The Canadian Hemophilia Society (CHS) strives to improve the health and quality of life for all people with inherited bleeding disorders, and to find a cure.

The CHS consults qualified medical professionals before distributing any medical information. However, the CHS does not practice medicine and in no circumstances recommends particular treatment for specific individuals. Brand names of treatment products are provided for information only. Their inclusion is not an endorsement of a particular product or company. In all cases, it is strongly recommended that individuals consult a hemophilia-treating physician before pursuing any course of treatment.

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Foreword

All About Hemophilia is a comprehensive guide for families. Many parents feel overwhelmed and frightened when they first find out that their child has hemophilia, even when there is a history of the condition in their family. The purpose of this book is to bring together detailed medical information, evidenced-based recommendations, practical tips, and real life stories, so that parents and other caregivers have a resource they can count on. The book is designed so that it will meet the different learning needs of parents. Some parents need to know “everything” all at once, while others prefer to learn in stages, as their child grows. The chapters are arranged so that they coincide with normal growth and development, but it is easy to access specific information about a topic from the chapter titles, as needed or desired. Many of the photographs have been pulled from family albums and offer intimate glimpses into everyday life that look remarkably familiar and even ordinary. It is our hope that no matter how you choose to use this book, it will help to inform and guide your decisions and reassure you that you have lots of support along the way.

All About Hemophilia: a Guide for Families keeps getting bigger and better! The reason it gets bigger and better is because our knowledge and expertise as a community increases every year. It is extremely important to each of the contributing authors that parents have accurate information. This is the second edition of All About Hemophilia. The first edition was published in 2001, and followed the immensely popular Hemophilia in Perspective, published by the Canadian Hemophilia Society in 1993. The original chapters have been revised and updated. Four new chapters have been added covering the topics of prophylaxis, physical activity and sports, transitions toward independence, and symptomatic carriers.

As with the original guide, the production of All About Hemophilia has called upon a large number of experienced healthcare professionals, family members and people with hemophilia, all with wide experience in its treatment. Over 35 authors contributed their work. Once again, families and hemophilia comprehensive care teams across the country responded to our request to supply photographs and quotations, enabling us to personalize the resource and provide real insights, tips and challenges. You will also hear from young men who were still children when the first books came out. They have become important experts, whose advice guided changes and additions in this 2010 edition.
Raising a child with hemophilia is challenging. Learning as much as we can, seeking the expertise of professionals and listening to the experience and advice other parents and older children have to offer can make it a lot easier. We know we will make mistakes along the way, but it is very good to know we do not have to do it alone. We also know that someday our grown children will point out our parenting flaws. Then it will be our turn to support them as they raise our grandchildren, with the next edition of All About Hemophilia. For now it is enough for you to know that your child and your family can have a happy and healthy life with hemophilia.

We have a lot of people to thank. First, thank you to each of our sponsors for recognizing how important this book is to Canadian families and caregivers: Baxter, Bayer HealthCare, CSL Behring, Novo Nordisk, Octapharma and Pfizer. Without their generous support this revised document would not exist. A special thanks to our project manager, Clare Cecchini, who worked hard to organize our ideas, delegate the work, and keep us on track. Thank you to our editor, Debbie Hum and our reviewer, David Page, whose skills, advice and common sense guided us to a finished product. The creativity and input into the graphic design of the original edition from Paul Rosenbaum and Jane Churchill is much appreciated. We would also like to acknowledge Soleine Buisson, Marie Préfontaine and Chantal Raymond who worked on the French production. Thank you to the parents and children who shared their personal stories with us. And finally, thank you to our 35 contributing authors who so generously volunteered their time to revise All About Hemophilia.

This was truly a labour of love and we are very proud to offer our finished product to you. We trust that this book will find an important place on your bookshelf and be used again and again by your family.

Pam Wilton, RN
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Reader’s Guide

The authors of *All About Hemophilia: A Guide for Families* have tried to make the resource as easy to read and useful as possible. We know there will be times when you want quick answers to your questions. For this reason, we have chosen a question-and-answer format.

To make information easy to find, the binder has several features:

- a **Table of Contents**, with the name of each chapter, at the front of the binder;

- a **tab** on the first page of each chapter, so you can easily locate the chapter you need;

- a **cover page** for each chapter that lists the questions covered in that chapter;

- a **Glossary** at the end of the book. The binder introduces many medical terms that may be new to you which are defined at the end of the book. You can always refer to the Glossary when you come upon a medical term that is not familiar.

Some information is covered in more than one chapter. For example, the inheritance of hemophilia is covered in detail in **Chapter 2, How a Child Gets Hemophilia**, and again, from a different angle, in **Chapter 14, Symptomatic Carriers**. To avoid repetition, we provide a reference to where you can find more information. So, for example, in **Chapter 14** you will find **See Chapter 2, How a Child Gets Hemophilia**.

Each chapter of *All About Hemophilia: A Guide for Families* is designed to stand alone. For this reason, the page numbers start at 1 at the beginning of each chapter. For example, the first page of **Chapter 4** is written **4-1**. The second page of **Chapter 6** is written **6-2**. The number of the chapter is written in large figures at the top of each page; the page number appears in the bottom corner.

All those who worked on the production of the second edition of *All About Hemophilia: A Guide for Families* sincerely hope that it will be a valuable resource for families raising a child with hemophilia.