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PEN'S BIENNIAL BLEEDING DISORDER RESOURCE GUIDE 2017

Jessica O'Donnell

BOOKS

Raising a Child with Hemophilia: A Practical Guide for Parents (5th ed.)

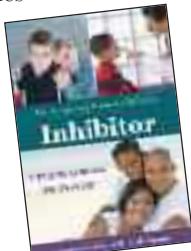
Laureen A. Kelley
LA Kelley Communications, Inc. 2016
Free to hemophilia families
www.kelleycom.com



Fifth edition of the world's first parenting book on hemophilia written by a parent of a child with hemophilia. Practical, easy-to-understand info on medical treatment, genetic transmission, child development, consumer issues, school, sports. Includes advice from experienced parents, compiled from interviews with more than 180 families. Sponsored by CSL Behring.

Managing Your Child's Inhibitor: A Practical Guide for Parents

Laureen A. Kelley with Paul Clement
LA Kelley Communications, Inc. 2010
Free to inhibitor families
www.kelleycom.com
World's first book on inhibitors. From parents' and patients' points of view, extensively covers



topics including pain management, surgery, family life, treatment.
Sponsored by an unrestricted grant from Novo Nordisk Inc.

Success as a Hemophilia Leader

Laureen A. Kelley
LA Kelley Communications, Inc. 2008
New edition coming in 2017!
English, Spanish
Free to qualified Hemophilia Leaders
www.kelleycom.com



World's first guide to founding, managing, and growing a grassroots hemophilia organization, or improving an existing one. Advice on creating vision and mission, forming a board, fundraising, producing a newsletter, programming, establishing an office, working with a medical advisory board. Sponsored by Grifols.

This is a sampling of the many resources available in the bleeding disorder community. Because these are less well publicized, most are non-NHF. Find more resources by viewing the publications or resources section of each website, or by contacting the company or organization (see p. 15).

Hemophilia

Michelle Raabe
Infobase Publishing 2008
amazon.com

Detailed, colorfully illustrated, easy-to-read book focusing on the science behind hemophilia treatment, symptoms, genetics. Includes stories of hemophilia's history; how various treatments are made, such as plasma-derived and recombinant; how gene therapy might work.



The Gift of Experience: Conversations About Hemophilia

Laura Gray, LICSW,
Christine Chamberlain
Boston Hemophilia Center 2010
Free from NHF; amazon.com



Compilation of personal stories from 21 hemophilia patients born before 1965 and caregivers who treated them. Practical info, guidance, support, insight into caregivers' struggles and achievements.

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welcome



While Christmas shopping, I marveled at the huge Barnes & Noble store at the mall. I thought, *Books are alive!* And the statistics back me up: a Pew Research Center survey* found that when Americans reach for a book, it's usually a traditional print book. In fact, 65% of Americans have read a print book in the past year, more than double the number who read an e-book (28%). But overall, the number of books (of any type) that we read each year has stayed the same since 2011, when Pew began tracking this stat: on average, Americans read 12 books per year.

I love print media, and it's our core business—bringing information to families with bleeding disorders. I see videos about hemophilia come and go, programs rise and fall, but books

like *Raising a Child with Hemophilia* are still here—in our case, after 26 years. Our new fifth edition, just released, took us 40 revisions and many months to review, because we wanted and needed to get it right. To me, that's one of the beauties and challenges of publishing: committing something to print means you're putting your reputation on the line. It's exciting and scary!

Raising a Child with Hemophilia may have set the standard back in 1991 when it was first published, but it's certainly not the only printed source on bleeding disorders. One reason we supply this Biennial PEN Resource Review is to show you how many great books—and videos and programs—are available. Check them out. We're committed to keeping all our books in circulation, and to providing even more in the coming years. Published information is vitally important, and reading is enjoyable and thought provoking. Consider ordering some of the free resources mentioned here...and pick up a best seller at your favorite bookstore! ☺

Laurie

* <http://www.pewinternet.org/2016/09/01/book-reading-2016/>

inbox

I HAVE SEVERE HEMOPHILIA A and was born 86 years ago in Newton-Wellesley Hospital, Massachusetts. When I was staying with grandparents in Brighton as a child, a young doctor, Louis Diamond, would take a trolley to Oak Square and come to the house to see me. My family moved to Connecticut in the early 1930s. There I was under the care of an exceptional pediatrician, Dr. Robert Salinger. I spent a great deal of my youth in hospital, as they had little idea how to treat bleeding episodes.

My world changed with the advent of factor. Though there have been many ups and downs, multiple surgeries, HIV, hepatitis C, I think I have been most fortunate. During the last 40 years, I have been able to travel a lot, live in foreign countries, teach in university, and enjoy a marvelous family. Wherever my journeys have taken me, I have attempted to participate in local hemophilia societies. All in all, it has been a remarkable life.

Warren Jewett

NORTH CAROLINA

THANK YOU SO MUCH FOR your articles. They are a great resource and perfect to include in our newsletters.

Ursela Lacer

Executive Director

KENTUCKY HEMOPHILIA FOUNDATION

MY SON, DAUGHTER-IN-LAW, AND I enjoyed so much the two PEN samples you included in my shipment of free books. The books are all amazing and I can't put down PEN. So many excellent, informative articles. So many of the people posting in Hemophilia Mother on Facebook could really benefit from these. You perform a great service to the hemophilia community and I thank you.

Helen Korn

ARIZONA

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PARENT EMPOWERMENT NEWSLETTER | FEBRUARY 2017

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PEN is a newsletter for families and patients affected by bleeding disorders. PEN is published by LA Kelley Communications, Inc., a worldwide provider of groundbreaking educational resources for the bleeding disorder community since 1990.

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as i see it



Evolution of Learning: From Print to Person to Social Media

Rita Epstein

In 1988, my 14-month-old son Nathan suffered a traumatic internal bleed that caused our pediatrician to refer us to a hematologist in New York City. At this point, I truly believed that my son only needed a shot of vitamin K. The word *hemophilia* was in my vocabulary but not in my family history or experience. After all, no one in our family had hemophilia. The pediatric hematologist in New York arrived at the official diagnosis through repeated lab work. She was not a hemophilia specialist and left us with a very pessimistic prognosis that included head bleeds, permanent injuries, even potential early death.

I went home to read the only reference book I had in my library: a 1957 edition of *Encyclopedia Britannica*. As far as I was concerned, hemophilia was a death sentence.

I immediately and thankfully called the hemophilia hotline that was in my local phone book—the second book I referred to after the encyclopedia! Tom Harrington, “guru” of Hemophilia Association of New York (HANY) at that time, called me back within seconds and would not get off the phone until he updated me on 30 years of changes in the medical field. He connected me to the Regional Hemophilia Treatment Center at Cornell Medical Center, where Dr. Margaret Hilgartner protected and advocated for “her children.” Tom also connected me to Isabel Brach, social worker extraordinaire at HANY. These wonderful people not only changed our lives, but I believe saved them. They talked me off the ledge.

Soon, support and information gathering and sharing began in full force, as well as a sense of collaboration and hope. In 1990, Laurie Kelley was just beginning to publish a small newsletter, PEN (in those days, the *Parent Exchange Newsletter*). Her articles, and the opportunity for me to write articles, were enormously reassuring. Then came the books! *Raising a Child with Hemophilia* connected so many families with hemophilia in the United States. Many more books followed over the years, for adults and children.

Our children now had storybooks about kids just like them. They were prepared for a slightly less typical medical journey than most children experienced. They could share these books in their classrooms. Our children felt special—after all, books were being written about them!

New York Hospital–Cornell Medical Center created workshops, social gatherings, and mentoring groups for parents. All of a sudden, we were nodding our heads in agreement, making eye contact, giving hugs, and watching our children thrive.

We could observe older children with hemophilia who were healthy. We could reach out and support newer members. Our children were not alone.

National Hemophilia Foundation annual conferences became more family and child centered. There were workshops just for children. Industry stepped up to create programs, supplies, and information that were more and more user friendly. There were smiles and laughter when we all met. There was hope.

Then, in 2004, came social media. I respect and use social media. I consider myself technologically comfortable when researching, meeting people, and communicating on social media. But there’s a difference between reading people’s posts of despair, confusion, and fear, and hearing them on the phone or being there to hug them and tell them it’s going to be all right. I remember calling some of my seasoned hemophilia moms early on and literally describing the bump, limp, and pain. We were all available day or night.

Certainly, social media has a place in our hemophilia world. We are now able to support our families internationally. Through Facebook, emails, and other social media options, families all over the world can share their experiences and look for support. Our village has become much larger. We are now able to respond to a parent’s moment of utter despair in almost real time.

The Internet is filled with the good, the bad, and the ugly about hemophilia. As always, it’s imperative that we become educated consumers. We need to keep asking the hard questions: Do I have the right to advocate for my child and request a different protocol? Can I change medical facilities? Can I explore insurance coverage that meets my child’s unique needs? We need to feel entitled to call and reach out to our doctors and nurses with



Rita's son, Dr. Nathan L. Rosenblum

Inhibitor Resources Guide 2017

Paul Clement

People with inhibitors greatly need educational materials: to help them learn to manage their condition effectively, and to minimize the impact of secondary complications such as joint damage. Here are resources, some not mentioned in PEN's feature article, produced especially for people with inhibitors.

BOOKS

A must-read for anyone with inhibitors is our own *Managing Your Child's Inhibitor: A Practical Guide for Parents*. This 279-page book is free to inhibitor families. Not only is it the most comprehensive book available on inhibitors, with in-depth coverage of everything you need to know, but it's the only book written from the point of view of parents and patients—and in clear, understandable language.

Canadian Hemophilia Society (CHS) has two books available for download: the 62-page *All About Inhibitors* and the 93-page *Challenges, Choices and Decisions: A Guide on Orthopedic Surgery for People with Hemophilia and Inhibitors*.

And don't forget children's books on inhibitors! Designed to help familiarize children with their bleeding disorder, these books will also encourage parent-child discussion about coping with the disorder. Read our review of *The Great Inhibinator* on page 13. And a great combination comic book and coloring book is *Summer Fun with Jake and Alex: An Activity Book for Kids with Inhibitors*. This colorful 28-page book tells the story of two brothers, Jake and Alex, who both injure a joint. Jake gets better after a factor infusion, but Alex does not. Alex learns he has an inhibitor and will need a different type of treatment. The book includes guidance for parents on talking to children about inhibitors.

WEBSITES

Several websites provide information to parents and individuals with hemophilia and inhibitors. Most are run by bleeding disorder advocacy organizations, pharmaceutical companies, or government health agencies. One caveat: although most pharma company websites provide a balanced view, others are thinly veiled marketing tools. Look for the sponsoring organization when reading info online: if the organization is in the business of selling products to consumers, be wary of bias. Detecting bias may not be easy—some websites are “unbranded” and may not mention their products or even the company name. This tactic can be used to mislead the reader.

National Hemophilia Foundation (NHF) is your go-to source for inhibitor information. Find basic inhibitor info for consumers and healthcare providers on the “Inhibitors and Other Complications” webpages. *Facts about Inhibitors* (2009)

Find It Online!

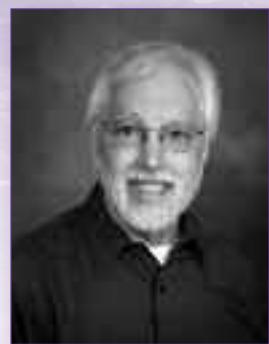
- *Managing Your Child's Inhibitor: A Practical Guide for Parents*
Laureen A. Kelley with Paul Clement. LA Kelley Communications, Inc., 2010 (new ed. forthcoming, 2017). Sponsored by an unrestricted grant from Novo Nordisk. www.kelleycom.com/managing_your_childs_inhibitor.html
- Canadian Hemophilia Society
www.hemophilia.ca/en/educational-material/printed-documents/inhibitors
- *Summer Fun with Jake and Alex: An Activity Book for Kids with Inhibitors*
Produced by Novo Nordisk. www.mynovosecure.com
- National Hemophilia Foundation
www.hemophilia.org/bleeding-disorders/inhibitors-other-complications
- Hemophilia Federation of America
www.hemophilafed.org
- World Federation of Hemophilia
www.wfh.org
- Centers for Disease Control and Prevention (CDC)
www.cdc.gov/ncbddd/hemophilia/inhibitors.html
- Know Inhibitors
www.knowinhibitors.com/us/1_about_inhibitors
- FEIBA.com
www.feiba.com/us/patient/hemophilia-inhibitors
- Inhibitorinfo.com
inhibitorinfo.com/en/web/inhibitors/home
- Novo Nordisk
www.mynovosecure.com

can be downloaded from HANDI, NHF's information resource center. NHF also hosts several programs, including Active Inhibitor Education Workshops. Inhibitor Education Summits, for people with inhibitors, cover most travel expenses for participants. These summits, usually held twice a year, are the only national educational forums for inhibitor patients to meet and learn about their rare complication. NHF also hosts Regional Inhibitor Education Conferences, where you can get together with healthcare professionals for a weekend of education to improve your health and quality of life; and free Inhibitor Education Webinars on advocating for your child, dealing with difficult bleeds, understanding disclosure, and fostering independence. And don't forget to search past issues of NHF's magazine, *HemAware*, for articles on inhibitors.

Hemophilia Federation of America (HFA) provides inhibitor info under “Inhibitor” in the “Bleeding Disorders” section of the website. Find recent news articles on inhibitors by searching for inhibitors under the “News and Stories” page.

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richard's review



Richard J. Atwood



© National Library of Medicine

Samuel Armstrong Lane

Treatment by Transfusion

Linda Weaver's Studio

The first reported successful blood transfusion in an attempt to treat bleeding due to hemophilia is truly a landmark historic event.

Samuel Armstrong Lane (1802–1892) submitted a long letter to the journal *Lancet* on September 28, 1840. The letter described *hemorrhagic diathesis*, now called hemophilia. Lane was a lecturer on anatomy and surgery at St. George's School in London, and had just met a hemophilic patient.

Probably in August 1840, 11-year-old George Firmin's father brought his son to the hospital to undergo surgery to relieve the "deformity of squinting." Lane performed the surgery unaware of George's bleeding condition—and no surgeon wants to be surprised by that news.

George bled more than usual and became faint during the minor surgical operation, but nothing else was noted. When bleeding subsided, George walked home at noon. Bleeding from his eye began 15 minutes later and continued for six or seven hours. That evening, after 30 minutes of effort, Lane successfully halted the blood flow for a brief remission. He then learned of George's bleeding history.

Twice in 1836, George had been admitted to St. George's Hospital with hemorrhages lasting 4 to 14 days after tooth loss. He also lost a lot of blood from a finger cut that was treated with pressure. In 1839 George had what Lane called an "affection" of the knee joint, which was treated with leeches at the hospital. Such treatment was common medical practice at that time, even for hemophilic patients. The leech wounds on George's skin would not easily heal, and were treated with needles, according to Lane, and ligatures (the tying off of arteries).

Back at home after his 1840 surgery, George continued to bleed from his eye—an alarming location for a bleed—with occasional intermissions for the next six days. The usual general and local remedies were applied; pressure and propping the patient in an upright position slowed the bleeding. By the sixth postoperative day, George's skin was pale and cold, and Dr. Lane could not feel George's pulse at the wrist.

Lane determined that his patient was dying of hemorrhage because his blood was "less disposed to coagulate." That evening at the Firmin home, Lane decided to transfuse blood with the assistance of surgeon Henry Ancell (1802–1863) and in the presence of several observers. At the time, blood transfusion was a risky procedure: some patients died from infection and reactions due to being infused with an incompatible blood type.

(Blood typing before an infusion would not be developed until 1910.)

Lane was prepared. He had already consulted the obstetrician and physiologist James Blundell (1790–1878) about blood transfusions. Lane obtained a commercially available tin-lined brass syringe, along with a funnel designed by Blundell to collect the blood and a pipe to insert into the patient's vein. A healthy young woman provided the blood from her arm vein.

For the actual transfusion—with no anesthesia—Lane made a one-inch incision parallel to George's vein at the bend of his elbow. He raised the exposed vein and opened it with a lancet (a sharp-pointed, usually two-edged instrument) before inserting the syringe pipe. The donated blood kept coagulating, so Lane washed the syringe four times. Still, only about half an ounce of blood could be pushed into the boy at each attempt. The young woman donated about 10 to 12 ounces (280–340 ml) of blood, of which George received about 5 ounces (150 ml), until the flow slowed from her arm.

Lane observed his patient for physical signs of distress. George's pulse returned immediately. After an hour, George sat up and drank a glass of wine and water. There was no more bleeding from his eye. The wound in his elbow healed in 10 days. George recovered his appetite and strength. He visited the country after three weeks, returning in a few days perfectly well, with his eye restored to the "straight position," according to Lane.

The blood transfusion was successful: the patient survived, even if the procedure was crude by today's standards. Yet some physicians have questioned the results. In 1981 Dr. A. D. Farr speculated that George Firmin did not have severe hemophilia, and that the lifesaving procedure by transfusion was more significant for partially restoring blood volume and oxygen-carrying capacity than for stopping the prolonged bleeding. Then in 1988, doctors D. J. Perry and A. MacWhannel proposed that the partial coagulation of the transfused whole blood generated an "activated clotting-factor complex" (possibly stimulating the clotting cascade, similar to using a bypassing agent for inhibitors, though it's unclear what the doctors meant), rather than a rise in factor VIII.

After George's case, Lane never published another article on hemophilia or on blood transfusions. He did not want to be considered a "specialist," though he maintained his lucrative practice of bladder stone surgery. And he later focused on medical education at St. Mary's Hospital of London.



Illustrating the Need for Early Education

Mike Nuckols

The diagnosis of hemophilia means facing much more than a bleeding disorder. It means questions, fears, and an overwhelming sense that life is out of control. The key to taking back control and to stop feeling like a victim of hemophilia: Education.

Meet three moms who went above and beyond to make sure their children got the education they needed.

Shannon Brush, Chris Perretti Barnes, and Ziva Mann all started their journeys as authors in a similar way: they set out to educate their children about hemophilia and found a huge gap. The educational materials they needed just weren't there. So they took matters into their own hands.



My First Factor (series)

Shannon Brush

Ages 0–3

The ten books in this series introduce the basic “sight” words that are central to life with hemophilia. Using a kid-friendly graphic style, these simple picture books take on the basics: what is hemophilia, infusions, HTC visits, and more.

Portraying hemophilia in a picture-book format helps normalize a child's situation. Children see these books and think, “It isn't just *me* with hemophilia.” That basic knowledge—that you're not alone—can make a huge difference.

These are all board books, so no worries about ripped pages. They're designed to be part of a child's everyday book collection, instead of being placed out of reach on a shelf.

Fathers with hemophilia have reported that the My First Factor books are also a great way to educate their own children about Dad's hemophilia.

Why Shannon wrote the books

Shannon was originally looking for a way to normalize infusions: “I noticed that the only time we talked about needles and factor was when we were on our way to the ER.” Her toddler had simple picture books with animals and colors, but Shannon saw the need for a book showing all the items associated with hemophilia—butterfly needles, alcohol wipes, factor vials. After publishing her first book, Shannon saw a larger need in the community: more books for toddlers! From there, the rest of the series followed.

Shannon's proudest moment

“I saw a photo of a boy in Guatemala. He had a bruise from a bleed and was in a fairly impoverished setting, but he was holding one of my books and had this big bright smile.”

One thing hemophilia has taught her

“Everyone has challenges in life. Hemophilia is just one of those challenges. You deal with it and go on with normal life.”



Guatemalan boy enjoying
My First Factor series



The Great Inhibitor (series)

Chris Perretti Barnes

Ages 4–13; main character ages through the series

Kids with inhibitors have to get doubly educated. They need to understand hemophilia, and then they need to understand how hemophilia with an inhibitor is different. The books in this series explain concepts at an appropriate level for kids. And they tell stories written to inspire kids to stand up to difficult situations.

The series starts with *The Great Inhibitor*. Readers follow Nate, the main character, on an exciting journey of empowerment that teaches the vital importance of education and attitude.

The other three books in the series show Nate's journey in dealing with other challenges. For example, when Nate goes to camp, readers see the impact life with hemophilia has on his two sisters (siblings can be an underserved audience in the bleeding disorder community). This book series is must-have for children with inhibitors.

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BOOKS CONTINUED

The Gift of Experience II: Conversations with Parents About Hemophilia

Laura Gray, LICSW,
Ziva Mann, Allie Boutin
Boston Hemophilia Center 2014
Free from NHF; amazon.com

Compilation of personal stories from parents and caregivers of hemophilia patients; offers insights into the daily life of raising a child with hemophilia.



Pooling Blood

Cheryl Nineff D'Ambrosio
iUniverse 2010
amazon.com

Personal recollection of a woman who raised two stepdaughters with factor V deficiency. Harrowing, poignant story of frustrations, fears, joys of raising a child with a chronic blood disorder.



Legacy: The Hemophilia of Yesterday

Matt Barkdull 2014
amazon.com

Possibly the first published diaries of hemophilia, the true story of a teenager with a passion for writing in a western farming community before World War II. He records his hopes, dreams of independence and romance, suffers excruciating pain, expresses profound faith.



BOOKLETS & BINDERS



Hemophilia in Pictures Educator's Guide

World Federation of Hemophilia
English, Spanish, French, Arabic,
Russian, Chinese
www.wfh.org

Hemophilia taught in pictures that provide detailed info for advanced learning. Includes tips for effective patient education, key talking points, review quizzes. Also available as CD.

Hello Tools: School Resource Guide

Shire
www.bleedingdisorders.com

Guide for caregivers and healthcare professionals to help them walk school educators and personnel through bleeding disorder 101.



Dental Care (series)

CSL Behring
www.mysourcecsl.com

Three-part series on dental care for individuals and families with bleeding disorders:

- *Dental Care for Infants, Toddlers, and Preschoolers with Bleeding Disorders*
- *Dental Care for Children with Bleeding Disorders: Ages 5 to 18*
- *Dental Care for Adults with Bleeding Disorders*



Educational Support Brochures

Novo Nordisk Inc.
www.mynovosecure.com
Contact your local HTC
Topics include how bleeding disorders fit into everyday life, resources for kids, games, tips on joint bleeds.



Perspectives

Shire
www.bleedingdisorders.com
Contact your local Shire rep
Series offers viewpoints and education on topics for people with bleeding disorders who are interested in aging well.

PROGRAMS & WORKSHOPS



Project SHARE

LA Kelley Communications, Inc.
www.kelleycom.com

Humanitarian program donates factor to developing countries. Recipients are patients, doctors, clinics, hospitals in countries where factor is scarce or unavailable.

Inhibitor Education Summits

National Hemophilia Foundation
www.hemophilia.org

NHF provides educational summits for people living with inhibitors, covering most travel expenses for participants. The only national educational forums for inhibitor patients to meet and learn about their rare complication. Made possible through a grant from Novo Nordisk Inc.

PROGRAMS & WORKSHOPS CONTINUED

Inhibitor Family Camp

Comprehensive Health Education Services
www.comphealthed.com

Camp addresses the unique needs of children with active inhibitors, and their families. Full weekend of education, support, fun. Held twice a year; camper costs covered. Sponsored by Novo Nordisk Inc.



Wingmen Foundation

www.wingmenfoundation.org

Nonprofit founded by two men with hemophilia offers support to people with bleeding disorders through physical fitness, fitness education, advocacy, financial assistance for physical rehabilitation, exercise equipment.



Rebuild

BioRx, part of Diplomat Specialty Infusion Group
www.diplomat.is/hemophilia

Collaborative preventive care program enhances physical therapy services and promotes positive therapy outcomes for people with hemophilia. Directed by physical therapist with 20 years of hemophilia experience.

BioBuddies Workshop

BioRx, part of Diplomat Specialty Infusion Group
www.diplomat.is/hemophilia

Workshop empowers children with bleeding disorders by educating about their condition through puppetry, dress-up, hands-on crafts, activities.



Transition Ignition

Contact your local Bayer rep

Interactive experience for parents and teens that jump-starts teens' responsibility for their own hemophilia and bleeding disorder care under parental and HTC guidance. Sponsored by Bayer HealthCare.



Generation X

Coalition for Hemophilia B
coalitionforhemophiliab.org

National mentoring program for young adults and teens with hemophilia B. Adventure education program led by Pat "Big Dog" Torrey teaches

mentoring skills through experiential learning in an unforgettable setting. Open to young men with hemophilia B, ages 14–30. Sponsored by Aptevor Therapeutics.

Writer's Workshop

BioRx, part of Diplomat Specialty Infusion Group
www.diplomat.is/hemophilia

Workshop seminar offered to chapters and HTCs focuses on learning to write about feelings of stress, anxiety, frustration.

CoRe Conversations

Biogen
biogenhemophilia.com

Series of webinars and live presentations developed and led by Biogen's Hemophilia CoRe team; topics designed to enrich, educate, motivate bleeding disorder community members.



Inalex Communications Workshops

www.inalex.com

Workshops with experts on goal setting and child rearing. Participants learn and share insights, support, practical advice on how bleeding disorders affect families, relationships, lives.

North American Camping Conference of Hemophilia Organizations (NACCHO)

Arizona Hemophilia Association, Inc.
www.arizonahemophilia.org

Weekend workshop held early in the year for planning, organizing, operating a bleeding disorder summer camp. Nationally known presenters share camp resources and techniques; explore camp programs and activities; facilitate networking and problem solving. Funded by Pfizer and Biogen.



Bayer Leadership U

 www.livingwithhemophilia.com/lead
Bayer offers motivated young people in the hemophilia community a paid internship at its US headquarters in New Jersey. Interns spend six weeks participating in activities for personal and professional growth; developing leadership skills to apply in a real-world corporate setting through independent projects.

HeroPath™ Life Coach

www.mynovosecure.com

Life coach Jeffrey Leiken offers teens and young adults with bleeding disorders coaching and peer support to help them excel in daily life and chart a clear path forward. Based on findings from HERO (Hemophilia Experiences, Results, and Opportunities) initiative, the largest international study on the psychosocial impact of hemophilia on patients and their loved ones.



Junior National Championship (JNC)

CSL Behring
www.mysourcecsl.com
 First national golf and baseball competition designed for the bleeding disorder community gives children the chance to compete; provides education and information sharing for participants, parents, caregivers.

Gettin' in the GameSM

CSL Behring
www.mysourcecsl.com
 Helps children with bleeding disorders participate in sports and get active. Local GIG events offer children and families sports tips from our national GIG athletes with bleeding disorders.

Common Factors®

CSL Behring
www.mysourcecsl.com
 Comprehensive program of patient-support resources offers educational info, guidance; bleeding disorder community advocates appear at live educational events.

Shire

www.bleedingdisorders.com



Hello Talk

Live educational programming for people at various stages of life as an individual or caregiver with a bleeding disorder.

My Factor My Body

Live educational program for school-aged children about hemophilia: how to treat a bleed, and how the right treatment for each patient is selected by a healthcare team.

Bullying

Teens with bleeding disorders may feel targeted by bullies. Live educational program provides info for teens about recognizing, responding to, coping with bullying.

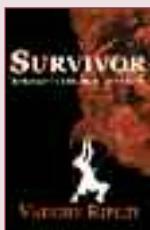
Patient Notification System (PNS)

Plasma Protein Therapeutics Association

www.patientnotificationsystem.org

Confidential 24-hour communication system provides info on plasma-derived and recombinant therapy withdrawals and recalls through automatic electronic updates.

HEMOPHILIA & HIV



Survivor: One Man's Battle with HIV, Hemophilia, and Hepatitis C

Vaughn Ripley 2010

amazon.com

Story of courage about being diagnosed with HIV: how Ripley turned his life around to become a professional database administrator, and how medical advances allowed him and his wife to become parents.

Dying In Vein: Blood, Deception...Justice

Kathy Steward MacKay, Stacy Milbouer 2004

amazon.com; kmackay@aol.com

Stirring photo journal of individuals and families with hemophilia affected by HIV and hepatitis. Portrays people who suffer, become advocates, and mourn loved ones.



Bleeder: A Memoir

Shelby Smoak 2013

amazon.com

Tender, exquisite memoir of Shelby's life from 1990 to 1998, with flashbacks to share college, dating, career difficulties experienced by a young adult with hemophilia and HIV.

Sponsored by BioRx.



Bad Blood: A Cautionary Tale

Necessary Films 2010

amazon.com

Gripping documentary about how HIV and hepatitis C contaminated the US blood supply in the 1970s and 1980s; the role of various organizations and companies; effects on hemophilic families; how community advocates changed the blood-banking system.



Vial023: A Father's Pursuit of Justice

Gary William Cross 2012

amazon.com

In this memoir, Cross recalls his pivotal role in the nation's "hemophilia HIV pandemic": his 17-year-old son Brad died in 1993 after becoming infected with HIV as a child through contaminated clotting factor.



LIVING WITH HEMOPHILIA B

Pfizer Inc.

benefix.com

PDF download; eBook formats



Hemophilia B: Paths to Empowerment

Learn how others impacted by hemophilia B define what it means to be empowered, and how to apply this concept to your hemophilia B.



Hemophilia B: A Family Perspective

How having a family member with hemophilia B can logically and emotionally affect parents, siblings, grandparents.



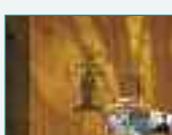
Navigating the Preteen Years

How hemophilia B can affect sense of self, family, friendships.



Hemophilia B: Your Point of View

The teen years: how relationships with parents and peers may take a bigger role.



Young Adults and Hemophilia B

Transitioning through college, finding a career, getting married, starting a family: what to consider with these new situations and responsibilities.



Learn from Experience: A Guide for Mature Adults

Mature adults with hemophilia B reflect on the experiences that have molded them while managing their disorder.



Many Faces of Hemophilia B: Challenges and Opportunities

Discussions about clinical challenges and complications of hemophilia B that affect daily life. Includes advice from medical professionals.



Hemophilia B in Early Childhood

Basics in caring for a child with hemophilia B; for parents and caregivers.

CD, DVD, VIDEO

My First Factor Song

Lyrics by Carri Nease

www.kelleycom.com

Sing along and teach

through song! To the

tune of "Alouette,"

teach your toddler with

hemophilia about bumps,

bruises, "boo-boos," factor.



Stop the Bleeding!

Believe Digital

believedigi.com; YouTube

Comedic web series about a goofy guy with hemophilia who thinks he knows how to run a nonprofit. Deeper Looks videos dig into what it means to be a person with hemophilia.



A Bright Future (series)

Inalex Communications

www.inalex.com

DVD series about living with hemophilia. Sponsored by Baxter Healthcare Corporation.

- *The Hemophilia Diagnosis for Parents:* Parents' testimonials on how they felt and coped inspires new parents to overcome fear and doubt.
- *The Hemophilia Diagnosis for the Extended Family:* Family members discuss how they coped with their relative's hemophilia diagnosis.
- *Teaching the Educators:* How to prepare your child's teachers to handle hemophilia in the classroom.
- *A Time of Transition:* How to encourage your teen to transition to adulthood and become responsible.
- *Healthy Aging:* Emphasizes the importance of health and living with the complications of hemophilia.

PPTA Gift of Life

Plasma Protein Therapeutics Association

English with Spanish subtitles

www.pptaglobal.org;

llovallo@pptaglobal.org

Donors, patients, physicians discuss reasons for donating plasma for plasma protein therapies; demonstrates industry's commitment to safety, quality, innovation.





KITS

Ingredients to Hemophilia Health in the School Setting

BioRx, part of Diplomat Specialty Infusion Group
www.biorxhemophilia.com; info@biorx.com

BioRx staff conducts program on request:
 helps educators, family, stakeholders ensure a
 safe, healthy school experience for students
 with bleeding disorders.

Shire
www.bleedingdisorders.com



Hemophilia Infusion Kit

Comprehensive overview on venous access options; info
 on transitioning to home and self-infusion.

Hemophilia Starter Kit

Info and advice for families just learning about hemophilia;
 supplements info provided by HTCs.

Pfizer Inc.

Available through Patient Affairs Liaison
www.hemophilavillage.com

Travel Kits

Zip-up travel kit keeps infusion supplies in one place,
 protected from water and dirt. Holds multiple infusion
 sets and additional supplies.

Hemophilia B Resource Starter Kit

Starter kit for newly diagnosed hemophilia B adults and
 children includes resources for extra support.

VON WILLEBRAND DISEASE



A Guide to Living with von Willebrand Disease

Renée Paper, RN, with Laureen A. Kelley
 LA Kelley Communications, Inc. 2012
New edition coming in 2017!

Free to families and patients
www.kelleycom.com

Third edition of the world's first book on the world's most
 commonly inherited bleeding disorder. Topics include
 learning to cope with VWD, inheritance, the medical
 system, treatment, women's issues, health insurance.
 Complete resource guide and real-life stories. Sponsored
 by CSL Behring.



100 Questions & Answers About von Willebrand Disease

Andra James, MD 2008
amazon.com

Addresses questions relevant to people
 recently diagnosed with VWD. Up-to-date,
 authoritative, practical, easy-to-under-
 stand info on diagnosis, treatment.



National Outreach for von Willebrand (NOW)

www.arizonahemophilia.org

National educational
 conference for individuals
 and families living with VWD. Info on new
 medical advances, tools to better manage VWD,
 sharing with others. Travel expenses paid; funded by a
 grant from CSL Behring.



Don't let insurance or financial challenges get between you and your treatment

- Trial Program at no cost to you
- Assistance during gaps in insurance coverage
- Co-pay support
- Patient support programs
- Live Helpline Support

CALL 1-800-288-8374 8:00 AM-8:00 PM (ET) Monday-Friday. Spanish-speaking Case Specialists are also available.

Restrictions apply. Please call 1-800-288-8374 for more information about the restrictions.

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CHILDREN & TEENS

What Is Hemophilia? (series)

Laureen A. Kelley

LA Kelley Communications, Inc. 1995

www.kelleycom.com

Developmentally arranged series explains 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. Note to Parents for each age level. Sponsored by CSL Behring.



Level 1: Joshua: The Knight of the Red Snake

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



Level 2: They Will Probably Ask You...“What is Hemophilia?”

Humorous story about Tony, who must explain hemophilia to his fourth-grade classmates. Includes glossary. Ages 7–11.



Level 3: Tell Them the Facts! (back order)

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



Must You Always Be a Boy?

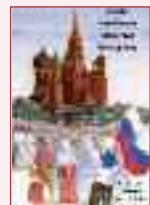
Laureen A. Kelley

LA Kelley Communications, Inc. 1991

www.kelleycom.com

Four illustrated, rhyming tales explore adult reactions to bleeds, overprotective parents, sibling rivalry, classroom bullies.

Ages 3–8. Sponsored by CSL Behring.



Alexis: The Prince Who Had Hemophilia

Laureen A. Kelley

LA Kelley Communications, Inc. 1992

www.kelleycom.com

True story of Alexis, youngest child of Tsar Nicholas II, and how hemophilia influenced events leading to the Russian revolution. Age 8 and older. Sponsored by CSL Behring.



My First Factor (series)

Shannon Brush

Illustrated by Brooke Henson

LA Kelley Communications, Inc. 2008–2015

www.kelleycom.com

Available as 10-book gift set or individually

Series of colorful, chunky books just right for small hands. World's first toddler books for children with hemophilia. Sponsored by Bayer HealthCare.

Ages 18 mo.–4 yr.

Words

One-word concepts about family and hemophilia.

Week

Regular infusions help a toddler stay active.

Fitness

Yoga, playing, laughing, and good food keep a toddler healthy.

HTC

Who does a toddler meet at the HTC?

Infusions

What are the steps in an infusion? A first look for toddlers.

Joints

Let's name all our joints! How do they work?

Camp

What will hemophilia camp be like, when you get older?

Self-Infusion

When you start growing up, you can do all sorts of things by yourself!

Safety

How do I stay safe? Ways a child learns to protect himself.

Mis primeras palabras del Factor

¡El primer libro de niño sobre la hemofilia en español!

Coloring Book

Download a copy at www.kelleycom.com

Illustrations from previous My First Factor books help keep your toddler busy and happy.



PERIODICALS

All periodical subscriptions listed here are free.

Parent Empowerment Newsletter (PEN)

LA Kelley Communications, Inc.
www.kelleycom.com

Quarterly. Oldest bleeding disorder newsletter in US produced and edited by a parent of a child with hemophilia. In-depth medical, scientific, consumer, parenting articles and news to empower parents and patients as educated consumers.



PEN's Insurance Pulse

LA Kelley Communications, Inc.
www.kelleycom.com

Annual. Only hemophilia newsletter completely dedicated to insurance issues from the parent and patient point of view. Sponsored by Shire.



Information Infusions

BioRx, part of Diplomat Specialty Infusion Group
www.diplomat.is/hemophilia

Monthly. Bleeding disorder consumer newsletter.



CHILDREN & TEENS



Curtis & Jerry on Mount Omega: Adventures with Hemophilia

Celynd Scaglione 2006
English, Spanish
bookrequest@bdipharma.com

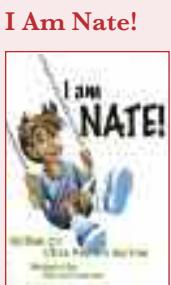
Two young pandas go camping with their fathers and learn what it means to live with hemophilia. Includes info about safe activities for children. Provided by BDI Pharma, Inc.



The Great Inhibitor

Chris Peretti Barnes
BioRx, part of Diplomat Specialty Infusion Group 2006
www.diplomat.is/hemophilia
Colorful story of Nate, a boy who has an inhibitor and creates a Halloween costume. Ages 4-7.

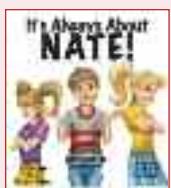
Produced by Bayer HealthCare and BioRx.



I Am Nate!

Chris Peretti Barnes 2007
BioRx, part of Diplomat Specialty Infusion Group
www.diplomat.is/hemophilia
Story about Nate, a boy who explains how having hemophilia affects his life. Ages 4-7. Produced by Bayer HealthCare and BioRx.

It's Always About Nate!



Chris Peretti Barnes
BioRx, part of Diplomat Specialty Infusion Group 2012
www.diplomat.is/hemophilia
How Nate's hemophilia affects the lives and feelings of his sisters and parents. Ages 4-7. Produced by Bayer HealthCare and BioRx.

Factor Nine News

Coalition for Hemophilia B
coalitionforhemophilab.org

Quarterly. Easy-to-read scientific info, research, community events related to hemophilia B.

Dateline Federation

Hemophilia Federation of America
www.hemophiliafed.org

Quarterly. Healthcare info and news about bleeding disorders, government, healthcare events, clinical studies, innovative programs.



Lifelines for Health

Comprehensive Health Education Services
www.comphealthed.com



First national publication for people with inhibitors; educational, inspirational tool for families and healthcare providers. Sponsored by Shire.

Post Script Informer

Patient Services, Inc.
www.patientservicesinc.org

Quarterly. Info on insurance changes for people with chronic disorders.

Factor in Wellness

Walgreens Infusion Services
healthcare.walgreens.com/bleedingdisorders

Quarterly. Latest news and treatments for people with bleeding disorders; articles from patient and parent perspectives.

The Source

Plasma Protein Therapeutics Association
www.pptaglobal.org

Quarterly. Info about the global plasma protein therapeutics industry. Interviews with key leaders; articles on safety and innovation; stories about patients and plasma donors; US and European legislative and regulatory topics.



PERIODICALS CONTINUED

OneVoice

Save One Life
www.saveonelife.net

Bimonthly. E-zine reports on partner organizations, camps, activities funded by Save One Life, the international nonprofit founded by Laurie Kelley that provides sponsorships to children with bleeding disorders in developing countries.



OneVoice

Hemophilia World

World Federation of Hemophilia
www.wfh.org

Triannual. Articles on WFH activities and what hemophilia organizations worldwide are doing to improve care.



HemAware

National Hemophelia Foundation
www.hemaware.org

Bimonthly. Newsletter of largest US hemophilia/bleeding disorder non-profit. Articles on medical research and treatment; families and children; community events; people making a difference.



ONLINE RESOURCES

MySource

CSL Behring
www.mysourcecsl.com
Resource for patient support programs, educational materials and info about live events.

Beyond the Bleed

Shire
www.beyondthebleed.com
For caregivers and people with VWD to learn about the disorder, hear from others, and discover resources.

Hematology

Shire
www.bleedingdisorders.com
Explore Shire scholarship opportunities, community

events, articles, advice, tips; connect with insurance resources and your Shire rep or HTC.

Bloodstream Podcast

Sponsored by National Hemophilia Foundation
www.bloodstreampod.com
Free monthly podcast examines current issues in bleeding disorders, news, interviews. Hosted by community member Patrick Lynch. Produced by Believe Limited.

Living with Hemophilia®

Bayer HealthCare
www.livingwithhemophilia.com
Info on clotting factors,

genetics, pain management, medical treatment, in a frank tone for patients and caregivers. Also home to Bayer Leadership U, Living Fit! and "Living with Hemophilia on Your Own Terms" video series that explains hemophilia terminology.

Hemophilia Village

Pfizer Inc.
www.hemophilavillage.com
Source for hemophilia support, info on life stages, mobile apps, prescription assistance programs, HTC or chapter locations, scholarships, financial assistance. Videos of constructive conversations on helpful topics. Interactive Patient Affairs Liaison Finder searches for liaison close to your community.

HemoAction Online Game

World Federation of Hemophilia
English, Spanish, French
www.hemoaction.org
Adventure game teaches children about hemophilia: how to prevent bleeds and manage hemophilia, the clotting process, types of bleeds, factor infusions, suitable physical activities.

Supporting Bleeding Disorders

Octapharma USA
www.facebook.com/supportingbleedingdisorders
Resource for bleeding disorder patients and families inspires, communicates about community events and educational programs.

Team Novo8™
Personal stories. Authentic connections.

Meet Team Novo8™

Novoeight® patient ambassadors are ready to connect with you. Each team member shares their history, their diagnosis, and their unique stories that can inspire you and your caregivers.

Visit NovoEight.com to learn more about each team member's journey.

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

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novoeight®
Antihemophilic Factor (Recombinant)

GADGETS!

BioRx, part of Diplomat Specialty Infusion Group

Free to US bleeding disorder community
www.diplomat.is/hemophilia



"Be A Hero" Infusion Mat

Infusion mat for kids designed to make infusions easier by providing easy-to-clean surface and colorful step-by-step instructions.

StrapWrap™

Medical alert device that can be attached to a seatbelt, stroller, backpack, anything else with a strap.



Arizona Hemophilia Association 826 North 5th Ave. Phoenix, AZ 85003 602-955-3947 www.arizonahemophilia.org	BioRx, part of Diplomat Specialty Infusion Group (DSIG) 7167 E. Kemper Rd. Cincinnati, OH 45249 877-977-9118 www.diplomat.is/hemophilia	CSL Behring 1020 First Ave. King of Prussia, PA 19406 888-508-6978 www.helixatefs.com	National Hemophilia Foundation (NHF) 116 West 32nd St., 11th Flr. New York, NY 10001 800-42-HANDI www.hemophilia.org	Plasma Protein Therapeutics Association (PPTA) 147 Old Solomons Island Rd., Ste. 100 Annapolis, MD 21401 800-UPDATE-U www.pptaglobal.org
Bayer HealthCare 100 Bayer Blvd. Whippany, NJ 07981 862-404-3000 www.kogenatefs.com	Boston Hemophilia Center 300 Longwood Ave., Fegan 6 Boston, MA 02115 617-355-7165 www.brighamandwomens.org	Grifols USA, LLC 2410 Lillyvale Ave. Los Angeles, CA 90032 888-474-3657 www.grifolsusa.com	Novo Nordisk Inc. 800 Scudders Mill Rd. Plainsboro, NJ 08536 609-987-5800 www.novonordisk-us.com	Save One Life 65 Central St., Ste. 204 Georgetown, MA 01833 978-352-7652 www.saveonelife.net
BDI Pharma, Inc. 120 Research Court Columbia, SC 29203 803-732-1018 www.bdipharma.com	Coalition for Hemophilia B 825 Third Ave., Ste. 226 New York, NY 10022 212-520-8272 www.coalitionforhemophiliab.org	Hemophilia Federation of America (HFA) 210 7th St. SE, Ste. 200 B Washington, DC 20003 800-230-9797 www.hemophilafed.org	Octapharma USA, Inc. 121 River St., Ste. 1201 Hoboken, NJ 07030 201-604-1130 www.octapharmausa.com	Shire 1200 Lakeside Drive Bannockburn, IL 60015 844-229-2582 www.bleedingdisorders.com
Biogen 133 Boston Post Rd. Weston, MA 02493 781-464-2000 www.biogen.com	Comprehensive Health Education Services 80 Washington St., D-24 Norwell, MA 02061 781-878-8561 www.comphealthed.com	Inalex Communications 38 East Ridgewood Ave., #374 Ridgewood, NJ 07450 201-493-1399 www.inalex.com	Patient Services, Inc. (PSI) PO Box 5930 Midlothian, VA 23112 800-366-7741 www.patientservicesinc.org	Wingmen Foundation, Inc. 1425 Grand Rd. Winter Park, FL 32792 407-340-3684 www.wingmenfoundation.org
		LA Kelley Communications, Inc. 37-39 West Main St., #8 Georgetown, MA 01833 978-352-7657 www.kelleycom.com	Pfizer 500 Arcola Rd. Collegeville, PA 19426 888-999-2349 www.hemophilavillage.com	World Federation of Hemophilia (WFH) 1425 Réné Lévesque Blvd. West, Ste. 1010 Montreal, Quebec H3G 1T7 Canada 514-394-2832 www.wfh.org



YOU... from page 6

Why Chris wrote the books

When Chris served as a trainer in a parenting program, she saw that kids with inhibitors needed to understand why their factor wasn't working. "Shortly thereafter," she exclaims, "The Great Inhibitor was born!"



Chris's proudest moment

"Two weeks ago I was on a HemoMom Facebook page, and another mom shared a picture of her son reading *The Great Inhibitor*. I didn't say anything, but it made me feel so good."

One thing hemophilia has taught her

"Hemophilia becomes your new normal of living a great life."



Just a Boy
Ziva Mann
Ages 6–10

A child refusing factor is something parents often face—and this book can help. It paints a real picture of the infusion process: the struggle, the fear, the pain, and the satisfaction of overcoming challenges.

Just a Boy gives us a ride through the adventures of managing bleeds and infusions. The artwork and text are purposely designed so young readers can identify the story as their own. The book walks step-by-step through the stress of infusions, and addresses pain management head-on.

Beyond its usefulness for your own child, this book is a valuable tool to introduce hemophilia and infusions to classmates and school staff.

Why Ziva wrote the book

"I wanted to offer a few more tools in the pain management toolbox."

Ziva's proudest moment

"In 6th grade, my son was on the school math team and had to take a major test. He told me afterward that he was nervous, and he used the breathing techniques from the book to help him get through it. I was so thrilled that my book had helped him."

One thing hemophilia has taught her

"It happens to regular kids, regular families, and regular people, and they're just trying to get through it."

How can you get these books?

These children's books and more are available from LA Kelley Communications (www.kelleycom.com). Laurie Kelley and her team are big believers in the power of community education. Parents of children with bleeding disorders have vast knowledge to share. Helping to create and distribute these books is an important way to share that knowledge.

Reading books together is an ideal way to start your child on the educational path. The children who come alive in these pages are more than just illustrated characters; they are guides to help kids with hemophilia feel connected, empowered, and in control of their condition. ☺

Mike Nuckols is an experienced writer in the world of hemophilia and has worked extensively with the Novo Nordisk Haemophilia Foundation. He also writes articles and educational materials in other medical areas. Mike was assisted on this project by his 13-year-old son, Jack Nuckols. Mike can be reached at mikenuck@yahoo.com or on Twitter @Nuckolball.

headlines

nonprofit

Young Adult Podcast Series

Hemophilia Federation of America's new podcast series is designed for young adults with bleeding disorders to learn tips for health and wellness. Learn more about weight lifting, yoga, and healthy eating! **Why this matters:** Hemophilia education experts are trying to find new ways to engage young adults about their hemophilia.

For info: www.buzzsprout.com/65377/436439-hfa-young-adult-podcast-weight-training

manufacturer

ACE910 Ups and Downs

In a clinical trial of Genentech/Roche's experimental hemophilia medicine emicizumab (ACE910), four patients with hemophilia and inhibitors suffered adverse events: thrombosis (unwanted blood clots) when being treated with an activated prothrombin complex concentrate (APCC) for breakthrough bleeding while on prophylaxis with ACE910. Separately, Genentech announced that its phase III study (HAVEN 1) evaluating ACE910 in people 12 and older with hemophilia A and inhibitors to factor VIII met its primary endpoint, including a statistically significant reduction in the number of bleeds over time in people treated with prophylactic ACE910 compared to their prior prophylaxis treatment with a bypassing agent. Adverse events reported in some patients taking ACE910 and an APCC may mean inhibitor patients may be restricted to using factor VIIa to treat breakthrough bleeds. **Why this matters:** ACE910 is being watched closely, especially by people with inhibitors, as an alternative to current therapy using factor or bypassing agents.

For info: www.roche.com

Launching Two Clinical Trials for Hemophilia A

Octapharma USA will fund INITIATE, a multi-center clinical trial to investigate a major challenge in hemophilia A treatment: the time it takes to decrease inhibitor levels. The study's goal is to shorten the time it takes to induce immune tolerance. Investigators plan to enroll 120 participants who have inhibitors equal to or more than 5 BU and less than 2% factor VIII activity. The study will use Wilate® (plasma-derived factor VIII) to induce immune tolerance. **Why this matters:** An optimal regimen for immune tolerance induction (ITI) has not yet been defined.

For info: Dr. Ducore, 916-734-2781, jmducore@ucdavis.edu

Prophylaxis, Teens, and Adherence

New webinar covers the full potential for teen prophylaxis, exercise, and healthy weight to ensure joint health. Reviews types of prophylaxis, exercise and fitness, who needs prophylaxis, and risks of not adhering to a prescribed prophylaxis regimen. **Why this matters:** Teenagers experience a dizzying array of social and physical changes, at a time in life when preventive hemophilia care is often on the back burner. Produced by National Hemophilia Foundation.

For info: www.youtube.com/watch?v=XZwIz7fxdOc

insurance

Marketplace Enrollment Begins

Time to look for new health insurance? Open enrollment began November 1 for health insurance plans on the Marketplace. This is the one time each year when you can modify, change, or reenroll in your insurance coverage. Open enrollment runs through January 31, 2017. **Why this matters:** Most states require that you enroll by the 15th for coverage that begins the 1st of the following month. For info: www.healthcare.gov

Expert Advice on Health Insurance

Hematology Support Center connects you with experts to examine plans offered by employers, private insurance providers, Marketplace or government programs. **Why this matters:** With a change in government in January, consumers need answers to any proposed changes to their policies. Provided by Shire.

For info: www.hematologysupport.com, 888-229-8379



science

Factor in a Capsule?

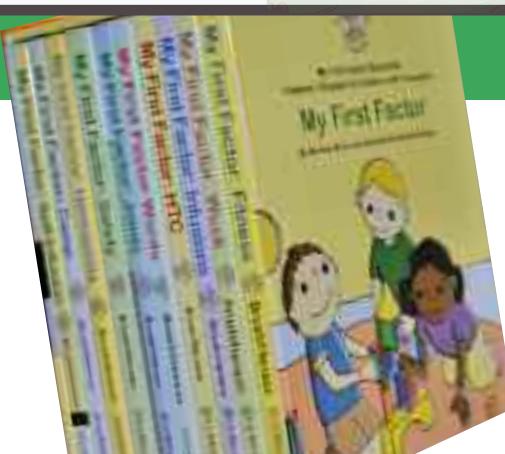
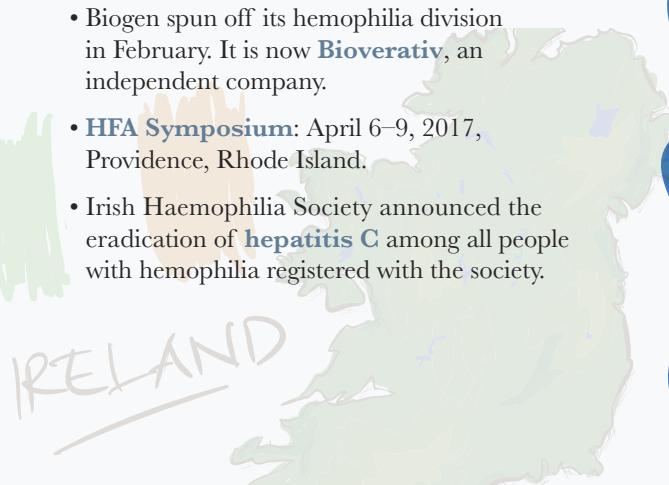
Engineers at University of Texas–Austin believe they've solved a problem: Normally, factor can't be taken orally because it's quickly destroyed in the stomach.

The engineers developed a capsule containing factor IX that can survive the stomach and breakdown in the small intestine, releasing factor early enough to be absorbed by the

intestines. Although several years away from FDA approval and commercialization, this delivery system could revolutionize factor administration. **Why this matters:** An oral delivery system would be revolutionary, making adhering to prophylaxis schedules easier.

For info: <http://kxan.com/2016/11/29/breakthrough-research-could-improve-quality-of-life-for-hemophiliacs>

- Novo Nordisk submitted a Biologics License Application (BLA) to the US FDA for approval of its **investigational long-acting factor IX product** to treat hemophilia B.
- Hemophilia A and B markets in the **Asia-Pacific region** are forecast to expand from \$444.9 million and \$76.3 million in 2015 to \$699.1 million and \$112.9 million by 2022, representing compound annual growth rates of 6.7% and 5.8%, according to GBI Research.
- Ten-year-old **Damien Phillips** of Terrebonne, Oregon, helped design a basketball shoe—Nike's Air Jordan Retro VII—for the Doernbecher Freestyle XIII event in Portland. The shoe design incorporates his favorite Marvel superhero character, Deadpool.
- **Roz and Ray** is a two-person drama charting the professional and personal relationship of a physician and the bisexual father of two boys with hemophilia, during the 1980s, before and after the advent of factor concentrates.
- **Alex Dowsett**, famed cyclist with hemophilia from the UK, will do a second Union Cycliste Internationale Hour record in early 2017 to try to regain the record from Bradley Wiggins.
- Biogen spun off its hemophilia division in February. It is now **Bioverativ**, an independent company.
- **HFA Symposium**: April 6–9, 2017, Providence, Rhode Island.
- Irish Haemophilia Society announced the eradication of **hepatitis C** among all people with hemophilia registered with the society.



Your baby's first set of books about hemophilia! *My First Factor* covers hemophilia concepts with beautiful illustrations and simple words. Gift boxed, free to parents. Written by Shannon Brush, mother of a child with hemophilia.



State of the World

World Federation of Hemophilia's Report on the Annual Global Survey 2015 surveys 134 WFH National Member Organizations on a variety of statistics. It identified a total of 304,362 people with bleeding disorders, an increase of 5.6% over 2014. This includes 151,159 with hemophilia A (including 3,099 with currently identified inhibitors), 30,310 with hemophilia B (154 with inhibitors), and 74,819 with VWD. At least 400,000, and possibly more than 500,000 people worldwide have hemophilia. **Why this matters:** More accurate statistics helps WFH appeal to governments to budget money to their people with bleeding disorders.

For info: www.wfh.org/globalsurvey111

Seven Summits Quest: Everest!

For the past six years, Chris Bombardier, who has hemophilia B, has been on a history-making journey to climb the Seven Summits, the highest mountains on each of the seven continents. He has completed five, and in May 2017 plans to summit Mt. Everest, the highest peak on earth! With him will be Believe Ltd, which is directing a documentary about Chris's quest that will showcase the disparity between life with hemophilia in developed and developing countries, and how the Nepalese hemophilia community was affected by the 2015 earthquake. Heading to base camp with Chris is Laurie Kelley, who has visited Nepal previously and is president of Save One Life, which supports about 80 children with hemophilia there. Chris is a board member of Save One Life. **Why this matters:** Chris will be the first person with hemophilia to attempt Everest, showing that people with hemophilia can live extraordinary lives with proper treatment.

For info: www.facebook.com/adventuresofahemophiliac



New from LA Kelley Communications



As I See It... from page 3

questions and concerns. Parents have personal experiences, but the medical community has research and cutting-edge information. And we have the right to reach out directly to the pharmaceutical companies. For example, some of my more informative discussions have been with patient representatives in those companies.

We also need to continue to reach out in person and through published books. When our children are diagnosed, we have the opportunity to become active in our local organizations. We can be present.

We all react to the diagnosis differently in our personal journeys. We need printed materials based on research and experience. We need each other. Ultimately, we need human contact. Living with a bleeding disorder is not a journey for the faint of heart. It takes courage and requires human support.

Social media allows us to connect through time and space. We are 21st-century families and have so many more options than our children did years ago. ☺

Rita Epstein has worked in education for over 50 years. Her postgraduate work has been in administration and gifted education. She has been the owner and director of Windsor Academy Educational Campus in upstate New York for almost 20 years. Rita lived in the US Virgin Islands for many years on her sailboat, The Dulcinea. She was involved in creating academically gifted programming in St. Thomas. When her now adult son, Dr. Nathan Rosenblum, was diagnosed with hemophilia in the mid-1980s, Rita became active in the New York State Department of Health Advisory Panel as a consumer representative. She has written for a variety of hemophilia publications and continues to be a strong advocate for education and self-advocacy.

Inhibitor Insights... from page 4

And under “Programs and Services,” in the “Helping Hands” section, look for “Inhibitor Support.” This HFA program provides inhibitor families with educational, travel, medical transportation, and tutoring/educational supplies.

World Federation of Hemophilia (WFH) has inhibitor information for consumers on its “About Bleeding Disorders” webpage. Select “Resources” to find links to downloadable booklets, including the 10-page *Dental Management of Patients with Inhibitors to Factor VIII or Factor IX* (2008); 9-page *Inhibitors in Hemophilia: A Primer* (2008); and 16-page *What Are Inhibitors?* (2009).

Centers for Disease Control and Prevention (CDC) has inhibitor info webpages and fact sheets on inhibitors, including “Have a Bleeding Disorder? Get Tested Regularly for an Inhibitor” and “Beyond Diagnosis: Treatment Options and Resources for People with Inhibitors” (find these in the “Free Materials” section). A wealth of statistical info on hemophilia and inhibitors is available, collected through the CDC’s hemophilia surveillance programs such as the Universal Data Collection System (which ended in 2011) and its replacement program, Community Counts.

Know Inhibitors is an unbranded website supported by Shire, containing a ton of info on inhibitors: FAQs, videos, and other inhibitor-related resources. One thing that sets this website apart from others is the substantial amount of info on the psychological aspects of dealing with inhibitors. The website has separate sections on the mental health of care-

givers as well as teens and adults with hemophilia and inhibitors.

FEIBA.com is Shire’s branded FEIBA webpage. It contains FEIBA product info, but includes many resources (mainly on healthcare and insurance) for people with inhibitors: click on the “Community” and “Tools and Resources” links.

Inhibitorinfo.com is a non-branded website sponsored by Grifols Biologicals, Inc. Although it offers a few resources for people with inhibitors, this website is currently a promotional tool for the SIPPET study (Survey of Inhibitors in Plasma Products Exposed Toddlers), which found that plasma-derived clotting factor concentrates have a lower incidence of inhibitors as compared to recombinant clotting factor concentrates.

Novo Nordisk provides a variety of resources for inhibitor patients. Do a web search to locate the downloadable 13-page booklet *Your Resource Guide to Help Care for Inhibitors*. Find more inhibitor info in the “Living Well with Inhibitors” section of the “Support, Stay Educated, Community University” webpage on the NovoSecure website. Unlike other websites with inhibitor info, this site requires you to enroll to view its resources.

The resources reviewed here are the best and most informative for people with inhibitors, but we haven’t covered every page of every website that mentions inhibitors. If you know of additional resources that deserve mention, please share them with us. And don’t forget to read the Headlines column in each PEN issue, where we highlight new resources and websites as they come online! ☺

Richard’s Review... from page 5

The next report of a blood transfusion to treat hemophilia appeared in 1905, after a gap of 65 years. Part of the delay was in overcoming obstacles such as improving the equipment and understanding blood groups for compatibility. And part of the wait was because doctors had to progressively learn about the true cause of hemophilia.

Given the high risk of death, Samuel Armstrong Lane most likely attempted blood transfusion in 1840 as a lifesaving measure

for his patient with hemorrhagic diathesis rather than as a treatment for hemophilia. Still, we acknowledge Lane’s brave effort—which today seems almost legendary—as the first whole-blood transfusion attempt to treat hemophilia. ☺

For a list of sources used in this article, see PEN at www.kelleycom.com.

WOMEN AND BLEEDING DISORDERS

I ENJOYED YOUR LAST ISSUE, and have two comments: First, a hang-up in getting little girls in hemophilia families tested is money. It depends how the HTC is organized. If it's independent, for example my lab when I was running it, then the tests can be run without triggering an insurance bill. If administrators are hovering over everything the lab does, demanding a bill, then the charge for the girl's factor level may fall into the deductible for that year, and the family may not have the resources to pay it easily. Somehow, the HTC has to set up a mechanism to avoid triggering that deductible. A subsidy for testing the girls in a family may be easier to arrange in an HTC with a profitable 340B program, but that's not true everywhere.

Second, a given factor level isn't always a good predictor of bleeding. For example, some women (and men) may wonder why they have excessive bleeding with 40% factor VIII. Sometimes there are other conditions, making the bleeding worse or better. A very recent paper by Danielle Nance* (a hematologist with severe hemophilia and the mother of a son with severe hemophilia) describes how a second defect made hemophilia more pronounced, and I think it's the tip of an iceberg. More such conditions will be described.

Dr. Carol Kasper
CALIFORNIA

*D. Nance, R. A. Campbell, J. W. Rowley, J. M. Downie, L. B. Jorde, W. H. Kahr, et al., "Combined Variants in Factor VIII and Prostaglandin Synthase-1 Amplify Hemorrhage Severity across Three Generations of Descendants," *Journal of Thrombosis and Haemostasis* 14, no. 11 (Nov 2016): 2230-40.

FROM THE BOTTOM OF MY HEART I thank you for this comprehensive and informative set of articles about women with bleeding disorders, and a call for women to get a diagnosis. Coming from PEN, this means so much, and to so many people: medical professionals, women, and family members who know about their female bleeders. Thanks for the work that you have done in so many areas to make the quality of life better for those with bleeding disorders—both men and women.

Cheryl D'Ambrosio
WASHINGTON

I READ WITH GREAT INTEREST the latest PEN about women and symptomatic carriers. This info must be shared with all families having a history of any bleeding disorder. And more important, it must be shared with the medical community. So many doctors are uninformed about bleeding disorders in males, but the new info concerning women is nonexistent. I would like 12 copies of this PEN issue so I can distribute them to my female relatives and a few doctors.

Steve Place
MASSACHUSETTS

I HOPE YOU KEEP INCLUDING info about women with hemophilia in future PEN issues.

Jenny Maywood
MICHIGAN

I AM SO THRILLED TO see this issue on women's bleeding disorders! Thank you so much for drawing the necessary attention to this topic! If you ever cover this in the future it would be amazing to see more print and research dedicated to women with platelet disorders, as we are even more rare than the women with hemophilia, and it is even more difficult for us to receive a correct diagnosis and treatment.

Thank you again. While the hemophilia community has been so welcoming to my family, it is even more special to see something focused on women.

Erika Bowles
CALIFORNIA

PROJECT SHARE

THANK YOU FOR YOUR SOLIDARITY with our boys with hemophilia. It is impressive that you never forget them, despite the distance that separates us. Unfortunately, they continue to be in need, and your help is significant. Thank you and God bless you. Your donation is limb-saving; it is so important for those who need major orthopedic intervention.

We remember always with great pleasure your visit to Buzias and Timisoara. It would be so pleasant for us to see you here again, and for you, it would be an opportunity to enjoy the beneficial results of your support.

Best wishes for health and success in your admirable activity.

Dr. Margit Serban
Chief Hematologist
Louis Turcanu Hospital
ROMANIA

"You gave him this day, Project SHARE."

MY MEDICAL DIRECTOR, Dr. Zeya ur Rehman, has spent his entire career at the Fatimid Foundation, since 1981. He is around age 75 now, and the board keeps renewing his contract because of his dedication to Fatimid and its patients. Today he told me, "Dr. Shabneez, this is the first time in my entire career that I saw treatment [factor] coming to Fatimid. Before leaving Fatimid...I see this day finally." You gave him this day, Project SHARE. Thank you is just not sufficient.

Dr. Shabneez Hussain
Fatmid Foundation
PAKISTAN

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