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PEN's Biennial

BLEEDING DISORDER

Resource Guide 2019

Jessica O'Donnell

We are pleased to present the community with a variety of resources to help in educating patients, finding support, and living with bleeding disorders. This guide contains a variety of resources, including books, digital content, apps, and tools.

BOOKS

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

Lauren A. Kelley

LA Kelley Communications, Inc. 2016

Free to hemophilia families

kelleycom.com

amazon.com



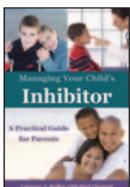
Fifth edition of the world's first parenting book on hemophilia written by a parent of a child with hemophilia. Practical, easy-to-understand info on medical treatment, genetic transmission, child development, consumer issues, school, sports. Includes advice from experienced parents, compiled from interviews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

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

Lauren A. Kelley with Paul Clement

LA Kelley Communications, Inc. 2010

Free to inhibitor families
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.

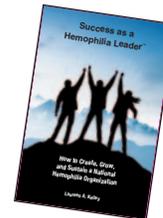
Success as a Hemophilia Leader

Lauren A. Kelley

LA Kelley Communications, Inc. 2018

Free to qualified Hemophilia Leaders

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 resources, most are non-NHF. Find more resources by viewing the publications or resources section of each website, or by contacting the company or organization. Also visit the websites of National Hemophilia Foundation (hemophilia.org), Hemophilia Federation of America (hemophiliafed.org), and World Federation of Hemophilia (wfh.org) for many more resources. Most of the resources listed here are free.



Hemophilia

Michelle Raabe

Infobase Publishing 2008

amazon.com

Detailed, colorfully illustrated, easy-to-read

book focuses on the science behind the treatment, symptoms, and genetics of hemophilia. 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, and

Christine Chamberlain

Boston Hemophilia Center 2010

Free from NHF: hemophilia.org

amazon.com

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



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welcome



“There is no friend as loyal as a book,” wrote Ernest Hemingway. Reading has always been my primary way of learning, traditionally in print, but now more and more in digital format. But not everyone considers books their best friends. People have different styles,

or modes, of learning. Luckily, the bleeding disorder community offers many ways to learn.

This issue of PEN is one of our most popular, because we cover so many educational resources from our corporate partners, nonprofits, and individuals. Through self-publishing, community members are able to tell their stories directly to their peers. Enjoy the feature article by Jessica O’Donnell.

Please also read YOU, where you tell us which modes of learning work best for you. And in Inhibitor Insights,

Paul Clement warns us not to believe everything we read on the internet about inhibitors. In As I See It, author Derek Markley, one of our community’s self-publishers, writes about his hopes for gene therapy. And Richard Atwood writes about our community’s celebrity spokesperson—sort of!

Enjoy this issue, and contact the sponsor of any resource that meets your needs: a book, newsletter, movie, DVD, podcast, or in-person meeting. The message: Keep learning. More news, products, and resources arrive daily. To manage your bleeding disorder effectively, it’s up to you to know your stuff! ☺

In the past, it was incorrectly believed that only men could have hemophilia, and women with the gene were labeled asymptomatic “carriers.” It’s now recognized that women are not just carriers of hemophilia, but can also have hemophilia and experience symptoms if less than 50% of their factor is active. Most diagnosed patients are male. For editorial simplicity in PEN articles, when we refer to a person with hemophilia, we may alternately use “he” or “she,” or just “he.”

inbox

THANK YOU SO MUCH FOR these PEN articles. They are always pertinent and well written. I appreciate being able to feature them in our newsletter as often as possible.

Ursela Lacer

Kentucky Hemophilia Foundation

YOU SENT US SOME BOOKS SHORTLY after our infant Luca was diagnosed, and they have been amazing tools to help our older children feel ready to support their baby brother’s infusions. The toddler books have meant so much to our family. My daughter

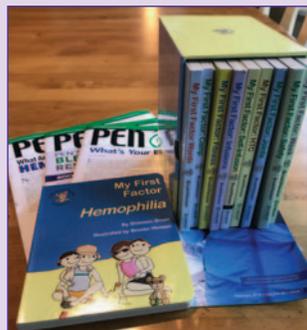
reads them to our baby son every day, and especially loves that one of the last pages of *My First Factor: Infusions* shows a big sister helping her little brother be so brave. The way they have blessed us brings me to (thankful, blessed, happy) tears!

Becky Steele

MICHIGAN



Baby Luca



PARENT EMPOWERMENT NEWSLETTER | FEBRUARY 2019

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Parents or patients with personal insurance questions should contact their employer’s human resource department, Medicaid or Medicare caseworker, payer representative, or HTC social worker.

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as i see it

Who Makes the Decision?

Derek L. Markley

It has been more than eight years since St. Jude Children's Research Hospital, University College London, and the Royal Free Hospital began a clinical trial using gene therapy to treat people with hemophilia B.

That same year, our family welcomed a new baby, Bubba, who has severe hemophilia B. We had recently located to central Illinois from east Tennessee when I accepted a position with Eastern Illinois University. Bringing a new child into the world is a wonderful and stressful time for any family. As parents who had no experience with bleeding disorders, my wife and I were wholly unprepared for a hemophilia diagnosis.

Six months after Bubba was born, I was headed to lunch with a friend after meetings in the state capitol building. I can still tell you exactly where I was standing when my friend handed me her phone and asked if I'd seen the *New York Times* article about gene therapy and hemophilia B.

Fast forward a few years, and we again relocated, this time to Tupelo, Mississippi. We were very fortunate to become patients at St. Jude. Little did we know that Bubba's physician would be one of the primary investigators in the gene therapy clinical trial. All of a sudden, the world of gene therapy was thrust directly in front of us.

We are now in a position, like many other hemophilia families, where the reality of a cure for hemophilia seems within reach. Presently, three phase III trials are beginning to test the efficacy of gene therapy in treating hemophilia B. Clinical research does not move quickly, but advancements in gene therapy over the past eight years have been amazing. The FDA has released new guidelines regarding gene therapy development, and funding for these ventures is in overdrive.

If gene therapy treatment becomes a reality, I'm forced to ask these questions: Is this a decision we can make for our son? Do the parents get to decide? How do we talk to our son about the risks and rewards of such a treatment? Bubba is only eight now, but it seems wise to begin thinking about how we'd handle this situation. Of course, the question is moot if insurers, treatment providers, and pharmaceutical companies can't agree on a feasible reimbursement strategy. There are a lot of variables at play, yet the



Derek Markley and his son Bubba

advancement of gene therapy treatment demands that Bubba's mother and I begin thinking about how we will make decisions if a gene therapy treatment becomes available for our son.

It's amazing that, of all the health conditions in our world, science and medicine have combined to put a treatment for our son's type of hemophilia at the forefront of gene therapy.

Bubba is a very active kid. My wife describes him as "all boy." His condition has done nothing to slow him down. Bumps, bruises, cuts, or scrapes, he weathers them all and refuses to be limited by his uncooperative blood.

We're reaching a time where Bubba's questions about hemophilia have become more mature, requiring us to be more introspective when talking with him. The greatest question we face is how do we determine his role in a decision about treatment if gene therapy becomes a reality? It is his life, and, like all parents, we hope that he'll be around for a long time after we're gone.

Bubba views infusions as an inconvenience. We know he secretly wants to play quarterback or wide receiver. He knows that hemophilia makes him different from his friends. Different isn't always easy for kids to understand or accept.

The problem is that his mother and I have more complex questions, not that Bubba's questions are unimportant. What if our government decides to once again unfairly punish people with pre-existing conditions? What if Bubba is in a serious accident? What if he develops a target joint? There are a million tough questions. What makes the situation even harder is that these questions are about things over which we have little or no control. There are far more questions than answers.

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Online Health Information: Is It Reliable?



It's an exciting time for people with inhibitors. In addition to bypassing agents, new products may prevent or control bleeds more effectively than previous products, while reducing the burden of treatment. But where can you find accurate information about these products?

Most commonly, people turn to the internet for health information. The problem? Much of this information is false or biased. And surveys have found that most internet users can't detect bias and don't know how to critically evaluate the health info they find online. How do you know what's reliable? Here are some questions to ask before trusting what you read on a website.

Who sponsors or funds the website?

Knowing who funds the website may indicate if the website has a bias. For example, while a pharmaceutical company will provide product information on its website, it also wants to influence you to buy its products—such as inhibitor therapies. Although the info on pharmaceutical websites is usually correct because the companies must follow FDA regulations, it can also be biased. Sites may contain “errors of omission”—when data is left out that might reflect badly on the product. Pharmaceutical websites may not provide all the facts you need to make an informed decision.

A website address, or URL, can help identify the funding or hosting. For example, in the URL www.kelleycom.com, the website name, or *domain*, is *kelleycom*. That's followed by the *domain extension* *.com*. The domain extension tells you what kind of organization is funding the website. Here are some domain extensions:

.gov identifies a US government agency, such as the Centers for Disease Control and Prevention (cdc.gov) or National Institutes of Health (nih.gov).

.edu identifies an educational institution, like a school, college, or university; this can include your hemophilia treatment center (HTC) if it's also a teaching hospital.

.org usually identifies nonprofits: professional groups, and scientific, medical, or research societies; and advocacy groups like National Hemophilia Foundation (hemophilia.org) or Hemophilia Federation of America (hemophiliafed.org). Many HTCs use *.org*.

.com is the most common domain extension, identifying commercial websites such as businesses, pharmaceutical companies, and sometimes hospitals.

.health identifies healthcare professionals, pharmaceutical companies, medical associations, hospitals and health systems, health products and services, public health organizations, and health blogs and publications. Organizations wishing to operate a *.health* website can use this extension only after being validated as a qualified member of the health industry.

Different domain extensions are associated with various levels of trustworthiness. Generally, *.gov* sites and *.edu* sites have the highest trustworthiness (about 70%), followed by *.org* and *.com*.^{1,2}

A company can set up almost any website name—it doesn't have to be the company name—or may use another company to host its site, making it harder to learn who actually funds or sponsors a website. Websites that display a company's name and products are *branded* websites. Their intent and biases are easy to determine. Websites that don't mention any company name or product are *unbranded*. On unbranded websites, it's harder for visitors to determine whether the site has a bias.³

» page 18

1. Analysis of 10th HON Survey of Health and Medical Internet Users, www.hon.ch/Global/pdf/2010_Internet_use_Analysis.pdf. 2. Although government websites have been associated with high trustworthiness, recently they have been affected by political pressure. Information on certain topics, including condom use and effectiveness, birth control, abortion, and climate change, has been watered down or removed from government websites, making the sites less reliable. 3. If a company name is mentioned inconspicuously, as in small text at the bottom of the homepage, the website is called *lightly branded*.

Richard J. Atwood

Linda Weaver's Studio



Basil Rathbone

Hemophilia Celebrity Spokesperson

Who would you pick as a celebrity spokesperson for our bleeding disorder community?

Celebrity status automatically captures the public's attention. And our community wants to be noticed—for public awareness, for outreach, and just for the pleasure of being recognized. Soon after its founding in 1948, National Hemophilia Foundation (NHF) chose actor Basil Rathbone as its celebrity spokesperson. From the beginning, NHF wanted to be recognized. But why Rathbone?

Basil Rathbone (1892–1967) may be familiar to you, especially if you enjoy older movies. At one time, Rathbone was very well known, most famously as Sherlock Holmes. He appeared in 83 films from 1921 to 1967. Plus, he performed in the theater, on the radio, and for live television.

Born in South Africa and raised in England, Rathbone began his career in 1913 as a classically trained Shakespearean stage actor. He saw combat in Europe during World War I.

In 1921, Rathbone debuted in his first silent film. He then moved to America. Rathbone kept his English citizenship, and he took frequent trips to London. Eventually, Rathbone wanted to return to his first love—acting onstage. In 1947 he left Hollywood for New York City, where NHF had its offices. So it made sense for NHF to ask Rathbone to be a celebrity spokesperson.

In the early 1950s, Rathbone was at the height of his acting career on stage, screen, and radio. He could sing and dance, and was a skilled swordsman. He did paid advertising for cigarettes, liquor, insurance, and diet food. Amazingly, he played 52 roles in 23 plays by Shakespeare. Over seven years starting in 1939, Rathbone starred in the role of detective Sherlock Holmes in 16 films and 275 radio episodes. Rathbone was rewarded with two Academy Award nominations. His popularity would peak again later in the 1960s, when his Sherlock Holmes films were broadcast on television.

Despite his wide range of roles on stage and screen, Rathbone is mostly remembered, regrettably, as a type-cast villain. His villainous roles include Mr. Murdstone in *David Copperfield*; the Marquis St. Evrémonde in *A Tale of Two Cities*; Captain Esteban Pasquale in *The Mark of Zorro*; and probably his most famous role, Sir Guy of Gisbourne in *The Adventures of Robin Hood*.

By coincidence, Rathbone performed in two movies that included hemophilia. He portrayed Prime Minister Disraeli in the 1961 television production of Laurence Housman's *Victoria Regina* on NBC's Hallmark Hall of Fame program. Julie Harris portrayed Queen Victoria, a known hemophilia carrier. Unfortunately, Housman's play, originally staged in 1936, includes some inaccuracies about hemophilia genetics.

In 1966, Roger Corman, a producer at American International, hired Rathbone for the film *Queen of Blood* (*Planet of Blood*). Rathbone played Dr. Farraday, who, in 1990, sends a team of astronauts to Mars to rescue a crashed spacecraft. The astronauts return with a survivor—a green woman named Velana. The astronauts quickly learn that Velana is a vampire who kills her captors, and that she also has hemophilia. Velana bleeds to death from a scratch, leaving behind her eggs. I admit, this is one of my all-time favorite science fiction/horror flicks, originally shown at drive-in theaters.

NHF chose Basil Rathbone as a celebrity spokesperson for only a short time. We don't know whether he had a family connection with hemophilia. Although he performed in two movies that include hemophilia, Rathbone was probably more concerned with earning a salary than promoting a cause. Yet we can always be grateful for any celebrity spokesperson.

Who would you choose to speak for our community today? 🗳️

For more info, read Rathbone's autobiography, *In and Out of Character* (1962); and Michael B. Druxman's biography/filmography, *Basil Rathbone: His Life and His Films* (1975).

New York Public Library Digital Collection



Basil Rathbone



What's the Best Way to Learn About Your Bleeding Disorder?

Laurie Kelley

Our world is biased toward visual information and learning, because humans are mainly visual beings. From advertising to teaching tools, we are all about sight, color, and shape. Studies have shown that 65% of people learn best visually.¹

But not everyone learns visually. It's now recognized that people have individual differences when it comes to learning, and even visual learners learn in different ways. For example, one person learns by visiting art museums, but another likes watching TV documentaries; both are visual methods.

Research in the field of learning modes, or styles, led to the widely cited Theory of Multiple Intelligences, developed in 1983 by Harvard University's Howard Gardner. Gardner found nine distinct types of "intelligences," which are now used to describe how people learn.

What's your preferred learning mode? And how can you harness it to learn about managing your bleeding disorder?

Nine Learning Modes

You may possess several of the nine modes listed here, with one being dominant. Or you may use different modes in various circumstances. For example, I'm a verbal learner who likes to learn in a solitary way. But I occasionally like to learn a new piece on the piano for fun, which requires visual, aural, and physical modes. You can also change your mix by developing and enhancing your less dominant modes. If you don't use particular learning modes, they may weaken.

1. Visual (spatial): pictures, images, understanding of space
2. Aural (auditory-musical): sound, music
3. Verbal (linguistic): words, in both speech and writing
4. Physical (kinesthetic): body, hands, sense of touch
5. Logical (mathematical): numbers, logic, reasoning, systems
6. Social (interpersonal): learning by being with other people
7. Solitary (intrapersonal): learning alone, using self-study
8. Natural: being outside; identifying plants, animals, maps
9. Existential: questioning human existence, the meaning of life and death, the human condition

The key to learning about bleeding disorders is to recognize how you learn best, and then to find resources that use your strongest modes to help you learn faster and more effectively.

In the Beginning, There Were Books

There was a time when virtually *no* information on hemophilia or von Willebrand disease (VWD) was available in any learning format, except meeting with your hematologist. That's one of the reasons I wrote *Raising a Child with Hemophilia* in 1990, and published all of our subsequent books: to reach the verbal-oriented people in our community, and to provide a tool for patients to use all the time, not just at in-person meetings. For me, social support group meetings weren't so useful. More experienced parents seemed to want to scare the rest of us with their bleeding horror stories! Medical journals and published articles seemed more logical and reliable.

Fortunately, for those who are not mainly verbal learners, we now have plenty of other ways to learn. Chapters hold more local meetings, which may appeal to more social-oriented people; national meetings offer scholarships for first-time participants; CDs, DVDs, podcasts, and YouTube videos are available; and now there's even a movie—*Bombardier Blood*. Just recently, *Hemophilia: The Musical* debuted!

Patrick "Big Dog" Torrey, founder of GutMonkey, offers the bleeding disorder community learning through physical and natural modes: rafting, hiking, zip-lining, and camping. No matter your learning style, there's bound to be some educational resource you'll enjoy, to help you understand your bleeding disorder.

What YOU Find Most Useful

We asked our Facebook friends what resources have helped them most. Their answers reveal preferred learning modes. Phillip Smith, for example, offered what sounded like a logical mode of learning: direct, scientific information. "I read product inserts, news releases from the company that produces the product, and company R&D pipeline info on future products."

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1. Richard M. Felder and Linda Silverman, "Learning and Teaching Styles in Engineering Education," *Engineering Education* 78(7), 674-81 (1988). This study later became a foundation for a standardized test called the Index of Learning Styles (ILS). Available at www.wiley.com.

BOOKS CONTINUED



The Gift of Experience II: Conversations with Parents About Hemophilia

Laura Gray, LICSW,
Ziva Mann, and 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 Neneff 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, and expresses profound faith.



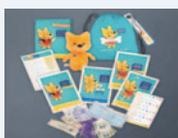
KITS



School Preparedness for Bleeding Disorders

Diplomat Specialty Infusion Group (DSIG)
diplomatpharmacy.com

Helps educators, family members, and others facilitate a safe, healthy school experience for students with bleeding disorders. Resource binder can accompany complete educational program for school teachers, nurses, staff.



Factor Friend™

Shire
bleedingdisorders.com

Personal therapeutic play kit helps children with hemophilia become familiar with infusing and the steps to self-care. Contact your local HTC to request the kit.



Hemophilia Starter Kit

Shire
English and Spanish
bleedingdisorders.com

Provides basic info about hemophilia, including science and treatment. Topics include learning the basics, recognizing bleeds, treating hemophilia, keys to healthy living.

PROGRAMS & WORKSHOPS



Project SHARE

Save One Life, Inc.
saveonelife.net

Humanitarian program donates factor to developing countries. Recipients are patients, doctors, clinics, hospitals in countries where factor is scarce or unavailable. Since 2002, SHARE has donated more than \$140 million to over 75 developing countries.

Inhibitor Education Summits

National Hemophilia Foundation (NHF)
hemophilia.org

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. Funded by Novo Nordisk Inc.

Inhibitor Family Camp

Comprehensive Health Education Services (CHES)
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.

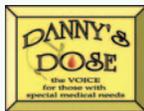


PROGRAMS & WORKSHOPS CONTINUED

Danny's Dose

dannysdose.com

Organization advocating for the change of emergency medical protocols for chronic illness and rare disease.



Transition Ignition

Bayer HealthCare

livingwithhemophilia.com

Helps teens establish a comfort level with hemophilia and practice skills for managing treatment away from home.



North American Camping Conference of Hemophilia Organizations (NACCHO)

Arizona Hemophilia Association, Inc.

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 Bioerativ.



Step Up Reach Out (SURO)

Bayer HealthCare

livingwithhemophilia.com

International youth program helps connect future leaders in the bleeding disorder community, with the goal of increasing treatment standards worldwide.



AFFIRM

Bayer HealthCare

livingwithhemophilia.com

International fellowship program helps men with hemophilia develop and expand leadership and advocacy skills by fostering networking within the bleeding disorder community.



Bayer Leadership U

Bayer HealthCare

livingwithhemophilia.com

Paid summer internship at Bayer's US headquarters in Whippany, New Jersey. College-aged members of hemophilia community can sharpen leadership skills while working alongside leaders at Bayer.



HeroPath™ Life Coach

mynovosecure.com

Coaching and peer support helps teens and young adults with bleeding disorders excel in daily life and chart a 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.

Game On

Bayer HealthCare

English and Spanish
livingwithhemophilia.com

Empowers young adults with hemophilia to be accountable for their treatment, stay healthy, maintain insurance coverage, and plan for college and careers.



Wingmen Foundation

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.



And Now...Back to You

Bayer HealthCare

English and Spanish
livingwithhemophilia.com

Helps adults with hemophilia rediscover goals related to career, education, or passions, and create a plan of action for success.



Rebuild

Diplomat Specialty Infusion Group

diplomatpharmacy.com

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

Parents Empowering Parents (PEP)

Bayer HealthCare

English and Spanish
livingwithhemophilia.com

Provides tools, skills, and emotional support to parents of children with hemophilia.



True Identity

Shire

bleedingdisorders.com

Members can hear stories, receive information, and connect with other community members.

Generation IX

Coalition for Hemophilia B
hemob.org



Adventure education program led by Pat “Big Dog” Torrey teaches tangible mentoring skills through experiential learning in an unforgettable setting. Open to young men with hemophilia B, ages 14–30. Sponsored by Aptevo Therapeutics.

Junior National Championship (JNC)

CSL Behring
csljnc.com

First national golf, baseball, swimming competition 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
cslbehring.com



Helps children with bleeding disorders participate in sports and get active. Local GIG events offer children and families sports tips from national GIG athletes with bleeding disorders.

Common Factors[®]

CSL Behring
800-676-4266

Community-based events unite and educate members of the bleeding disorder community. Common Factors Advocates share personal experiences and give presentations on topics for the community.

Hello Talk

Shire
English and Spanish
bleedingdisorders.com



Live education program for the bleeding disorder community. More than 25 Hello Talk topics cover disease state and lifestyle education.

Patient Notification System (PNS)

Plasma Protein Therapeutics Association
patientnotificationsystem.org

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

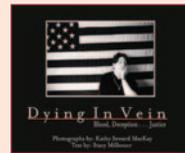
HEMOPHILIA & HIV



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 and
Stacy Milbouer 2004
amazon.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 Diplomat Specialty Infusion Group.



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 families; how community advocates changed the blood-banking system.



Vial 023: A Father’s Pursuit of Justice

Gary William Cross 2012
amazon.com

In 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.

BOOKLETS & BINDERS



Hemophilia in Pictures Educator's Guide

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

Perspectives

Shire
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.



LIVING WITH HEMOPHILIA B — B2B BOOK SERIES



Pfizer Inc.

hemophiliavillage.com
PDF download; eBook formats

- ▶ **Hemophilia B: Her Voice, Her Life**
Provides support and encouragement to women with hemophilia B on the path to empowerment.
- ▶ **Know Your Numbers: Knowledge Is Power**
Explains importance of knowing and understanding specific sets of numbers, test values, and other hemophilia B data through all life stages.
- ▶ **Hemophilia B: Paths to Empowerment**
What empowerment means to patients and caregivers, and how it affects their lives.
- ▶ **Hemophilia B: A Family Perspective**
Real-life examples and guidance for families living with hemophilia B.
- ▶ **Navigating the Preteen Years**
Advice and support for preteens with hemophilia B.
- ▶ **Hemophilia B: Your Point of View**
Advice and tips to help you deal with challenges you may encounter as an adolescent or teen.
- ▶ **Young Adults and Hemophilia B**
Information for young adults about dating, moving out, starting a career, starting a family.
- ▶ **Learn from Experience: A Guide for Mature Adults**
Helpful info to make life decisions and stay healthy today and in the future.
- ▶ **Hemophilia B in Early Childhood**
What to expect when raising a child with hemophilia B.

PODCASTS



BloodStream™ Podcast

Believe Limited
bloodstreampod.com

Provides 360-degree look at the bleeding disorder community, with news, updates, community contributions. Sponsored by NHF. Hosted by Patrick James Lynch.

B2B Podcast: B's in a Pod

Pfizer
hemophiliavillage.com

Podcast series: patients, caregivers, friends in the hemophilia B community discuss advocacy groups, sibling relationships, self-infusion, camp, ER visits, dating, marriage.

MUSIC & VIDEO

My First Factor Song

Lyrics by Carri Nease
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
stbhemo.com; YouTube

Award-winning comedic web series about a dysfunctional nonprofit organization serving the bleeding disorder community.



Blood Vibrations

bloodvibrations.bandcamp.com

Ongoing grassroots project that collects music created by people with bleeding disorders. Provides a forum for creativity, expression, sharing, learning, wellness.

DIGITAL GAMES, APPS & MEDIA

GAMES

Hemocraft

Pfizer

hemocraftquest.com

Virtual world designed for people with hemophilia, ages 8–16.

Slay the Ender Dragon; craft components of an infusion kit; monitor the “factor bar” to prepare for adventure; share game strategy with friends and family to explain what it’s like to manage hemophilia.

HemoAction Online Game

World Federation of Hemophilia

English, Spanish, French
hemoaction.org

Adventure game teaches children about how to prevent bleeds and manage hemophilia, the clotting process, types of bleeds, factor infusions, suitable physical activities.

APPS

HemMobile®

Pfizer

iPhone users: download on App Store

Android users: download on Google

Helps patients keep track of bleeds and infusions; log infusions quickly; record bleeds precisely; generate reports to share with the treatment team; monitor factor supply.

HemMobile® Striiv® Wearable

Pfizer

hemmobilewearable.com

Striiv Wearable paired with HemMobile offers activity tracking to monitor daily activity, heart rate, number of steps. Tracking intensity of activity means better discussions with the medical team about intense activities, staying prepared, and managing hemophilia.

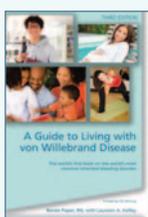
myPKFiT™ for Advate®

Shire

advate.com

Patients mobile application: first and only mobile app in US that allows appropriate Advate patients, 16 and older, to track treatment, view estimated factor levels, export data for healthcare provider review. App has age and weight restrictions, so talk with your doctor. Valid QR code provided by doctor is required to activate app.

VON WILLEBRAND DISEASE



A Guide to Living with von Willebrand Disease

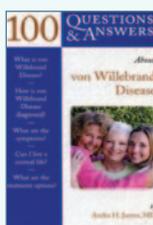
*Renée Paper, RN, with
Lauren A. Kelley*

LA Kelley Communications,
Inc. 2012

New edition coming in 2019!

Free to families and patients
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-understand info on diagnosis, treatment.

VWD Connect Foundation

vwdconnect.org

Foundation was formed to serve the bleeding disorder community, focusing on severe VWD. Provides

education and connection for patients and families; supports research to benefit the VWD community.

National Outreach for von Willebrand (NOW)

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.





WHAT IS HEMOPHILIA? Series

Lauren A. Kelley

LA Kelley Communications, Inc. 1995

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

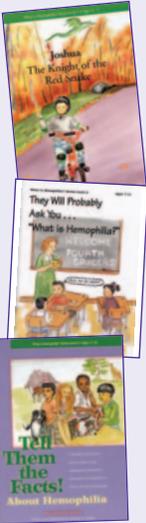
Empowering story about a preschooler with hemophilia. Illustrated large-text format ends on a note of joy and confidence. Ages 3–7.

▶ Level 2: They Will Probably Ask You... “What is Hemophilia?” (back order)

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 preadolescents 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?

Lauren A. Kelley

LA Kelley Communications, Inc. 1991

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

Lauren A. Kelley

LA Kelley Communications, Inc.

New Edition 2018!

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.



MY FIRST FACTOR Series

Shannon Brush

Illustrated by Brooke Henson

LA Kelley Communications, Inc. 2008–2015

kelleycom.com

World’s first toddler books for children with hemophilia. Series of colorful, chunky books just right for small hands. Available as 10-book gift set or individually. Ages 18 mo.–4 yr. Sponsored by Bayer HealthCare.

▶ 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?

▶ Hemophilia

What is hemophilia? Bruises, “owie,” factor!

▶ 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 kelleycom.com

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

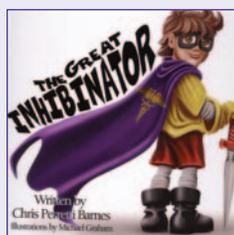
PERIODICALS

All periodical subscriptions listed here are free.

Parent Empowerment Newsletter (PEN)

LA Kelley Communications, Inc.
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.

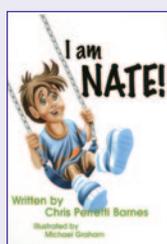


The Great Inhibinator

Chris Perretti Barnes
Diplomat Specialty Infusion Group
diplomatpharmacy.com

Colorful story about Nate, a boy who has an inhibitor, that centers on creating a Halloween costume.

Ages 4–7. Produced by Bayer HealthCare and Diplomat Specialty Infusion Group.

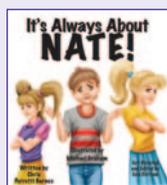


I Am Nate!

Chris Perretti Barnes
Diplomat Specialty Infusion Group
diplomatpharmacy.com

Story about Nate, a boy who explains how having hemophilia affects his life. Ages 4–7.

Produced by Bayer HealthCare and Diplomat Specialty Infusion Group.



Quest for Infusion: It's Always About Nate!

Chris Perretti Barnes
diplomatpharmacy.com

How Nate's hemophilia affects the lives and feelings of his sisters and parents. Ages 4–7. Produced by Bayer HealthCare and Diplomat Specialty Infusion Group.

PEN's Insurance Pulse

LA Kelley Communications, Inc.
kelleycom.com

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



Factor Nine News

Coalition for Hemophilia B
coalitionforhemophiliab.org

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

Dateline Federation

Hemophilia Federation of America (HFA)
hemophiliafed.org

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



Lifelines for Health

Comprehensive Health Education Services (CHES)
comphealthed.com

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



Hemophilia World

World Federation of Hemophilia (WFH)
wfh.org

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

The Source

Plasma Protein Therapeutics Association (PPTA)
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.



OneVoice

Save One Life
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 impoverished countries.

HemAware Magazine

National Hemophilia Foundation (NHF)
hemaware.org

Quarterly. Magazine of US NHF. Articles on medical research and treatment; families and children; community events; people making a difference.



ONLINE RESOURCES



Beyond the Bleed

Shire
beyondthebleed.com

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

BleedingDisorders.com

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

Hello Tools: School Guide

Shire
bleedingdisorders.com

Website contains main presentation and downloadable PDFs; workbooks compile individualized reference guide from multiple programs; toolkits give patients and supporters info to get started; school resource guide supports academic success, development, well-being of students with bleeding disorders.

Hemophilia Village

Pfizer
hemophiliavillage.com

Provides info about programs and resources to assist the hemophilia community, including Constructive Conversations.

Living with Hemophilia®

Bayer HealthCare
livingwithhemophilia.com

Info on clotting factors, genetics, pain management, medical treatment for patients and caregivers. Website features Bayer Leadership U, Living Fit! and “Living with Hemophilia on Your Own Terms” video series explaining hemophilia terminology.

PPTA Gift of Life

Plasma Protein Therapeutics Association

English with Spanish subtitles
pptaglobal.org
Donors, patients, physicians discuss reasons for donating plasma for plasma protein therapies; demonstrates industry’s commitment to safety, quality, innovation.

Supporting Bleeding Disorders

Octapharma USA
facebook.com/supporting-bleedingdisorders
Resource for bleeding disorder patients and families inspires; communicates about community events and educational programs.

GADGETS!



“Be A Hero” Infusion Mat

Diplomat Specialty Infusion Group
diplomatpharmacy.com

Infusion mat for kids makes infusions easier with easy-to-clean surface and colorful step-by-step instructions.

StrapWrap™

Diplomat Specialty Infusion Group
diplomatpharmacy.com

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



Emergency Headrest Covers

Danny’s Dose
dannysdose.com

Car headrest covers include a pocket for Emergency & Medical Information Cards featured on Danny’s Dose website.

Automobile Alert Decals

Danny’s Dose
dannysdose.com

Car decals to be placed on cars in case of emergency. General Medic Alert and bleeding disorder specific decals available.



But any learning mode may shift when you're stressed. It's normal for people to want to be with others for support, which results in learning. So social learning may become dominant for a while. Given that, it's no surprise that many Facebook friends mentioned chapter meetings, symposia, and especially meeting with hemophilia treatment center (HTC) staff to get information about bleeding disorders.

"I most value learning from the experiences of those who are living and thriving with hemophilia," commented one mother of a child with hemophilia. Jasmine Eaglin, another mother, wrote, "First I learned about NHF, then I got involved with the New York City chapter and attended every single event I could. Eventually, I made it to an HFA conference in 2017. The organizations provide so much information!" Heather Coons, mother of a 13-year-old with hemophilia, wrote, "I learned from books, but talking to the HTC staff and families helped me the most."

And not surprisingly, many who started with only books, back in the 1990s and 2000s, are now turning to online resources. Diana Lynn shared: "In the beginning it was *Raising a Child with Hemophilia*. Now that our son is older, we look to meetings and websites (mainly medical/journal articles) for our information."

Allison Pohl summed up this change in information sources: "When our son was diagnosed in 2000, the main resource for information on hemophilia was our HTC staff, and *Raising a Child with Hemophilia*. There was no social media back then, and most information we received was passed face to face or by snail mail."

With all the options available, Allison still relies mainly on her HTC. But, she noted, "In addition, we read PEN, speak to product reps, and go to our local chapter meeting. If I want info about products or trials, I usually google scientific journals. I try to stay away from anecdotal info and stories on social media. While I like the personal experiences, sometimes the advice given is not correct."

Social Media: Not Just for the Young and Brave

Young people with bleeding disorders seem to gravitate toward social media for information. Dakota Rosenfelt cited Twitter ("HUGE," he wrote), NHF's website, and even the European Haemophilia Community website. One mother of a two-year-old with hemophilia wrote, "I love online resources, and found most of social media to be an amazing resource."

Knowing that learning styles are changing, and tapping into the way young people learn about their world, Patrick J. Lynch's company Believe Ltd. has focused on social media

and digital resources like podcasts (BloodStream Media), videos ("HTC Guided Tour"), plays (*Stop the Bleeding*), forums ("Powering Through"), and now musicals (*Hemophilia: The Musical*). These resources represent a combination of learning modes, including social, aural, physical, and visual. Indeed, multimedia is becoming the best way to reach all types of learners.

On the Fringe

But a preferred learning mode may not matter when you have limited resources. People with VWD or rarer bleeding disorders, as well as those living in developing countries, don't always have the luxury of choice in learning modes.

Leticia Nevarez, a Facebook friend, points to our book *A Guide to Living with von Willebrand Disease* as the first resource she ever had about VWD. Fortunately, a national conference (NOW; see page 11) offers a weekend of presentations and socializing, as well as Facebook social media pages where patients can share VWD experiences. Helen Smith, a woman with Glanzmann's thrombasthenia, started Glanzmann's Research Foundation, a nonprofit organization dedicated to offering information to patients. She now wants to hold a weekend retreat to allow patients to share in person.

Patients and families in developing countries are perhaps most limited. Without books translated into their national language, and with travel to events almost impossible, they rely mainly on the internet, accessed through their phones. This includes Facebook, which offers translation.

Patients from Kenya to Pakistan, from Nigeria to the Philippines shared their thoughts on accessing information. Samad from Pakistan learns mostly from his doctors; Sarah from Kenya learns from other patients; and one doctor from Cambodia cites Twitter and Facebook as his primary source of info. WhatsApp is popular with youth everywhere, allowing them to share experiences as a private group.



When learning about your bleeding disorder, think about how you learn in general. Which modes make you happiest? Which help you learn best? Seek out bleeding disorder resources that match your preferred learning modes.

Suzanne Harpell-Smedley summed up how multimedia learning can work: "Initially, we devoured anything by NHF. Then we found LA Kelley Communications' books. With medical complications, we researched online and have auto-email updates sent to us. We regularly attend inhibitor summits and occasionally our local hemophilia groups. Last of all, we turn to Facebook for real-world experiences."

Whatever your preferred learning mode, the key is to find out about your disorder, and to make learning effective and fun! ☺

nonprofit



HFA's 25th Anniversary

San Diego

April 4-7, 2019

Hemophilia Federation of America celebrates its 25th year of education and advocacy for the bleeding disorder community. Guest speakers, games, and social events make this a valuable time for all. **Why this matters:** A special history room will display materials, books, newsletters, and photos paying tribute to the community's legacy of struggle, sacrifice, advocacy, and perseverance, as well as HFA's role in this history.

For info: hemophiliafed.org



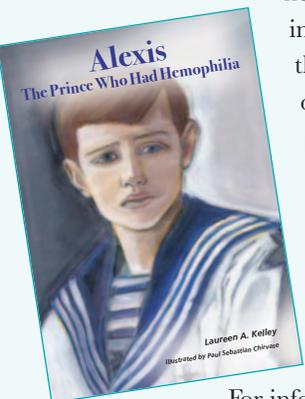
LA Kelley Communications

Alexis: The Prince Who Had Hemophilia

2018 was the 100th anniversary year of the assassination of the Russian royal family, including its youngest member, Alexis, who had hemophilia.

Read about Alexis, the heir to the throne, and how the mad monk Rasputin influenced the royal family through his hypnotic powers over the young prince. The story has been reissued, with new illustrations by a Romanian man with hemophilia. **Why this matters:** The story of Alexis and his hemophilia is a vital part of world history.

For info: kelleycom.com



More Gene Dreams

Sangamo Therapeutics announced positive preliminary data from its phase 1/2 Alta clinical study evaluating SB-525, a gene therapy for treating hemophilia A. The Alta study will assess the safety and tolerability of SB-525 in up to 20 adults with severe hemophilia A. To date, five patients have been treated at three dose levels, with no treatment-related serious adverse events and no use of tapering courses of oral steroids. A dose-dependent effect has been observed in the study, with patients in the second dose cohort reporting reduced use of factor VIII replacement therapy. The fifth patient enrolled in the study, and the first at the highest dose level, was treated in June and has reached therapeutic factor VIII activity levels. **Why this matters:** Phase 1/2 is an important first step in achieving approval of a new therapy.

For info: sangamo.com

Worth Repeating: One Step Closer

uniQure has treated three patients in its phase 2B dose-confirmation study of AMT-061, an investigational gene therapy for patients with severe or moderate hemophilia B. AMT-061 uses an AAV5 vector carrying the Padua variant of the factor IX gene. Six weeks after administration, the factor IX activity for the three patients was 31% of normal, considered enough to significantly reduce the risk of bleeding events. Patient enrollment is also underway in the global phase 3 HOPE-B clinical trial to evaluate the safety and efficacy of AMT-061. **Why this matters:** AMT-061 could be a major advance in gene therapy for hemophilia B patients, says Dr. Steven Pipe, principal investigator of the HOPE-B clinical trial.

For info: uniquire.com





More Good News on Hemlibra®

On October 4, 2018, the US FDA approved expanded use of Genentech's Hemlibra (emicizumab-kxwh). It can now be used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, newborn and older, with hemophilia A without factor VIII inhibitors. Hemlibra is a bispecific antibody that mimics the function of factor VIII. It was first approved in November 2017 for prophylaxis to prevent or reduce the frequency of bleeding episodes in people with hemophilia A and inhibitors. In clinical trials, Hemlibra significantly decreased the number of treated bleeds compared to previous factor VIII prophylaxis. It's administered subcutaneously weekly, bi-weekly, or monthly. **Why this matters:** Hemlibra will now compete with standard clotting factor therapy for all hemophilia A patients.

For info: emicizumabinfo.com

soundbites

- New factor product: **Jivi®**, Bayer's extended half-life treatment for hemophilia A.
- CSL Behring's **Idelvion** now comes in five vial sizes: 250, 500, 1,000, 2,000, 3,500 IU.
- Genentech's new web portal for patients and caregivers provides accurate info on any serious adverse events for **Hemlibra**: emicizumabinfo.com.
- Hemlibra has been launched in **13 countries**, including the US, UK, Germany, France, Japan.

As I See It... from page 3

The best answer we have right now is that we're thankful for the treatment presently available for our son and the prospect of what some are beginning to call a cure. There are too many parents with children afflicted by conditions that have no available, effective treatments. When we picked Bubba up after his first bleeding disorder camp last summer, he told us that some of the kids said he was lucky because he only infused once a week. I think those interactions gave him his first insight into the fact that living with hemophilia is not the same for everyone.

Science can do amazing things. As a species, we're quite ingenious at times. I have no doubt that hemophilia will cease to exist one day, but I have no idea when that day will come. As parents, we can only put our son's best interests first, stay informed about medical advances, and trust that our team at St. Jude will continue to help us make the best decisions based on the options available.

Bubba won't want to hear it, but his mom isn't going to let him play football anyway.

Derek lives in Saltillo, Mississippi, with his wife Ashley and their children Abbey and Bubba. He is the executive director of two University of Mississippi regional campuses and an assistant professor in the School of Education. Ashley is a fifth-grade math teacher in the Tupelo Public School District. Derek is the author of 'The Bubba Factor,' available on Amazon in Kindle format and in paperback. ☺



Pfizer Hemophilia

Our goal is to understand the needs of the hemophilia community as a whole, and our commitment to you extends far beyond our products. We're proud to have listened and learned from you for more than 20 years.

Visit HemophiliaVillage.com to find tools and resources inspired by your needs.

PP-HEM-USA-1106-01
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September 2018



Why would a company run a website without its name? For pharmaceutical companies, direct-to-consumer marketing of drugs is heavily regulated and subject to an FDA policy called “fair balance.” Fair balance requires pharma advertisers to present the drug’s negatives alongside the positives, including side effects and other conditions that make taking that drug risky. An unbranded website is not subject to the fair balance rule and is lightly regulated, allowing the company to quickly get a website running, increase “disease awareness,” and offer consumers more educational info about a medication—but not mention side effects. And this may mean a greater risk of misleading consumers. Make no mistake: pharma is funding these websites to gather general patient information or to make money by converting patients to their product. Also be wary of unbranded sites that require a “registration” process to access—websites should not ask for personal info.

For example, one pharmaceutical company runs a lightly branded inhibitor website that heavily pushes the results of the SIPPET study, suggesting that patients use a factor VIII product with von Willebrand factor (VWF). No product names are mentioned on the site, and the company name is only in small text at the bottom of a page. But it turns out that this company is also the only company selling a plasma-derived factor VIII-VWF product in the US—and this product is being promoted by the website. So, although the website provides good info on inhibitors, it also tries to convince consumers to switch to a VIII-VWF product (the company’s own), while at the same time avoiding FDA fair balance rules.

Who reviewed the info before the website’s owner posted it?

Health-related websites should provide the credentials of people who prepared or reviewed the material. Here are some questions to ask yourself: Do you recognize the author? What knowledge

or skills does the author have in the subject? What else has the author written? Does the author acknowledge other viewpoints and theories? Does the site have an editorial board? Is the info reviewed by editors or experts before being posted? Does the author clearly state what’s fact or opinion? Are opinions or advice set apart from info that is “evidence based” (based on research results)? Testimonials from people who have tried a particular product or service are not evidence based and usually can’t be confirmed.

How does the website document its supporting evidence?

Websites should identify the medical and scientific evidence that supports the material presented. Medical facts and figures should cite references, such as articles published in medical journals. Be skeptical. You want current, unbiased information based on research. An article that cites no evidence and includes no references is a red flag. Things that sound too good to be true often are. Always cross-check multiple sources of info from different websites. Never rely solely on one website.

How current is the info on the website?

Medical research and knowledge are constantly progressing, sometimes making old material obsolete. How do you know if the material you’re reading on a website is up-to-date? Articles and web pages should be dated. Experts should review and update articles regularly, and then label the material with the most recent review date. Even if the info has not changed in a long time, the site owner should indicate that it’s periodically reviewed to ensure it’s still valid.

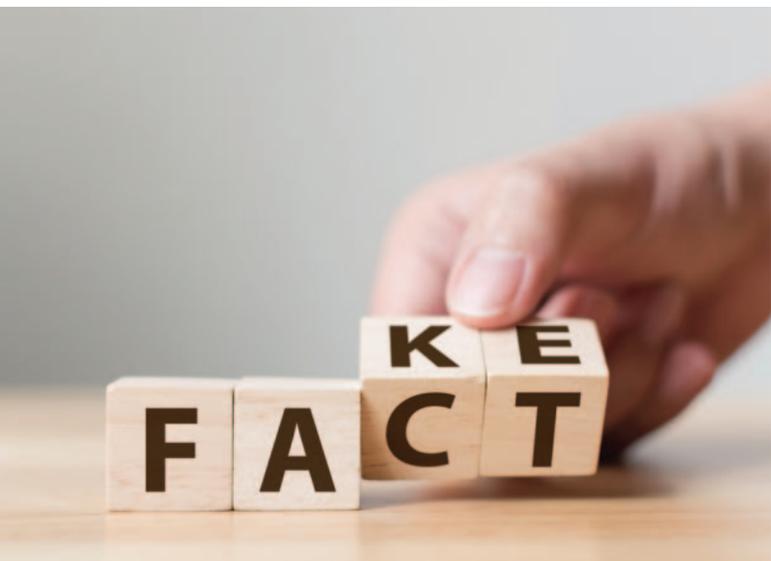
Can you communicate with the website’s owner?

Can you easily find contact info on the web page? Does the website provide names, emails, and a physical address? Or is the only way to contact the owner through a webform? More red flags: anonymous articles, and lack of contact info. Websites should always offer a way for users to contact the owner with problems, feedback, and questions.

What about social media?

According to a PwC Health Research Institute survey, more than one-third of US consumers use YouTube, Facebook, or Twitter to find medical information. And 90% of respondents aged 18 to 24 said they would trust medical info shared on their social media networks. Also, 80% said they would share their own personal medical info online (more than twice the percentage of 45- to 65-year-old participants).⁴

4. “Social Media ‘Likes’ Healthcare: From Marketing to Social Business,” April 2012, www.pwc.com.



Social media is great for support, but as a source of reliable health information, it's inadequate. Take anything you learn on a social media site with a grain of salt, and verify by visiting more reliable websites.

Be a savvy health info consumer!

Just knowing that some websites are biased and others are not can help you search for health information. Start with searches on .gov and .edu sites. When searching on .com sites, ask yourself why the sponsor is providing the website.

Learn how to use the US National Library of Medicine, National Institutes of Health database PubMed (ncbi.nlm.nih.gov/pubmed). PubMed contains more than 28 million citations for peer-reviewed biomedical literature from Medline, life science journals, and online books. Many of these citations are abstracts (short descriptions of an article); others are full text. Most PubMed citations are from medical journals, and the jargon makes difficult reading at first. But the reading gets easier over time because you'll see the same terms over and over, and eventually, some will stick with you. Several websites, including

5. Download HON apps at www.hon.ch.

Medical Library Association's *What Did My Doctor Say?* page (mlanet.org/p/cm/ld/fid=580), can help you decipher "medspeak."

In addition, several organizations rate the reliability and credibility of health-related websites for consumers. The best known is Health on the Net Foundation (HON). HON issues certificates to medical and health websites that agree to abide by the HON Code of Conduct. The HONcode symbol indicates that a site follows HON standards, so readers know the source and purpose of the medical info. But remember: HON does not verify the truth of the info on websites. More than 8,000 websites display the HONcode. The HON site has a search engine, a toolbar, and search apps.⁵



The bottom line: Not everything you read on the internet is true! Visit respected sites, and always verify information on multiple sites. Use dedicated health search engines like HON's. Be skeptical of what you read online. Be aware of bias. And if you need clarification on a topic dealing with bleeding disorders, contact your HTC hematologist. ☺

Inbox... from page 2

Project SHARE

JUST WANTED TO SAY A BIG thank you to Project SHARE for the factor donations, and to Andrea Trinidad Echavez and the officers of Hemophilia Advocates Philippines for making it possible for us to have access to factor concentrates, especially factor IX. I've been suffering from an elbow and shoulder bleed for six days now, and sleeping has been hard because of the pain and swelling. I know after this infusion, the swelling will subside, and I can finally have a decent sleep and go back to my daily routine. Thank you for extending your kind heart to us! God bless!

Mikko Gonzaga
PHILIPPINES



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