

PEN

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Zoraida Rosado

PEN's Biennial Bleeding Disorder Resource Guide 2011

Books



Raising a Child With Hemophilia: A Practical Guide for Parents

Laureen A. Kelley
LA Kelley Communications, Inc. 2007
www.kelleycom.com

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

Hemophilia

Michelle Raabe
2008

\$33.01 from amazon.com

Scientifically detailed, colorfully illustrated, easy-to-read book focusing on the science behind the treatment, symptoms, genetics of hemophilia.

Includes stories of hemophilia's history; explanation of how various treatments are made, such as plasma-derived and recombinant; and how gene therapy might work.



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

Laureen A. Kelley with Paul Clement
LA Kelley Communications, Inc. 2010
www.kelleycom.com
\$18.95

World's first book on inhibitors. From parents' and patients' point 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. 2004
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 Talecris Biotherapeutics, Inc.



Teach Your Child About Hemophilia

Laureen A. Kelley
LA Kelley Communications, Inc. 2007
www.kelleycom.com

In-depth exploration of how children think and understand hemophilia as they mature. Examines children's understanding, at different ages, of hemophilia concepts: cuts, healing, blood, severity levels, blood clotting, infusions, genetic transmission. Explores how children on prophylaxis understand hemophilia. Prepares parents to answer children's questions and encourage independence. Sponsored by CSL Behring.

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Most resources are free, except where prices are noted. Visit the publishers' and providers' websites on page 13 to learn more.

welcome



Laurie Kelley

PEN's *Biennial Bleeding Disorder Resource Guide* is one of our most popular issues. We love reviewing the current literature and programs to select titles that might interest you most. When we started PEN in 1990, there were almost no books or programs available for our community, and certainly no DVDs! Now you have a wide choice, and always something new to learn.

Be daring in 2011: read something new. If you want to know more about hemophilia in developing countries, try

OneVoice, which reports on child sponsorship programs—you might even want to sponsor a child! Learn about our unique past by viewing *Bad Blood: A Cautionary Tale*, the new documentary. Attend an Inalex program to hear family experts discuss how to be a more effective parent. Or pick up a new children's book, and read it to your child enthusiastically.

We have a fabulous variety of resources today, so be sure to take action and learn. It's tempting to spend time on Facebook these days for quick information, but nothing can take the place of a well-researched, well-edited book, newsletter, program, kit, or movie to shed light on living with a bleeding disorder. We hope we've presented some great ones here—enjoy! ☺

inbox

Bad Blood, Good Movie?

VERY WELL WRITTEN ARTICLE ABOUT *Bad Blood*. At least now we have a document that captures history as a legacy. May we never become complacent or asleep at the wheel again. May history not repeat itself. Many people gave their lives to make the future better.

Dana Kuhn, PhD
President
Patient Services, Inc.



I WANT TO THANK PEN FOR CALLING ATTENTION TO *Bad Blood* and the greater issues it addressed. The objective of the film had little to do with assigning blame. This “cautionary tale” is intended to dissect the more significant breakdowns in public policy, private enterprise, and doctor/patient relationships so that we can learn, with the benefit of 20/20 hindsight, how not to repeat those mistakes in the future when inevitably faced with a different threat. So when PEN characterized that the film “interprets 30-year-old, complex events in 20/20 hindsight, creating a black-and-white, simplistic story,” I take that as a compliment for having achieved the intended purpose.

I have no doubt that everyone involved in this tragedy, whether directly or indirectly, will struggle to reconcile their own painful memories with the communal experience laid out, for the first time, in a larger, historical

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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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Ranjana Kulkarni, MD

Homeopathy and Hemophilia

The Hemophilia Society, Nashik Chapter, affiliated with

Hemophilia Federation (India), is located in Nashik, India, about 150 miles northeast of Mumbai (Bombay). We support 150 patients with hemophilia and their families. In this part of India, because of poor public awareness and lack of medical training, we have few health professionals with everyday experience treating hemophilia.

I've treated patients with hemophilia for ten years, and I'm frustrated that I can infuse factor only during an active bleed, due to the exorbitant cost. We can do nothing between bleeding episodes except counseling or physical therapy for patients. Most patients do not receive factor because they are too poor to travel to the hemophilia treatment center (HTC). We have few HTCs, so most patients must travel long distances. When patients can't come to the HTC, due to either ignorance or poverty, they may consult a local health professional who is unaware of their special needs. The result is usually incorrect or inadequate treatment, which may cause permanent damage—sometimes death. As a result, we often see patients with severely damaged joints when they arrive at our HTC for the first time.

This is the situation at almost all HTCs in India. Hemophilia patients here lead lives filled with pain. If patients can't afford a single visit to the HTC, how can we expect them to take regular physical therapy?

The best treatment is factor, but this is impossible to prescribe for most patients here. Yet, India is home to many alternative

therapies: Ayurveda, Unani, Siddha [different forms of traditional complementary and alternative medicine], and homeopathy. One government sector (AYUSH) even encourages research into these branches of medicine. Watching my patients suffer, I seriously considered alternative medicines for hemophilia.

Following one of my presentations at Homeopathy Medical College, Nashik, to create awareness about hemophilia,

Dr. Kundu, head of homeopathy medicine, offered immediately to start a drug trial with me for hemophilia patients. It would be a double-blind placebo control trial: some patients would receive homeopathic medicine, and others would receive a placebo.

In December 2007, we began the trial to apply homeopathic remedies to hemophilia. Our main concern was relieving severe pain after joint and muscle bleeds.

We applied these remedies:

- Lachesis 30 for pain and bleeding
- Silicea 30 (silica) for patients requiring repeated factor
- Bryonia 30 + calcaria carb 30 (calcium carbonate) for excruciating pain
- Hamamelis virginiana (witch hazel) for local application and gum bleeds

The selection and combination of each drug depended on each patient's history and personality type. We have found that generalized use for any person with hemophilia is not effective.

The evaluation and follow-up of patients was based on the Wong-Baker FACES Pain Rating Scale, the Child Adaptive-Maladaptive Behavior Scale, and the Joint Mobility Assessment SF-32 scale.

We observed significant pain relief in the majority of cases, along with other benefits.

In the past ten years, I have often observed aggression and depression in children with hemophilia. But following our homeopathic drug trial, the changes were amazing. Alleviation of pain was accomplished and accompanied by

- reduced duration of bleeding;
- reduced frequency of bleeds;
- reduced school or work absenteeism;
- improved range of motion in the affected joints.

The most significant change: children were more friendly and cheerful, less irritable and depressed during painful bleeding episodes. Families reported a positive improvement in attitude toward living with hemophilia.

Encouraged by these promising results, we have extended this trial to three more chapters in western India. I'd like to expand the database and include more patients and chapters. If similar results are obtained in more patients, we can continue the trial throughout India and perhaps in other developing countries where factor is unaffordable.

As an allopathic doctor, I believe strongly in holistic health. I believe the majority of patients will benefit from appropriate homeopathic medicine prescribed by homeopathic physicians.* My faith is based on the results of my personal follow-up of patients for the past two years. Though this is a short period, I believe that the results of our trial invite a larger, multicentric trial on a bigger scale.

Support in any form for this unique project will help to open some unexpected and promising new doors in hemophilia treatment, especially in developing countries. We someday want to see *Hemophilia without disability; children free of pain*, the vision of Hemophilia Federation (India). ☺

Dr. Ranjana Kulkarni is a pathologist and president of Hemophilia Society Nashik, India.

* Allopathy and homeopathy are two different branches of medicine. In allopathic medicine, we provide pain medicine to relieve pain and infuse factor to control bleeding. In homeopathic medicine, medications are given for overall constitutional effects and not for any specific complaint like pain.

The opinions expressed in *As I See It* are not necessarily those of the editors. Always consult a qualified medical specialist when making any treatment decisions.

When to Suspect an Inhibitor

Let's face it: an inhibitor is a major complication of hemophilia. It develops when the body's immune system does not recognize infused factor as a normal part of blood. Instead, the body thinks that factor is a foreign invader, like a virus or germ, and it develops antibodies to attack the factor and make it harmless—and useless. So despite an infusion of factor, your child continues to bleed.

Prolonged bleeding, even after a factor infusion, is the most common sign that your child may have an inhibitor. But other symptoms may also tip you off.

Unresolved bleeds

You may suspect an inhibitor the hard way: when factor no longer works well to stop bleeds. If you're new to hemophilia, this may be difficult to judge—how long *should* it take for a bleed to stop after an infusion? It may not immediately dawn on you that the infused factor isn't working properly, especially if your child is already well into a muscle or joint bleed. It's common for parents to think that they simply need to give their child more frequent infusions, or give a higher dose per infusion. If you think your child's bleed is not resolving normally, or wonder whether you should dose higher or more frequently, please call your hemophilia treatment center (HTC).

Increased bruising

Bruising in young children with severe hemophilia is common. But if your child is on prophylaxis and you notice increased bruising, this may be a sign of an inhibitor.

Routine clinic visit

A blood test at your child's HTC comprehensive clinic visit can identify an inhibitor. Low-level inhibitors are often diagnosed in this way. It's wise to have a child with hemophilia tested for inhibitors routinely. Learning that he has an inhibitor prior to surgery or a major

bleed allows parents to have a plan in place and the correct treatment on hand.

Breakthrough bleeds while on prophylaxis

Prophylaxis is the scheduled infusion of factor to help prevent bleeding. Many children with hemophilia on prophylaxis receive factor two to three times a week, enough to allow circulating factor to prevent most spontaneous bleeds and abnormal bruising. When a child on prophylaxis starts bruising or bleeding more often than usual, an inhibitor may be inactivating some of the factor, lowering his factor level and increasing his risk of bleeding.

Bleeding after surgery

Any kind of surgery on a child with hemophilia requires careful planning and monitoring of factor levels, and any child who continues to bleed following surgery, even with adequate factor, should be immediately tested for an inhibitor. Ideally, all children with hemophilia should be tested for an inhibitor *before* any surgery. If you see any kind of bleeding following surgery, call your HTC immediately.

Reaction following infusion

An allergic reaction is a response by the immune system to environmental contaminants such as pollen, animal dander, or food. It can also happen after an infusion of factor. Symptoms may include sneezing; itching; hives; rapid swelling of the skin, neck or face; wheezing; faintness; fast heart rate; low blood pressure. Allergic reactions are especially worrisome with hemophilia B. An allergic reaction after a factor IX infusion is sometimes the first sign that an inhibitor to factor IX has developed. A whopping 45% of people with hemophilia B and inhibitors also develop allergic reactions at about the same time that they develop inhibitors.

Don't downplay allergic reactions. They may start out mild but then increase in severity after repeated exposure to products containing factor IX, often to a

serious, life-threatening allergic reaction called *anaphylaxis*. If your child has severe hemophilia B, his first 20 infusions of factor IX concentrate should be done in a hospital or clinic with expertise in treating severe allergic reactions.

Following a major bleed or emergency

Whenever your child receives large amounts of factor—in response to a major bleed or during and after surgery—he may be at higher risk of developing an inhibitor. Experts aren't sure if large amounts of factor stimulate inhibitor development, or if the body is more susceptible to inhibitor development during a medical crisis because the immune system is on high alert. But whatever the reasons, be aware that the risk of developing an inhibitor is slightly higher during an illness or surgery.

Later in life

If a person with hemophilia develops an inhibitor, it's usually while he's a child, almost always before exposure day 100. And he probably has severe hemophilia. But in rare cases, an inhibitor develops in a teen or an adult—usually in people with mild or moderate hemophilia, and usually after intensive exposure to factor during and after surgery or traumatic injury.



Inhibitors are scary to contemplate. Even when your child passes exposure day 100, don't be lulled into thinking that he may never develop one. You can always request an inhibitor test from your HTC. Never try to diagnose on your own, or change your child's dosing regimen on your own.

In your favor? A great array of educational resources, listed in this issue, and a wonderful team of medical experts. Don't be afraid! Be proactive, just as you were when you learned about hemophilia. Inhibitors are one obstacle to overcome on your family's hemophilia journey. ☺



Kevin Correa

Considering Long-Term Health in Your 20s

By the time teens with hemophilia transition into their 20s, ideally they've built a firm foundation on which to manage their disorder. Among many skills, young adults should be able to self-infuse and negotiate health insurance. But when you're healthy and your hemophilia is under control, it's easy to overlook general health maintenance beyond hemophilia.

It's uncommon for 20-somethings to consider the long-term impact of their lifestyle choices. *So what if I've gained a few pounds? I only smoke when I'm out with friends. I look so much better with a tan.* But young adulthood is the time to develop the habits that will help maintain a healthy body in the decades ahead.

I'm Independent. Now What?

Perhaps more than any other time in our lives, the 20s are a decade of major transformation. Many young adults move out of their parents' home. Others graduate from college. Even those who've diligently managed their hemophilia may be thrown for a loop by all the changes in their lives.

Your hemophilia treatment center (HTC) may no longer be in the same town or even the same time zone. And finding an HTC is just one of the myriad issues you'll need to address: *Where will I buy groceries? How long will my commute be? When will I find time to renew my driver's license?*

These changes may take priority, and if you're feeling healthy, find-



Kaori Furutashiki

Ian Muir, a triathlete with hemophilia, now struggles to find the hours to train

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Imagine caring for your child with hemophilia—
with no factor, refrigerator, running water, electricity, or transportation to a clinic. This is the reality for thousands of families in developing countries. For just \$20 a month, you can help an impoverished child with hemophilia.

Become a sponsor today!



www.saveonelife.net / contact@saveonelife.net

Caring for people with hemophilia around the world—one at a time.



sponsored by
Baxter BioScience

richard's review

Richard J. Atwood



Thicker Than Water: A Documentary by Bradley Rappa

2009, Reel Travelers
72 minutes, not rated

Director: Bradley Rappa
Awards: Prairie Spirit Award, Fargo Film Festival;
Best Central New York Film, Syracuse International
Film Festival

Eleven-year-old Tony Rappa had to make the most important decision in his life. Should he follow his dream to join a competitive ice hockey league in which checking—hard physical contact—was allowed? Or should he be sensible, and quit the game forever?

Either decision seemed possible. Because of his severe hemophilia, Tony had learned that contact sports could have dire consequences. Yet he was part of a sports-minded family and was talented enough to earn a place on the traveling hockey team. Tony and his friends shared a passion for being on the ice—and in White Bear Lake, Minnesota, such things were expected of boys. “It’s a rite of passage,” explains the film’s director.

But Tony didn’t have to make this decision alone. His parents, Lori and Scott, were supportive and encouraging but not pressuring. His physician and nurse at the hemophilia treatment center had fully explained the medical consequences. Even his hockey coach was involved. And Tony knew that he needed a prophylactic infusion of factor concentrate before every hockey practice and game.

The award-winning documentary *Thicker Than Water*, directed by Tony’s paternal uncle, Bradley Rappa, was filmed from 2000 to 2002. “I noticed how well adjusted Tony was to his disorder,” recalls Rappa, “and I thought that Tony and his family

would be a great inspiration to other families and individuals dealing with chronic illness.”

As in many documentaries, the key characters in *Thicker Than Water* are interviewed in head shots and provide valuable insights. The rest of the documentary is filmed like a reality show, using a hand-held camera that intimately follows the actions of daily life. On film, Tony seems well adjusted and informed. When he is interviewed outdoors in the snow, the film turns from color to black and white, in eerie contrast to Tony’s sensible dialogue. Though most 11-year-olds are naturally egocentric and present-oriented, Tony is unusually mature, contemplating both short- and long-term consequences. He is obviously enthusiastic about hockey and has fun playing; some of the hockey scenes are comically sped up.

The viewer would expect the documentary to be about Tony’s sports decision. And so it is; but his family’s medical history is also systematically revealed. Tony’s maternal uncle John had hemophilia and HIV, and died of AIDS complications. Tony’s grandmother died of cancer soon after. Then Tony’s mother Lori was diagnosed with breast cancer. So Tony’s choice about

any further hockey playing is significant: the decision-making process teaches him how to thoroughly think through a difficult problem. As Rappa explains, “I wanted to make a film that encourages everyone to face each challenge in life with love, hope and positivity.” Yet Tony’s hockey-playing dilemma pales in comparison to what is *unexpected*, as the documentary

becomes a memorial with an impact far greater than any hockey check could ever deliver. ☺

Bradley Rappa has directed nine films. He and his wife Nicole Koschmann formed the production company Reel Travelers to produce videos for non-profit organizations and individuals working to promote environmental and human rights causes. To learn more: www.bradleyrappa.com



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Keep your Factor on Track!

The first **FREE**, customizable mobile app designed to help you track and record your hemophilia A Factor VIII infusions:

- ▶ If you’re on a prophylaxis regimen, the app reminds you when to infuse.*
- ▶ If you infuse on-demand, the app records your bleeds and infusions.

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LivingWithHemophilia.com/FactorTrack

FactorTrack™ is part of Living Fit! A Joint Effort™.

**Please note that an internet connection is required to receive infusion reminders.*

This app is not intended to offer or replace professional medical advice. Speak to your nurse or physician if you have any health concerns. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

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The Gift of Experience: Conversations About Hemophilia

Laura Gray, LICSW, and
Christine Chamberlain
Boston Hemophilia Center. 2007
Free from NHF; \$12.50 from
amazon.com



Compilation of
personal stories
from 21 hemophilia
patients born before
1965 and caregivers
who treated them.

Practical informa-
tion, guidance, support, and insight
into caregivers' struggles and achieve-
ments at that time.



Pooling Blood

Cheryl Nineff
D'Ambrosio

iUniverse. 2010

\$17.90 from amazon.com

Personal recollection of a
woman who raised two stepdaughters
with factor V deficiency. Harrowing,
sometimes hysterical, poignant story of
the frustration, fear and joys of raising
a child with a blood disorder.

Booklets & Binders

Inhibitors in Hemophilia A: What Patients and Families Need to Know



Grifols

www.grifolsusa.com

Topics include defining
inhibitors, discussing
treatment. Provides inhibitor
log for long-term use.

Safety of Hemophilia Therapies: What Patients and Families Need to Know

Grifols

www.grifolsusa.com

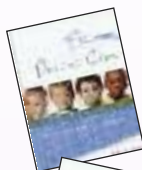
Describes the many safety steps
taken in the manufacture of
human plasma-derived factor
concentrates used to treat
hemophilia A and B.

Dental Care (series)

CSL Behring Choice Support Center.
2010

www.CSLBehring-US.com

Three-part series on dental care for individ-
uals and families with bleeding disorders.



► Dental Care for Infants, Toddlers, and Preschoolers With Bleeding Disorders



► Dental Care for Children and Teens With Bleeding Disorders: Ages 5 to 18



► Dental Care for Adults With Bleeding Disorders

Educational Support Brochures



Novo Nordisk Inc.

www.novonordisk-us.com/biopharm

Contact your local HTC

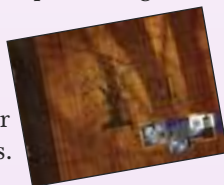
Topics include introduction to inhibitors,
surgery, traveling with inhibitors, ER
visits, school teen issues, adult issues.

B2B Speaking from Experience

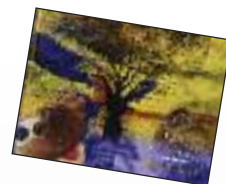
Coalition for Hemophilia B. 2006
www.coalitionforhemophiliab.org

Colorful booklet
for adults and teens
shares personal
experiences of factor
IX deficient patients.
User-friendly infor-
mation for people

already living successfully with
hemophilia B. Sponsored by Pfizer.



B2B Speaking from Experience: A Guide for Mature Adults



Coalition for Hemophilia B. 2007
www.coalitionforhemophiliab.org

Helpful knowledge for making informed
life decisions and remaining healthy
today and in future. Sponsored by Pfizer.

B2B Perspectives on Hemophilia B in Early Childhood

Coalition for Hemophilia B. 2010
www.coalitionforhemophiliab.org

Tips from parents who have raised
infants, toddlers,
and preschoolers
with hemophilia B;
insight from med-
ical professionals
who treat children
with hemophilia B.
Sponsored by Pfizer.



Hemophilia B: From Your Point of View

Coalition for Hemophilia B. 2010
www.coalitionforhemophiliab.org

Tips from peers with hemophilia B
on dealing with
challenges during
adolescent and teen
years. Sponsored
by Pfizer.



Living with Hemophilia B

Pfizer

www.hemophiliavillage.com

Colorful, comprehensive overview of
hemophilia B. Topics include genetic
transmission, carrier testing, treatment,
resources, bleed symptoms, physical
activities, managing hemophilia as your
child grows.

A Family Guide to Hemophilia B

CSL Behring. 2005

www.CSLBehring-US.com

Discusses unique challenges faced
by families living with hemophilia B,
treatments, recent advances. Includes
easy-to-understand dosing tools, exercise
guides, self-infusion directions.



Programs & Workshops

Project SHARE

LA Kelley Communications, Inc.
www.kelleycom.com/projectshare



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

Pulse on the Road

Pulse on the Road

LA Kelley Communications, Inc.
www.kelleycom.com

Unique three-hour program addresses insurance and healthcare reform topics of urgent importance to families with bleeding disorders. Sponsored by Baxter Healthcare Corporation.

Karing for Kids®

Accredo's Hemophilia Health Services
Karing for Kids

Accredo's Hemophilia Health Services
www.HemophiliaHealth.com

Educational, creative workshops for children and families with bleeding disorders. Emphasizes learning through play, with interactive learning stations. Parents learn how children understand hemophilia at different ages, while children enjoy fun activities. Customizable for age groups: *Hemophilia Basics* (ages 2–6), *My Amazing Blood* (ages 7–10), *Junior Scientist* (ages 11–15).

Living with Hemophilia

Bayer HealthCare
www.livingwithhemophilia.com

Practical tips and tools for patients and families living with hemophilia. Includes interactive meetings at local HTC nationwide and an online magazine.



School Preparedness Kit

Coram Hemophilia Services
www.coramhemophilia.com

Helps parents of children with hemophilia set the stage for a safe, happy, rewarding educational experience. Series of presentations teach families and HTC staff how to educate school personnel and students about hemophilia.

Great Escapes™ Travel Program

Coram Hemophilia Services
www.coramhemophilia.com

National program designed to help patients travel comfortably and safely—across the country or across the globe. Includes travel checklist for patients with hemophilia.



Inalex Communications Workshops for People with a Bleeding Disorder

www.inalex.com
English, Spanish



Fun, interactive workshops, retreats, teleconferences led by nationally known experts who discuss practical advice on family relationships and hemophilia.

Gettin' in the GameSM

CSL Behring
www.GIGJNC.com

Highlights the importance of physical activity. Attendees receive sports tips from athletes living with hemophilia; meet others living with hemophilia; learn how proper treatment can improve overall health.



Junior National Championship (JNC)

CSL Behring
www.GIGJNC.com

Series of one-day athletic competitions gives children with bleeding disorders and their families the opportunity to enjoy competing in appropriate sports such as golf and baseball.

Dads in Action

Hemophilia Federation of America (HFA)
www.hemophiliafed.org

Network of involved fathers helps other fathers face challenges of raising children with bleeding disorders. Resources, educational programs, and answers to questions about children's growth and development with a bleeding disorder.

CEO

Baxter BioScience
www.thereforu.com

Contact your NHF chapter or HTC



Full day of interactive activities helps young adults develop skills in career planning and financial understanding; consider their interests and skills; manage real-world finances; explore career options. Facilitated by professionals in career development.

Facts First

Baxter BioScience
www.thereforu.com

Contact your NHF chapter or HTC



Series of educational events hosted by a chapter or HTC to help people and families with hemophilia learn in a unique way. Topics include pain management, joint health, emergency care, nutrition.

HemophiliaMoms

CSL Behring
www.hemophiliamoms.com

Connects mothers to build awareness about bleeding disorders and maintain a support network; offers events and retreats where mothers build friendships and share their unique issues.



North American Camping Conference of Hemophilia Organizations (NACCHO)

Hemophilia Association, Inc.
www.hemophiliaz.org



Weekend workshop 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.

Patient Notification System (PNS)

Plasma Protein Therapeutics Association

www.patientnotificationsystem.org

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

BioBuddies Workshop

Chris Perretti Barnes

www.biorx.net

Introduces children to hemophilia. Includes reading *The Great Inhibinator* and *I am Nate?*; dressing up in superhero costumes; watching a puppet show; discussing infusions; making "blood." Sponsored by BioRX.

A Day in the Life

Chris Perretti Barnes

www.biorx.net

Workshop for children with bleeding disorders. Instruction on blood components and clotting; roundtable discussion of scenarios and challenges; "Hemophilia Life" game; instruction on self-infusion techniques through interactive DVD. Ages 12–16. Sponsored by BioRX.

A Guide to Living With von Willebrand Disease

Renée Paper, RN, with

Laureen A. Kelley

LA Kelley Communications, Inc.

3rd ed. 2011

www.kelleycom.com



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. Resource guide and real-life stories. Sponsored by CSL Behring.

100 Questions & Answers About von Willebrand Disease

Andra H. James, MD

2008

\$15.56 from amazon.com

Addresses questions relevant to people recently diagnosed with VWD. Up-to-date,



authoritative, practical, easy-to-understand information about diagnosis and treatment.



von Willebrand Disease: What Patients Need to Know

Grifols

www.grifolsusa.com

Reviews basics about living with VWD, treatment, general recommendations.

Healthy Body, Healthy Mind: Von Willebrand Disease

Grifols

www.grifolsusa.com

DVD (Spanish subtitles)

Provides interviews of physicians and patients with VWD; includes patient journal.

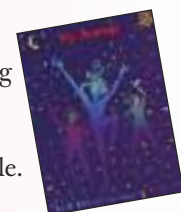


My Journal

CSL Behring

www.helixatefs.com

Educates women with bleeding disorders about menstruation. Includes easy-to-use bleeding journal to track menstrual cycle.



Kits

Self-Infusion Training Kit

Pfizer

www.HemophiliaVillage.com

Contact your HTC



Synthetic hand and elbow model for practicing infusion techniques. Includes

replaceable

skin and veins for inserting a butterfly needle and infusing factor; infusion mat, tourniquet, butterfly needles; biohazard disposal container.

Advocacy Toolkit

Bayer HealthCare

www.kogenatefs.com

Comprehensive toolkit offers strategies to help our community protect against threats to factor coverage. Explains how to write effectively to legislators; organize meetings or speak at hearings; write for newspapers or speak on radio; convey understanding of insurance issues.



Baxter BioScience

www.thereforyou.com

Contact your HTC

► Home Infusion Kit

Helps caregivers start child's factor replacement at home.

Includes educational activities, step-by-step guides, infusion logs, infusion CD/DVD, emergency contact card, children's book *Just a Boy*.



► Hemophilia—A School Toolkit

Helps healthcare professionals provide school personnel with resources to understand hemophilia. Offers specific guidelines for dealing with injuries or emergencies. Includes Inalex DVD *Hemophilia: Teaching the Educators*.



Children & Teens

What is Hemophilia? (series)

Laureen A. Kelley

LA Kelley Communications, Inc. 1995

www.kelleycom.com

English, Spanish

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.



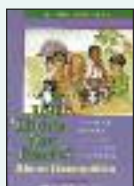
► Level 1: Joshua The Knight of the Red Snake

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



► Level 2: They'll 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!

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.

Just A Boy

Ziva Mann

LA Kelley Communications, Inc. 2009

www.kelleycom.com

Whimsical storybook about an imaginative child with hemophilia who learns to control his pain as he transitions to needlesticks. Ages 3–6. Sponsored by Baxter BioScience.

My First Factor (series)

Shannon Brush

LA Kelley Communications, Inc. 2008, 2010, 2011

www.kelleycom.com

Series of colorful, chunky books just right for small hands.

World's first toddler books for children with hemophilia.

Ages 18 months–4 years.



► My First Factor Words

One-word concepts about family and hemophilia. Sponsored by Factor Support Network.

► My First Factor: Week

Regular infusions helps a toddler stay active. Brought to you by Bayer HealthCare.



► My First Factor: Fitness

Yoga, playing, laughing, and good food keep a toddler healthy. Brought to you by Bayer HealthCare.

► My First Factor: Infusions

What are the steps in an infusion? A first look for toddlers. Sponsored by Factor Support Network.

► My First Factor: HTC

Who does a toddler meet at the HTC? Sponsored by Factor Support Network.

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.

Periodicals

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

Only hemophilia newsletter completely dedicated to insurance issues from the parent/patient point of view. Sponsored by Baxter Healthcare Corporation.

Factor Nine News

Coalition for Hemophilia B

www.coalitionforhemophiliab.org



Quarterly. Easy-to-read scientific information, research, community events.



Alexis: The Prince Who Had Hemophilia

Laureen A. Kelley
LA Kelley Communications, Inc. 1992
www.kelleycom.com
English, Spanish

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.



Factor Fun!

Diane Horbacz
LA Kelley Communications, Inc. 2006
www.kelleycom.com

Illustrated activity book teaches about hemophilia, safety and self-esteem; colorful mazes, matching, glyphs, counting. Activities arranged by color-coded topic. Ages 4-7.

Curtis & Jerry on Mount Omega: Adventures with Hemophilia

Celynd Scaglione
2006
orders@bdipharma.com
English, Spanish

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



Infusion Time

Diane Horbacz
Accredo's Hemophilia Health Services. 2007
www.HemophiliaHealth.com

Interactive, rhyming, multi-sensory book teaches basic steps of infusing through a port. For curious children who want to be involved in medical care. Includes teaching tips for parents to promote confidence and self-esteem. Ages 3-11.



Infusion Time 2

Diane Horbacz
Accredo's Hemophilia Health Services. 2006
www.HemophiliaHealth.com

Colorful graphics, activities, rhymes teach children basic steps of infusion using venous access, and encourage participation. Age 3 and older.



The Great Inhibinator

Chris Perretti Barnes
BioRX. 2006
www.biorx.net

Colorful story about Nate, a boy who has an inhibitor, centers on creating a Halloween costume. Ages 4-7. Produced by Bayer HealthCare and BioRX.



I Am Nate!

Chris Perretti Barnes
BioRX. 2007
www.biorx.net

Story about Nate, a boy who explains how having hemophilia affects his life. Ages 4-7. Produced by Bayer HealthCare and BioRX.

Quest for Infusion: Nate Goes to Camp

Chris Perretti Barnes
BioRX. 2009
www.biorx.net

Nate, a boy with hemophilia, goes to summer camp, where he learns to self-infuse and makes an unlikely friend. Produced by Bayer HealthCare and BioRX.



Bob the Puppet Story Books (series)

Pfizer
Contact your local HTC

Positive, colorful, easy-to-read books promote discussions between parents and children about clinic visits and hemophilia.



► Bob the Puppet Has His Annual Checkup

Bob visits an HTC for a routine physical. Ages 4-7.

► Bob the Puppet Goes to School

Bob attends a new school and talks about hemophilia. Ages 4-7.



Dateline Federation

Hemophilia Federation of America (HFA)
www.hemophiliafed.org
Quarterly. Healthcare information and news about bleeding disorders, government, healthcare events, innovative programs.

COTT News

Committee of Ten Thousand (COTT)
www.cott1.org
Quarterly. Information, reports, viewpoints about issues and events important to grassroots healthcare advocacy and support; focus on political and policy events in Washington, DC.

Quest

Coram Hemophilia Services
www.coramhemophilia.com
Quarterly. Newsletter for hemophilia patients features patient profiles, news, new products and services.



Web-Based Programs

Mind Over Matters

Pfizer

www.BeneFIX.com/MindOverMatters

Story about Bill, a young man with hemophilia B, and his life adventures: opposing forces of fear and confidence battle in his mind as he tries to win the affection of Grace.

AllAboutBleeding.com

CSL Behring

www.AllAboutBleeding-US.com

Online resource with information about hemophilia and VWD; patient shared experiences; expert Q&A; program and service listings.

www

CD, DVD & Video

Hemophilia in Pictures

World Federation of Hemophilia. 2005

www.wfh.org

English, Spanish, French, Arabic, Russian, Chinese

Web module, PDF, or CD

Pictorial guide to hemophilia for healthcare workers, parents, patients reflects multicultural diversity of global hemophilia community. Useful for teaching people with low literacy levels.



The Gift of Life

Plasma Protein Therapeutics Association

www.pptaglobal.org

English; Spanish subtitles

How plasma protein therapy is created, from plasma donor to patient. Interviews with plasma donors, physicians, consumers; information on the industry's commitment to safety, quality, innovation.



Function of FVIII at the Site of a Bleeding Joint

Bayer HealthCare

www.kogenatefs.com

Patient-friendly CD illustrates the role of factor VIII in repairing a bleed. Explains clot formation and the role of the factor VIII molecule.



The Villager

Pfizer

www.HemophiliaVillage.com

Hard copy or e-newsletter

Information about hemophilia treatment; tips for living an active life; inspirational stories; news on Pfizer programs and services.

Post Script Informer

Patient Services, Inc. (PSI)

www.patientservicesinc.org



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

Hemophilia World

World Federation of Hemophilia (WFH)

www.wfh.org

Triannual. Articles on WFH activities and what hemophilia organizations around the world are doing to improve care.



The Source

Plasma Protein Therapeutics Association (PPTA)

www.pptaglobal.org

Quarterly. Information 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

www.SaveOneLife.net

Quarterly. Reports on partner organizations, camps, activities funded by Save One Life, international nonprofit founded by Laurie Kelley that provides sponsorships to children with bleeding disorders in impoverished countries.



TFY

Baxter BioScience

www.thereforeyou.com



Quarterly. Inspirational stories about families with hemophilia; Baxter BioScience product information.

The Infusion Inquirer

Walgreens Hemophilia Services
bleedingdisorders@walgreens.com

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



periodicals

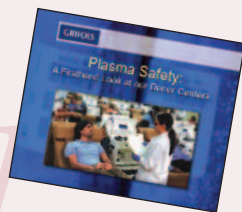
Plasma Safety: A Firsthand Look at our Donor Centers

Grifols

www.grifolsusa.com

English, Spanish

Tour of the plasma donation process and safeguards that assure donor health and plasma quality and safety.



Product Purity: A Look Inside Our State-of-the-Art Facilities

Grifols

www.grifolsusa.com

English, Spanish

Describes how therapeutic plasma proteins are isolated and purified.



A Bright Future (series)

Inalex Communications

www.inalex.com

DVD series about living with hemophilia. Sponsored by Baxter BioScience.



- ▶ The Hemophilia Diagnosis
- ▶ The Extended Family
- ▶ Teaching the Educators

Ordering Information

Accredo's Hemophilia Health Services

201 Great Circle Road
Nashville, TN 37228

800-800-6606

www.HemophiliaHealth.com

Hemophilia Association, Inc.

818 East Osborn Road, Suite 105
Phoenix, AZ 85014

602-955-3947

www.hemophiliaz.org

www.naccho.com

Baxter BioScience

One Baxter Parkway
Deerfield, IL 60015

800-423-2090

www.thereforyou.com

Bayer HealthCare

6 West Belt
Wayne, NJ 07470

888-606-3780

www.kogenatefs.com

BioRX

10828 Kenwood Road
Cincinnati, OH 45242

866-44-BIORX

www.biorx.net

Boston Hemophilia Center

300 Longwood Avenue, Fegan 701
Boston, MA 02115

617-355-7165

CSL Behring

Choice Support Center

1020 First Avenue
King of Prussia, PA 19406

888-508-6978

www.helixatefs.com

Coalition for Hemophilia B

825 Third Avenue, Suite 226
New York, NY 10022

212-520-8272

www.coalitionforhemophiliab.org

Committee of Ten Thousand (COTT)

236 Massachusetts Avenue NE #609
Washington, DC 20002-4971

800-488-2688

www.cott1.org

Coram Hemophilia Services

555 17th Street, Suite 1500
Denver, CO 80202

888-699-7440

www.coramhemophilia.com

Factor Support Network

900 Avenida Acaso, Suite A
Camarillo, CA 93012-8749

877-FSN-4-YOU

www.factorsupport.com

Grifols USA, LLC

2410 Lillyvale Avenue
Los Angeles, CA 90032

888-474-3657

www.grifolsusa.com

Hemophilia Federation of America (HFA)

210 7th Street SE, Suite 200 B
Washington, DC 20003

800-230-9797

www.hemophilafed.org

Inalex Communications

38 East Ridgewood Avenue, #374
Ridgewood, NJ 07450

201-493-1399

www.inalex.com

LA Kelley Communications, Inc.

65 Central Street
Georgetown, MA 01833

978-352-7657

www.kelleycom.com

National Hemophilia Foundation (NHF)

116 West 32nd Street, 11th Floor
New York, NY 10001

800-42-HANDI

www.hemophilia.org

Necessary Films

167 East 67th Street, Suite 10EF
New York, NY 10065

212-639-9383

www.necessaryfilms.com

Novo Nordisk Inc.

100 College Road West
Princeton, NJ 08540

609-987-5800

www.novonordisk-us.com/biopharm

Patient Services, Inc. (PSI)

PO Box 5930

3104 East Boundary Court
Midlothian, VA 23112

800-366-7741

www.patientservicesinc.org

Pfizer

500 Arcola Road
Collegeville, PA 19426

888-999-2349

www.hemophilavillage.com

Plasma Protein Therapeutics Association (PPTA)

147 Old Solomons Island Road, Suite 100
Annapolis, MD 21401

800-UPDATE-U

www.patientnotificationsystem.org

Save One Life

65 Central Street, Suite 204

Georgetown, MA 01833

978-352-7652

www.SaveOneLife.net

Talecris Biotherapeutics, Inc.

4101 Research Commons

79 TW Alexander Drive

Research Triangle Park, NC 27709

919-316-6300

Walgreens Hemophilia Services

517 Ivy Street

Truth or Consequences, NM 87901

www.walgreenshomecare/bleedingdisorders

866-436-4376

World Federation of Hemophilia (WFH)

1425 René Lévesque Boulevard West,
Suite 1010

Montreal, Quebec H3G 1T7

Canada

514-875-7944

www.wfh.org

Hemophilia & HIV

Dying in Vein: Blood, Deception ... Justice

Kathy Steward MacKay and Stacy Milbouer
Hollis Publishing Company. 2004

kmackay@aol.com

\$20

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



Bad Blood: A Cautionary Tale

Necessary Films. 2010

Directed by Marilyn Ness

www.necessaryfilms.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.



New Website for von Willebrand Disease

Octapharma USA has launched a comprehensive website to offer healthcare professionals and patients easily accessible information, news, and updates relating to its recently approved wilate[®] (von Willebrand factor/factor VIII concentrate). **Why this matters:** Get to know this newest drug for VWD in the US market.

For info: www.wilateusa.com

Korean Green Cross to Export Factor to US

Starting in 2015, the Korean Green Cross will export GreenGene-F, a drug to treat hemophilia. Green Cross is currently conducting clinical tests in the US with an aim to obtain FDA approval in 2014. **Why this matters:** The US is the largest market for hemophilia treatment; expect to see new drugs enter the market in future.

Source: englishnews@chosun.com (Dec. 16, 2010)

Shortage of DDAVP, Intravenous Formulation

Last fall, the FDA reported a shortage of desmopressin acetate (DDAVP), intravenous formulation, due to increased demand and manufacturing delays. Additional product should be available now. **Why this matters:** Don't confuse reports about shortages of the intravenous formulation with information about CSL Behring's nasal spray formulation, used to treat mild hemophilia and VWD.

For info: Contact your HTC

Porcine Factor Making a Comeback

The European Commission granted orphan drug status for Inspiration Biopharmaceuticals' OBI-1, a recombinant porcine (pig) factor VIII to treat patients with acquired hemophilia A and hemophilia A and inhibitors. Inspiration expects to have OBI-1 in pivotal clinical trials in 2011. **Why this matters:** Recombinant porcine factor VIII avoids the risk of viral transmission from pig plasma possible with earlier plasma-derived products. Although 89% of people exposed to OBI-1 in clinical trials developed antibodies to porcine factor VIII, the antibodies don't seem to affect the product's efficacy or safety.

For info: www.inspirationbio.com

Long-Acting Factor Shows Promise

Bayer HealthCare's new long-acting recombinant factor VIIa variant (BAY 86-6150) for non-bleeding patients with moderate to severe hemophilia A or hemophilia B (with or without inhibitors) was not associated with any adverse events, according to findings from a 16-subject phase I study. **Why this matters:** Phase I clinical studies are the first step to getting product approval by demonstrating product safety.

For info: clintrials.gov

Factor XIII Product in Trials

Novo Nordisk presented positive clinical data on two investigational compounds to treat factor XIII deficient patients, at the 52nd American Society of Hematology Annual Meeting and Exposition in December. Novo Nordisk plans to file for FDA approval of the recombinant factor XIII in the first half of 2011. **Why this matters:** This will be the first factor XIII product to be licensed in the US and the only recombinant factor XIII product available worldwide.

For info: www.novonordisk.com/press/news/news.asp

Bayer Hemophilia Leadership Development Program: *Apply Now!*

This exciting program for sophomore, junior, or senior college students with hemophilia provides hands-on training in marketing and communications, project design, and public policy at the corporate level. Eight-week paid internship (May-July 2011) at the Bayer facility in Wayne, New Jersey, includes housing and transportation. **Why this matters:** Past participants have helped to create programs, booklets, and web material accepted by Bayer for use in patient education.

Application deadline:
March 14, 2011

For info: www.LivingBeyondHemophilia.com



nonprofit

NHF and HFA Partner to Survey the Community

National Hemophilia Foundation (NHF) and Hemophilia Federation of America (HFA) are collaborating on a national survey to assess what bleeding disorder consumers know about healthcare reform. **Why this matters:** The information gathered will help the organizations address policy issues impacting access to care, and help target advocacy efforts to meet the community's needs.

To complete the survey:

www.surveymonkey.com/s/VCZV9M5

Advocacy Front and Center at HFA April 14–16, 2011

Louisville, Kentucky

Hemophilia Federation of America's Annual Symposium focuses on healthcare reform, with a variety of expert speakers. **Why this matters:** The bleeding disorder community must speak as one voice to Congress and payers concerning healthcare reform; this symposium helps set the national agenda.

For info:

www.hemophiliafed.org/programs-and-services/symposium



New from LA Kelley Communications

Second Annual Alex Lieber Memorial Scholarship Award



LA Kelley Communications will offer four \$500 scholarships for young adults with bleeding disorders, in memory of Alexander Lieber. Alex was born in South Miami, Florida, on January 22, 1986. Despite the challenges, hemophilia never dismayed or stopped him. Alex passed away at age 16 on December 21,

2003, after a brief bout with bacterial meningitis. **Why this matters:** Alex is greatly missed, but through this scholarship, his inquisitive and caring spirit lives on.

Application deadline: June 1, 2011

For info: www.kelleycom.com



international

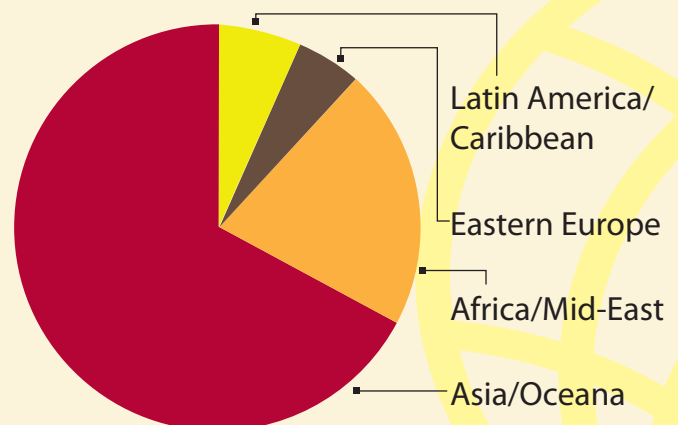


Project SHARE Donates \$5 Million Worth of Factor

Project SHARE donated over \$5 million worth of factor concentrates, or 5.7 million IU, to 36 countries in 2010. The program collects unwanted or unused factor from patients, HTC's, chapters, and home care companies, then ships free to patients and clinics in developing countries.

Why this matters: Rather than throw away unused factor, US families, HTC's, and corporations can donate it to save lives. Patients must show a medical reason for donating factor prescribed for them.

For info: www.kelleycom.com



ing a local dentist or doctor doesn't seem all that pressing. Plus, who has the time?

Not Enough Hours in the Day

Entering the 9-to-5 world for the first time is a big deal that can have a major impact on your health—and not just for those in *Deadliest Catch*-type occupations. For many, this is their first experience sitting behind a desk for several hours a day. A tangible and common consequence is weight gain. The Centers for Disease Control and Prevention (CDC) reports that an astounding 20% of Americans in their 20s are obese. Not only is extra weight bad for your joints, but obesity is a contributing factor to several leading causes of death, including heart disease, stroke, and certain types of cancer.

The effects of “a few extra pounds” may not be immediately apparent, but that's the point. In your 20s, you need to establish good habits to protect your body for the long run. This means adjusting what you're eating while maintaining some form of routine exercise. Neither is easy to accomplish when you're just starting life on your own.

Ian Muir, a 25-year-old with hemophilia, took a new job recently and is slowly figuring out how to get all the pieces of his life to mesh. In college, Ian competed in triathlons, training 25 hours a week. “In school, you had the motivation of working out with your teammates,” says Ian. “And you had a relatively flexible schedule.” Now he's struggling to find the hours to train for just a fraction of that time. And like many of his peers, Ian has let his diet suffer: “I know I need to get back to eating food that's good for me, and not just what's convenient.”

Living healthy in your 20s doesn't necessarily require big time commitments. In some cases, you just have to make better choices: When you can, take the stairs instead of the elevator. Cut back on the amount of alcohol and caffeine you consume. And if you're among the 1 in every 5 Americans who smoke, quit now. According to the CDC, smoking

causes more deaths in the US than alcohol, illegal drugs, and motor vehicle accidents *combined*.

Sure, you may not have all the time in the world, but your general health should sit atop your list of priorities.

Molehills Can Become Mountains

While you lived at home with your family, you probably had a stable network of medical resources. But once you're on your own, you may need to rebuild that network by establishing a relationship with your new HTC, plus maintaining all facets of your health.

Dental health is one of the most neglected aspects of overall well-being. By the time you're in your 20s, Mom or Dad probably don't schedule your dentist appointments, which means that nobody does...until a minor toothache becomes something worse.

Ian tells a common tale. “I've been a bit derelict when it comes to the dentist. What probably wouldn't have been a big deal had I stayed on top of it, ended with a root canal.”

Your primary care physician (PCP) can be your best ally. You'll turn to your PCP when you can't kick that cough you've had for three weeks or are worried about anything from a wart on your foot to your sexual health.

As Ian assembles the medical resources he needs near his new home, he sees the value in finding the right PCP. “You want someone you can go talk to about health concerns that aren't hemophilia related,” he says. “Someone who knows you and your medical history and if necessary, who can point you to the right specialists.”

In addition to addressing your current health concerns, your PCP will review your family history with you, assessing your risk for ailments like heart disease, diabetes, and certain cancers. Armed with this information, together you can develop a plan to reduce some of the risks.

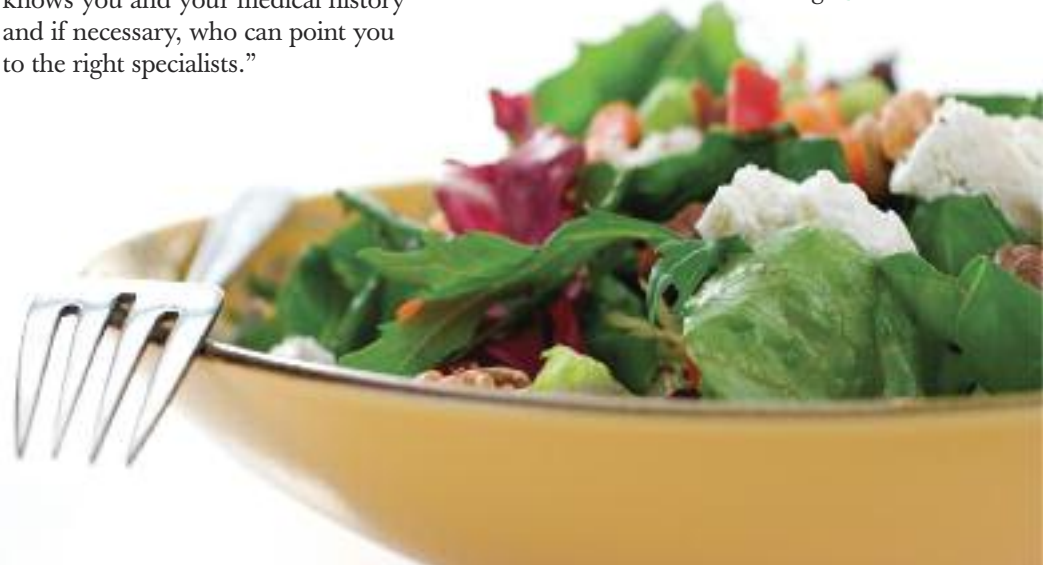
Why Do Today What I Can Put Off 'til Tomorrow?

Throughout your 20s, medical concerns may surface that have nothing to do with hemophilia, and everything to do with the natural aging process. You'll begin to shed the cloak of invincibility you donned as a teen, and realize that you need to act with an eye to your future.

So manage your total health as attentively as you manage your hemophilia:

- Eat a healthy, balanced diet.
- Maintain your optimal body weight.
- Make exercise a priority.
- If you drink or smoke, reduce your alcohol consumption, and quit smoking!
- Schedule all the exams you've neglected for so long.
- If you don't have a local dentist, eye doctor, or PCP, contact your HTC or insurance company. They can help you find one.

True, for now, you can ignore the incessant commercials for “old people” drugs like Lipitor. But let them serve as a reminder for the not-too-distant future. *What's Lipitor anyhow?* It's a drug that controls cholesterol. *What's cholesterol?* It's one of many topics you and your doctor should start discussing. ☺



context. Which is why Terry Tenbrunsel, recently retired from Bayer and long-time member of the hemophilia community, said to me while I was still researching the film, “If you’ve done your job right, if you are fair and balanced, no one in the community will like your film.” (I am relieved the film is well received, if sometimes criticized.)

Industry was understandably skeptical during the research and production of the film. Unfortunately, it only offered Jan Bult [president of Plasma Protein Therapeutic Association] as an interview subject. While Jan has been incredibly supportive since the release of the film, he could not provide the first-hand account that was necessary to elucidate the decisions of the time. I was grateful that David Castaldi, former president of Hyland/Baxter, did consent and provided what I found to be very meaningful insights—I only wish I had more industry perspective to include.

The film chronicles the interrelationships among government, industry, doctors, and patients, and puts the FDA at the center of that web. Your article notes, “At the beginning of the AIDS epidemic around 1982, the FDA was short-handed, demoralized, and in disarray, which greatly compromised its ability to react to the emerging health crisis.” I wholeheartedly agree. And yet despite what happened to the hemophilia community, the situation is not much better today. There are currently 10,000 employees to regulate one-fourth of the nation’s gross domestic product: the food we eat, the drugs we take, the blood we need in life-threatening situations, and cosmetics! I find it frightening that we as a country have not yet strengthened the regulatory authority we look to as our main line of defense for almost everything we use every day. To me, the greatest call to action from my film is to properly equip this agency to fulfill its essential mission, well beyond what even the hemophilia community requires.

In the end, I hope the film poses questions it does not have time to answer and motivates audiences to ask difficult follow-up questions, as PEN has. Further, I hope industry and the medical community will assure audi-

ences that—for this community, at least—things have changed, products are safe, and the gatekeepers always keep this tragedy in the back of their mind as they make treatment decisions for the community. I believe those conversations alone will serve to protect at least one more generation.

I hope that *Bad Blood* becomes a testament passed from generation to generation in this community, with the rallying cry, “Stay safe! Never forget!” And so I thank PEN for saying [in its *Welcome*], “The film is a gut-wrenching rollercoaster ride that everyone in the community must see.” That alone would be a fitting memorial to my friend Matt and the thousands of others lost in the wake of this country’s worst and often forgotten medical disaster.

Marilyn Ness
Director/Producer
Bad Blood: A Cautionary Tale

I AM THE FATHER OF TWO SONS WITH hemophilia; one died in 1991, and one in 1996. I read with great interest your article on *Bad Blood*. Because I was involved very early in the investigation of how and why this “hemophilia holocaust” occurred, I want to comment on some very important issues.

When you stated that heat treatment was not such an easy fix for the purification of factor concentrate, you left out some historical facts. First, the purification of the product wasn’t a high priority, so therefore, we really do not know how much time and money was being devoted to that research. When I first met with Dr. Edward Shanbrom in early 1992, we discussed purification, and he told me that it took him nine months to develop his solvent-detergent process for purifying concentrate. Remember that Dr. Shanbrom developed the process to make factor concentrate when he worked for Hyland Laboratories in Orange County, California.

The other historical fact is that a blood banker from Chicago, Dr. Garrot Allen, was warning the blood banking industry about hepatitis in the 1950s. Peer Association gave Dr. Allen a Warrior for Justice award posthumously

in late 1992. I have a copy of the article “The High Cost of Cheap Blood” that Dr. Allen wrote for the *New England Journal of Medicine* in March 1976. So hepatitis has been an issue for a long time.

Your statement “Infection with hepatitis rarely resulted in serious disease” is totally false. I possess a copy of the results of a meeting involving several government agencies and NHF concerning the current medical status of persons with hemophilia. This meeting took place in 1975 and showed how hepatitis was affecting the liver. (This was also happening on the battlefield in World War II, when plasma was first being used.) The obvious problem with the fractionators at the time was the blatant targeting of high-risk donors and then using large-volume pools of plasma to manufacture clotting factor. From 1994 to 1995, I donated plasma at a facility in San Diego to have an understanding of what was happening. I could tell you lots of horror stories about the donor population. Remember that this was in the 1990s, and [plasma collectors] still had not cleaned up their act.

My final comment is for all the young families just starting out having to deal with hemophilia. Remember that knowledge is power, and never be afraid to ask lots of questions. Stay very vigilant regarding the products your loved one is using. Conflict of interest was a major contributor in the “hemophilia holocaust” at many levels. It began with NHF and continued through the regulatory agencies. Never forget that! Read the Institute of Medicine (IOM) report (1995) and the book *Blood: An Epic History of Medicine and Commerce* by Douglas Starr.

Dick Valdez
Former President, Peer Association
Former Board Member, Committee of Ten Thousand (COTT)

Ed. note: Read the statistics on hepatitis at the CDC website: www.cdc.gov/hepatitis and in the *For Health Professionals* section, click on any type of hepatitis to visit the FAQ page *Overview and Statistics*. The 1995 IOM report “HIV and the Blood Supply: An Analysis of

Crisis Decisionmaking” discusses why hepatitis infection from factor concentrates was considered a “medically acceptable risk” and why their use was encouraged in the 1970s and early 1980s. See www.nap.edu/catalog.php?record_id=4989

YOU DID A GREAT JOB PRESENTING A comprehensive, balanced perspective on the movie and hemophilia’s HIV history. The article provides invaluable information to enable the community to better understand its past so it can better move forward into its future. Of your many fine articles over the years, this is perhaps your most significant. Congratulations and thank you.

David Linney
Wisconsin

THANK YOU FOR SHARING THIS POWERFUL review with us. I have forwarded a copy to our board of directors, and we are in the process of scheduling a preview of *Bad Blood* in our community. Your review is helping us select our panel of experts to ensure that the message is balanced and fair. You helped us understand the importance of reaching younger families with this cautionary tale, but in a positive way that empowers them to take charge of their treatment.

Lynne Capretto
Executive Director
Northern Ohio Hemophilia Chapter
NHF

I HOPE THAT EVERY PERSON WITH A clotting disorder, as well as their relatives, will read your article. The movie *Bad Blood* is so misinformative and biased that no amount of education may balance the damage. The movie creates an insidious aura surrounding the companies and people who supply plasma. Those who give factual information about the current safety and efficacy of plasma-derived clotting factors might alleviate these falsehoods, but there will still be doubts. *Bad Blood* is sensational, and ultimately irresponsible for its slanted message, which affects the lives of many patients.

Anonymous

AS ALWAYS, YOUR ARTICLES ARE educational, newsworthy and timely. Thanks for all the work you do in our community, here and abroad.

Barb Forss
Washington

I ENJOYED READING YOUR REVIEW OF *Bad Blood*. It was balanced, well thought out, thoroughly researched, and reassuring. Your review brought back many memories of my years with the World Federation of Hemophilia. It was a painful yet wonderful experience, and at times humbling. I had the honor of living with people who were dealing with the fact that they were dying. It was an experience I will never forget. I had, and still have, some extraordinary friends from those years, and cherish my friendship with each one. They were fighters and never quit.

Declan Murphy
President
Novens, Inc.

WHEN I WATCHED *BAD BLOOD* WITH MY parents, my mom cried as she explained that my uncle actually died from HIV, not a brain hemorrhage. I couldn’t believe what I was hearing after 25 years. I felt extremely upset after hearing this, but I realize the timing was perfect for me to get involved and assist in this matter. My hero is my uncle, as well as the 10,000 who died to make our lives better. Also, my mother has always been my hero, and is even more so now. I found out that many women of her time went through a lot with the uncertainty of their children’s future. This was a scary time for them, and I am so grateful for everything I have.

Jason Patel
Indiana

I AM IN THE MIDDLE OF READING THE *Bad Blood* review. I’m crying my eyes out and had to take a break to write. I’m relatively new to the world of hemophilia—I’ve only been with my current employer for two and a half years. I thought I had an understanding of the crisis of the 1980s,

but this really drives it home. I work every day to help patients with hemophilia become better advocates, and fight to get them good healthcare coverage. Now I will work and fight harder. I haven’t seen the film but I definitely will, and am prepared now thanks to your analysis.

Anonymous

I HAVE SOME CONCERNS. ONE IS THAT you seem overprotective of pharmaceutical manufacturers. Another is that [you condescend to] consumers who may not treat bleeds [with plasma-derived products] now just because of a historical movie. That’s not giving consumers much credit for being able to think on their own. Do war movies prevent people from joining the military?

Third, anyone who ever thought that HCV couldn’t be passed through blood just wasn’t thinking logically.

It’s childish of the manufacturers to not want anyone to see the movie. That shows greed at its finest. The movie is about a topic at a time in history. Marilyn Ness doesn’t need to promote new science and treatments; others can do that. I was pleased to see you show facts about Ronald Reagan’s foolishness. Too many people think he was the perfect president. He’s just as responsible for HIV in people with hemophilia as anyone else. Some might say he was a murderer. He never publicly used the term *HIV* during his presidency.

Tom Albright
Arkansas

Ed. note: Neither the film nor our article stated that anyone thought HCV could not be passed through the blood supply. We stated that in the late 1970s, the presence of HCV was unknown and “at the time, no one knew that HCV was in the factor.” The idea that manufacturers do “not want anyone to see the movie” is not in the film or the PEN article. In contrast, the opinion of the plasma pharmaceutical companies, speaking through PPTA, is represented by Jan Bult’s (PPTA president) statement, “Everyone should see it.”

I REALLY APPRECIATE YOUR ASSISTANCE IN the hemophilia community and can't wait for the next substantive issue. The whole insurance thing, the vertical integration of factor producers—so many issues you cover in strategic ways. No one else can do it like you, a mother of a child with hemophilia who understands it from a parent's and advocate's standpoint as well as the policies. After the AIDS scare of the 1980s, we feel blessed to have our son still with us. We buried lots of people with hemophilia and went to a lot of funerals. We don't forget, and we're grateful to you for educating us over the years and giving us advocacy tools, insurance tools, and wisdom.

Douglas J. Anderson
New York

Managing Your Child's Inhibitor

THANK YOU FOR THE BOOK on inhibitors. It was a wonderful surprise. We appreciate all your hard work and commitment in making this book. I cannot emphasize enough how much it will help the hemophilia community.

Eleth Ridenhour
Kansas



YOUR WORK HAS BEEN A WONDERFUL addition to my curriculum this year. I am studying in India with my children as part of their education, and my youngest has hemophilia A. This has really opened his eyes to a lot of things.

Anonymous

I READ YOUR CHAPTER ON PAIN IN THE inhibitor book. It was excellent! I commend you on your research and grasp of knowledge about pain. My expertise is in pain management. I am certified in palliative and hospice care, and I am the primary investigator for the National Pain Study.

inbox

I am always reviewing things I see in the hemophilia world, and they rarely have the accuracy this chapter exhibited. I wanted to express my appreciation of your accuracy, completeness, and willingness to include this important information in your book and newsletters.

Michelle Witkop, DNP, FNP-BC
Bleeding Disorders Nurse Practitioner
Northern Regional Bleeding
Disorders Center
Traverse City, Michigan



Project SHARE

THANK YOU FOR YOUR DONATION. Through God's blessing, Project SHARE has been the instrument for extending the life of my son, Denol. I truly appreciate you for always helping us.

Dennis Encarnacion
Philippines

THANK YOU FOR THE FACTOR THAT YOU gave my son Angelo. He is recovering; the doctors said that he needs a steady supply of factor VII. For now, they gave him cryoprecipitate because we don't have the finances to buy factor. Without your help, we could not have afforded all of Angelo's medical needs.

Angelie Delas Llagas
Philippines

A CHILD WITH HEMOPHILIA 18 DAYS old was circumcised, and the bleeding had not stopped for five hours. I provided the family with factor VIII and referred them to the Lahore hospital quickly. In the emergency department, a doctor injected factor and the bleeding finally stopped. Your donation of this factor saved the child's life.

Imran Zia
Pakistan



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