



# Hemophilia Library

Updated 3/17/11

The following is a list of materials currently in the BioRx library. You may order any of the books, brochures, booklets, videos or DVD's through our main office free of charge. Call 1-866-442-4679 to order or request something that is not on our list. We will do our best to find it for you.

## Books about Living with Hemophilia

1) Kelley, Lauren Raising a Child With Hemophilia: A Practical Guide for Parents Edition 4, September, 2007

This is an excellent book written by a parent, for parents, with other parent comments, opinions, and advice. This is a great book for newly diagnosed parents.

2) Kelley, Lauren Empower Yourself About Hemophilia: How to be more effective and less victimized (*Temporarily Out of Stock*)

This is a great book to help parents adjust to the diagnosis of hemophilia. How to avoid victimization, set new goals, identify feelings, and accept responsibility.

3) Paper, Renee, R.N. with Kelley, Lauren A Guide to Living with von Willebrand Disease 2006 (*Temporarily Out of Stock*)

The world's first book on the world's most commonly inherited bleeding disorder. Covers learning to cope with vWd inheritance.

4) Kelley, Lauren Teach Your Child About Hemophilia

This new book, formerly known as "My Blood Doesn't Have Muscles" is about teaching hemophilia in a developmentally appropriate manner. Based on interviews with 100 hemophilia patients, ages 3-18.

5) Kelley, Lauren Tell Them the Facts 1995

A question and answer book on hemophilia for pre-adolescents and adolescents.

6) Kelley, Lauren Alexis: The Prince Who Had Hemophilia 1992

The true story of Alexis, the youngest child of Russian Tsar Nicholas II and how his hemophilia influenced events ultimately leading to the Russian Revolution. Ages 8 and up.

7) Kelley, Lauren Must You Always be a Boy? (1991)

Four fun and entertaining fictional stories about how a child (or cute monster) deals with having hemophilia. It is recommended for ages five to ten.

8) Kelley, Lauren They Will Probably Ask You..."What is Hemophilia? (2001)

This book is a child's perspective about what hemophilia is and how to tell someone who may not know anything about bleeding disorders. It is fun and interesting for ages seven to eleven.

9) Kelley, Lauren Joshua: The Knight of the Red Snake (2001)

Joshua is a typical young boy who loves to play pretend with his friends. But when he falls and hurts his knee, he shows his friends the real world of treating a bleed. This book is entertaining for young children aged three to seven.

## Booklets and Brochures from the National Hemophilia Foundation

10) The following are a series of brochures by the National Hemophilia Foundation:

- A. FAST FACTS
- B. Frequently Asked Questions About Hemophilia
- C. Inheritance of Hemophilia Fact Sheet

11) Caring for your Child with Hemophilia

This thirty one page booklet is written to give an overview of hemophilia, treatments, common bleeds and injuries, as well as, tips for babies and toddlers with hemophilia. There are sections about nutrition and dental care that is helpful also.

12) The Child With a Bleeding Disorder: First Aid for School Personnel (*Temporarily Out of Stock*)

Guidelines for treating specific bleeding episodes that may occur in school.

13) The Child With A Bleeding Disorder: Guidelines for Finding Childcare

This pamphlet contains guidelines and general information about childcare options. It stresses the importance of knowing the kinds of care available and the specific needs of a child with a bleeding disorder.

14) Inherited Bleeding Disorders And Child Abuse Investigations (1998)

This is a resource for day care and school personnel, healthcare workers, and emergency room providers. Many children are diagnosed with an inherited bleeding disorder after an investigation of suspected child abuse. This brochure gives information about hemophilia and Von Willebrand Disease.

15) A Guide for Women and Girls with Bleeding Disorders (1998)

Written by Jill Williams

This forty seven page booklet helps woman and girls who may have signs and symptoms of a bleeding disorder. There is information about bleeding disorders, and discussions about treatments and living with a bleeding disorder.

16) Inheritance of Hemophilia (1998)

This booklet is designed to teach people about the inheritance of hemophilia by giving a brief history and discussing the causes of hemophilia. There are helpful tables and graphs of Queen Victoria's Family Tree and tables of chromosomes explaining how a gene is affected.

17) The Treatment of Hemophilia: Current Orthopedic Management (1996)

This booklet is a very extensive and intensive study in orthopedic manifestations, explaining that the most common site of bleeding in a person with hemophilia is into the musculoskeletal system. Further explanation about how to treat the problems with bleeding into these areas is discussed.



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## Von Willebrand Disease (VWD)

**18)** The following are FAQ's about von Willebrand Disease:

- A. Stay Healthy... Stay Active: Important information for boys with von Willebrand disease  
CSL Behring, 2007
- B. Stay Healthy... Stay Active: Information for girls about VWD and menstruation. Regular physical exercise and the importance of it to maintain good health
- C. Can We Talk?  
Von Willebrand disease, menstruation, and your daughter  
CSL Behring, 2007
- D. Von Willebrand Disease: A Patients Guide to Understanding  
CSL Behring, 2007

## Living with HIV/AIDS and Hepatitis

**19)** My Parents Have HIV/AIDS: Some Advice from an Eight-Year-Old (1994) By Stephanie and Kathy Gerus (available in Spanish)  
This is a very personal account of hemophilia and HIV/AIDS written and illustrated by a young girl for other young people. It explains HIV and AIDS in very easy-to-understand terms.

For more information on AIDS/HIV, go to <http://AIDSinfo.nih.gov>  
Or contact AIDS Information Service at 1-800-448-0440

- 20)** Take Care of Your Liver  
Sponsored by Hepatitis Foundation International  
This brochure teaches the many roles of the liver, and gives six concrete steps to take care of your liver.
- 21)** Living with Hepatitis C: A Survivors Guide by G.T. Everson, MD and J. Weinberg  
Sponsored by Hepatitis Foundation International  
This hard cover book is an invaluable tool with new information on the latest treatments including Ribavirin with new chapters on hepatitis C and women and children with HIV. This book brings help and hope to those with the disease.
- 22)** Liv and Lucky in Liverland (DVD)  
Sponsored by Hepatitis Foundation International  
This cartoon animation teaches kids from an early age how to take care of their liver.
- 23)** The Invisible Threat (DVD)  
Sponsored by Hepatitis Foundation International  
This twelve minute DVD has information about effective prevention education, a look into the development of health policies, and promoting healthy life styles.

## Games, Activities, DVD's and Videos

- 24)** A Long and Happy Life The Great Lakes Hemophilia Foundation Sponsored by the National Hemophilia Foundation, 2004  
This twenty minute video gives parents advice on how they can best prepare a child who has a bleeding disorder transitioning from childhood to adulthood. The advice from parents for parents is on a very personal level.
- 25)** The Baxter Factor by Baxter Healthcare Corporation  
\*Spanish version *only* available\*  
This is a memory challenge card game for children ages 5 and up. The pictures on the cards have something to do with living with hemophilia.
- 26)** Living Fit Program DVD Kit & Living Fit Program Brochure  
A new series from Bayer Healthcare to inform bleeding disorder patients in how to live a healthier lifestyle and become more fit. The brochure identifies problems with excess weight on joints resulting in more bleeds and the DVD kit contains ways in which to combat both.
- 27)** EZ Log Overview Video – CD-Rom(PC Format)  
By Bayer Healthcare and Kogenate FS  
Slide this CD into your computer and view a quick overview about using the EZ Log. The EZ Log is free to all patients who use Kogenate FS and helps the patient (or the parents) record infusions accurately and easily.



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## Booklets and Brochures from World Federation of Hemophilia

- 28) What is Hemophilia? (booklet)  
An Introduction to Gene Therapy
- 29) Growing Up with Hemophilia: Four Articles on Childhood
- 30) Hepatitis C Infection and its Management
- 31) Inhibitors in Hemophilia: A Primer
- 32) Oral Care for People with Hemophilia or a Hereditary Bleeding Disorder
- 33) Protocols for the Treatment of Hemophilia and vonWillebrand Disease
- 34) The Pain Management Book for People with Hemophilia and Related Bleeding Disorders
- 35) What is VonWillebrand Disease? Published by the World Federation of Hemophilia (WFA) 2008
- 36) Symptomatic Carriers of Hemophilia by Eveline P. Mauser-Bunschoten, Utrecht, The Netherlands published by WFA
- 37) Plasma-Derived and Biotech Products: What is the Future of Haemophilia Therapy? By Brian O'Mahoney, President, WFA
- 38) Dental Management of Patients with Inhibitors to Factor VIII or Factor IX by Andrew Brewer, Glasgow, Scotland

**For more information from the World Federation of Hemophilia go to: <http://www.wfh.org/index.asp?lang=EN>**

## Additional Titles for Adults and Children

- 39) Bob the Puppet Goes to School  
By Wyeth, 2006  
This is a book about the puppet, Bob, who goes to school and makes lots of friends, learning about all subjects, and making arts and crafts.
  - 40) Bob the Puppet Takes a Trip  
By Wyeth, 2006  
Bob takes a trip with his family and some friends. He learns that planning and being prepared for a bleed is very important in his life.
  - 41) I am Nate! By Chris Perretti Barnes  
Nate tells his own personal life story of what his life is like in preschool and at home. Everyday activities make Nate feel like a big kid, including helping his parents infuse him with factor.
  - 42) The Great Inhibinator by Chris Perretti Barnes  
Six year old Nate Bowen becomes powerful over his diagnosed inhibitor by creating a Halloween costume out of his imagination and then goes out trick or treating. Funded by Grant from Bayer Healthcare (2<sup>nd</sup> in the Nate Series)
  - 43) Quest For Infusion: Nate Goes to Camp by Chris Perretti Barnes  
Ten year old Nate Bowen goes to hemophilia camp and discovers talents he didn't know he had. Nate also learns to infuse himself and helps others as well. (2009, by Bayer Healthcare)
  - 44) Your Child's Hemophilia (series by CSL Behring Choice Support Center, 2001)  
This three part series is for parents about what to expect during different phases of a child's development. The series includes the titles, *Your Child's Hemophilia*, *What to Expect During Infancy*, *What to Expect During the School Age Years*, and *The Young Adult Years*.
- ### My First Factor (series), Shannon Brush
- LA Kelley Communications, Inc. 2008, 2010, 2011:
- 45) My First Factor Words  
One-word concepts about family and hemophilia.
  - 46) My First Factor: Week  
Regular infusions helps a toddler stay active.
  - 47) My First Factor: Fitness  
Yoga, playing, laughing and good food keep a toddler healthy.
  - 48) My First Factor: Infusions  
What are the steps in an infusion? A first look for toddlers.
  - 49) My First Factor: HTC  
Who does a toddler meet at the HTC?
  - 50) B2B Speaking from Experience (2006)  
The Coalition for Hemophilia B ([www.coalitionforhemophiliab.org](http://www.coalitionforhemophiliab.org))  
This colorful booklet for adults and teens shares personal experiences of factor IX deficient patients. Developed using recommendations from Wyeth Consumer Advisory Board.
  - 51) Radionuclide Synovectomy Procedure: A Patient's Guide  
A patient educational guide produced in cooperation with South Texas Hemophilia Treatment Center's Radio Synovectomy Program and BioRx, LLC
  - 52) Exercise Healthy Joints by Bayer Healthcare  
This print material accompanies the Living Fit Program series on helping those with bleeding disorders find ways in which to combat bleeding into joints and maintaining a healthy lifestyle with exercise and healthy eating habits.



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- 53) Managing Your Child's Inhibitor** by Laureen A. Kelley with Paul Clement

This book compiles research, treatment information, and the stories of 40 patients and families to help you know better what to expect when you child is diagnosed.

*The following paperback books are a series of manuals for children and their families about the symptoms and treatment of Hemophilia. They are designed to help children understand their bleeding disorder in a unique way. They are written by Joanna A. Davis, MD and sponsored by Baxter Bioscience:*

- 54) Understanding Hemophilia**
- 55) Shoulders, Elbows, Knees, and Toes**
- 56) My brother has Hemophilia**
- 57) I Have Von WilleWhat?**
- 58) I Can Do It Myself!**
- 59) Everyone Can Learn Something**
- 60) An Inhibitor? What's That?**
- 61) What's Immune Tolerance?**

## Materials for the Spanish Speaking Community

- 62) Playing It Safe: Bleeding Disorders, Sports and Exercise** Brochure by the National Hemophilia Foundation  
(written in both English and Spanish—please specify)

- 63) VWD: Just the FAQ's** (2000) Spanish version by NHF

- 64) NHF National Preventative Program: 5 Key Steps Today for Giant Strides Tomorrow**  
(written in both English and Spanish - please specify)

- 65) Raising a Child with Hemophilia in Latin America (2006)**  
By Laurie Kelley