians Development in Hemophilia Care Project**
Comprehensive program open to physicians from developing countries, featuring courses on the genetics of hemophilia, research methods, physical therapy, therapy in clinical settings, home therapy, and challenges in the 21st century. Participating physicians tour laboratories to gain practical, hands-on experience.

For more information on the One World program, please visit www.aventisbehring.com



At the Movies: *Forever and Ever*

by Richard Atwood

The full-length feature film *Forever and Ever* has been released on DVD. This reality-based drama portrays a mother's love and support for her son, Siu Fu, who has hemophilia and wants to be a writer. Siu Fu contracts HIV from a contaminated blood transfusion, and must come to terms with his own fate—dying of AIDS. The young writer overcomes challenges to find inspiration for the greatest work of his brief career.

Forever and Ever was written and directed by Raymond To. The film is in Cantonese and Mandarin, with subtitles in English, traditional Chinese, and simplified Chinese. The cast includes Sylvia Chang as the mother, Lee Pui Shing, and Josie Ho.

Forever and Ever, 2001. Universe, 96 minutes.

How to Order Films

Forever and Ever is available on DVD at www.bestchinashop.com/movie-chinese/forever_and_ever.html for \$22.95.

The Doe Boy, a coming-of-age drama concerning hemophilia [At the Movies, *PEN*, Nov 2002], is available from amazon.com on DVD (\$22.48 new or \$16.00 used), and on VHS (\$59.98 new or \$32.00 used).

SHARING HOPE

Project SHARESM
extends a hand
globally

by Denise D. Vermeulen

A PHOTO OF A SMALL BOY living at the other end of the earth motivates Pam Mosesian. Every day, as Pam sits at her desk, little Fellag of Algeria stares back at her with eyes that know the ache of hemophilia, and of living in an impoverished country. He touches her soul and serves as a daily reminder of her mission.



Fellag Boussad, age 14

As Director of Project SHARE (Supplying Hemophilia Aid & Relief Everywhere), Pam feels a sense of urgency about serving the hemophilia community in developing countries. Fellag was unable to walk when his uncle contacted her. Project SHARE donated the factor Fellag so desperately needed. Today, he is thriving. But there are many others like Fellag, who suffer from bleeding disorders but have little or no opportunity for treatment. They despair in a hopelessness we rarely see in the American hemophilia community.

Enter Project SHARE, the brainchild of Laurie Kelley, LA Kelley Communications President. In her work with dozens of hemo-

philia communities in developing countries, Laurie has seen the need for short-term aid.

“People with hemophilia are on the edge,” Laurie explains, “and struggling day by day.” Patients in developing countries are typically without transportation and equipment like wheelchairs and crutches. Parents frequently carry their disabled children on their backs. They lack basic medical supplies, such as syringes, tourniquets and Band-Aids®. Hemophilia patients are often malnourished and have skin diseases. The children lack school supplies and toys. Untreated bleeds are disastrous, frequently damaging joints or threatening lives.

Laurie was moved by the plight of these patients. In 1997, in partnership with Kyle Callahan, President of Hemophilia Health Services, she quietly began seeking and receiving donations of factor and medical goods. By January 2002, donations were pouring in. The fledgling volunteer effort became an officially funded program, and Laurie invited pharmaceutical companies and home care companies to help form Project SHARE. Alpha Therapeutic Corporation, Bayer Corporation, Baxter BioScience, and Hemophilia Health Services rallied to the cause. The partnership, formed in August 2001, represents the first time that pharmaceutical and



LA Kelley Communications, Inc.

Members of the Project SHARE Board of Directors at the 2002 NHF Annual Meeting in Orlando (left to right): Sally Johnson (Hemophilia Health Services), Robert Adams (Baxter BioScience), Pamela Mosesian (Director, Project SHARE), Patrick Wong (Alpha Therapeutic Corporation), Laurie Kelley (LA Kelley Communications), Bill Zabel (Bayer HealthCare)

medical supplies and toys are kept. Many pharmacies and home care companies keep a steady supply of factor coming in. But Project SHARE is also counting on major support from the hemophilia community, right here in the US. Pam's primary goal for 2003 and beyond is to establish a network of volunteers throughout the American hemophilia community, to help identify potential donors and contacts.

"The United States represents less than 4% of the world's population with hemophilia, yet we consume more than 33% of the world's supply of factor. It's time to give back," says Laurie. She adds, "It's up to us to take care of our own. We're a global family and we need to let others know they're not alone."

Surely little Fellag knows he's not alone.

How You Can Help

To volunteer or make a donation, contact Pam Mosesian at (800) 249-7977 or pam@kelleycom.com. Become part of the Project SHARE network being established throughout our nation. Visit www.kelleycom.com to learn more. Project SHARE is not a registered nonprofit organization at this time.

What We Need

- Antihemophilic factor
- Ancillary medical supplies (syringes, needles, alcohol swabs, tourniquets, Band-Aids)
- Used and new medical equipment (especially children's crutches, wheelchairs, walkers)
- Cash donations
- Funding for pallet shipments
- Toys for children of all ages (new or used, in good condition, no batteries required)
- Toiletries (small soaps, shampoo, toothpaste, tooth brushes)

"The United States represents less than 4% of the world's population with hemophilia, yet we consume more than 33% of the world's supply of factor."

home health service companies in the hemophilia community have joined together to run a program solely devoted to helping the world's poor with hemophilia. Pam, who speaks Spanish and French and has a working comprehension of German, was hired as Director. "We're dedicated to providing short-term medical relief and daily living necessities to hemophilia patients in the developing world," she says. And Pam means business.

How successful is Project SHARE? In 2001, Project SHARE donated **4.1 million units of factor** to the developing world—medicine

that would normally have been destroyed. In 2002, Project SHARE directly donated or brokered 3.57 million units to patients in 25 countries, with an estimated value of \$2 million. Two major pallet shipments, totaling 3,330 lbs. of ancillary medical supplies, clothing, computer equipment and toys, were shipped to the Dominican Republic. Smaller shipments were made to Honduras, The Bahamas, St. Vincent and Zimbabwe.

These are impressive numbers for a small, young organization. But it's the individual stories that motivate. A four-year-old in Guatemala survived a brain bleed because of Project SHARE's intervention. The mother of two boys with hemophilia living on a remote Caribbean island had no medicine and no access to a treatment center. Project SHARE was the only organization able to provide her with medical training to treat her sons, and a perpetual supply of factor.

A six-member Board of Directors oversees Project SHARE, which plans to become the central US clearinghouse for donations to people with hemophilia living in the developing world.

Other companies not on the board have also contributed: New England Biolabs donates factor shipping costs; the American Red Cross contributes funds; and Aventis Behring funds the storage facility, where wheelchairs, crutches,



NHF Programs

- **HANDI (comprehensive educational resources)**
- **Project Red Flag (women's bleeding disorders)**
- **NHF YouthWorld**
- **Nursing Working Group**
- **First Step (for families new to hemophilia)**
- **National Prevention Program (to prevent or reduce the complications of bleeding disorders)**
- **It's Time for a Cure (multi-million dollar fundraising campaign; research grants)**
- **Online Education (offering educational seminars online)**

To contact NHF

National Hemophilia Foundation
116 W. 32nd St., Floor 11
New York, NY 10001

1-800-42-HANDI

www.hemophilia.org

www.youthworld.org (for teens)

info@hemophilia.org

handi@hemophilia.org

President

Gina Shreve, Ph.D.
(mother of child with hemophilia,
Wayne State University)

Executive Director

Richard Hellner
(hired October 2002)

Two Organizations, Two Visions... continued from cover

Today, the Benders are active NHF members. Stephen serves on the NHF Board of Directors, and Shari has produced two informative videos for the organization. She has also served on a task force that developed a program to aid parents who have children newly diagnosed with hemophilia. The program, *First Step*, hopes to establish new parent groups throughout the US, and provides extensive information tailored to specific ages. The Benders are active fundraisers, personally raising \$500,000 for NHF's *It's Time for a Cure* campaign, which provides research funds toward a cure.

The \$9 million organization, which has a paid staff of 35, is headquartered in New York City. Over one hundred volunteers serve on the NHF Board of Directors, committees and working groups. An additional thousand volunteers are involved at the chapter level in 30 states. The NHF is funded through a combination of individual philanthropy and corporate sponsorships, government support, advertising revenue, and proceeds from special events.

The Hemophilia Foundation (later changed to the National Hemophilia Foundation) was founded in 1948 by Robert Lee Henry, a Long Island attorney whose son had hemophilia. He was inspired by an article he read about the suffering of a young boy with hemophilia who was not as advantaged as his own son. Henry's idea for the foundation was "to make grants and donations for research and clinical study of hemophilia, abnormal blood conditions, and similar ailments, to publish information and knowledge related to the prevention of these diseases; to provide medical scholarships, to provide funds for persons suffering from hemophilia and kindred ailments."

A CHALLENGING VISION

Henry's hope lives on in the NHF's amazing vision: to cure all bleeding disorders. According to Mark Skinner, board member and person with hemophilia, the NHF is the only American hemophilia organization dedicated to this specific vision. Its mission, reflected in all its programs and activities, is education, research and advocacy on behalf of people with bleeding disorders. The NHF is officially recognized by the World Federation of Hemophilia (WFH) as the representative organization of the American hemophilia community.¹ Skinner asserts, "No other organization comes close in reaching the level of services offered."

While dedication and sincere commitment to the hemophilia community are evident in other organizations, Skinner's remarks are easily supported. The NHF Medical and Scientific Advisory Committee (MASAC) is the preeminent hemophilia medical authority in the world. MASAC defines policies and issues statements for treatment recommendations and standards of care. Its published Advisories are sent worldwide, and the international community respects its commentaries and policies. The NHF boasts an extensive and informative website, a bimonthly magazine, an electronic newsletter (also available in print), numerous support programs [see box at left], far-reaching research endeavors, government lobbying activities, and fundraising efforts.

"The *Time for a Cure* campaign," explains Skinner, "is one of the three cornerstones of the NHF. The organization's research program provides substantial grants to investigators and laboratories around the country that are engaged in cutting-edge research into better treatments and a cure for hemophilia." Education and advocacy are the two other elements of NHF's base.

The NHF provides education through a variety of programs for a variety of audiences. For example, *On the Road* offers daylong training in prevention



Mark Skinner,
NHF board member

¹ The WFH has a policy of recognizing only one national hemophilia organization, regardless of how many exist in a country. The NHF was the first recognized hemophilia organization, and remains the largest.



Coyne family

Michael Coyne, former NHF board member, with his son Conor

education for consumers, and HTC and chapter staff. It brings the NHF to regions and families that may not be able to enjoy direct access to NHF meetings and activities. And it offers conferences on relevant issues for local communities. *Project Red Flag* is a public relations campaign to promote awareness of women suffering from bleeding disorders. An online educational system provides, among other topics, an introduction to bleeding disorders for nurses entering the field of hematology. Educational opportunities for young people are available through a website link and annual meetings.

Dr. Michael Coyne, an ER physician in Massachusetts, is a former NHF board member, and currently serves on MASAC and as Chairman of the Gene Therapy Working Group. He points out that the NHF is “doing a very good job reaching out to the community. I’m seeing parents more educated than they were years ago.” Dr. Coyne, who is the father of a child with hemophilia, is quick to note the major advantages of the NHF’s advocacy role: “The NHF serves as a voice for the hemophilia community and addresses any serious concerns we have. They’re there to advocate for us.”

COMMUNICATING WITH THE HEMOPHILIA COMMUNITY

One of the things the NHF does best is communicate. It publishes myriad educational resources for the hemophilia community. The organization’s website offers a plethora of information, including links to other sites, news updates, program information and annual meeting basics. The NHF’s main publication, *HEMAware*, targets all members of the bleeding disorders community, including patients, caregivers and health care providers. Each issue features a range of articles providing timely education and information. A new pullout section, *HEMAware Jr.*, has been added for young readers. And free to those who register online is *eNotes*, an online news bulletin with the latest information for the bleeding disorders community.

One of the most valuable NHF resources is HANDI.² Ann Rogers, Executive Director of the NHF Delaware Valley Chapter in Glenside, Pennsylvania, calls HANDI “the largest body of information in the world on bleeding disorders.” She adds, “It’s all there, and if it’s not sitting there, they’ll get it for you!” HANDI can be accessed either through the NHF website, or by calling its toll-free number (1-800-42-HANDI). The free service provides resources on bleeding disorders including books, pamphlets and fact sheets. Information specialists are available to answer questions, conduct library searches, and refer people to other agencies when necessary. Each request is tailored to meet the individual’s needs.

² The acronym HANDI stands for Hemophilia and AIDS Network for the Dissemination of Information, coined over ten years ago when the NHF was more heavily involved in HIV and AIDS education and public awareness.



Hemophilia Federation
of
America



HFA Offerings

- Helping Hands (financial crisis intervention)
- Women with Bleeding Disorders
- Dads in Action (focus on the father’s role)
- New Families Group
- Hemophilia Independence Project (fundraising campaign)
- Scholarship Funding for Annual Symposium
- Teen Connection

To contact HFA

Hemophilia Federation of America
102B Westmark Boulevard
Lafayette, LA 70506

1-800-230-9797

www.hemophiliafed.com

jhamilton@hemophiliafed.org

President

Bob Marks

(person with hemophilia,
home care company employee)

Vice President

Barbara Chang

Executive Director

Jan Hamilton

(mother of child with hemophilia)



Ann Rogers (left), Executive Director,
NHF Delaware Valley Chapter

Finally, each fall the NHF organizes the largest national meeting of the bleeding disorders community. Last year, the 54th Annual Meeting of the NHF registered nearly 2,500 people who attended a variety of educational sessions for all segments of the community. The meeting included sessions designed just for children and adolescents.

A STRATEGY TO BE HEARD

Bringing more families and attendees to annual meetings is part of a long-term strategy. The NHF sets a strategic plan every five years and, according to Dr. Coyne, does “an excellent job of defining what they should spend their time on.”

The NHF is an active and powerful lobby entity, proud of its efforts to secure passage and funding for the Ricky Ray Hemophilia Relief Fund Act.³ It claims success in obtaining Medicare coverage for clotting factor in all settings including the home, making clotting factor one of the only drugs to be eligible for home care coverage under Medicare. The NHF has garnered support for its other lobbying efforts, including an increase in federal funding for the nationwide network of hemophilia treatment centers. It is also working on increasing federal commitment to fund biomedical research, and various insurance reform initiatives.

THE FACE OF NHF

Ann Rogers has watched the NHF evolve over the last 30 years into “a bigger, broader organization.” She points to advances made in advocacy, lobbying, and training of medical professionals. But some organizations and patients feel that while the NHF is heavily involved in major issues on a national level, it does not generally touch the day-to-day lives of individuals living with hemophilia. This, believes Rogers, is where local NHF state chapters can play a vital role.

Rogers began her affiliation with the NHF as a young mother of three boys, two of whom were diagnosed with hemophilia. “I remember exactly what I was wearing and where I was standing when we received my son’s diagnosis 30 years ago.” She adds, “You can’t understand what hemophilia means until you live it.” It was her access to information, and to other families living with hemophilia, that gave her the strength and ability to carry on. She credits her local NHF chapter with providing that help.

The Delaware Valley Chapter is one of the founding chapters of the NHF. It advocates for over 1,700 hemophilia

patients in the region. “The face of the national organization—NHF—is the local chapter,” asserts Rogers. There are 43 affiliated NHF chapters in the US. Chapters pay membership fees, and are allowed to use the NHF logo and affiliation in their programs and fundraising. Yet several state groups, including the Alaska Hemophilia Association, the Puerto Rican Hemophilia Association, and Hemophilia of Iowa, have elected not to become chapters. They are independent of the NHF, and have separate policies and protocol.

“We review this question every year,” says Yolanda Vega, Executive Director of the Puerto Rican Hemophilia Association, and mother of a child with hemophilia. “But we have not been able to determine a reason to join that would benefit us directly. The NHF graciously communicates with us regularly even though we are not a chapter. We receive their publications, invitations and medical advisories. We are a small organization, and struggle economically. The membership fee is beyond our budget. At this time our board has decided not to join.”

Ann Rogers is currently part of an NHF task force seeking to find a way to develop more local chapters. She encourages the chapters that are independent of the NHF to join. “What would it take for them to come into the fold?” she asks. The banding together of a chapter from each state would, in Rogers’ opinion, serve as a powerful, united voice when the NHF heads to Washington for lobbying.

Each state organization that is independent of the NHF has its own reasons for refusing affiliation. But one organization took a major stand, not only by existing apart from the NHF, but by establishing itself as a national advocacy group.

THE HEMOPHILIA FEDERATION OF AMERICA

In the spring of 1993 in Alexandria, Virginia, a handful of people formerly affiliated with the NHF joined to form a new hemophilia organization, the Hemophilia Federation of America (HFA). Why—when a national organization and dozens of local chapters already existed?

The HFA was organized in reaction to “a perceived gap in services,” according to HFA Executive Director Jan Hamilton, mother of a child with hemophilia. The group felt the need for more one-on-one interaction with patients, and more advanced chapter development. “The chapter development issue had fallen by the wayside,” says Hamilton. The move for a new organization was also an emotional reaction—people were angry over the NHF’s handling of blood safety issues in the 1980s.

When the group set up office in Washington, D.C., its first annual budget was \$30,000. Five years later, HFA headquarters moved to Lafayette, Louisiana, where it has remained. Today, the HFA operates with a budget approaching \$1million.

The modest budget and small staff (two full-time and three part-time employees) is a far cry from that of the NHF. “We have a miniscule budget in comparison,” agrees Hamilton. The NHF, according to Mark Skinner, receives

³ The Ricky Ray Relief Fund Act secured government compensation for parties with hemophilia affected by HIV infection through factor concentrates.

about 45% of its funding from pharmaceutical companies; very little comes from home care companies. Skinner notes that the NHF is committed in its strategic plan to no reliance on industry funding for its core operations. The HFA receives about 80% of its funding from home care companies. HFA President Bob Marks also works for a home care company, but not in sales or marketing. The concern always exists over potential conflict of interest from different funding sources within each organization. Both groups have strict policies governing the way money is accepted and used.



Bob Marks, President of the HFA Board of Directors

The HFA hopes to expand its base of contributions. It has recently started to accept money from pharmaceutical companies, reversing a policy in place since the group's inception. According to HFA documents posted on its website, the organization defends this new policy, noting, "Industry is now more committed to ensuring product safety." Bob Marks adds, "The policy change came about because our world is changing. It's time to move on." The decision was an emotional one, he says, but reflects a desire to expand the organization. The HFA also garners financial support from fundraising activities, such as its *Hemophilia Independence Project (HIP)*, sponsorships, events and memorials.

Years ago, the two groups felt some animosity. Disagreement centered on policy differences regarding blood safety, and dependence on sources of funding. Today, this animosity has largely disappeared. Both organizations now agree that it is in the hemophilia community's best interest to work together, particularly on patient advocacy issues. On January 14, 2003, NHF CEO and Executive Director Richard Hellner visited Jan Hamilton in Louisiana—marking the first time the NHF has voluntarily visited the HFA in a spirit of cooperation. Hamilton was pleased with the meeting, and with the NHF's initiative.

HFA VISION AND MISSION

The HFA and NHF are different organizations, with differing infrastructures, focus, resources and, most of all, differing visions. The HFA's unofficial vision (still under review), stresses Hamilton, is "to ensure equal access to medical treatment, product, and support services, with choice belonging to the consumer." The NHF vision focuses on the very thing that would someday put it out of business—a complete cure.

Bob Marks of the HFA explains, "The HFA is a consumer-oriented advocacy group that's concerned with the issues [the hemophilia community] deals with." He continues, "First and foremost are the blood safety issues. We don't deal with them as much as we used to, but this is what brought us into existence." Marks, who describes himself as a person with hemophilia who had been "ignoring the challenges of his health," got involved with HFA at the urging of a home health care representative. He says his life has changed, and he is now

passionate about the issues facing the hemophilia community.

Other advocacy issues the HFA has been addressing include government legislative initiatives, insurance caps, and complex reimbursement concerns. Barbara Chang, HFA Vice President, has an extensive background in medical technology and global marketing of hemophilia products, and heads the HFA public relations committee. She says the HFA "is a consumer advocate, constantly fighting for the needs of the community. HFA is putting a face on hemophilia."

Iwonne Salvador is Executive Director of the Hemophilia Foundation of Southern California (HFSC) in Pasadena. She notes the HFA's strong history of advocacy for the needs of the community. "Starting with the successful grassroots fight to pass the Ricky Ray Hemophilia Relief Fund Act nearly ten years ago, they have continued advocating for blood safety and availability."

"HFA is an organization with a real heart," says Chang. "We care so much, in every which way. We've never been about being a big organization." Hamilton agrees. "We'll grow, but we'll never be as big as NHF." The HFA invites all US hemophilia organizations to join, and currently has 15 member organizations.

THE ANNUAL SYMPOSIUM

Bob Marks gets excited about the HFA's annual meeting, describing the joy he feels when he sees two parents connect and learn from each other. This year's March meeting, expected to attract 600 attendees, will be held in Houston. The focus of the HFA symposium is always on consumers. Speakers address the audience appropriately, without "talking down," and are available afterward for questions. The HFA likes to present its annual meeting as a family reunion, offering reasonable rates and free childcare. This year, a "first" for the hemophilia community: due to the event's location, it will be the first hemophilia annual meeting that is simultaneously presented in English and Spanish.

Teenagers will have a chance to gather at the meeting. *Teen Connection*, an HFA program, was designed to develop the leadership skills of teens in the hemophilia community. Participating teens help fundraise, and promote awareness of issues at various conferences. The group is developing a website and message board to connect teen members of the community.

Another way that HFA reaches out to the community is with scholarships to its annual symposium. Shannon Pennington and her family live in a remote area of Oklahoma, and have benefited from these scholarships. Pennington, whose 13-year-old son has hemophilia, explains, "Without HFA, we wouldn't have a lot of the information we have." And, she says, her family would not have been able to attend any hemophilia annual meeting. Last year, the HFA offered Pennington and her son a scholarship to attend the Cleveland symposium. This year Pennington, who is an art teacher and an alternate on the HFA Board of Directors, is helping to plan the event. She designed the 2003 Annual Meeting T-shirt, and is planning arts and crafts activities, with an art contest for the children.

NEW PROGRAMS

Recently, the HFA launched *Dads in Action*, a groundbreaking program. The idea is to help fathers understand their roles when their families are touched by hemophilia. "The percentage of dads who take a walk is very high," admits Jan Hamilton. The HFA hopes to help fathers learn to take responsibility and be better listeners.

An ambitious program is now being established to improve the education of ER staff who care for patients with hemophilia. Pennington tells horror stories of mismanagement of her son's hemophilia during ER trips. "Each one of us in the hemophilia community has had a terrible experience in the emergency room. They need to take us seriously when we say we have a bleed."

The HFA hopes to put an end to frustrating trips to the ER. Hamilton says that twelve \$10,000 grants will be issued to member organizations in heavily populated areas. Hospitals, medical and nursing schools, and others will be educated about hemophilia and why it is key to treat quickly. An educational CD is being developed for use with in-services.

The HFA is busy on other fronts, too. It is taking action based on statistics identifying 35,000 needless hysterectomies performed each year in the US. Barbara Chang heads up the "Women with Bleeding Disorders" committee that seeks to recognize and offer appropriate treatment for women, including carriers. A new families group provides networking and support to newly diagnosed members of the hemophilia community. And the HFA actively visits its chapters around the country to give presentations on various chapter development issues.

The unique program *Helping Hands* reflects the HFA's desire to reach out and personally touch the hemophilia community in crisis. The Helping Hands Fund is a "crisis management fund," explains Hamilton, that addresses daily life challenges: fixing someone's car so he can make it to the treatment center; providing funds to prevent eviction, home repossession, or utility cut-off. Hamilton says the annual budget for *Helping Hands* is \$40,000 but the HFA could use twice that amount. All requests are verified, and no one can dip into the fund for more than \$500 per twelve-month period.

All of the HFA's programs are covered regularly in its quarterly newsletter, *Dateline Federation*.

MORE CONSUMER OPTIONS

Hemophilia organizations and individuals can join either, or both, the NHF and HFA without restriction. Julie Frenkel, Assistant Executive Director of the Hemophilia Association of New Jersey (HANJ), belongs to a proactive group with a formidable reputation for its independent direction. Formerly a chapter, HANJ broke with the NHF primarily because of differences in the handling of the HIV crisis in the late 1980s, and other accountability issues. Today HANJ boasts 800 members, various programs, fundraisers, and a well-attended annual meeting. It is a member organization of the HFA.

Frenkel recommends that members of the hemophilia community carefully assess their options when considering joining an organization. She feels that if someone has access to a local chapter that is active and strong, it's best to join that group first. But, she says, consider tapping the resources of the national organizations as well. "I use [NHF's] HANDI all the time. It's the best thing out there." On the other hand, Frenkel adds, "HFA has a lot of heart. They need to get strong, active participation on the part of their members. But they really do want to hear the consumer."

Iwonne Salvador of the HFSC believes that her organization benefits from membership in both the HFA and NHF, and her Board of Directors agrees. "Both organizations have their own unique sets of strengths and weaknesses," she notes, "but both are representative and provide valuable service to our community."

Choices and responsibilities, as always, rest in the consumer's lap. Participation in one or more hemophilia organizations is likely to enhance knowledge and build a reliable network. The most important key is to get involved—it can make all the difference in the world. ☐

Denise D. Vermeulen has been a freelance writer for almost ten years. She was formerly the public relations director at two pediatric hospitals. Denise lives in Massachusetts with her husband and three children.

a new year.
a new focus.
a new way of
communicating.



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Carrier Status Fears

Q I JUST FOUND OUT THAT I AM A SYMPTOMATIC CARRIER FOR SEVERE FACTOR VIII DEFICIENCY. MY SON MICHAEL IS 11, and it took me that long to find out about my carrier status. What surprised me was the shock I felt when I got the news. The information won't change my life, but I experienced the same feelings I had when my son was diagnosed at birth. The health care provider gave me the results over the phone, quickly mentioned concerns like surgery and terms like DDAVP®, and hung up. I realized it was up to me to do the legwork—go online, consult books, do the research. I find it hard to make the effort for myself, because it's "minor" compared to my son's needs. I work full-time and have two other children, without hemophilia. After 11 years, I felt that hemophilia was in the appropriate pocket of my life—but now, I'm shaken. My dad is 65, my mom 61. They are both interested in having their factor levels checked, to see if there is a link. Is it worth it? I have three brothers, and I wonder if their children carry the gene. So far, Michael is the only diagnosed person with hemophilia in the family. My five-year-old daughter had her factor VIII levels checked, and they were fine. We'll probably have her checked for carrier status when she's older.

Cheryl Howard
MASSACHUSETTS

A I AM ALSO A CARRIER of the factor VIII gene. My physician tells me that my factor levels are fine. However, the fact that I am a carrier explains the heavy periods and numerous nosebleeds I had as a child. My mother was tested and is not a carrier, so I guess the mutation occurred in me. I can understand the guilt that a carrier feels for passing this disorder to her son. That feeling never goes, although you learn to ignore it. Learning to live with hemophilia is a process. At the beginning, it's very tough, especially when children are small and everything becomes a challenge. As they get older, and develop a routine at school, it becomes easier. Then, another challenge comes along, and once again you must come to terms with the full implications of the disorder. What amazes me about properly managed hemophilia—with no inhibitors—is that

boys today have a full life. When my son Jordan was diagnosed over ten years ago, I didn't envision him living such a normal life. I have changed a lot since the diagnosis, but his life is on track with other ten-year-olds, apart from the infusions he gets three times a week.

Linda Gallant
CALIFORNIA

A LIFE IS FAR BETTER now than we expected when my oldest (age six) was diagnosed. I was diagnosed as a carrier early; I can understand that unexpected "punch in the stomach" when you learn your carrier status later in the game. When those feelings resurface, it can be pretty dramatic. My mom was finally tested, four years after my son was born, and we learned that she wasn't a carrier. For four years, we had thought she was a carrier because of her medical history. When we learned she wasn't, I

felt much of what Cheryl describes. I felt alone and disappointed. But my mom felt let off the hook. It's been quite a journey, and I have a feeling that my family has quite a way to go.

Fill Lathrop
WISCONSIN

A I'M TO BE TESTED THIS month. I've got a scared feeling about it that makes no sense—if I'm fine with Elisha having hemophilia, why should my having the gene mutation bother me? Perhaps being a carrier makes the situation more concrete, or more personal, literally a part of me. But how much more personal can it get than my little boy? It'll be a blow, either way the results come: if I'm a carrier, I may feel more a part of Elisha's world. If I'm not, I may feel like a spectator who is fibbing when she says, "I understand."

Ziva Mann
MASSACHUSETTS

CHERYL'S REPLY

I felt that either test result would give me some inclusion or exclusion. As crazy as it sounds, I'm glad I am symptomatic. We obviously have hemophilia in our family now, and I'd rather have it begin with my genes than have my son feel that he "started" it. I don't feel guilty because I believe that all things happen for a good reason, and the reason may not be apparent at first. I had no control over my genes. Michael is such a beautiful person—I can't carry guilt because he has hemophilia. I think this disorder has made him extremely sensitive, caring and attuned to others' feelings. Yet he's so "boyish" with his basketball, karate and baseball. My bond with Michael has always been very strong, possibly due to our dealing with hemophilia together. Now, I think that he doesn't feel so singled out, knowing I have hemophilia of sorts. Finding out did make things concrete; that may be one reason that it took me 11 years to decide to get tested. I don't think a mom who says "I understand" is ever fibbing, because we live so much in our children's emotions, especially when they're young. Knowing that others have shared my feelings helps!

➔ The information provided in Parent-to-Parent should **not** be construed as medical advice. It is advice from one parent to another. Please consult your HTC for information on any medically related questions.

If you use Plasma Derived Hemophilia Products...

THE PLASMA INDUSTRY WILL NOT BE REQUIRED TO NOTIFY donors of positive **parvovirus B19** test results, according to the **Plasma Protein Therapeutics Association (PPTA)**. The decision is based on recommendations by the FDA Blood Products Advisory Committee (BPAC). PPTA representatives provided testimony and data demonstrating the lack of public health benefit from donor notification of this relatively benign condition. Donor notification would have required extensive clinical trials and FDA-licensed testing. "Given the prevalence of parvovirus B19, the current collection, testing and manufacturing infrastructures would have quickly been overwhelmed," noted a top PPTA official.

Source: International Blood/Plasma News, Dec 2002

ReFacto On the Way

WYETH PHARMACEUTICALS ANNOUNCED FDA APPROVAL of its facility in St. Louis, Missouri, to manufacture its recombinant factor VIII product, ReFacto[®]. Wyeth will manufacture ReFacto in St. Louis, ship to an existing facility in Stockholm, Sweden, for final processing, and return the product to the US for distribution to HTC's, home cares and hospitals.

Source: www.wyeth.com/news

Wyeth to Change ReFacto Labeling

WHY HAS **WYETH PHARMACEUTICALS** VOLUNTARILY changed the labeling of its ReFacto[®] recombinant factor VIII concentrate? Two reasons: occasional reports of a lack of effect, primarily in prophylaxis patients in some European and US treatment centers, and reports of high inhibitor titers in previously treated patients (PTPs). Wyeth's clinical consultants believe that the observation of high inhibitors in PTPs is not unique to ReFacto, and is not unexpected. Yet Wyeth is advising treaters to consider high titer inhibitors in PTPs as a possible cause of unexpected or prolonged bleeding in patients being treated with ReFacto. Wyeth is conducting several post-marketing studies, with some of the centers reporting this finding, to compare efficacy and product consumption in patients before and after using ReFacto.

Source: International Blood/Plasma News, Dec 2002

The US Centers for Disease Control estimates that one-fourth of the roughly 900,000 HIV-positive people in the US are not aware that they are infected.

Fresh Frozen Plasma Recalled Due to West Nile Virus

SO FAR, 13 PEOPLE HAVE BEEN IDENTIFIED WHO ACQUIRED **West Nile Virus (WNV)** from infected blood components from eight blood donors. In a joint statement, the American Association Of Blood Banks, American Red Cross and America's Blood Centers recommended a **voluntary recall** of all inventoried units (>30,000) of fresh frozen plasma in 36 states. These states experienced WNV outbreaks during the second half of 2002. Also subject to the recall are much smaller quantities of cryoprecipitate units, and frozen red blood cells collected during a "risk period" defined for each state. The risk period starts seven days prior to the first documented case, ends seven days after the last case, and ranges from 70 to 130 days for most states. This recall recommendation does not include source or recovered plasma supplied to fractionators. All major fractionators have extensively documented the effective elimination of WNV or similar viruses in their manufacturing processes.

Source: www.aabb.org

Greater Convenience: "Super-High Potency" Hemofil M[®] Now Available

BAXTER BIOSCIENCE NOW HAS A "SUPER-HIGH POTENCY" vial size of Hemofil M[®] monoclonal antibody-purified factor VIII concentrate I, in the range of 1701 and 2000 IUs per vial.

Source: www.hemophiliagalaxy.com/3_NEWS/NEWS_BRIEFS/index.html#4

Amazing news: Rapid HIV Test Approved by FDA

A NEW RAPID HIV DIAGNOSTIC test kit provides **results in as little as 20 minutes**, instead of the two days to two weeks required with standard HIV tests. The **OraQuick® Rapid HIV-1 Antibody Test** is manufactured by OraSure, of Bethlehem, Pennsylvania, and has been cleared for marketing by the FDA. Although the OraQuick test has a sensitivity of 99.6%, if it gives a reactive result, it must be confirmed with an additional HIV test.

Source: www.orasure.com



OraSure Technologies

OraQuick® Rapid HIV-1 Antibody Test

Generosity Plus: Aventis Behring Foundation Awards Second Round of Grants

THE AVENTIS BEHRING FOUNDATION FOR RESEARCH AND ADVANCEMENT of Patient Health, a nonprofit organization, has selected a second round of 2002 grant recipients in the bleeding disorders community, for a total of \$1 million in 2002 to fund a variety of educational and outreach initiatives designed to benefit the bleeding disorders community.

Nine applicants from the second grant cycle funding will receive grants for website development, education, training, outreach campaigns, winter retreats and annual programs.

Source: www.aventisbehring.com

Aventis Behring and Bayer Merger Off

THE PROPOSED MERGER OF AVENTIS BEHRING AND THE BAYER BIOLOGICAL Products Division of Bayer HealthCare has been called off. According to both companies, negotiations to create a joint venture of the two companies' global blood plasma businesses ceased because a final agreement on the terms of the transaction could not be reached.

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Please Send in Your Survey!

In late October, we mailed HTC PEN subscribers an important research survey about the changing face of hemophilia treatment and its costs. If you haven't already done so, please send your response to LA Kelley Communications today. We count on and appreciate your participation!

For an additional copy of the survey, contact Stephanie Allen at stephanie@kelleycom.com

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Inside:

The NHF and HFA:
Two Organizations, Two Visions