

Parent Empowerment Newsletter

PEN'S BIENNIAL Bleeding Disorders Resource Guide 2009

BY ZORAIDA ROSADO

BOOKS

Raising a Child With Hemophilia: A Practical Guide for Parents

Lauren A. Kelley, 2007
LA Kelley Communications, Inc.
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: www.cslbehring.com

Raising a Child With Hemophilia in Latin America

Lauren A. Kelley with Ana L. Narváez, 2006
LA Kelley Communications, Inc.
www.kelleycom.com
English (PDF only), Spanish, Portuguese

First book about hemophilia in Latin America. Based on interviews with dozens of families and patients in five countries. Written for parents by a parent of a child with hemophilia. Topics include differences in hemophilia treatment, genetics, transmission, family dynamics, government policies, being a smart consumer, medical complications. Sponsored by Baxter BioScience: www.hemophiliagalaxy.com



Success as a Hemophilia Leader

Lauren A. Kelley, 2004
LA Kelley Communications, Inc.
www.kelleycom.com
Free to qualified Hemophilia Leaders
English (CD only), Spanish

World's first guide to founding, managing and growing a grassroots hemophilia organization, or improving an existing one. Valuable 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.: www.talecris.com

Teach Your Child About Hemophilia

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

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



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- 6 Transitions: Be Honest. Just Not Too Honest.
- 7 Homefront: When "we" have a bleed

*All listed resources are free, although some restrictions may apply.
Visit the publishers' websites to register and learn more.
See page 15 for a list of publisher mailing addresses.*