

The hemophilia newsletter
by the families...

and for the families.

**Inside:
The *PEN*
Hemophilia
Resource
Guide**

ADDRESS SERVICE REQUESTED



Sign up to receive **PEN!**

PEN is now available FREE either in hard copy or electronically. To receive *PEN* electronically in a PDF file, you must download Acrobat Reader (free through Adobe at www.adobe.com). The PDF file saves us postage, and arrives about two weeks before the hard copy. To receive *PEN* by mail, or request it in PDF format, please fill out this form and return it to **LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833, U.S.A.** Or subscribe online at www.kelleycom.com/order.htm.

Name _____

Street Address _____

City/State/Zip/Country _____

Daytime Phone () _____ E-mail Address _____

Name & Date of Birth of Child(ren) _____

Child(ren) with Hemophilia _____

Factor Deficiency Type & Severity _____



Check any that apply...

- patient parent medical treater
 educator hemophilia organization
 hemophilia company

I would like to receive *PEN*...

- electronically only (PDF file)
 by post only (hard copy)
 both electronically and by post

Join our Research Team...

PEN maintains a special network of parents of children with hemophilia to provide us with information for upcoming articles and projects. We want to get your ideas, opinions and experiences periodically through telephone surveys, interviews, or written questionnaires. If you'd like to be on our team, check the box below!

Do you want to join the *PEN* Research Team?

The PEN Hemophilia Resource Guide

Francis Bacon wrote, "knowledge is power." This axiom is especially true for those living with chronic bleeding disorders like hemophilia. You may be coping with the fear, anger, shock or guilt of hearing that your child has been diagnosed with a rare bleeding disorder. You may be dealing with an emergency room physician who wants to order blood tests for your already diagnosed child "to check his bleeding time." In situations like these, knowledge is a powerful tool. Knowledge reduces fear and stress, and empowers you to be your child's best advocate. In this issue of *PEN* we have gathered resources that will enrich your knowledge of bleeding disorders and arm you to be your child's best advocate—and your own!

continued on page 4



Note: Please use your consumer savvy when contacting corporations directly. Some of the publications listed here are published by the marketing departments of companies who seek your business. We have purposely omitted e-mails to avoid consumer/corporate one-to-one communication in which a company can get your personal information without your direct consent. We provide phone numbers, addresses and web addresses, which allow more discreet contact. Your personal information is valuable to all companies, and should be released only with your consent.

U.S. patients and families who want more information beyond what is represented here should call the National Hemophilia Foundation at (800) 42-HANDI.

In this issue:

The PEN Hemophilia Resource Guide	cover story
■ The Value of Reading a Good Biography	4
■ Scholarships for People With Hemophilia	6
■ Parent-To-Parent	16
■ Meet the Staff	18

From the Editor

"Knowledge is power" is a frequently used expression that encourages people to read, inform themselves, and improve their lives. I'd like to take it one step further: *Applied* knowledge is power. The world is full of well-educated people, but it is also the less educated who redirect their lives and make surprising changes. Why? They have combined knowledge with *action*; they have created the kind of power that causes deep change in their personal lives, that gives them the strength to change their destinies.



I don't mean to sound like an infomercial, but I've seen some parents and patients who lament their lot in life, or who still don't know how to make decisions about treatment and child-rearing—simply because they fail to take action. They want a book, but they don't call. They get a free book, but they don't read it. They read it, but they don't apply the suggestions in it.

In this issue of *PEN*, we give you lots of ways to educate yourself and take action. Here are the best resources in our community, with contact information, most free of charge. You'll find resources addressing every method of learning: audio, video, CD ROM, books, storybooks, comic books, and interactive books. And more publications keep coming.

But all these resources won't help if they sit on shelves or in warehouses! What are you waiting for? Hemophilia organizations and chapters: Order in bulk for family gatherings, camps and annual meetings. Hematologists and nurses: Order copies for your waiting rooms, and urge your patients to sign up to receive regular publications. Parents and patients: Call the listed numbers today, and sign up for your free copies. Read everything you can, and apply what you learn. Only then will you know that knowledge is really power! ♦

To the Editor

AVANCES and our readers benefit so much from the information in *PEN*. Kevin Kelley's articles on gene therapy [*PEN*, Feb. 2002] were so thorough that there was no point in attempting to "reinvent" the information. We just reprinted the articles. Thank you again for your collaboration.

Eunice Hereditia, Editor, Avances

Mr. Kelley's article, "Risk-Benefit Considerations Far Different in the Developing World" [*PEN*, Feb. 2002], makes me wonder whether it is a good idea to have the big pharmaceutical companies controlling the most promising gene therapy research and technology. I suspect these companies have a vested interest in going as slowly as possible [in order to recoup their investments in research and manufacturing facilities for factor products], and may have a conflict of interest that could be challenged in the international court. Allowing limited use of intramuscular AAV for factor IX in the Third World would go a long way to allaying my suspicions.

D.O. Lewis, Missouri Farm, Toledo, Belize, Central America

Thank you for sending me *Factor Fun!* It is another great help to our children.

Maria de Lourdes Fonseca, Vice-President, Associação Portuguesa Dos Hemofílicos

Your very valuable magazines and information are excellent for us. I congratulate you on your superior publications and the work you do.

Germán Osorio R., Chile

continued on page 19

LA Kelley Communications

68 East Main Street, Suite 102
Georgetown, Massachusetts 01833
United States of America
Tel: 978-352-7657 • 800-249-7977
Fax: 978-352-6254
info@kelleycom.com • www.kelleycom.com

Editor-in-Chief: Laureen A. Kelley
Managing Editor: Paul Clement
Copy Editor: Sara P. Evangelos
Layout Designer: Tracy Brody
General Manager: Pam Thayer

PEN is a newsletter for families affected by hemophilia 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.

All names, addresses, phone numbers and letters are confidential and are seen only by the *PEN* editorial staff. *PEN* publishes information only with written consent. **Full names will be used unless otherwise specified.** *PEN* is privately sponsored; the sponsor has no rights to production, content or distribution, and no access to files. The views expressed by various contributors to *PEN* do not necessarily reflect those of the editor. *PEN* is in no way a substitute for medical care. Parents who question a particular symptom or treatment should contact a qualified medical specialist.

Articles may be reprinted from *PEN* without permission with proper citation only. *Citation must include LA Kelley Communications, Inc. company name and address.*

FUNDING PROVIDED BY GENEROUS GRANTS
FROM OUR CORPORATE SPONSORS
(SEE PAGE 19)

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 \$500 for original feature articles, and \$50 for As I See It. For submission guidelines, contact Paul Clement at peclem@earthlink.net. *PEN* will work with authors on editing and content but cannot guarantee that submissions will be printed. Overseas authors welcome!

To the Editor

continued from page 2

I did a quick review of *PEN* online. When I got to the story about the adoption of Michael Paul ["Adopting a Child with Hemophilia," *PEN*, Feb. 2002], I stopped to read it. What a beautiful story—the tears are flowing. Thanks for bringing it to us, and for helping facilitate this child's adoption.

Renée Paper R.N., CCRN, Executive Director, Hemophilia Foundation of Nevada

I have never forgotten the heart-touching *PEN* article about Miraslav and his need for medical treatment ["Adopting a Child With Hemophilia," *PEN*, May 1997]. We are the parents of a ten-year old son with severe type A hemophilia, and know the importance of medical treatment and pain management.

I have often thought about Miraslav, and wondered how many other children have little hope of being adopted because of special medical needs, and the costs involved in raising a child with hemophilia. I was once again captivated by the recent article about adoption [*PEN*, Feb. 2002]. This time I decided to do something about it.

Parent-to-Parent

continued from page 16

potentially difficult birth. Every mother, pregnancy, delivery and newborn are so different, and offer so many potential variables that it's impossible to impose "absolutes." My son Sam was born vaginally, took 36 hours of difficult labor, and didn't suffer a bit. When we had him circumcised we found out he had hemophilia. He was delivered in a small rural hospital where no one would have known much about delivering a child with a bleeding disorder, but we had a good pediatrician, so Sam was diagnosed with no complications.

We knew our second son, Nat, was a boy. We operated on the assumption that he had hemophilia, and delivered via C-section after 18 hours of fairly normal labor that failed to progress. Nat was delivered by a perinatologist, an obstetrician specializing in high-risk pregnancies. We tested the cord blood, which showed that Nat had hemophilia, but everything seemed fine. Later, however, Nat developed a serious subgaleal hematoma (under

My husband and I have three children. We are curious about adopting a child with hemophilia, and want to gather some information. Are there children in the U.S. in need of adoption? Are there international children in need of adoption? What are the immigration laws governing international adoption? What costs are associated with adopting a child with hemophilia? How does one begin the process?

Accurate information is necessary to make good decisions. I would be grateful for any information as we contemplate whether this would be a good choice for our family.

Nancy Petron, Georgia ♦

Editor's note: The staff of Kelley Communications has contacted Nancy and provided her with some preliminary information. We would like to help other families interested in adopting children with hemophilia. Contact us at info@kelleycom.com.

the skin between skin and skull, rather than intracranial). We infused Nat for the first time at 18 hours old, with Sam's factor. Looking back, I don't think we could have done anything differently, as I would not have infused him immediately following birth.

When I delivered my second child, we had an experienced obstetrician and delivered in a much larger hospital, with the guidance of our HTC—and we still faced trouble. That proved to us that each experience is unique. Research puts the risk of intracranial hemorrhage between 1 and 5%, which is very low. If a parent or physician is worried about ICH, I assume the physician would insist on amniocentesis and a C-section. I can't imagine a physician putting a child at risk (and risking a lawsuit) if medicine is available and not used, but I would be surprised to hear that a physician would infuse factor before knowing that a child had hemophilia. ♦

PEN gratefully acknowledges our corporate sponsors...



888-GENTIVA
888-436-8482
www.gentiva.com



Biological Products

800-288-8370
www.bayer.com

International postage by

Baxter



800-423-2862
www.hemophiliagalaxy.com
Baxter's website for hemophilia families



**GENETICS INSTITUTE
HEMOPHILIA GROUP**
PROVIDING RECOMBINANT
PEACE OF MIND

617-876-1170
product inquiries: 888-999-2349
www.hemophiliavillage.com
e-mail: info@genetics.com

NuFACTOR

At home with your care, at home in your community™

800-323-6832
www.nufactor.com

meet the Staff

LA Kelley Communications has recently undergone some exciting changes. We've incorporated, moved to new offices in Georgetown, and hired three new employees. And we've developed dynamic programs, based on what our readers, friends and colleagues request. Why the big changes? Primarily, our incorporation reflects the need to become a legal entity, due to the large amounts of factor we donate each year to the developing world. Last year, we shipped **4.5 million units** of donated factor to impoverished and suffering patients in 17 countries. To continue this high level of humanitarian aid, we have hired more staff, implemented new policies, and legally incorporated. It's been a challenging task, and we appreciate the patience shown by many of you as we settle in. We hope to provide an even higher level of service, both to American families and companies, and to those in dire need overseas.

Please contact us and continue to share your feedback and concerns. We invite you to meet our newest members—please come visit us when you are in the Boston area!



Vice President

Roann Karns grew up in central New Jersey, and earned a bachelor's degree in International Studies from The American University in Washington, D.C. Roann focused on event management and marketing while working for Brown Brothers Harriman, America's oldest private bank, and Inc. Magazine. At LA Kelley Communications, Roann applies her organizational skills to marketing; managing publications, information systems and office operations; overseeing the Eric Dostie Memorial Scholarship, and supervising the many activities and programs of L.I.G.H.T. She works closely with Laurie Kelley to grow and develop new and existing programs for the company.

Roann lives in Newburyport, Massachusetts with her husband Pete, a Senior Product Manager for an e-business software company, and their daughter Abby. Contact Roann at Roann@kelleycom.com.



General Manager and Director, Project SHARE

Pam Thayer grew up in Hampton, New Hampshire, and received her bachelor's degree in political science from the University of New Hampshire. She also studied Spanish, French and German while at UNH. After college, she worked for six years as an international sales coordinator. As Director of Project SHARE, Pam collects donated factor concentrate, medicine, medical supplies, and non-medical goods such as toys and clothing for the hemophilia community in the developing world. She is also responsible for accounting at LA Kelley Communications.

Pam enjoys reading, and Mexican dining. She is an avid movie aficionado. She lives in Newburyport, Massachusetts with her fiancé, Jerry. Contact Pam at Pam@kelleycom.com.



Executive Assistant

Karen Guadiso grew up in Peabody, Massachusetts. Before joining LA Kelley Communications, Karen worked as Administrative Assistant for a scientific staffing firm. Karen uses her skills to maintain correspondence with our clients, patients, and publication and newsletter sponsors. She also updates our extensive mailing list, fulfills publication requests, and manages all travel and delivery arrangements. Karen is proud of being part of a team that helps benefit patients around the world in need of medical, educational and emotional support.

Karen lives Peabody, where she enjoys reading, writing and spending time with her fiancé, John, and his daughter, Hannah. Contact Karen at Karen@kelleycom.com.

The PEN Hemophilia Resource Guide

continued from page 14

Home Infusion Kits

Information and supplies parents need to begin infusing their children at home; step-by-step infusion guide, a puppet, and coupons.

Self-Infusion Kit

Detailed, step-by-step guide providing photos and materials to make self-infusion easier for children.

The Zack Pack

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

The Value of Reading a Good Biography



by Richard J. Atwood

Reading is one of the most pleasurable pastimes imaginable. Reading stimulates your mind, expands your knowledge, and engages your imagination. Reading allows you to share your thoughts and ideas with others through discussion. Reading can also be a form of therapy, especially if you have hemophilia or know someone who does.

As therapy, reading the life histories of those with hemophilia is extremely rewarding; it's another way to learn about hemophilia. Even if we cannot have face-to-face contact with someone more experienced, we can read a biography as a way to learn.

Hemophilia biographies are a fairly recent, but steadily growing, phenomenon. What began with a single biography published in the 1970s grew to four publications in the 1980s, and nine in the 1990s. Story forms include biography, autobiography, poetry, plays, prose—something for everyone! These publications are of good quality; both a play, *The Yellow Boat* (1993), and a book of poems, *The Hemophiliac's Motorcycle* (1993), won national awards. Two biographies were made into movies: *Go Toward the Light* (1992) and *The Ryan White Story* (1988). Most hemophilia biographies are available and affordable in softcover, and many are easily obtained through used editions, libraries, or borrowing.

Hemophilia biographies tell the stories of children and adults. We may even know these people personally, since ours is a small community. From the early 1900s to the present; in America, England, Canada, and Australia; from novice writers and family members to professional writers—these biographies document the time periods of hemophilia, the players, and the places.

Hemophilia biographies are enjoyable, well organized and clearly presented. Most authors include photographs. While some are written as a form of therapy for the biographer, to release the intense emotions of enduring hemophilia or losing a loved one, they can also elicit a strong emotional reaction in you, the reader: the stories can be heart-wrenching. You may read these biographies to gain motivation for political or social action. Or you may read them simply to appreciate the sometimes tragic histories of those who lived with hemophilia, or the enduring spirits of those who suffered and survived.

I hope that this list can be expanded in the future, with additional hemophilia biographies to benefit everyone: those now living with hemophilia, those in need of support, and those yet to be born.

Biographies by Parents

Journey. Robert Massie and Suzanne Massie. 1975. New York, Alfred A. Knopf. 417 pp.

This extremely well written and engaging story covers the impact hemophilia had on a young family in the 1950s and '60s. The diagnosis spurred both parents to become renowned writers, and act to improve care for all patients. This is the biography to which others are compared, especially for its presentation of the historical background of treatment.

Mark. Jay Hoyle. 1988. South Bend, Langford Books. 280 pp.

The story of a Swansea, Massachusetts family's struggle to keep their young son Mark in school and embraced as an AIDS victim in their hometown.

Go Toward the Light. Chris Oyler with Laurie Beckland and Beth Polson. 1988. New York, Harper & Row Publishers. 246 pp.

The touching story of a mother's difficulty dealing with her hemophilic son's impending death from AIDS. This biography was made into a movie in 1992.

continued on page 15

Books



Living with Haemophilia

Jones, Peter, MD. 5th ed. available May 2002. 374 pp. Oxford University Press, 200 Madison Ave., New York, NY 10016. (800) 451-7556. Approximately \$45.00 (\$26 softcover) plus shipping and handling. Also available from the WFH, 1425 René Lévesque Boulevard West, Suite 1010, Montreal, Quebec, H3G 1T7, Canada. (514) 875-7944. \$23.00 plus shipping and handling.

In-depth and informative book written by an internationally renowned pediatric hematologist with extensive experience. Covers many aspects of hemophilia, and general anatomy and physiology. Reference manual for health care practitioners, excellent guide for parents.



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. (978) 352-7657. www.kelleycom.com. Free.

Comprehensive softcover book that uniquely weaves practical information about hemophilia with actual stories from more than 150 parents. The only book about hemophilia containing practical, everyday medical, child development and consumer information written by a parent of a child with hemophilia.

How Children Understand Hemophilia: From Preschool to Adolescence

Kelley, Lauren A. 2nd ed. available November 2002. 152 pp. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833. (978) 352-7657. www.kelleycom.com. Free.

How do children understand hemophilia, genetics or prophylaxis, and what is the best way to teach them? Interviews with 100 children with hemophilia reveal what children are likely to think at different developmental stages. Includes quotations from children, and "do" and "don't" lists to help parents and clinicians more effectively explain hemophilia to children. Appendices show how to conduct your own interview with your child, and include the questionnaire used during interviews.



Diseases and People: Hemophilia

Willett, Edward. 2001. 128 pp. Enslow Publishers, Inc. 40 Industrial Road, Box 398, Berkeley Heights, NJ 07922. www.enslow.com/index.html. \$20.95.

An informative hardcover book for children and young adults that presents a good overview of hemophilia. This easy-to-read book is a good resource for teachers, babysitters, and others who care for people with hemophilia.

Binders



Haemophilia in Pictures

World Federation of Hemophilia. 1998. WFH, 1425 René Lévesque Boulevard West, Suite 1010, Montreal, Quebec, H3G 1T7, Canada. (514) 875-7944. www.wfh.org. \$35.00 (plus shipping and handling) for WFH members, \$50.00 U.S. for non-members.

Pictorial guide to hemophilia designed to teach health care workers, parents and people with hemophilia. More than 30 illustrations with easy-to-understand captions. Useful for teaching people with a low literacy level. Illustrations and text reflect the multicultural diversity of the global hemophilia community. Includes teaching notes. Illustrations by Doug Knutson, father of a child with hemophilia.



The Hemophilia Handbook

1998. 300 pp. Hemophilia of Georgia Inc., 8800 Roswell Road, Suite 170, Atlanta, GA 30350-1844. (770) 518-8272. www.hog.org. Approximately \$22.00 plus shipping and handling. Free to Georgia residents.

In-depth, richly diagrammed document, covering questions parents ask when they first learn their child has hemophilia. Large print for easy reading. Written primarily for parents by a social worker, with assistance from medical personnel. Spiral-bound.

All About Hemophilia: A Guide for Families

2001. 300 pp. Canadian Hemophilia Society, 625 President Kennedy Boulevard, Suite 1210, Montreal, Quebec H3A 1K2, Canada. Free to Canadian families through Canadian hemophilia treatment centers. www.hemophilia.ca/en/13.html



Bulletin Board

Name Changes

American Home Products Corporation, the pharmaceutical company that owns Wyeth/Genetics Institute (makers of Refacto® and BeneFIX®), has changed its name to Wyeth. Known for 76 years as American Home Products, Wyeth is streamlining and unifying the branding of its operating subsidiaries.

"Over the years, we have evolved from a holding company with diversified businesses to a world leader in research-based pharmaceutical products," said Robert Essner, Wyeth's President and Chief Executive Officer. "The Wyeth name, with its long and well-respected association with the health care community, better conveys the skills of our people, the promise of our science, the quality of our products and our position as a world leader in the pharmaceutical industry." Other name changes at Wyeth include Wyeth-Ayerst Laboratories, which will now be known as Wyeth Pharmaceuticals, and Wyeth-Ayerst Research, now known as Wyeth Research.

Source: www.wyeth.com/news/index.asp

Aventis Behring to join Bayer

Bayer AG and Aventis signed a non-binding letter of intent to establish a joint venture for biological products. The companies plan to combine Bayer's Biological Products Business Group with the Aventis subsidiary Aventis Behring. Bayer will own a majority interest, with operational control. Included are the marketing rights to factor VIII products that will continue to be manufactured by Bayer using genetic engineering techniques: Kogenate® FS, KOGENATE® Bayer and Helixate® FS/Nexgen®. The implementation of this plan will follow the negotiation of a final agreement, and approval by the company boards and regulatory authorities.

Source: www.bayerbiologicals.com

Factor supply continues to improve

The worldwide recombinant factor shortage continues to ease. The Plasma Protein Therapeutics Association (PPTA) recently reported that the Ratio of Inventory to Distribution for recombinant factor VIII in the U.S. is almost four times higher than this time last year—a sign that rFVIII supplies are returning to normal. Supplies of recombinant factor VIII products are expected to continue to increase as Bayer releases additional lots of Kogenate® FS, and Wyeth/GI begins releasing Refacto® from its U.S. manufacturing facility.

Source: www.plasmatherapeutics.org/ppta_worldwide/index.htm

RECOMBINATE rAHF **NOT** involved in HIV seroconversion

In January, an adult with hemophilia in western Canada, who used RECOMBINATE™ rAHF produced by Baxter BioScience, tested positive for HIV. Reports of this seroconversion continue to cause alarm.

All information points to other risk factors, and not the use of factor concentrates, as the cause of the seroconversion. The patient admitted to high-risk behaviors (unprotected sex), which put him at risk for HIV.

All five lots of RECOMBINATE™ rAHF used by this patient over the past two years have passed more than 400 quality assurance tests. At the request of the Canadian Hemophilia Society and the National Hemophilia Foundation, Baxter BioScience conducted additional non-routine tests on the retention samples from each of the five lots. **Highly sensitive PCR tests, which can detect viral DNA, were negative for HIV on all samples.**

According to Dr. Bruce Ritchie, Chairperson, Association of Hemophilia Clinic Directors of Canada, and David Page, Canadian Hemophilia Society, Blood Safety Coordinator: "This seems to be the first case of a hemophiliac, who happens to be using a recombinant factor concentrate, being diagnosed with HIV. It represents a good opportunity to remind people... that other behaviors, and not the use of factor concentrates, still put a person at risk for HIV."

For more information, visit www.hemophiliagalaxy.com

New program teaches children about hemophilia

Wyeth/Genetics Institute recently introduced the Puppets as Teachers in Hemophilia (PATH) program. Health care professionals use a custom-made PATH puppet to teach children with hemophilia about their disorder. The Hemophilia Training Puppet was developed in conjunction with Patient Puppets, Inc., Winnipeg, Manitoba, Canada.

The PATH puppet allows children to see many of the conditions associated with hemophilia, such as a hematoma, a healthy knee joint, and a bleeding joint. To teach about hemophilia treatment, the puppet has an implantable venous access, an external catheter and a prominent vein.

Initially, a limited supply of hand-sewn PATH puppets, and accompanying educational materials, will be provided to HTC's by the manufacturer.

Source: *Wyeth news release*





Parent-To-Parent

Online correspondence reprinted with permission of contributors, through the International Hemophilia Club (IHC) hemophilia e-group at <http://groups.yahoo.com/group/hemophilia> or www.geocities.com/hemophiliacub

Q Would you want to know if your child has hemophilia before he is born?

Michelle Bloodworth, Illinois

People have strong feelings and varied opinions about testing. We wanted to know, and that probably had to do with my brother's experience. My brother is profoundly mentally retarded because doctors didn't know he had hemophilia at birth, and delivered an 11-pound baby with forceps. This has made me anxious about something going wrong, so we wanted to have the right birth plan. And I wanted to know ahead of time so I could finish any grieving I needed to do about hemophilia—long before the birth. When my sons were born, we were prepared. We had gotten over the news, so there was only joy at their births. Although our twins were ten weeks early and the birth was pretty scary, we knew about the hemophilia, and that helped us make many crucial decisions fast. Information is power!

Stacey Rainer, Illinois

I don't think I would have genetic testing done on the baby. My sister is pregnant, and having a sonogram to determine the baby's sex. If it's a boy, she will deliver with the assumption that he has hemophilia, with all necessary precautions taken. Cord blood will be drawn and tested at birth; she is delivering in a small hospital where they can't run factor levels, so it will have to be sent out. My doctor thinks that if they can't get results within two hours, the baby should be infused regardless. The issue is getting the hospital to have factor on hand.

Our doctor advocates infusing at birth because 4% of all babies are born with ICH (intracranial hemorrhage), or brain bleeds. The bleeds are tiny, and will resolve themselves almost immediately in babies with normal factor levels. However, if our boys had fallen into that 4%, it could have caused brain damage or death. For that reason, our doctor chooses to infuse any baby born with hemophilia at birth. Our HTC is involved in a study to determine if this has any negative effect on the appearance of inhibitors later in the lives of children infused at birth.

Femke Meijer, Netherlands

When I was pregnant with my second child, I already knew that I'm a carrier because we had done the testing. We had an ultrasound, and it was a boy. We decided to deliver as if he had hemophilia. But I didn't want to deliver in the HTC since I knew that would mean a Cesarean (not because of the hematologist—the gynecologists here prefer that). So I delivered in a hospital where they couldn't check factor, but we brought enough of our own factor, just in case. A pediatrician checked the baby and declared him fine. Ten days later, we had him tested in our own HTC. Our son turned out to have beautifully clotting blood.

Andrea Scarano, Maryland

We didn't infuse at birth, although we knew Chase was a boy, and that I was a carrier because my father has hemophilia. We had factor on hand at the hospital for either of us after delivery—for Chase in case he needed it from birth trauma, and for me in case I hemorrhaged. I think automatically infusing at birth is unnecessary; with the risk of inhibitors, there is no real reason to do it. Chase wasn't circumcised because we were suspicious, and weren't going to have it done anyway.

Kathy Mackay, Georgia

Although we didn't know the first time, I would want to know the sex of my baby before birth. If it was a boy, I would go the step further and find out if he had hemophilia. Everyone could be prepared, and surprises related to hemophilia could be minimized.

We didn't find out about our son Ian's hemophilia until he was nine months old. We were all extremely fortunate that nothing happened to him during his birth. The risk of a brain bleed is real; knowing that most medical staff are uneducated about hemophilia, I believe that knowing ahead of time, and having factor available during the birth, are important safety issues.

I would make certain that my obstetrician and staff thoroughly understand the complications and symptoms of intracranial bleeding. If I knew beforehand that my baby had hemophilia, I would want him infused at birth, and his factor level checked immediately. I could make any other decisions once that information was available.

Tabatha Mayhan, Illinois

Fortunately, we found out that Jesse had hemophilia before he was born. The only positive way to test beforehand is through amniocentesis. I know that the word itself scares people, but it really wasn't bad. It was done at the hospital with my own doctors, and performed under an ultrasound. Things have really changed over the years. I got the results four months before Jesse was born, so we were all prepared for the birth, which was a scheduled C-section.

Jill Lathrop, Wisconsin

I had a first child, Sam, with hemophilia, and a second child on the way who we knew was a boy. I can understand the considerations that go into planning for a

continued on page 19

A three-ring-bound informational guide with twelve chapters on genetics, therapy, home infusion, complications, staying healthy, and the future of care. Includes resource section, glossary and self-test. Expertly written and diagrammed, with user-friendly layout and terminology.

Workbook



Basic Concepts of Hemophilia: A Self-Study and Planning Workbook for Families with a New Diagnosis of Hemophilia

Butler, Regina; Crudder, Sally O.; Riske, Brenda; Toal, Susan. 2001. 248 pp. Centers for Disease Control and Prevention. www.cdc.gov. Free.

This large-format (8.5" x11") workbook is designed to give parents of children with hemophilia, and adolescents and young adults with hemophilia, an understanding of the basics of hemophilia. Intended for use as part of an educational program with hemophilia treatment center staff. Contact your local HTC, the NHF or the CDC for a copy.

Booklets



Go For It

Jones, Peter, MD; Buzzard, Brenda, MCSP; and Heijnen, Lily, MD. 1998. 72 pp. WFH, 1425 René Lévesque Boulevard West, Suite 1010, Montreal, Quebec, H3G 1T7, Canada. (514) 875-7944. \$10.00. www.whf.org. Free to members.

Pocket-size, colorful, attractively designed booklet that appeals to coaches, teachers, parents and teens. Discusses sports and physical activities, emphasizing that people with hemophilia can participate in a wide variety of activities to improve quality of life. Section on first aid, glossary.

Your Child's Hemophilia Series

Aventis Behring. 2001. Call AB Choice Member Support Center. (888) 508-6978.

This three-part series helps parents learn what to expect during different phases of their child's development. Titles include *Your Child's Hemophilia: What to Expect During Infancy*, *Your Child's Hemophilia: What to Expect During the School Age Years*, and *Hemophilia: The Young Adult Years*.



Dental Care Series

Aventis Behring. 2001. Call AB Choice Member Support Center. (888) 508-6978.

This four-part series discusses dental care for those with bleeding disorders; primarily people and families affected by hemophilia A, hemophilia B and VWD. Titles include *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*, and *Dental Care for Adults with Bleeding Disorders*.

Understanding Hemophilia A: A Guide for Parents and Young Adults

Aventis Behring. 2001. Call AB Choice Member Support Center. (888) 508-6978.

Provides parents and young adults affected by hemophilia A with an overview of the history, science and treatment of this bleeding disorder.

A Family Guide to Hemophilia B

Aventis Behring. 2001. Call AB Choice Member Support Center. (888) 508-6978.

Provides families with an overview of the history, science and treatment of hemophilia B.



Don't Be Victimized by Hemophilia

Kelley, Laureen A. 1994. 23 pp. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833. (978) 352-7657. www.kelleycom.com. Or Alpha Therapeutic Corporation, 5555 Valley Boulevard, Los Angeles, CA 90032. Free.

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

continued on page 10

Scholarships

for People

PEN 2002 Annual Review

The following scholarships are available only to U.S. citizens. *PEN* encourages readers to contact their local or national hemophilia organizations for scholarship opportunities outside the U.S. This list was created in 1996 by LA Kelley Communications, Inc., and is updated annually. If you are interested in a scholarship, contact the sponsoring organization early, since submission dates, restrictions and awards may change. This list is also available on our website at www.kelleycom.com and may be reproduced in Chapter newsletters and websites with proper citation only, which must include "© LA Kelley Communications, Inc."

Scholarships
Amount
Candidate
Deadline
Contact
Amount
Candidate
Deadline
Contact
Amount
Candidate
Deadline

American Red Cross Hemophilia Education Fund

Three one-year scholarships of up to \$5,000 each: two scholarships awarded to students receiving treatment, and one scholarship awarded to a child of a parent receiving treatment.

High school senior or graduate, or student already enrolled in full-time college. Must be either receiving treatment for hemophilia, or the child of parents who are receiving treatment. Student must be enrolled full-time no later than fall 2003 at an accredited two- or four-year college or vocational school.

January 17, 2003

Hemophilia Education Fund
Citizens' Scholarship Foundation of America, Inc.
1505 Riverview Road
PO Box 297
St. Peter, MN 56082
(507) 931-1682
www.csfa.org

Arthur B. Kane Memorial Scholarship

At least four scholarships per year of up to \$25,000 each

Aventis Behring Choice member with confirmed diagnosis of hemophilia or VWD. Students who are accepted to, applying to, or currently enrolled at an accredited two- or four-year college, university, or vocational/technical school in the U.S.

April 1

Contact

Aventis Behring Choice
Member Support Center
(888) 508-6978

Amount

Avances Educational Fund

Total of \$5,000 in amounts of \$500 and \$1,000

Candidate

Latino person with hemophilia or other bleeding disorder, and family members, living in the U.S. and its territories. Includes high school seniors accepted at a college or university, and students currently enrolled, or planning to enroll, in a college or university or vocational/trade school.

Deadline

August 30

Contact

Apex Therapeutic Care, Inc.
1731 East Mountain St.
Pasadena, CA 91104
(626) 791-1506

Amount Candidate

Bill McAdam Scholarship Fund

\$2,000

Person with hemophilia, VWD or other bleeding disorder, or spouse, partner, child or sibling planning to attend an accredited college or university or certified training program.

Deadline

May 15

Contact

Kathy McAdam Scholarship Fund
22226 Doxtator
Dearborn, MI 48128
(734) 563-0515

Amount

Calvin Dawson Memorial Scholarship

Up to \$1,000

Biographies by Parents (continued)

Blood Brothers: Ryan, Chris, and Hemophilia. Nancy Shaw. 1989. Wilson, NC, Star Books. 109 pp.

A mother documents with deep love the story of her young son, Ryan, who had hemophilia and asplenia syndrome, a congenital heart condition from which he died at an early age. Her nephew, Chris Wright, also had hemophilia and died from AIDS. Chris's mother channeled her depression by crusading for hemophilia and AIDS.

April Fool's Day: A Modern Love Story. Bryce Courtenay. 1993. Australia, William Heineman. 666 pp.

This book fulfills the last wish of Damon, of Sydney, Australia, who had hemophilia A and AIDS. Damon asked that his story about living with AIDS and hemophilia be told by his father, a fiction writer.

The Yellow Boat. David Saar. 1997. New Orleans, Anchorage Press. 78 pp.

Benjamin Saar of Arizona had hemophilia and AIDS, which isolated him socially. He expressed himself through drawing. His father, a playwright, wrote this play in 1993 for teenagers. It received the American Alliance for Theater and Education Distinguished Play Award.

Beloved Warrior: Hemophilia and Other Battles. Virginia Nyman Arver. 1997. Privately published. 303 pp.

David Bruce Arver's mother wrote and published this journal of extended family life as therapy following the death of her son with hemophilia, from complications related to cancer.

Weeding Out the Tears: A Mother's Story of Love, Loss and Renewal. Jeanne White with Susan Dworkin. 1997. New York, Avon Books. 225 pp.

Ryan White's mother, Jeanne Hale, documents her role as mother and advocate in her son's ongoing battle against ignorance about AIDS. She describes her grief, and her continuing efforts to improve treatment and compensation for those suffering with AIDS.

Cry Bloody Murder: A Tale of Tainted Blood. Elaine DePrince. 1997. New York, Random House. 210 pp.

The story of a mother who loses three sons to AIDS, and turns her grief into activism for the AIDS community.

Biographies by Partners of People With Hemophilia

Julian Wintle: A Memoir. Anne Francis. 1984. England, Dukeswood. 138 pp.

The struggles related to hemophilia B in England from the 1960s through 1980s. Francis Julian Wintle marries, has two children, and becomes a successful award-winning radio, film and television producer.

A Brave Man's Journey. Francine Gelinias-O'Meara. 1994. Ray, Sherbrooke, QC, Camira Publishing. 227 pp.

The moving story of the struggle to survive: first, hemophilia in Canada, and later HIV.

Autobiographies by People With Hemophilia

Ryan White: My Own Story. Ryan White and Ann Marie Cunningham. 1991. New York, Dial Books. 277 pp.

Ryan White, diagnosed with hemophilia and AIDS, became a national celebrity during his successful legal battles to attend school, and to create national AIDS education campaigns. After Ryan died of AIDS complications, his story was made into a movie in 1988.

The Hemophiliac's Motorcycle. Tom Andrews. 1994. Iowa City, University of Iowa Press. Poetry, 77 pp.

After setting a world's record for continuous hand clapping at age 11, Tom was diagnosed with hemophilia A at age 15. Tom has written poetry and taught writing courses at universities, and was encouraged to publish his autobiographical poems, for which he won the 1993 Iowa Poetry Prize. He expanded these poems into a book of prose.

Codeine Diary: True Confessions of a Reckless Hemophiliac. Tom Andrews. 1998. Boston, Little, Brown & Company. 238 pp.

What began as Tom Andrews' diary of a serious bleed in 1989 developed into an introspective reflection on the role of hemophilia in his life. The prose revisits and expands upon his collection of autobiographical poems. ♦

Richard J. Atwood MA, MPH, works at Wake Forest University School of Medicine in Winston-Salem, North Carolina.

For a more complete annotated bibliography, please visit our website www.kelleycom.com under "Resources."

For von Willebrand Disease



All About von Willebrand Disease

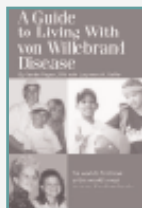
Canadian Hemophilia Society, 625 President Kennedy Boulevard, Suite 1210, Montreal, Quebec H3A 1K2, Canada. Available through website in PDF format. 81 pp.

Spiral-bound booklet. Introductory, mainly medical guide for patients with VWD, in easy-to-read question-and-answer format. Topics include VWD types, symptoms, diagnosis and treatment. Resource guide pertains only to Canada.

Von Willebrand Disease School Presentation

Suzie Coleman, Beverly Whiteman, and Cheryl Granville of Mary M. Gooley Hemophilia Center, Inc., Rochester, New York. 1996. Alpha Therapeutic Corporation, 2410 Lillyvale Avenue, Los Angeles, CA 90032. (800) 292-6118. www.alphatherservices.com. Free. Available to health care professionals only.

Teaching tool for VWD consists of desktop flip chart that covers topics like heredity, diagnosis, types of disease, types of trauma and appropriate therapies.



A Guide to Living with von Willebrand Disease

Renée Paper, R.N., with Lauren A. Kelley. 2002. LA Kelley Communications, Inc. 68 East Main Street, Suite 102, Georgetown, MA 01833. (978) 352-7657. www.kelleycom.com. Or AB Choice Member Support Center. (888) 508-6978. www.allaboutbleeding.com. Free.

The world's first book on the world's most common inherited bleeding disorder. Covers learning to cope with the diagnosis, growing up with VWD, inheritance, the medical system, treatment, woman's issues, health insurance and a complete resource guide to information. Includes real-life experiences of 50 contributing patients.



Diane Dino's Dilemma

Aventis Behring. 2001. Call AB Choice Member Support Center. (888) 508-6978. www.allaboutbleeding.com.

Richly illustrated storybook about a little dinosaur with VWD who explains living with VWD simply, for patients age 5–9.

CD ROMs



Learn About Hemophilia

Hemophilia Resources of America. PO Box 2011, 45 Route 46 East, Suite 609, Pine Brook, NJ 07058. (800) 549-2654. www.hrahemo.com. Free.

Available in PC or Macintosh format. Explains basic concepts about hemophilia symptoms and diagnosis, medication and monitoring, lifestyle, joint bleeds, genetics. Uses "Dom," the domino character. Program is mostly text, with some illustrations, accompanied by music. Concepts and vocabulary suited to children age ten and older, or for anyone new to hemophilia. Accompanies *Learn About Hemophilia Coloring Book* (see *Books for Children*).



The Basics of Gene Therapy

2001. Baxter BioScience. 1627 Lake Cook Road, Deerfield, Ill. 60015 (800) 423-2090. www.hemophiliagalaxy.com. Free.

Covers the basics of hemophilia gene therapy, with up-to-date resources.

Kits

2001. Baxter BioScience. 1627 Lake Cook Road, Deerfield, Ill. 60015 (800) 423-2090. www.hemophiliagalaxy.com. *The following kits are available free from Baxter BioScience, through your local hemophilia treatment center only.*

continued on page 18

With Hemophilia

Scholarships

Candidate

Florida resident with bleeding disorder attending a college, university or trade school.

Deadline

April 30

Contact

Hemophilia Foundation of Greater Florida
1350 North Orange Avenue, Suite 227
Winterpark, FL 32789
(800) 293-6527

Chitwood Acres, Hemophilia Access, Inc. Scholarship Fund

Amount

Several awards of \$500 and \$1,000

Candidate

Person or immediate family member, children, spouse, and siblings with hemophilia pursuing educational goals past high school. Not limited to people challenged with physical or mental handicaps.

Deadline

Call HAI to request an application for the coming year

Contact

Hemophilia Access, Inc.
ATTN: Lea Mosley
PO Box 367
Nolensville, TN 37135
(800) 399-RELY
fax: (888) 499-7359

Christopher Pitkin Memorial Scholarship

Amount

Three \$1,000 scholarships

Candidate

All members of the hemophilia community, including spouses and siblings.

Deadline

Mid-August

Contact

Hemophilia Foundation of Southern California
(626) 793-6192
www.hemosocal.com

Eric Delson Memorial Scholarship

Amount

One \$1,500 award per year, renewable up to four years, for private high school. One \$2,500 award per year, renewable for up to four years, for college or trade school.

Candidate

Person with any bleeding disorder.

Deadline

July 1

Contact

The Eric Delson Memorial Scholarship Program
Citizens' Scholarship Foundation of America, Inc.
ATTN: Heather Post
P.O. Box 297
St. Peter, MN 56082
(800) 225-5967
www.csfa.org

Eric Dostie Scholarship

Funded by a generous contribution from Patrick M. and Diane Schmidt of Fallbrook, CA

Amount

Eight \$1,000 awards

Candidate

Person or family member with hemophilia or other bleeding disorder, enrolled full-time in an accredited college.

Deadline

March 1 (request application after November 1)

Contact

LA Kelley Communications, Inc.
68 East Main Street, Suite 102
Georgetown, MA 01833
(978) 352-7657
fax: (978) 352-6254
www.kelleycom.com

Hemophilia Federation of America

Amount

Between one and three \$1,500 scholarships for the 2003–2004 school year

Candidate

Person with hemophilia or VWD attending any accredited two- or four-year college, university or vocation/technical school in the U.S.

Deadline

December 1

Contact

Hemophilia Federation of America (HFA)
Mary Beth Carrier
102 B Westmark Blvd.
Lafayette, LA 70506
(800) 230-9797
fax: (337) 991-0087

continued on next page

Scholarships

for People

PEN 2002 Annual Review

Amount
Candidate
Deadline
Contact
Amount
Candidate
Deadline
Contact
Amount
Candidate
Deadline
Contact
Amount
Candidate
Deadline
Contact

Hemophilia Foundation of Michigan Academic Scholarship

Awards vary from \$500 to \$1,500
Person with hemophilia or other inherited bleeding disorder residing in Michigan, or immediate family member.

March 11 (applications available in January)

HFM Academic Assistance
The Hemophilia Foundation of Michigan
2301 Platt Road, Suite 100
Ann Arbor, MI 48104
(800) 482-304
(734) 975-2838
fax: (734) 975-2889

The Hemophilia Health Services Memorial Scholarship Program

\$500 to \$1,000 for a full academic year (number of awards depends on funds available). Recipients may reapply each year. There is a new competition for the awards each year.

U.S. citizen with hemophilia, VWD, or other bleeding disorder. Must be high school student about to attend college, college student, college senior planning to attend graduate school, or graduate school student.

May 1

Scholarship Committee
Hemophilia Health Services
6820 Charlotte Pike
Nashville, TN 37209-4234
(800) 800-6606 ext. 5175
fax: (615) 850-5100
www.accredohealth.net/hhs/patients/scholarship/scholarship.html

Amount
Candidate

Deadline
Contact

Hemophilia Resources of America, Inc. Scholarship

Varies; depends on funds available
Person with hemophilia or VWD, or son or daughter.

April 30

Hope Crawley
Hemophilia Resources of America (HRA)
48 Route 45 East, Suite 609
PO Box 2011
Pine Brook, NJ 07058
(800) 549-2654
fax (973) 575-0868
www.hrahemo.com/about/scholarship.html

Amount
Candidate

Deadline
Contact

The Kevin Child Scholarship

\$500 and \$1,000
Person with hemophilia or VWD. Must be high school senior planning to attend college, university or vocational school; or college student pursuing post-secondary education.

June 30

Renee LaBrew
Dept. of Finance, Administration & MIS
The National Hemophilia Foundation
116 West 32nd Street, 11th Floor
New York, NY 10001-3212
(212) 328-3700 or (800) 42-HANDI
Or: Mary Child Smoot
(203) 968-2776

Amount
Candidate

Deadline
Contact

Michael Bendix Sutton Foundation

Two \$2,000 scholarships
Person with hemophilia pursuing pre-law study.

March 30

Michael Bendix Sutton Foundation
c/o Marion B. Sutton
300 Maritime Avenue
White Plains, NY 10601



Belonging

Caremark Therapeutic Services, 1127 Bryn Mawr Avenue, Redlands, CA 92374. (800) 225-5967. www.caremark.com. 17 pp. Free.

Quarterly. Easy-to-read general articles about hemophilia and bleeding disorders, often in question-and-answer format. Includes family and patient portraits and practical information.

The Common Factor

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

Published as funding permits, but at least biannually. COTT is a national advocacy organization for those with hemophilia and HIV/AIDS, and their affected family and friends. Topics include medical updates and lobbying efforts. COTT also sends out national communiqués. Postings made over the internet on the Hemophilia Support List, and regionally within the New England area.

International Periodicals



Hemophilia Leader

LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833. (978) 352-7657. www.kelleycom.com. Free.

Quarterly. Newsletter of L.I.G.H.T., an international program helping hemophilia organizations and individual leaders in the global hemophilia community. Profiles leaders worldwide who have overcome special challenges to improve hemophilia care in their developing country. Provides business advice on managing, marketing and writing, as well as starting, organizing and running a hemophilia organization.



Haemophilia World

World Federation of Hemophilia, 1425 René Lévesque Boulevard West, Suite 1010, Montreal, Quebec H3G 1T7 Canada. (514) 875-7944. www.wfh.org. Free with paid membership.

Quarterly. Provides news and information about WFH efforts to improve hemophilia care worldwide, and reports by individual member countries on national activities and achievements.

Periodicals For Children



FactorMan®

Caremark Therapeutic Services, 1127 Bryn Mawr Avenue, Redlands, CA 92374. (800) 225-5967. www.caremark.com. 14 pp. Free.

Quarterly. Colorful, dynamic and appealing comic book about a boy with hemophilia. His hero, FactorMan®, joins him on exciting adventures to fight evil forces. Each issue contains an overall lesson for living with hemophilia, profile of a young reader with hemophilia, and general information.



Mis'N Factors

Hemophilia Resources of America, Inc., PO Box 2011, 45 Route 46 East, Suite 609, Pine Brook, NJ 07058. (800) 549-2654. www.hrahemo.com. 2 pp. Free.

Quarterly. Designed to inform and inspire the teenage hemophilia population. Presents stories about young people, and spotlights careers and people who have overcome adversity. Also contains information about topics like college and sports.

Lil' Factors

Hemophilia Resources of America, Inc., PO Box 2011, 45 Route 46 East, Suite 609, Pine Brook, NJ 07058. (800) 549-2654. www.hrahemo.com. 8 pp. Free.

Quarterly. Helps children better understand their bleeding disorder. Presents stories, "Karing for Kids" activities, and articles by and about children with hemophilia and vWD. Dom the Domino is featured host.

Periodicals



HemAware

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

Quarterly. Hemophilia medical research and treatment articles, with current information on community events and professional achievements in the hemophilia community. Shares information from different professional disciplines: social work, physical therapy, orthopedics, dental, nursing, and articles for families. Free with paid NHF membership.



Hemalog

Materia Medica/Creative Annex, Inc., 208 East 51st Street, Box 234, New York, NY 10022-6501. (212) 219-2727. 32 pp. Free.

Quarterly. Family-oriented magazine containing articles about hemophilia. Non-technical, easy-to-read format. Topics range from curing hemophilia to treating bleeds; prenatal testing to choice of sports. Readers welcome to write in. Color photos and diagrams. Funded by Aventis Behring. Special issues available in Spanish.



The Parent Empowerment Newsletter (PEN)

LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833. (978) 352-7657. www.kelleycom.com. Free.

Quarterly. In-depth articles on topics of interest to families and consumers with hemophilia. The only newsletter available produced and edited by a parent of a child with hemophilia. Empowers parents as educated consumers and advocates. Readers encouraged to write in and share experiences.

Factor Nine News

Coalition for Hemophilia B, 225 West 34th Street, Suite 710, New York, NY 10012. (212) 554-6800. Free.

Quarterly. Brief newsletter that keeps readers up-to-date with latest news and treatment about hemophilia B. From a nonprofit organization dedicated to improving quality of life for people with hemophilia B by supporting basic and applied research, education, and liaison with the pharmaceutical industry.



Bloodstone Magazine

Hemophilia Health Services, 6820 Charlotte Pike, Suite 100, Nashville, TN 37209. (800) 800-6606. www.hemophiliahealth.com. 16 pp. Free.

Quarterly. General information about hemophilia. Easy-to-read and informative articles written by HHS employees and contributing writers. Promotes positive view of living with hemophilia. Includes children's color comic strip about "Welligan Hugsley," a little bear who makes people feel better with hugs.



Other Factors

Hemophilia Resources of America, Inc., PO Box 2011, 45 Route 46 East, Suite 609, Pine Brook, NJ 07058. (800) 549-2654. www.hrahemo.com. 4 pp. Free.

Quarterly. Newsletter containing brief articles about families living with hemophilia, current hemophilia treatments, products, insurance and legal issues.



Hemophilia Reports

Multimedia Healthcare Freedom, LLC, Office Center, Princeton Meadows, Bldg. 300, Plainsboro, NJ 08536. 8 pp. Free.

Bimonthly. Each issue contains concise summaries of several up-to-date medical journal reports on hemophilia. Medically and technically oriented. Funded by Bayer Corporation.



Dateline Federation

Hemophilia Federation of America, 102 B Westmark Boulevard, Lafayette, LA 70506. (800) 230-9797. www.hemophiliafed.org. Free.

Quarterly. Provides consumers with up-to-date health care information about bleeding disorders; upcoming events; analysis of current government and health care events and innovative programs.

With Hemophilia

Amount
Candidate

Mike Hylton and Ron Niederman Memorial Scholarships

Ten \$1,000 scholarships

Person or family member with hemophilia or other bleeding disorder pursuing post-secondary education at college, university, trade or technical school.

Deadline
Contact

July 15 (winners notified by September 1)

Patient Services Coordinator
Linda Leigh Sulser
Patient Services Coordinator
Factor Support Network Pharmacy
900 Aventura Acaso, Suite A
Camarillo, CA 93012
(877) FSN-4-YOU
fax: (805) 482-6324
www.factorsupport.com/scholarships.htm

Deadline
Contact

student. Awards based on academic achievement, recommendations, and personal essay or statement.

July 15 (applications available in May)

Wyeth/Genetics Institute, Inc.
555 East Lancaster Avenue
St. Davids, PA 19087
(888) 322-6010
fax: (610) 995-3316
www.hemophiliavillage.com/con_prog_scholar.asp

The Todd Richardson Memorial Scholarship

Oneida Savings Bank
585 Main Street
Oneida, NY 13421
Or: Make-A-Wish Foundation of Central New York
Suite 900, MONY, Tower II
120 Madison Street
Syracuse, NY 13202

© LA Kelley Communications, Inc. 2002

Amount
Candidate
Deadline
Contact

Rachel Warner Scholarship

Funds are varied and limited

Person with bleeding disorder.

May 1

The Committee of Ten Thousand
c/o Rachel Warner Scholarship
236 Massachusetts Avenue, Suite 609
Washington, DC 20002
(800) 488-2688
fax: (202) 543-6720

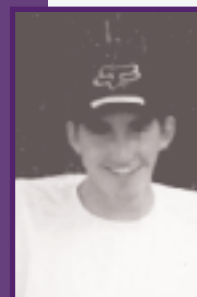
Soozie Courter Sharing a Brighter Tomorrow Hemophilia Scholarship Program Wyeth/Genetics Institute, Inc.

Twelve \$5,000 college awards, and twelve \$1,000 vocational awards to applicants with hemophilia A or B. (Twenty scholarships worth a total of \$76,000 awarded in 2001.)

Amount
Candidate

Student with hemophilia A or B who is a high school senior (or has graduate equivalency diploma), college student (undergraduate and graduate), or vocational school

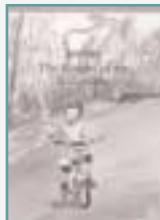
HRA is pleased to provide an additional \$2,000 scholarship in memory of Todd M. Richardson. Todd



passed away in January 2002 at age 23, from AIDS and Hepatitis C. A former HRA scholarship winner, Todd's drive for education, coupled with his community involvement, epitomized what HRAs scholarship program is all about. Todd will always be remembered as

a true "winner," for he achieved what many struggle for throughout a lifetime—a true sense of self. ♦

Books For Children



What is Hemophilia? Series

Kelley, Lauren A. 1995. 152 pp. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833. (978) 352-7657. www.kelleycom.com. Free.

The first developmentally arranged series of books explaining hemophilia to children, using language and concepts appropriate for three age levels: preschool, school age and adolescent. Each book is designed to cover the same topics, in educationally and cognitively different ways. Each contains a "Note to Parents" explaining how children at each age level comprehend hemophilia. Ages 3–16.



Level 1: Joshua, Knight of the Red Snake

Story about a preschooler with hemophilia. Fully illustrated with large text for beginning readers. Ends on a note of joy and confidence to empower children.



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

A humorous story about Tony, who must explain hemophilia to his classmates at the beginning of fourth grade. Includes a glossary for children.



Level 3: Tell Them The Facts!

Question-and-answer book for preadolescents and adolescents. The material on genetics is divided into two sections, for ages 11–14 and 14–16. Designed for children, but valuable for parents of newly diagnosed children, teachers, and anyone new to hemophilia. Glossary.



Factor Fun!

Horbacz, Diane. 2001. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833. (978) 352-7657. www.kelleycom.com. Or American Red Cross, 1616 North Fort Meyer Drive, Arlington, VA, 22209. (703) 312-8483. www.redcross.org/plasma. Free.

Developmentally appropriate activity book for children with hemophilia, age 4–7. Teaches concepts about hemophilia and self-esteem, through four-color illustrations and 25 interactive activities, such as mazes, matching, glyphs and counting.



Infusion Time

Horbacz, Diane. 1998. Hemophilia Resources of America, PO Box 2011, 45 Route 46 East, Suite 609, Pine Brook, NJ 07058. (800) 549-2654. www.hrahemo.com. Free.

Designed for children age 3–11. Interactive book that helps children with Port-A-Caths® understand the infusion process. Rhymes and tactile features make learning about infusion fun.



My Brother is Getting a New Port!

Horbacz, Diane. 2000. Hemophilia Resources of America, PO Box 2011, 45 Route 46 East, Suite 609, Pine Brook, NJ 07058. (800) 549-2654. www.hrahemo.com. Free.

Based on real experience. A young boy living with hemophilia, who infuses his factor via a port, helps prepare his younger brother, who also has hemophilia, for surgery.

Learn About Hemophilia Coloring Book

Hemophilia Resources of America, PO Box 2011, 45 Route 46 East, Suite 609, Pine Brook, NJ 07058. (800) 549-2654. www.hrahemo.com. Free.

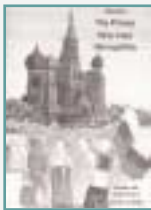
Hemophilia tutorial for children, coupled with 20-page coloring book featuring "Dom" the domino. Topics covered include hemophilia definition, types, severity, joint bleeds, diet, ancillaries and exercise. Younger children may enjoy interactive characters and pictures to color, but vocabulary and topics are more appropriate for age 7–11.



Must You Always Be a Boy?

Kelley, Lauren A. 1991. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833. (978) 352-7657. www.kelleycom.com. Free.

Four rhyming tales, in Dr. Seuss style, with colorful illustrations, exploring adult reaction to a bleed, overprotective parents, sibling rivalry and the classroom bully. Age 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. (978) 352-7657. www.kelleycom.com. Free.

Set in the early 1900s, this is the true story of the youngest child of Tsar Nicholas II, last Tsar of Russia. The story chronicles how Alexis's hemophilia influenced the course of events in Russia that ultimately led to the Russian Revolution. Age 8 and older.



Full of Facts and Fun

1997. Bayer Corporation, Biological Products, 400 Morgan Lane, West Haven, CT 06516-4175. www.bayerbiologicals.com. Free.

A 26-page booklet with word games and a maze, for children age 9–15. Explains various aspects of hemophilia and treatment.

Videos

The Winning Spirit

1993. Delaware Chapter of NHF, 222 South Easton Road, Suite 107, Glenside, PA 19038. (215) 885-6500. Free.

Upbeat 20-minute video covering what every new parent should know about and expect from hemophilia. Topics include being a parent, initial feelings after the diagnosis, developmental stages, computer animation of what happens inside during a bleed, factor therapy, sports and activities, and keeping life normal.



Inside a Bleeding Joint

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

Narrated by a child, this animated video describes hemophilia and its symptoms. Detailed, step-by-step illustrations explain how joints work, and what happens when a child gets a bleed in a joint. Covers joint damage, self-infusion, and the importance of early detection of bleeds. Targeted for children; ideal for school, summer camp and home education.

Learning about Hemophilia

Caremark Therapeutic Services, 1127 Bryn Mawr Avenue, Redlands, CA 92374. Attn: Michelle Tambi. (800) 323-8083 x5588. www.caremark.com. Video and booklet free. *Currently unavailable, revised edition to be released later. Patients should contact Caremark to be placed on a waiting list.*

Presents a clear and simple overview of hemophilia. Topics include an explanation of hemophilia, severity levels, genetics, feelings, normalcy, physical activity, comprehensive care, bleeds and factor replacement therapy.

Taking Control: Open Up Your World

Aventis Behring. Call AB Choice Member Support Center. (888) 508-6978. Free.

Step-by-step video guide to learning self-infusion.



RECOMBINATE rAHF Proven Video

2001. Baxter BioScience, 1627 Lake Cook Road, Deerfield, Ill. 60015. (800) 423-2090. www.hemophiliagalaxy.com. Free.

Provides a tour of the main processing facility for this recombinant product; interviews with patients; and Baxter's programs and services. Gives parents and patients a general overview of how recombinant products are made.