

Parent Empowerment Newsletter

THE *PEN* Bleeding Disorders Resource *Guide* 2004

Knowledge is a powerful tool. Expanding your knowledge of bleeding disorders reduces fear and stress, and empowers you as your child's best advocate. You may be coping with the common fear, anger, shock or guilt of a diagnosis of hemophilia or von Willebrand Disease. You may be unsure about a doctor's recommendation for treatment. As always, *PEN* stresses consumer information and consumer responsibility. To help you make wise decisions for your family, we present a list of resources concerning bleeding disorders. Enrich your knowledge, and arm yourself to face the future with confidence.

BOOKS



Raising a Child With Hemophilia: A Practical Guide for Parents

Kelley, Lauren A. 3rd ed., 1999. 398 pp. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833 (978) 352-7657

www.kelleycom.com Sponsored by and also available through Aventis Behring. AB Choice Member Support Center (888) 508-6978 www.aventisbehring.com
Available in English, Spanish. FREE.

Practical medical, child development and consumer information about hemophilia, and stories from parents. Written by a parent of a child with hemophilia. Made possible through a grant from Aventis Behring.

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The *PEN* Bleeding Disorders Resource Guide 2004

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welcome

PEN is pleased to bring you its review of books, newsletters, programs, CD ROMs and videos for the hemophilia community. Parents will appreciate the tremendous amount of energy and funds contributed to the community by sponsors that help us and our children cope better with hemophilia.



You may notice that some resources are missing since the previous *PEN* review. While it's true that some books and newsletters are now out of print, and some companies have changed ownership and discontinued programs, LA Kelley Communications, Inc. has instituted a new policy limiting the number of resources it will include.

To help us fulfill our mission to educate and empower our community worldwide and ship factor concentrate to developing countries, we have decided to showcase resources from companies that actively partner with us. We feel that these companies believe in our mission and vision. We also present the publications and programs of many nonprofit organizations, as a free service.

We have decided to showcase only a few of the major NHF publications. The NHF's excellent booklets, pamphlets and programs are too numerous to mention here. We encourage you to view and order all NHF publications at www.hemophilia.org. And please go directly to our corporate partners' websites to review all that they offer. When you visit these websites, you are casting a vote for their support of our work at LA Kelley Communications.

letters

Six years ago our son was diagnosed with mild hemophilia. It wasn't a complete shock, but we were discouraged by the lack of information we received. I called LA Kelley Communications, and was pleasantly surprised to speak to Laurie Kelley. The most important thing she said was to be proactive and learn as much as I could. Today I am director of communications of our provincial chapter and an active participant and leader within our hemophilia community. I now have people calling me for information and support! I'm also the editor of *Mainline*, our chapter's newsletter. If you would like to view a copy, please visit www.hemophilia.ca and click on the provincial

PARENT EMPOWERMENT NEWSLETTER FEBRUARY 2004

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PEN is a newsletter for families affected by bleeding disorders that is produced and edited by a parent of a child with hemophilia. It is 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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Funding provided through generous grants from our corporate sponsors (page 19)

LA Kelley Communications

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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!

chapters link. We are located in Newfoundland and Labrador. Thank you for giving me support and encouragement when I needed it most!

COLLEEN BARRETT, Canada

We just received the most recent issue of *PEN*. We appreciate all that you do for the hemophilia community! Your books have helped so many people cope and live with bleeding disorders. We are very thankful for your work, as are many other families.

ALLISON POHL, Houston, Texas



Savvy Consumers Use Reliable Resources

Should you believe that “milk thistle will stop nose bleeds and strengthen the body’s immune system?” Your immediate reaction should be, “Who said that? What’s the source of that information?” Whether information comes from the news media or another parent, always verify it using reliable resources.

How do you go about finding reliable resources? Patty is the mother of 2 1/2 year old Erik, who has severe hemophilia. Patty came to our hospital when Erik was diagnosed at age one month. At 18 months, Erik began to have frequent bleeds and needed more frequent infusions. Unfortunately, infusing was difficult because Erik found it hard to sit still. Our doctor began discussing prophylaxis with Patty. Patty agreed to the idea, but balked when the doctor introduced the possibility of a central venous access device (CVAD). “A central line with the possibility of infections?” asked Patty. “No way.” Struggling with the doctor’s recommendation, she wondered, “Is this an experimental procedure?”

Like Patty, when parents first learn of their children’s medical diagnosis or a new treatment procedure, the need for information and support is critical. Milton Seligman, Ph.D.¹, is a noted author and researcher on families of children with chronic illness. He believes that the most important kind of help parents receive from professionals is *information*. However, Seligman notes that parents may continue to feel powerless, even with accurate information from their doctors.

After spending considerable time thinking, and learning from our medical team, Patty decided to contact HANDI² at the National Hemophilia Foundation for more information. HANDI sent Patty several articles, including MASAC’s recom-

mendations³ and a *PEN* article, “Which Central Venous Access Device to Use?”⁴ Patty and her husband learned that placing a CVAD is not an experimental procedure. They learned more about the types of implantable venous access devices, and where they could be placed on Erik’s body. They also discovered that an increasing number of families benefit from CVADs. Meanwhile, our medical team obtained permission to give Patty the name of another parent, Bonita, who had been successful in managing her son’s CVAD. Armed with their newly acquired knowledge, Patty and her husband met Bonita and her son Mikey. It was helpful to see a CVAD on the chest of a real child, instead of on a mannequin, and to imagine how Erik’s CVAD would look.

Patty and her husband were now ready to make an informed decision for Erik. Knowledge had lessened their fear of the unknown. They now understood the doctor’s recommendation, and were familiar with their options and possible outcomes. They felt proud and empowered by the decision they finally reached.

As I see it, when we feel overwhelmed by a diagnosis or new treatment recommendation—even an alternative treatment claim like milk thistle—we need to be proactive. As educated and savvy consumers, we can build a sound knowledge base from reliable resources, enabling us with greater confidence to make positive decisions for our children and ourselves. ☺

Elizabeth Fung, Ph.D., is a social worker at Children’s Memorial Hospital in Chicago and a NHF board member. She is currently conducting a research study on the non-affected sibling’s experience.

¹Seligman, M. and Darling, R. B., 1997. *Ordinary families, special children: A systems approach to childhood disability*. ²HANDI is the information service of the NHF and provides up-to-date resources on bleeding disorders. (800) 42-HANDI. ³MASAC is the Medical and Scientific Advisory Council of the NHF. MASAC Recommendation #115: “MASAC Recommendations Regarding Central Venous Access Devices Including Ports and Passports, June 9, 2001.” ⁴Jill Lathrop, “Which Central Venous Access Device to Use?” *PEN*, May 2001, Volume 11, Issue 2.

Quang Nguyen's BRIEF HOLIDAY FROM PAIN

by Annie Schwechheimer

Quang Nguyen

Quang Nguyen loves to swim. Although he also enjoys drawing, playing with LEGOS, watching Chinese Kung Fu movies and *Superman*, swimming is his favorite hobby. In the water, the legs that normally cause him so much pain are weightless, allowing him to imagine, if only briefly, what life would be like if circumstances were different. If he hadn't been born with severe hemophilia A. If he hadn't been born in a country with limited medical resources.

Ten-year-old Quang lives in Ho Chi Minh City, Vietnam, with his mother, father and 13-year-old brother Quyen. Because of Quang's hemophilia, the family must daily endure tremendous emotional, financial and physical burdens. The factor needed to treat Quang's bleeds, when available, is too expensive for the Nguyen family. Quang is unable to walk on his own, and must rely on his mother to carry him to and from school. The school Quang attends is not handicapped accessible, so he must sit in the same seat for hours, watching his friends run and play at recess.

Quang's mother Ngoc worries about him when he is at school. "As he gets older, his bleeds get [more] frequent," she explains. "That makes me worry more, but I cannot think about his future." Ngoc has even put Quang on a special diet of rice to keep his weight down. If he gains weight, she says, it will increase his chance of bleeding and he will need more factor. Right now, the biggest challenge for the Nguyen family is finding factor when a serious bleed occurs.

photos: Julia Nguyen



Humiliating conditions:

Because Quang's legs are permanently damaged, his mother must carry him everywhere—even to the bathroom at school.

Frequent bleeds:

As he gets older, Quang experiences more frequent bleeds, leaving him confined to a wheelchair and unable to do basic tasks for himself.

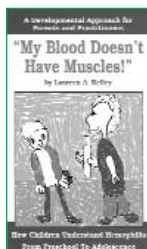


Thankfully, Project SHARE has been able to help Quang. We first learned about him in January 2001 when his aunt Julia, who lives in the US, contacted us on Quang's behalf. During the past three years, we have made several donations of medicine and supplies to Quang. When he was hospitalized in April 2003 with bleeding in his knees, nose, eyes and abdomen, a donation of 20,000 IUs enabled him to recover.

Although he's occasionally depressed about hemophilia and its challenges, Quang takes comfort in the knowledge that there are other children like him in the world. He is especially grateful for programs like Project SHARE. When factor from Project SHARE arrives at the Nguyen home, the family rejoices. For a brief time, their worries about providing medicine for their son are over.

To learn more about Project SHARE and how you can help patients like Quang, please visit www.kelleycom.com/iha/projshare.html or contact Director Annie Schwechheimer at (978) 352-7657 or annie@kelleycom.com.

Project SHARESM is an international humanitarian program administered by LA Kelley Communications, Inc., in partnership with Aventis Behring, Baxter BioScience, Bayer HealthCare, Hemophilia Health Services and Novo Nordisk Pharmaceuticals, Inc. Factor donations are primarily from private sources.

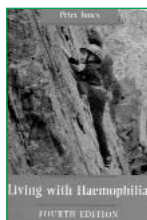


How Children Understand Hemophilia: From Preschool to Adolescence*

Kelley, Lauren A. 1993. 152 pp. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833 (978) 352-7657 www.kelleycom.com Sponsored by and also available through Aventis Behring. AB Choice Member Support Center (888) 508-6978 www.aventisbehring.com Available in English, Spanish. FREE.

*Currently out of print. Second edition available late 2004.

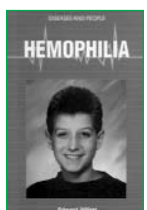
How children understand hemophilia, genetics and prophylaxis, and suggested teaching methods. Interviews with children illustrate different developmental stages. Appendices show how to conduct your own interview with your child. For parents and clinicians.



Living with Haemophilia

Jones, Peter, M.D. 5th ed. 374 pp. Oxford University Press, 200 Madison Avenue, New York, NY 10016 (800) 451-7556 Approximately \$29.00 (softcover) plus shipping and handling. Also available from WFH, 1425 René Lévesque Boulevard West, Suite 1010, Montreal, Quebec H3G 1T7, Canada (514) 875-7944 www.wfh.org \$30.00 US for WFH members, \$37.00 US for non-members. Shipping and handling additional.

Covers in depth many aspects of hemophilia, general anatomy and physiology. Written by internationally renowned pediatric hematologist. Reference manual for healthcare practitioners, guide for parents.



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

Overview of hemophilia for children and young adults. Easy-to-read resource for teachers, babysitters and caregivers.

Emotional Support in Hemophilia

Arranz, P.; Costa, M.; Bayés, R.; Cancio, H.; Magallón, M.; Hernández, F. 2000. WFH, 1425 René Lévesque Boulevard West, Suite 1010, Montreal, Quebec H3G 1T7, Canada (514) 875-7944 www.wfh.org. Available in English, Spanish.

Practical publication primarily for healthcare professionals. Contains suggestions and guidelines for helping patients and families during critical times. Real-life clinical situations used as examples for handling different emotional situations.

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 \$45.00 US for WFH members, \$60.00 US for non-members. Shipping and handling additional. Available in English, Spanish, French.

Pictorial guide to hemophilia for healthcare workers, parents and patients reflects the multicultural diversity of the global hemophilia community. Illustrated by Doug Knutson, father of a child with hemophilia. Useful for people with low literacy levels. Includes teaching notes.

Please use your consumer savvy when contacting companies directly. Some of the publications listed here are published by marketing departments of companies seeking your business. To avoid unwanted consumer-corporate personal communication, we do not provide email addresses. Instead, we provide phone numbers, street addresses and web addresses to allow our readers more discreet contact.



All About Hemophilia: A Guide for Families

2001. 294 pp. Canadian Hemophilia Society, 625 President Kennedy Boulevard, Suite 1210, Montreal, Quebec H3A 1K2, Canada www.hemophilia.ca/en/13.html Available to US citizens only through website in PDF format. **FREE.**

User-friendly informational guide to genetics, therapy, home infusion, complications, staying healthy, and the future of care. Includes resource section, glossary and self-test.

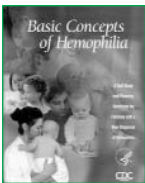


First Step

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

Resource guide for parents and families of children newly diagnosed with bleeding disorders. Contains information about NHF programs, hemophilia, von Willebrand Disease, treatments, childcare, parenting, healthcare, scientific and medical issues.

WORKBOOKS

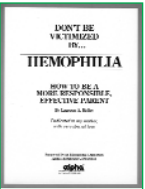


Basic Concepts of Hemophilia: A Self-Study and Planning Workbook for Families with a New Diagnosis of Hemophilia

Butler, Regina; Crudder, Sally O.; Riske, Brenda; Toal, Susan. 2001. 248 pp. Centers for Disease Control and Prevention www.cdc.gov Also available from your local HTC or the NHF. **FREE.**

Large-format workbook on hemophilia basics for parents of children, adolescents and young adults with hemophilia. Intended for use as part of an educational program with HTC staff.

BOOKLETS



Don't Be Victimized By Hemophilia*

Kelley, Lauren A. 1994. 23 pp. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833 (978) 352-7657 www.kelleycom.com or Grifols USA, 5555 Valley Boulevard, Los Angeles, CA 90032 www.grifols.com Available in English, Spanish, Russian, Chinese. **FREE.**

*Currently out of print. Second edition available late 2004.

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



Go For It

Jones, Peter, M.D.; Buzzard, Brenda, MCSP; Heijnen, Lily, M.D. 1998. 72 pp. WFH, 1425 René Lévesque Boulevard West, Suite 1010, Montreal, Quebec H3G 1T7, Canada (514) 875-7944 www.whf.org \$4.00 US for WFH members, \$14.00 US for non-members. Shipping and handling additional.

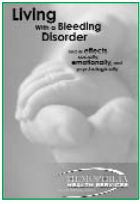
Pocket-size booklet on sports, physical activities and first aid for coaches, teachers, parents and teens. Emphasizes a wide variety of activities to improve quality of life for people with hemophilia. Includes section on first aid.



Your Child's Hemophilia (Series)

Aventis Behring. 2001. AB Choice Member Support Center (888) 508-6978 www.aventisbehring.com **FREE.**

Three-part series for parents about what to expect during different phases of children's development. *Your Child's Hemophilia: What to Expect During Infancy.* *Your Child's Hemophilia: What to Expect During the School Age Years.* *Hemophilia: The Young Adult Years.*



Living With Bleeding Disorders

Hemophilia Health Services. 2002. 8 pp. Hemophilia Health Services, 6820 Charlotte Pike, Nashville, TN 37209-4234 (800) 800-6606 www.hemophiliahealth.com Available in English, Spanish. **FREE.**

Explores psychosocial issues of families with bleeding disorders. Explains treating the whole patient, not just the bleeding disorder. Written by a social worker.



Understanding Hemophilia A: A Guide for Parents and Young Adults

Aventis Behring. 2001. AB Choice Member Support Center (888) 508-6978 www.aventisbehring.com **FREE.**

Overview of the history, science and treatment of hemophilia A. For parents and young adults.



A Family Guide to Hemophilia B

Aventis Behring. 2001. AB Choice Member Support Center (888) 508-6978 www.aventisbehring.com **FREE.**

Overview of the history, science and treatment of hemophilia B for families.



Living with Hemophilia and Inhibitors: A guide for patients, parents and caregivers

Novo Nordisk Pharmaceuticals, Inc., 100 College Road West, Princeton, NJ 08540 (609) 987-5800 www.novoseven.com **FREE.**

Helps patients, parents and caregivers understand and manage living with hemophilia with inhibitors. Explains what inhibitors are, how they work, and treatment options including NovoSeven®. Recommendations for staying healthy through active living.



The Management of Women with Bleeding Disorders

Canadian Hemophilia Society. 28 pp. Canadian Hemophilia Society, 625 President Kennedy Boulevard, Suite 1210, Montreal, Quebec H3A 1K2, Canada www.hemophilia.ca/en/13.html Available to US citizens only through website in PDF format. **FREE.**

Discusses management of bleeding disorders for women through multidisciplinary clinics, laboratory investigation, medical treatment of menorrhagia and pregnancy management.



Factor XIII Deficiency, an Inherited Bleeding Disease

Canadian Association of Nurses in Hemophilia Care. 28 pp. Canadian Hemophilia Society, 625 President Kennedy Boulevard, Suite 1210, Montreal, Quebec H3A 1K2m Canada www.hemophilia.ca/en/13.1.php Available to US citizens only through website in PDF format. **FREE.**

General information booklet about factor XIII deficiency for patients, families and healthcare providers.

Factor VII Deficiency, An Inherited Bleeding Disorder

Canadian Association of Nurses in Hemophilia Care. 28 pp. Canadian Hemophilia Society, 625 President Kennedy Boulevard, Suite 1210, Montreal, Quebec H3A 1K2m Canada www.hemophilia.ca/en/13.1.php Available to US citizens only through website in PDF format. **FREE.**

General information booklet about factor VII deficiency for patients, families and healthcare providers.



Dental Care (Series)

Aventis Behring, 2001. AB Choice Member Support Center (888) 508-6978 www.aventisbehring.com **FREE**.

Four-part series on dental care, primarily for people and families with hemophilia A, hemophilia B and VWD. *Dental Care for Infants, Toddlers, and Preschoolers with Bleeding Disorders*. *Dental Care for Children With Bleeding Disorders: Ages 5 to 10*. *Dental Care for Adolescents With Bleeding Disorders: Ages 11 to 18*. *Dental Care for Adults with Bleeding Disorders*.



Dental Care for People with Bleeding Disorders

Hemophilia Health Services, 2002. 8 pp. Hemophilia Health Services, 6820 Charlotte Pike, Nashville, TN 37209-4234 (800) 800-6606 www.hemophiliahealth.com Available in English, Spanish. **FREE**.

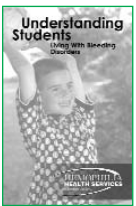
Dental care techniques for infants, school age children and adults. Tips for good oral health; information to give your dentist and when to use factor.



Finding Child Care for Children With Bleeding Disorders

Hemophilia Health Services, 2003. 8 pp. Hemophilia Health Services, 6820 Charlotte Pike, Nashville, TN 37209-4234 (800) 800-6606 www.hemophiliahealth.com Available in English, Spanish. **FREE**.

Information about hemophilia and its treatment so patients can educate babysitters and daycare centers. Includes a page for emergency contact information.



Understanding Students With Bleeding Disorders

Hemophilia Health Services, 2000. 8 pp. Hemophilia Health Services, 6820 Charlotte Pike, Nashville, TN 37209-4234 (800) 800-6606 www.hemophiliahealth.com **FREE**.

Explains basics of hemophilia and its treatment to teachers and school nurses. Information on physical education and psychosocial issues. Includes a page for emergency contact information.



Passport for Life

Baxter BioScience, 1627 Lake Cook Road, Deerfield, IL 60015 Sign up online at www.passportforlife.com or call (866) 433-9284 for a print brochure. **FREE**.

Personalized online and print program to help hemophilia patients manage life and health. Offers goal-setting tools, quizzes and activities, educational resources; programs for stress and weight management, smoking cessation and nutrition. For adults. Special online health program for teens.

Travel Guide for People with Hemophilia

Baxter BioScience, 1627 Lake Cook Road, Deerfield, IL 60015 Available online only at www.hemophiliagalaxy.com **FREE**.

Travel guide lists HTC's in 50 US states and 30 countries.



Taking Control: Infusion Log Book

Aventis Behring, AB Choice Member Support Center (888) 508-6978 www.aventisbehring.com **FREE**.

Step-by-step directions for logging infusions using peel-off vial labels. Can be ordered and used with or without *Taking Control: Open Up Your World* video and guide. Ages 11-18 and adults.

Patient Notification System Brochure & Log Book

Baxter BioScience, 1627 Lake Cook Road, Deerfield, IL 60015 (800) 423-2090 www.hemophiliagalaxy.com **FREE**.

Explains how to register for the Patient Notification System led by the Plasma Protein Therapeutics Association (PPTA). System keeps you informed of withdrawals, regulatory changes. Log book helps track infusion dates and therapeutics.



FACTOR ASSIST Program Brochure

Baxter BioScience, 1627 Lake Cook Road, Deerfield, IL 60015 (800) 423-2090 www.hemophiliagalaxy.com **FREE**.

Details on receiving Baxter hemophilia therapeutics, including Advate, without charge during insurance lapses.

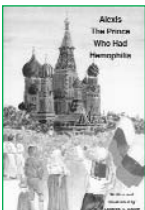
BOOKS AND GAMES FOR CHILDREN



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 Sponsored by and also available through Aventis Behring. AB Choice Member Support Center (888) 508-6978 www.aventisbehring.com **FREE**.

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



Alexis: The Prince Who Had Hemophilia

Kelley, Lauren A. 1992. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833 (978) 352-7657 www.kelleycom.com Sponsored by and also available through Aventis Behring. AB Choice Member Support Center (888) 508-6978 www.aventisbehring.com Available in English, Spanish. **FREE**.

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



What is Hemophilia? (Series)

Kelley, Lauren A. 1995. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833 (978) 352-7657 www.kelleycom.com Sponsored by and also available through Aventis Behring. AB Choice Member Support Center (888) 508-6978 www.aventisbehring.com Available in English, Spanish. **FREE**.

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

Level 1: Joshua, Knight of the Red Snake

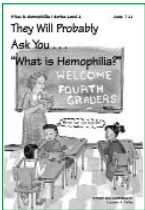
Empowering story about a preschooler with hemophilia. Illustrated large-text format. Ends on a note of joy and confidence to empower children. Ages 3–7.

Level 2: They’ll Probably Ask You “What is Hemophilia?”

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

Level 3: Tell Them the Facts!

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





Factor Fun!

Horbacz, Diane. 2001. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833 (978) 352-7657 www.kelleycom.com **FREE**.

Activity book teaches about hemophilia and self-esteem with colorful mazes, matching, glyphs and counting. Illustrated. Sponsored by American Red Cross. Ages 4-7.



Hemophilia: It's Logical!*

Kelley, Lauren A. 1995. 44 pp. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833 (978) 352-7657 www.kelleycom.com **FREE**.

*Currently out of print. Second edition available late 2004.

Puzzles, word games, logic problems and mazes introduce hemophilia vocabulary and concepts while strengthening ability to think logically about problems in a challenging and fun way. Ages 7 and older.



Infusion Time

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

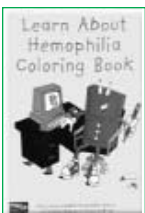
Interactive book helps children with Port-A-Caths® understand the infusion process. Rhymes and tactile features make learning about infusion fun. Ages 3-11.



My Brother is Getting a New Port!

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

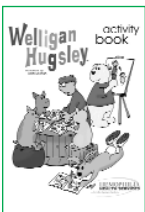
Story of a boy living with hemophilia who infuses his factor via a port, and helps prepare his younger brother with hemophilia for surgery.



Learn About Hemophilia Coloring Book

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

Hemophilia tutorial for children about hemophilia types, severity, joint bleeds, diet, ancillaries and exercise. Includes coloring book featuring "Dom" the domino. Ages 7-11.



Welligan Hugsley Activity Book

Hemophilia Health Services. 2003. 16 pp. Hemophilia Health Services, 6820 Charlotte Pike, Nashville, TN 37209-4234 (800) 800-6606 www.hemophiliahealth.com **FREE**.

Colorful activity book with games, puzzles and activities teaches children about hemophilia. Includes box of four crayons. *Contains Spanish instructions.*



Full of Facts and Fun

Bayer Corporation. 1997. 26 pp. Bayer Corporation, Biological Products, 400 Morgan Lane, West Haven, CT 06516-4175 www.bayerbiologicals.com **FREE**.

Booklet with word games and maze explains hemophilia and treatment. Ages 9-15.



Factor Match: The Memory Challenge Game

Baxter Healthcare Corporation. 1995. Baxter BioScience, 1627 Lake Cook Road, Deerfield, IL 60015 (800) 423-2090 www.hemophiliagalaxy.com **FREE**.

Card game helps children remember what to do if they get hurt, and how to take factor; reminds them of things they can do just like everyone else. Can be played as matching game or flash cards.

VIDEOS AND DVDS

The Winning Spirit

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

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



Inside a Bleeding Joint

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

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



Taking Control: Open Up Your World

Aventis Behring, AB Choice Member Support Center (888) 508-6978 www.aventisbehring.com **FREE**.

Step-by-step video and booklet teach self-infusion.

PERIODICALS



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

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



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 **FREE** with paid NHF membership.

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



Hemalog

Materia Medica/Creative Annex, Inc., 208 East 51st Street, Box 234, New York, NY 10022-6501 (212) 219-2727 *Special issues available in Spanish.* **FREE**.

Quarterly. Non-technical, easy-to-read articles about hemophilia for families. Topics range from curing hemophilia to treating bleeds; prenatal testing to choice of sports. Color photos and diagrams. Funded by Aventis Behring.

Factor Nine News

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

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



Bloodstone Magazine

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

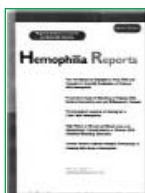
Quarterly. Easy-to-read general hemophilia information written by HHS employees and contributing writers. Presents positive view of living with hemophilia. Features “Welligan Hugsley” color comic strip for children.



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 **FREE**.

Quarterly. 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 **FREE**.

Bimonthly. Concise summaries of 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. Healthcare information about bleeding disorders; government and healthcare events, innovative programs and upcoming events.



The Common Factor

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

Biannual. Published more often if funding permits. Topics include medical updates and lobbying efforts. COTT is a national advocacy organization for people with hemophilia and HIV/AIDS, and affected family and friends.

INTERNATIONAL PERIODICALS



Hemophilia Leader

LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833 (978) 352-7657
www.kelleycom.com. **FREE** to nonprofits, corporate partners and international hemophilia organizations. \$20.95 yearly (hard copy) or \$12.95 yearly (PDF) for other subscribers. *Available in English, Spanish*.

Quarterly. Newsletter of the Leadership Institute for Global Hemophilia Training (L.I.G.H.T.), a private, international leadership consulting program for nonprofit hemophilia societies in developing countries. Contains profiles of international leaders; advice on managing, marketing, writing, and creating and running a hemophilia organization.



Haemophilia World

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

Quarterly. News and information about WFH efforts to improve hemophilia care worldwide. Reports by member countries on activities and achievements.

PERIODICALS FOR CHILDREN



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 **FREE**.

Quarterly. Informs and inspires teens with hemophilia. Spotlights careers, and profiles people who overcame adversity. Contains information about 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 **FREE**.

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

FOR VON WILLEBRAND DISEASE



A Guide to Living With von Willebrand Disease

Paper, Renée, R.N., with Kelley, Lauren A. 2002. LA Kelley Communications, Inc., 68 East Main Street, Suite 102, Georgetown, MA 01833 (978) 352-7657 www.kelleycom.com Sponsored by and also available through Aventis Behring. AB Choice Member Support Center (888) 508-6978 www.aventisbehring.com **FREE**.

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



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

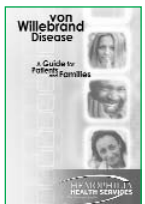
Aventis Behring. 2001. AB Choice Member Support Center (888) 508-6978 www.aventisbehring.com

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

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

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

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



von Willebrand Disease: A Guide for Patients and Families

Hemophilia Health Services. 2002. 12 pp. Hemophilia Health Services, 6820 Charlotte Pike, Suite 100, Nashville, TN 37209 (800) 800-6606 www.hemophiliahealth.com Available in English, Spanish. **FREE**.

Overview of VWD, types, inheritance, diagnosis and treatment.



All About von Willebrand Disease

Canadian Hemophilia Society. 86 pp. Canadian Hemophilia Society, 625 President Kennedy Boulevard, Suite 1210, Montreal, Quebec H3A 1K2m Canada www.hemophilia.ca/en/13.1.php Available to US citizens only through website in PDF format. **FREE.**

Introductory, mainly medical guide for VWD patients, in question-and-answer format. Topics include VWD types, symptoms, diagnosis and treatment. Includes resource guide for Canada.

Von Willebrand Disease — The Most Common Bleeding Disorder: Your Questions Answered

Canadian Hemophilia Society. 66 pp. Canadian Hemophilia Society, 625 President Kennedy Boulevard, Suite 1210, Montreal, Quebec H3A 1K2m Canada www.hemophilia.ca/en/13.1.php Available to US citizens only through website in PDF format. **FREE.**

General information on VWD symptoms, diagnosis and treatment.



Diane Dino's Dilemma

Aventis Behring. 2001. AB Choice Member Support Center (888) 508-6978 www.aventisbehring.com **FREE.**

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



Diane Dino's Exploring Activities Kit

Aventis Behring. AB Choice Member Support Center (888) 508-6978 www.aventisbehring.com **FREE.**

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

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.**

Explains basic concepts about hemophilia symptoms, diagnosis, medication, monitoring, lifestyle, joint bleeds and genetics. Features “Dom” the Domino. Text with some illustrations, and music. Accompanies *Learn About Hemophilia Coloring Book*. Age ten and older, or anyone new to hemophilia. PC or Macintosh format.



The Basics of Gene Therapy

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

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



Infusion Tracker

NuFactor, 1093 County Center Drive, Temecula, CA 92591 (800) 323-6832 www.nufactor.com **FREE.**

Software program helps patients record, analyze and visualize bleeding episodes for selected range of dates, on color-coded map of the body. Helps patients identify target joints; track prophylaxis schedule effectiveness; learn seasonal bleeding patterns; document factor usage and record lot numbers permanently; review statistics and print usage reports. PC or Macintosh format.

KITS

The following three kits are available FREE from Baxter BioScience, 1627 Lake Cook Road, Deerfield, IL 60015 (800) 423-2090 www.hemophiliagalaxy.com



Home Infusion Kit

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



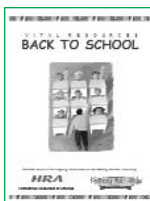
Self-Infusion Kit

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



The Zack Pack

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



Back to School Kit

Hemophilia Resources of America, Inc., PO Box 2011, 45 Route 46 East, Suite 609, Pine Brook, NJ 07058 (800) 591-KIDS www.hrahemo.com FREE.

Contains resources to educate children and schools about hemophilia. For parents, school nurse, classroom and gym teachers.

PROGRAMS



Karing for Kids: Innovative Learning

Hemophilia Resources of America, Inc., PO Box 2011, 45 Route 46 East, Suite 609, Pine Brook, NJ 07058 (800) 591-5437 www.hrahemo.com/about/karingforkids.html

Helps children with hemophilia and their families gain confidence and control in managing hemophilia. Live workshops, educational resources and other services. *PARENTLine*[™] toll-free number provides support, education, resources and advice on parenting issues. *Kids' Corner* resource library and *Kids' Workshops* activities teach children about hemophilia. Directed by Diane Horbacz, M.A., M.Ed.



The PEP Program (Parents Empowering Parents)

www.pepprogram.org Funded by Bayer Corporation, Biological Products.

Peer-to-peer skills program helps parents improve parenting skills, understanding and confidence. Topics include therapeutic relationships, response to bleeding episodes, behavior management, discipline and self-esteem. Team presentations by parents of children with bleeding disorders, social worker and nurse offer peer support and professional expertise. Available at select US HTC's.



The Kids on the Block Program on Hemophilia

Kids on the Block, Inc. 9385-C Gerwig Lane, Columbia, MD 21046 (800) 368-KIDS www.kotb.com Developed in conjunction with and funded by Bayer Corporation, Biological Products.

Entertaining life-size puppet programs teach children about hemophilia, treatment, functions of blood, myths, and social and parental issues. Encourages sensitivity to others; helps create positive attitude and behavioral changes. Four scripts available: *Garbage Pals* (Grades 3–6), *Trips Don't Always Lead to Falls* (Grades 3–6), *Back to School* (Grades 3–6), *Our Busy BUSY Blood!* (Grades 1–3). More than 1,000 puppet troupes worldwide.



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

Bayer Corporation, Biological Products, 400 Morgan Lane, West Haven, CT 06516-4175 www.bayerbiologicals.com Available in Canada only.

Friendly dinosaurs Kogee and Kojo help children learn about hemophilia and life. Club members receive regular newsletters with educational activities, stories, puzzles, holiday and birthday treats, and a diary. Certificates awarded for improving and mastering self-infusion. Members attending one of many Canadian summer camps receive Club knapsacks. Postage-paid enrollment cards available at Canadian HTC's.

news notes

CSL to Acquire Aventis Behring

Australian biopharmaceutical company **CSL** is acquiring **Aventis Behring** to combine with its ZLB Bioplasma operations by mid-2004. The new organization, **ZLB Behring**, will be managed from the head office in King of Prussia, Pennsylvania. Both companies are considering all options regarding their future joint product lines, with patients' needs a top priority. ZLB Behring will retain Aventis Behring's distribution agreement with Bayer, and will have long-term access to recombinant factor VIII, which Aventis Behring sells as Helixate[®]FS/NexGen[®]. The new company will continue to have direct access to high-quality plasma through its plasma collection and testing organization; and will continue to support patient and community activities.

For more information visit www.aventisbehring.com or www.csl.com.au

Source: *Aventis Behring and IBPN, December 2003*

vCJD Transmission Risk Very Low in US

The **Plasma Protein Therapeutics Association** (PPTA) recently announced that there is no evidence that plasma therapies can transmit variant Creutzfeldt-Jakob disease (vCJD), the human form of mad cow disease. According to the PPTA, the disease is most commonly transmitted by eating infected beef or beef products. The announcement comes after a recent report of a possible 1996 UK transmission of vCJD through a blood transfusion, occurring before vCJD safeguards were applied to Britain's blood safety. The PPTA states that the manufacturing process applied to plasma therapies effectively removes infectious agents thought to be responsible for vCJD transmission. In addition, US collection centers have a number of precautionary measures for vCJD; most notably donor deferral for people who have traveled to the UK, France and certain other European locations during critical time periods.

For more information visit www.pptaglobal.org or www.hemophilia.org

Source: *Plasma Protein Therapeutics Association and the National Hemophilia Foundation*

Online correspondence reprinted with permission of contributors, through the Bleeding Disorders mailing list at <http://groups.yahoo.com/group/Bleeding-Disorders>.

Port Surgery:

What Should You Expect?

Q After our son suffered several bleeds in rapid succession, our doctors determined that he has severe hemophilia, not moderate. At his last checkup, the doctors asked us to consider having a port inserted when he is 18 months old, or after his first joint bleed. The very next morning, he woke up with a joint bleed! We took him to the ER two days in a row because the first catheter came out and we needed another inserted; then we treated him at home for three days. With our doctor and nurse, we decided that we didn't want to continue the trauma of ER visits and catheters, so we scheduled our son's port surgery for later this month. I mistakenly thought that we would never have to worry about a port or prophylaxis! Our lives have done a 180-degree turn in the past two weeks, and I'd like some advice. What should we bring to the hospital for our son? What will happen before, during and after surgery? The doctors mentioned home health care, and something 'sticking out of his chest' until he heals. It's all a blur, and I feel overwhelmed.

Heather Quigley

WASHINGTON

[A] WHEN WE TOOK IAN in for his first of two port surgeries, we brought videos, his favorite stuffed animals, CD player and CDs. I tried to make his room feel as much like his own as possible. Ian didn't seem concerned by the surgery, and was up and active when he returned from recovery. Ian had an inhibitor, so they worked to increase his factor levels before surgery. This required several boluses of factor administered through an IV, which was the worst part of the process. Once his factor levels were up, Ian's surgery was performed. For us, one problem was the need to check his factor levels through the IV; unfortunately, Ian's IV had to be reinserted because

he was so active. Ian was hospitalized for a week because of his inhibitor, and we learned to access his port in the hospital.

The 'something sticking out of his chest' is the access needle, used to infuse medicine into the body through the port. It will probably be kept in the port until your son is released and sent home, when you'll be taught to access it. I believe it's essential to learn to access a port. For families, the great power of the port is being able to treat your son when you think it's necessary without going to the ER. We were told that we could leave the port accessed up to seven days, but I don't recommend this because Ian suffered several portinfections. For the first few weeks after surgery, the tissue

will be tender, so the less you have to access it the better the site will heal. However, leaving it accessed is an invitation to bacteria, so keep the site as sterile as possible. If your son is getting the port for prophylaxis, leaving it accessed probably won't be an issue. It might help to ask to see someone with a port for a demonstration of its use. I now wish we had asked for this before our surgery. Although your life has changed, the good news is that you'll be able to care for your son at home and reduce your ER visits. The port has greatly normalized our lives. Keep asking questions!

Kathy Mackay
GEORGIA

[A] WE WENT THROUGH PORT

surgery when our son Stephen was nine months old. I have learned that every HTC does things differently, but our HTC sent Stephen home from the hospital with the port accessed and the needle still in. A nurse came to give him infusions twice a day for the first few days, then daily for a week. It's not as scary as it sounds. I was scared at first—but looking back, it was no big deal. We still haven't learned to access the port ourselves, but that will change. We felt uncomfortable doing it ourselves, but now we're almost comfortable with attempting to access the port.

Leslie Houwenagle
KENTUCKY

[A] MY SON HAS SEVERE

hemophilia A, and got his port when he was 15 months old. My homecare company had shown me exactly what different types of ports look like under the skin. I was more interested in how the port would feel, and if pushing on it would bother him. He's now 20 months old, and the port just barely shows under his skin. I can feel it when I push on it. It doesn't bother him to touch it, and he 'plays' with it when his shirt is off.

So you'll know what to expect, ask your surgeon about port placement: some ports are in the middle of the chest, some on the side, some low on the chest. After my son's surgery, I was surprised at how well he did. He was playing within two hours. His port was accessed for five days.

Bring to the hospital anything that your son loves and will miss. Most hospitals have high chairs and swings. Our hospital doesn't provide food for parents, so take some snacks. Most floors have a microwave and refrigerator. Your family members will love to bring

things, so ask for goodies or meals. Ask people to schedule their visiting times. The first time we were in the hospital, the room was packed with visitors every evening but no one stopped by in the morning! So we asked people to visit during the day if possible. Ask your hospital about its services: laundry, and volunteers to stay with your son while you take a shower, meal or walk. You may be surprised at the services hospitals offer.

Even at age nine months, kids can feel when we're nervous, and that affects them. So before you go to the hospital, get to where you feel comfortable. Take a day, or even a few hours, for yourself—to relax, and believe that your son and family will be well cared for.

Randi Clites
OHIO

[A] WHEN ELISHA WAS

diagnosed as moderate, I was told repeatedly that we should be glad he wasn't severe. Then he was re-diagnosed after a nasty arm bleed. Luckily, our hematologist stayed with me for nearly an hour while I tried to calm down and absorb everything she said. No wonder you didn't catch the details about the port! Here's the way our Boston HTC does it: the operation takes about an hour under general anesthesia. You walk your child into the operating room and stay until he goes to sleep, if you're calm and the anesthesiologists agree. They gave Elisha something to relax him and he giggled, then fell asleep while I sang him a lullaby. I left the room when the anesthesiologists were about to insert an oxygen tube into his mouth. Then I waited.

About an hour later, the surgeon tells you it's over. Your son is moved to a post-anesthesia unit, where they monitor him and call you when he

wakes. He'll be sleepy and a little red in the face from the anesthesia. The port will probably be accessed, with a needle in it. This won't bother your son, because these needles are bent at a 90-degree angle so the external part lies flat on the skin. There will be a bandage on top, and a tube trailing out from the bandage. The tube is attached to the needle. I advise you to learn quickly how to use the tube—it's just like an IV.

Unfortunately, we had an infected port before we left the hospital. One way to protect against that is to give all medications yourself, with clean hands and an alcohol wipe *every time*. Sounds simple, but nurses cut corners when they are rushing—and they're always rushing! Our nurses respected my wish to be the one handling the tube, and liked handing me a syringe to administer the factor. I explained that my taking control was part of the learning process, and nobody minded.

Your son will feel tired for a day, then he'll be bouncing around again. When we recently had a port inserted, Elisha lay in bed and watched videos for 24 hours, then hopped up and started prowling the hospital halls. We were home within 48 hours of the surgery (even with an inhibitor), and the port stayed accessed for five days. Then a nurse arrived, de-accessed the port and showed us how to access it. Elisha didn't need pain medications for either port.

Books on ports are available, with nice pictures. I wore a mask and put Elmo to sleep, then gave him a 'port'—a big round button that Elisha watched me sew into his chest. We used empty syringes to give Elmo 'factor,' always cleaning him with 'alcohol' first.

Ziva Mann
MASSACHUSETTS

[A] MY SON WAS EIGHT

months old when he got his first port, and 15 months the second time. I went into the operating room for both port surgeries. Of course they don't want hysterical parents, so you have to be calm. I held my son while they put the gas mask over his face. I enjoy going in, but my husband doesn't—it's not for everyone.

It's nice to be familiar with the hospital, so visit first if you can. It's helpful to know about parking, cafeteria hours and available services *before* the day of surgery.

We don't have an HTC. Make sure it's clear whether you or your hospital will supply the factor. Before surgery, make sure you have enough factor and supplies at home. Find out how long your son must go without food prior to surgery, and try to get an early morning surgery time. Babies don't like to go without food for too long.

Get the needle out of your son's chest as soon as you can. The needle was left in the first time we had a port placed, and that was the start of our infection problems.

My son was upset when he first woke up from surgery. After the first surgery, he was groggy and slept all day—they used morphine. For his second surgery, they used fentanyl and he was walking around within 90 minutes of surgery.

The port normalized our lives. However, be prepared: it will take some time to get used to infusing him yourself, just as it took time for you to get used to his diagnosis.

Sandy Knight
CALIFORNIA

[A] AFTER MY SON'S FIRST

port became infected and was finally removed, we switched HTCs. When we finally considered another port, the staff at the new HTC told us that they *never* access a port until it's had a month to heal; and they *never* leave a needle in place because of an increased risk of infection. I don't know whether any recent studies have been done on this. I do know that kids with inhibitors are at higher risk of infection, but I still get cold chills when I hear about a port being accessed immediately after surgery. If you can imagine seeing pus pouring out of the needle site and down your kid's chest after you've removed the needle, you'll understand why I feel this way. I think you should at least ask the doctors at the HTC whether they know of any recent data about this issue. And yes, my sterile technique is wonderful.

Laura Chalfin, M.D.
NEW YORK

[A] CHASE'S SURGERY WENT

better than I expected, despite some problems. Since your son is so young, don't let them make you wait in the OR! We had to wait for three hours after the scheduled surgery time due to an emergency. Bring toys, books, videos, snacks, coins for vending machines and cash for the cafeteria. It's scary to think of your son being in surgery, but the benefits are worth it.

Andrea Scarano
MARYLAND

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www.hemophiliagalaxy.com
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800-800-6606
www.HemophiliaHealth.com
info@hemophiliahealth.com

→ 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.

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