**PEN’s Biennial
Bleeding Disorder Resource Guide 2015**

*Laurie Kelley and Zoraida Rosado*

This resource guide is a sampling of the many resources available in the bleeding disorder community. Because these are less well publicized, most are non-NHF. You can find more resources by viewing the publications or resources section of each website, or by contacting the company or organization.

**Books**

**Raising a Child with Hemophilia: A Practical Guide for Parents**

Laureen A. Kelley

LA Kelley Communications, Inc.

5th edition coming in 2015

www.kelleycom.com

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

**Hemophilia**

Michelle Raabe

Infobase Publishing

2008

amazon.com

Scientifically detailed, colorful, easy-to-read book focusing on the science behind the treatment, symptoms, 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.

**Managing Your Child’s Inhibitor: A Practical Guide for Parents**

Laureen A. Kelley with Paul Clement

LA Kelley Communications, Inc.

2010

Free to inhibitor families

www.kelleycom.com

World’s first book on inhibitors. From parents’ and patients’ points of view, extensively covers topics including pain management, surgery, family life, treatment. Sponsored by an unrestricted grant from Novo Nordisk Inc.

**Success as a Hemophilia Leader**

Laureen A. Kelley

LA Kelley Communications, Inc.

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 Grifols.

**Teach Your Child about Hemophilia**

Laureen A. Kelley

LA Kelley Communications, Inc., 2007

Free to hemophilia families

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.

**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.

**The Gift of Experience: Conversations about Hemophilia**

Laura Gray, LICSW, and Christine Chamberlain

Boston Hemophilia Center, 2008

Free from NHF

amazon.com

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

**Pooling Blood**

Cheryl Nineff D’Ambrosio

iUniverse, 2010

amazon.com

Personal story of raising two stepdaughters with factor V deficiency highlights

frustrations, fears, joys of living with a rare chronic blood disorder.

**Legacy: The Hemophilia of Yesterday**

Matt Barkdull

amazon.com

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

**Booklets & Binders**

*Hemophilia in Pictures World Federation of Hemophilia*

2008

English, Spanish, French, Arabic, Russian, Chinese

www.wfh.org

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

**Dental Care (series)**

CSL Behring

2010

www.mysourcecsl.com

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

* **Dental Care for Infants, Toddlers, and Preschoolers with Bleeding Disorders**
* **Dental Care for Children with Bleeding Disorders: Ages 5 to 10**
* **Dental Care for Adolescents with Bleeding Disorders: Ages 11 to 18**

**A Family Guide to Hemophilia B**

CSL Behring

2005

www.mysourcescsl.com

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

**Educational Support Brochures**

Novo Nordisk Inc.

www.changingpossibilities-us.com

Contact your local HTC

Topics include how bleeding disorders fit into everyday life, resources for kids, games, tips on joint bleeds.

**Publications on Living with Hemophilia B**

Pfizer Inc.

benefix.com

PDF download; eBook formats

* **Hemophilia B: A Family Perspective**

2014

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

* **Navigating the Preteen Years**

 2014

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

* **Hemophilia B: Your Point of View**

 2014

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

* **Young Adults and Hemophilia B**

 2014

Transitioning through college, finding a career, getting married, starting a family.

* **Learn from Experience: A Guide for Mature Adults**

 2014

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

* **Many Faces of Hemophilia B: Challenges and Opportunities**

 2014

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

* **Hemophilia B in Early Childhood**

 2014

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

**Programs & Workshops**

**Project SHARE**

LA Kelley Communications, Inc.

www.kelleycom.com

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

**Pulse on the Road**

LA Kelley Communications, Inc.

www.kelleycom.com

Unique three-hour symposium for local bleeding disorder communities brings experts in insurance and urgent healthcare reform; answers questions about personal health insurance, state healthcare reform, national trends and changes. Run in partnership with NHF. Sponsored by Baxter Healthcare Corporation.

**Inhibitor Education Summits**

www.hemophilia.org

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

**Inhibitor Family Camp**

Comprehensive Health Education Services

www.comphealthed.com

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

**CoRe Conversations**

Biogen Idec

www.biogenidechemophilia.com

Series of webinars and live presentations developed and led by Biogen Idec’s Hemophilia CoRe team. Topics designed to enrich, educate, motivate bleeding

disorder community members.

**Inalex Communications Workshops**

www.inalex.com

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

**North American Camping Conference of Hemophilia Organizations (NACCHO)**

**Hemophilia Association, Inc.**

www.hemophiliaz.org

Weekend workshop held early in the year for planning, organizing, operating

a bleeding disorder summer camp. Nationally known presenters share camp resources and techniques; explore camp programs and activities; facilitate networking and problem solving.

Funded by Pfizer and Biogen Idec.

**Bayer Hemophilia Leadership Development Program (BHLDP)**

www.livingwithhemophilia.com

BHLDP interns with hemophilia A build foundational leadership skills, deepen connections to the local hemophilia community. Interns travel to Bayer’s US headquarters in New Jersey for six weeks of activities that foster personal and

professional growth.

**HeroPath™ Life Coach**

www.changingpossibilities-us.com

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

**Wingmen Foundation**

www.wingmenfoundation.org

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

**REBUILD**

BioRx

www.biorxhemophilia.com

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

For eligibility requirements: rebuild@biorx.com

**BioBuddies Workshop**

BioRx

www.biorxhemophilia.com

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

**Transition Ignition**

Contact your local Bayer representative

Interactive experience for parents and teens that jump-starts teens’ responsibility for their own hemophilia and bleeding disorder care under parental and HTC guidance.

Sponsored by Bayer HealthCare.

**Generation IX Project**

Coalition for Hemophilia B

coalitionforhemophiliab.org

National mentoring program for young adults and teens with hemophilia B. Adventure education program led by Pat “Big Dog” Torrey teaches mentoring skills through experiential learning in an unforgettable setting. Open to young men with hemophilia B, ages 14–30. Sponsored by Emergent BioSolutions.

**Multiple Needs**

BioRx

www.biorxhemophilia.com

Workshop informs and empowers parents and caregivers of children with bleeding disorders and other medical or psychosocial needs.

**Junior National Championship (JNC)**

CSL Behring

www.cslbehring-us.com

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

**Gettin’ in the GameSM**

CSL Behring

www.cslbehring-us.com

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

**Patient Notification System (PNS)**

Plasma Protein Therapeutics Association

www.patientnotificationsystem.org

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

**Families Supporting Families**

Walgreens Infusion Services

healthcare.walgreens.com/bleedingdisorders

Mentoring program offers ongoing support from parents of children with bleeding disorders to parents of bleeding disorder patients.

**Kits**

**Ingredients to Hemophilia Health in the School Setting**

www.biorxhemophilia.com info@biorx.com

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

**Baxter Healthcare Corporation**

Available through HTCs only nava.baxter.com

* **Hemophilia Infusion Kit**

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

* **Hemophilia School Toolkit**

Enlighten school staff about hemophilia through guidelines for handling injuries and emergencies, and Teaching the Educator DVD.

* **Hemophilia Starter Kit**

 Info and advice for families just learning about hemophilia; supplements info

provided by HTCs.

**von Willebrand Disease**

**A Guide to Living with von Willebrand Disease**

Renée Paper, RN, with

Laureen A. Kelley

2012 (3rd ed.)

Free to families and patients

www.kelleycom.com

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

Sponsored by CSL Behring.

**What You Should Know about von Willebrand Disease**

CSL Behring

www.allaboutbleeding-us.com

Patient’s guide to awareness, diagnosis, treatment.

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.

**National Outreach von Willebrand (NOW)**

www.arizonahemophilia.org

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

**Children & Teens**

**What is Hemophilia? (series)**

Laureen A. Kelley

LA Kelley Communications, Inc.

1995

www.kelleycom.com

Developmentally arranged series explains hemophilia to children using language and concepts appropriate for three age levels: preschool, school age, adolescent. Each book covers the same topics in educationally and cognitively different ways. Note to Parents for each age level. Sponsored by CSL Behring.

* **Level 1: Joshua The Knight of the Red Snake**

Empowering story about 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! (backorder)**

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.

**My First Factor (series)**

Shannon Brush; illustrated by Brooke Henson

LA Kelley Communications, Inc.

2008–2015

www.kelleycom.com

Series of colorful, chunky books just right for small hands. World’s first

toddler books for children with hemophilia. Sponsored by Bayer HealthCare, except where noted. Ages 18 mo.–4 yr.

* **My First Factor Words**

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

* **My First Factor: Week**

Regular infusions help a toddler stay active.

* **My First Factor: Fitness**

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

* **My First Factor: HTC**

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

* **My First Factor: Infusions**

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

* **My First Factor: Joints**

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

* **My First Factor: Camp**

When you get older, what will it be like to go to hemophilia camp?

* **My First Factor: Self-Infusion**

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

* **Mis primeras palabras del Factor**

A toddler’s first book about hemophilia in Spanish!

* **My First Factor: Safety**

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

* **My First Factor Coloring Book**

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

**Must You Always Be a Boy?**

Laureen A. Kelley

LA Kelley Communications, Inc.

1991

www.kelleycom.com

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

Sponsored by CSL Behring.

**Alexis: The Prince Who Had Hemophilia**

Laureen A. Kelley

LA Kelley Communications, Inc.

1992

www.kelleycom.com

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

**Curtis & Jerry on Mount Omega: Adventures with Hemophilia**

Celynd Scaglione

2006

English, Spanish

bookrequest@bdipharma.com

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

**The Great Inhibinator**

Chris Perretti Barnes

BioRx

2006

www.biorxhemophilia.com

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

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: It’s Always About Nate!**

Chris Perretti Barnes

BioRx

2012

www.biorxhemophilia.com

How Nate’s hemophilia affects the lives and feelings of his sisters and parents. Ages 4–7.

Produced by Bayer HealthCare and BioRx.

**Periodicals**

***All periodicals listed are free.***

**Parent Empowerment Newsletter (PEN)**

LA Kelley

Communications, Inc.

www.kelleycom.com

Quarterly. Oldest bleeding disorder newsletter in US produced and edited by a parent of a child with hemophilia.

In-depth medical, scientific, consumer, parenting articles and news to empower parents and patients as educated consumers.

**PEN’s Insurance Pulse**

LA Kelley Communications, Inc.

www.kelleycom.com

Annual. Only hemophilia newsletter completely dedicated to insurance issues from the parent and patient points of view.

Sponsored by Baxter Healthcare Corporation.

**Information Infusions**

BioRx

www.biorxhemophilia.com

Monthly. Bleeding disorder consumer newsletter.

**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)

www.hemophiliafed.org

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

**Lifelines for Health**

Comprehensive Health

Education Services

www.comphealthed.com

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

Sponsored by Baxter Healthcare International.

**COTT News**

Committee of Ten Thousand (COTT)

www.cott1.org

Quarterly. Info, 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.coramhc.com

Quarterly. Newsletter for hemophilia patients features patient profiles, news, products, services.

**Post Script Informer**

Patient Services, Inc. (PSI)

www.patientservicesinc.org

Quarterly. Info 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 worldwide are doing to improve care.

**The Source**

Plasma Protein Therapeutics

Association (PPTA)

www.pptaglobal.org

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

**OneVoice**

Save One Life

www.saveonelife.net

Quarterly. 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.

**Factor in Wellness**

Walgreens Infusion Services healthcare.walgreens.com/

bleedingdisorders

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

**HemAware**

National Hemophilia Foundation (NHF)

www.hemaware.org

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

**Online Resources**

**Hemophilia Village**

Pfizer Inc.

www.hemophiliavillage.com

Multifaceted website with info on life stages, mobile apps, prescription trial programs, HTC or chapter locations, scholarship assistance, insurance savings cards.

**NAVA**

Baxter Healthcare Corporation

nava.baxter.com

Connects patients to resources: local HTCs, info on managing hemophilia and insurance, personal mentors with one-to-one coaching, unique Baxter programs, patient and family stories, advice from hemophilia experts, advocacy info. Call center/live chat available six days a week.

**HemoAction Online Game**

World Federation of Hemophilia

English, Spanish, French

www.hemoaction.org

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

**There’s More to Life than Hemophilia**

Baxter Healthcare Corporation

Facebook page

Info and support for all stages of life with hemophilia. Social media extension of NAVA; most posts link back to website. Specialized info, tools, downloads through tabs.

**Stop the Bleeding!**

Believe Digital

believedigi.com or YouTube

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

**MySourceCSL.com**

CSL Behring

www.mysourcecsl.com

Resource for patient support programs, educational materials, info about live events.

**Living with Hemophilia®**

Bayer HealthCare

www.livingwithhemophilia.com

Internships, mobile apps, Living Fit! program, tips on safety and treatment.

**CD, DVD & Video**

**My First Factor Song**

Lyrics by Carri Nease

www.kelleycom.com

Sing along and teach through song! To the tune of “Allouette,” teach your toddler with hemophilia about bumps, bruises, “boo-boos,” factor. Sponsored by Baxter Healthcare.

**PPTA Gift of Life**

Plasma Protein Therapeutics Association

English with Spanish subtitles

www.pptaglobal.org

llovullo@pptaglobal.org

Donors, patients, physicians discuss reasons for donating plasma for plasma protein

therapies; demonstrates industry’s commitment to safety, quality, innovation.

**A Bright Future (series)**

Inalex Communications

www.inalex.com

DVD series about living with hemophilia.

Sponsored by Baxter Healthcare Corporation.

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

**Hemophilia & HIV**

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

Vaughn Ripley

amazon.com

A 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.

**Bad Blood: A Cautionary Tale**

Necessary Films

2010

Directed by Marilyn Ness

www.necessaryfilms.com

amazon.com

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

**Vial023: A Father’s Pursuit of Justice**

Gary William Cross

2012

amazon.com

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

**Bleeder: A Memoir**

Shelby Smoak

2013

amazon.com

Free from LA Kelley Communications

Tender memoir of Shelby’s life from 1990 to 1998, with flashbacks to share college,

dating, career difficulties experienced by a young adult with hemophilia and HIV.

Sponsored by BioRx.

**Dying In Vein: Blood, Deception…Justice**

Kathy Steward MacKay and Stacy Milbouer

2004

amazon.com

kmackay@aol.com

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

**Ordering**

**Baxter Healthcare Corporation**

One Baxter Parkway

Deerfield, IL 60015

800-423-2090

nava.baxter.com

**Bayer HealthCare**

100 Bayer Boulevard

Whippany, NJ 07981

862-404-3000

www.kogenatefs.com

**BDI Pharma, Inc.**

120 Research Court

Columbia, SC 29203

803-732-1018

www.bdipharma.com

**Biogen Idec**

133 Boston Post Road

Weston, MA 02493

781-464-2000

www.biogenidec.com

**BioRx**

5800 Creek Road

Cincinnati, OH 45242

866-44-BIORX

www.biorxhemophilia.com

**Boston Hemophilia Center**

300 Longwood Avenue, Fegan 701

Boston, MA 02115

617-355-7165

www.brighamandwomens.org

**Coalition for Hemophilia B**

825 Third Avenue, Suite 226

New York, NY 10022

212-520-8272

www.coalitionforhemophiliab.org

**Committee of Ten Thousand**

36 Massachusetts Avenue NE #609

Washington, DC 20002-4971

800-488-2688

[www.cott1.org](http://www.cott1.org)

**Comprehensive Health Education Services**

80 Washington Street, D-24

Norwell, MA 02061

781-878-8561

www.comphealthed.com

**Coram Specialty Infusion Services**

555 17th Street, Suite 1500

Denver, CO 80202

800-267-2642

www.coramhc.com

**CSL Behring**

1020 First Avenue

King of Prussia, PA 19406

888-508-6978

www.helixatefs.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 Association, Inc.**

818 East Osborn Road, Suite 105

Phoenix, AZ 85014

602-955-3947

www.hemophiliaz.org

www.naccho.com

**Hemophilia Federation of America (HFA)**

210 7th Street SE, Suite 200 B

Washington, DC 20003

800-230-9797

www.hemophiliafed.org

**Inalex Communications**

38 East Ridgewood Avenue, #374

Ridgewood, NJ 07450

201-493-1399

www.inalex.com

**LA Kelley Communications, Inc.**

37–39 West Main Street, #8

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.**

800 Scudders Mill Road

Plainsboro, NJ 08536

609-987-5800

www.novonordisk-us.com

**Patient Services, Inc. (PSI)**

PO Box 5930

Midlothian, VA 23112

800-366-7741

www.patientservicesinc.org

**Pfizer Inc.**

500 Arcola Road

Collegeville, PA 19426

888-999-2349

www.hemophiliavillage.com

**Plasma Protein Therapeutics**

**Association (PPTA)**

147 Old Solomons Island Road,

Suite 100

Annapolis, MD 21401

800-UPDATE-U

www.pptaglobal.org

**Save One Life**

65 Central Street, Suite 204

Georgetown, MA 01833

978-352-7652

www.saveonelife.net

**Walgreens Hemophilia Services**

517 Ivy Street

Truth or Consequences, NM 87901

healthcare.walgreens.com/

bleedingdisorders

**Wingmen Foundation, Inc.**

1425 Grand Rd

Winter Park, FL 32792

407-340-3684

www.wingmenfoundation.org

**World Federation of Hemophilia (WFH)**

1425 Réne Lévesque Boulevard West, Suite 1010

Montreal, Quebec H3G 1T7 Canada

514-394-2832

www.wfh.org