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For More Information

This chapter provides information on the following:

- The Canadian Hemophilia Society
- Hemophilia Treatment Centres
- Resources for Families of Children with Hemophilia
- Test Your Knowledge... Answers



The Canadian Hemophilia Society

For information about the CHS and its chapters
please contact:

Canadian Hemophilia Society

400-1255 University Street

Montreal, Quebec H3B 3B6

Tel: 514-848-0503

Toll-free: 1-800-668-2686

Fax: 514-848-9661

E-mail: chs@hemophilia.ca

Web site: www.hemophilia.ca



Canadian Hemophilia Society
Help Stop the Bleeding

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

Our Vision
A world free from the pain and suffering of inherited bleeding disorders.

Welcome.



Hemophilia Treatment Centres

BRITISH COLUMBIA

- **Hemophilia Program – Adult Division**
St. Paul's Hospital
Comox Building, Room 217
1081 Burrard Street
Vancouver, British Columbia V6Z 1Y6
Tel: 604-806-8855
Toll-free: 1-877-806-8855
Fax: 604-806-8784
- **Hemophilia Program**
BC Children's Hospital, Room 1A13
4480 Oak Street
Vancouver, British Columbia V6H 3V4
Tel: 604-875-2345 ext. 5335
Fax: 604-875-2533

ALBERTA

- **Southern Alberta Pediatric Bleeding Disorder Program**
Alberta Children's Hospital
2888 Shaganappi Trail NW
Calgary, Alberta T3B 6A8
Tel: 403-955-7311
Fax: 403-955-7393
- **Southern Alberta Rare Blood & Bleeding Disorders
Comprehensive Care Program – Adult Division**
Foothills Medical Centre, Unit 57B
1403 29 St. NW
Calgary, Alberta T2N 2T9
Tel: 403-944-4057
Fax: 403-944-3220

- **Dr. John Akabutu Comprehensive Centre
for Bleeding Disorders**

University of Alberta Hospital
Stollery Children's Hospital
7-109 Clinical Sciences Building
8440 112th Street
Edmonton, Alberta T6G 2B7
Tel: 780-407-6588
Fax: 780-407-2605

SASKATCHEWAN

- **Saskatchewan Bleeding Disorders Program**

Royal University Hospital
103 Hospital Drive, Box 113
Saskatoon, Saskatchewan S7N 0W8
Tel: 306-655-6504 (main office)
Tel: 306-655-6424 (nurse's office)
Fax: 306-655-6426

MANITOBA

- **Bleeding Disorders Program**

Health Sciences Centre
FE 349-685 William Ave.
Winnipeg, Manitoba R3E 0Z2
Tel: 204-787-2465
Pager: 204-787-2071 # 3346
Fax: 204-787-1743

ONTARIO

- **Hemophilia Program**
Hamilton Health Sciences Corporation
McMaster Division, 3F Clinic
1200 Main Street West
Hamilton, Ontario L8N 3Z5
Tel: 905-521-2100 ext. 75978 or 75970
Fax: 905-521-2654
- **Bleeding Disorders Program**
London Health Sciences Centre
Victoria Hospital, Room E4-201
800 Commissioners Road East
London, Ontario N6A 5W9
Tel: 519-685-8500 ext. 53582
Fax: 519-685-8543
- **Hemophilia Program**
Thunder Bay Regional Health Science Centre
980 Oliver Road
Thunder Bay, Ontario P7B 6V7
Tel: 807-684-7251/684-7200
Fax: 807-684-5807
- **Comprehensive Hemophilia Care Centre**
St. Michael's Hospital
30 Bond Street, Room 4-169, Cardinal Carter North
Toronto, Ontario M5B 1W8
Tel: 416-864-5129
Pager: 416-685-9404
Fax: 416-864-5310
- **Comprehensive Care Hemophilia Program**
Sears Cancer Clinic
Hospital for Sick Children
555 University Avenue
Toronto, Ontario M5G 1X8
Tel: 416-813-5871
Pager: 416-377-9716
Fax: 416-813-7221

- **Hemophilia Pediatric Program**
Hematology/Oncology Clinic – 6W/MDU
Children’s Hospital of Eastern Ontario
401 Smyth Road
Ottawa, Ontario K1H 8L1
Tel: 613-737-7600 ext. 2368/2470
Pager: 613-239-5698
Fax: 613-738-4846
- **Regional Comprehensive Care Centre for Hemophilia and Hemostasis**
Ottawa Hospital, General Campus
501 Smyth Road, Box 248
Ottawa, Ontario K1H 8L6
Tel: 613-737-8252
Pager: 613-715-8162
Fax: 613-737-8157
- **Hemophilia Program, Sudbury & North-Eastern Ontario**
Laurentian Site of HRSRH
41 Ramsey Lake Road
Sudbury, Ontario P3E 5J1
Tel: 705-523-7059
Fax: 705-523-7077
- **South Eastern Ontario Regional Inherited Bleeding Disorders Program**
Kingston General Hospital
Douglas 3, Rm. 8-312
76 Stuart Street
Kingston, Ontario K7L 2V7
Tel: 613-549-6666 ext. 4683
Fax: 613-548-1356

QUEBEC

- **Clinique d'hémophilie**
CHUS – Hôpital Fleurimont
3001 12^e Avenue Nord, Room 23, Letter H
Sherbrooke, Québec J1H 5N4
Tel: 819-346-1110 ext. 14560
Pager : 819-346-1110 # 3771
Fax: 819-820-6492 / 564-5434 (hematology)
- **Service d'hémostase congénitale**
L'Hôpital de Montréal pour enfants
2300 Tupper, Room A-216
Montréal, Québec H3H 1P3
Tel: 514-412-4420
Fax: 514-412-4424
- **Centre d'hémostase**
CHU Sainte-Justine
Pavillon Lucie et André Chagnon du Centre de
cancérologie Charles-Bruneau
1st Floor, Ward 12
3175 chemin de la Côte-Sainte-Catherine
Montréal, Québec H3T 1C5
Tel: 514-345-4931 ext. 6031
Tel : 514-345-4830 (clinic)
Fax: 514-345-7749
- **Quebec Centre for Inhibitors of Coagulation**
Centre d'hémostase
CHU Sainte-Justine
Pavillon Lucie et André Chagnon du Centre de
cancérologie Charles-Bruneau, 1st Floor, Ward 12
3175 chemin de la Côte-Sainte-Catherine
Montréal, Québec H3T 1C5
Tel: 514-345-2360
Fax: 514-345-7749

- **Centre d'hémophilie pour l'Est du Québec**

CHA, Hôpital de l'Enfant-Jésus
1401 18^e Rue, sous-sol porte D
Local J-S067
Québec, Québec G1J 1Z4
Tel: 418-649-5624
Pager: 418-641-3479
Fax: 418-649-5996

NEW BRUNSWICK

- **Hemophilia Clinic**

Horizon Health Network, Zone 1, Moncton
135 MacBeath Avenue
Moncton, New Brunswick E1C 6Z8
Tel: 506-857-5465
Pager: 506-558-7158
Fax: 506-857-5464
Emergency number: 1-888-475-9922

- **Inherited Bleeding Disorder Clinic**

Saint John Regional Hospital
400 University Avenue
P.O. Box 2100
Saint John, New Brunswick E2L 4L2
Tel: 506-648-7286
Pager: 506-646-3757
Fax: 506-648-7379

NOVA SCOTIA**• Pediatric Bleeding Disorder Clinic**

IWK Health Centre
PO Box 9700
6th Floor Ambulatory Children's Site
5850/5980 University Avenue
Halifax, Nova Scotia B3K 6R8
Tel: 902-470-8752
Fax: 902-470-7208

• Hereditary Bleeding Disorders Program

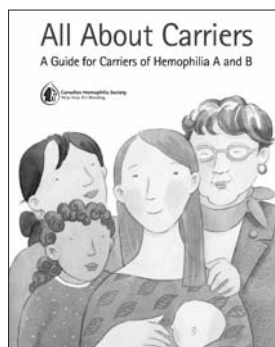
QE II Health Sciences Centre
Room 4020, Victoria Building
1276 South Park St.
Halifax, Nova Scotia B3H 2Y9
Tel: 902-473-5612
Pager: 902-473-2220 # 2226
Fax: 902-473-7596

NEWFOUNDLAND AND LABRADOR**• Hemophilia Program**

Eastern Health
Room 2J755, Janeway Site
300 Prince Philip Drive
St. John's, Newfoundland and Labrador A1B 3V6
Tel: 709-777-4388
Fax: 709-777-4292

Resources for Families of Children with Hemophilia

Printed resources



Available from the Canadian Hemophilia Society or in PDF on the CHS Web site at www.hemophilia.ca

A Home Treatment Guide and Notebook

A colourfully illustrated guide and educational tool to assist individuals on home infusion. Developed by the Western Canadian Hemophilia Nurses. Published by Biomedical Communications, Health Sciences Centre, Winnipeg.

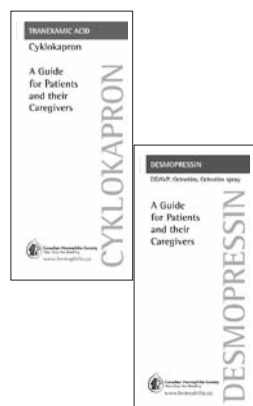


All About Carriers

A comprehensive guide for carriers of hemophilia A or B. Developed and published by the Canadian Hemophilia Society.

All About Inhibitors

A comprehensive guide about inhibitors for affected individuals and their families. Developed and published by the Canadian Hemophilia Society.



Cyklokapron: A Guide for Patients and their Caregivers

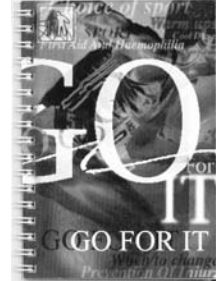
A simple brochure providing basic information on the uses and administration of this drug. Developed by the Canadian Association of Nurses in Hemophilia Care (CANHC). Published by the Canadian Hemophilia Society (revised in 2009)

Desmopressin: A Guide for Patients and their Caregivers

A simple brochure providing basic information on the uses and administration of DDAVP, Octostim, Octostim Spray and Stimate. Developed by the Canadian Association of Nurses in Hemophilia Care (CANHC). Published by the Canadian Hemophilia Society. (revised in 2009)

Go For It

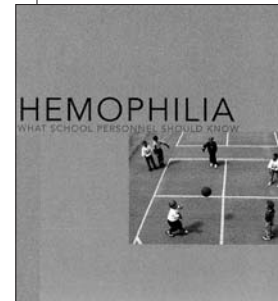
Published by the World Federation of Hemophilia. Available from the Canadian Hemophilia Society. A beautifully designed booklet that provides guidance on physical activity and sports for people with hemophilia and related bleeding disorders.

**Hemophilia from Diagnosis to Homecare: Support for the Journey**

Educational package designed to help new parents work through the challenges of raising a child with hemophilia. Also include two activity books for children. Developed by a hemophilia nurse coordinator, a mother of two boys with hemophilia, and several youth affected by bleeding disorders from Winnipeg, Manitoba.

Hemophilia: What School Personnel Should Know

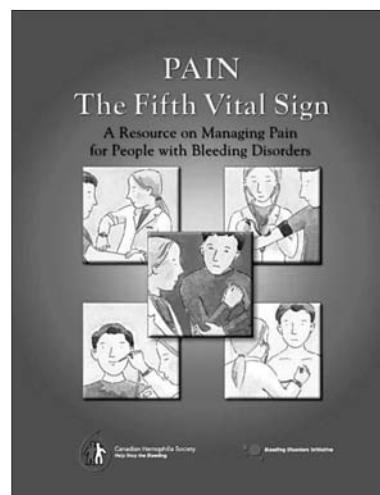
An information booklet about hemophilia for teachers and other school personnel. Developed by the Atlantic Hemophilia Nursing Group of the Canadian Association of Nurses in Hemophilia Care (CANHC).

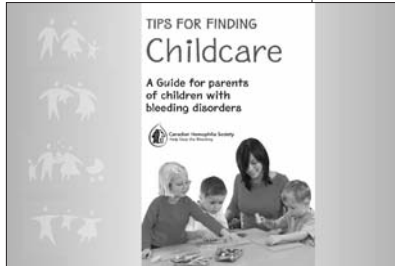
**Information Booklet on Mild Hemophilia**

Mild hemophilia can be very serious and even life-threatening if injuries or bleeds are not treated promptly and adequately. This new information booklet for people living with mild hemophilia and their families was developed by the Atlantic Hemophilia Nurses Group of the Canadian Association of Nurses in Hemophilia Care (CANHC). Published by Bayer HealthCare.

Pain: The Fifth Vital Sign

A resource on managing pain for people with bleeding disorders.





Tips for finding childcare: A Guide for parents of children with bleeding disorders

Starting childcare is a major step for families living with a bleeding disorder. For both parents and children, the transition is an important part of learning how to live with a bleeding disorder. However, making decisions about childcare and finding the right caregiver can be a challenging process. This booklet provides information to help parents of children with bleeding disorders assess their childcare needs and suitable options, with steps for finding the right caregiver. The booklet also outlines basic medical, health and safety information that caregivers need to know.

How to Recognize and Treat Bleeds and Bruises

A poster for day care workers and other caregivers on how to recognize and treat common bleeds in children with bleeding disorders. It includes a space for information on who to contact if a child has prolonged bleeding or a serious injury.

How to recognize and treat bleeds and bruises
Check routinely after play, nap or snack time - from head to toe.

Look for

- bruising, with or without bumps
- swelling or redness
- pain, distress or fussiness for no apparent reason
- decreased activity or unusual lethargy

Feel for

- warmth and/or swelling
- tenderness over joints or muscles

Check for

- difference in movement (compare arms, legs, hands, feet, etc.)
- difficulty with movement (crawling, walking, running)

Signs of a head bleed

- red or purple bumps
- nausea and/or vomiting
- headache, dizziness or disorientation
- irritability and confusion
- lethargy and unsteady gait

Signs of a soft tissue bleed

- a lump, swelling or bruise
- a soft swelling

Signs of an abdomen bleed

- red or purple bumps
- tenderness, pain or fever
- no stool

Signs of a joint bleed

- pain or tenderness over a joint or part of the body, especially the knee, ankle, elbow, the wrists, and hands and movement (swelling, locking, locking)
- difficulty with moving a particular joint
- redness and swelling of a joint, area

Signs of a muscle bleed

- redness, tenderness or sore of arm or leg
- swelling, muscle aching or tightness at a joint or area of the body
- tenderness when a part of the body is moved or touched

Bleeds in the following areas are especially serious and require immediate attention:
• HEAD • EYE • NECK • ABDOMEN • GROIN • HIP
Call 9-1-1 for immediate medical attention.

Treating common bleeds in children with bleeding disorders
Children with bleeding disorders bleed longer than normal. Minor cuts and scrapes are not life threatening.

Wound and joint bleeds

- Do not give the child aspirin, ibuprofen, acetaminophen or the use of cooling pads or heat packs to the injured area.
- Do not use a tourniquet for bleeding. If bleeding has not stopped after 10 minutes:
- Call 9-1-1.

Muscle bleeds

- Do not give the child aspirin, ibuprofen, acetaminophen or the use of cooling pads or heat packs to the injured area.
- Do not use a tourniquet for bleeding. If bleeding has not stopped after 10 minutes:
- Call 9-1-1.

Head injury

- Do not give the child aspirin, ibuprofen, acetaminophen or the use of cooling pads or heat packs to the injured area.
- Do not use a tourniquet for bleeding. If bleeding has not stopped after 10 minutes:
- Call 9-1-1.

Do not use any medications except with specific permission. Contact your doctor or pharmacist for more information. Do not use any medications if you are unsure if it is safe to use in a bleeding disorder.

Contact parents immediately for instructions if child has prolonged bleeding or serious injury.

Child: _____
Parent: _____
Phone number: _____
Home address: _____
Nearest hospital: _____

www.hemophilia.ca

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For More Information

Videos

Self-Infusion: Confidence, Autonomy, Freedom

A video starring young people with bleeding disorders describing their journey to learn to self-infuse clotting factor concentrates and the difference this has made in their lives. Approx. seven minutes. Produced in 2006 by the Canadian Hemophilia Society and Eclipse Productions.

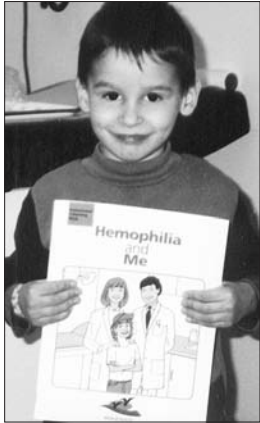
Hemophilia: What School Personnel Should Know

This video is designed for teachers and other personnel in a school with a student who has hemophilia. Properly informed, school staff can ensure that a child with hemophilia gets the care he needs, and that he feels accepted in his school environment. The video was developed by the CHS, in collaboration with parents and hemophilia treatment centre healthcare professionals.



Booklets for Children

The Bleed Stops Here



Developed by Canadian Hemophilia Nurses, 65 pages, spiral bound, available from the Canadian Hemophilia Society. An activity book for children with hemophilia and other inherited bleeding disorders. Provides information on the history of hemophilia and its care, information on the disease itself and a guide to self-infusion and includes word games, quizzes and illustrations. (1st edition, 1997)

The following books are available from Kelley Communication:
Tel: 1-800-249-7977 E-mail: info@kelleycom.com

Must You Always Be A Boy

Four rhyming tales, in Dr. Seuss Style with colourful illustrations that explore adult reactions to a bleed and other topics. Ages 3 to 8.

Alexis: The Prince Who Had Hemophilia

Set in the early 1900's, the true story of the youngest child of Tsar Nicholas II, last tsar of Russia. Ages 8 and older.

Hemophilia: It's Logical

An activity book with mazes and logic and word puzzles. Ages 8 and older.

Joshua: The Knight of the Red Snake

Fully illustrated story which empowers children to feel comfortable with their hemophilia.

They Will Probably Ask You "What is Hemophilia?"

Designed with comic balloons, this story explains hemophilia to classmates. Ideal for school projects.

Periodicals

Hemophilia Today

Published 3 times yearly by the Canadian Hemophilia Society. Includes information about the activities of the CHS, articles related to the safety and supply of factor concentrates, research and the treatment of hemophilia and related bleeding disorders. Free. Contact: Canadian Hemophilia Society National Office, E-mail: chs@hemophilia.ca or toll-free: 1-800-668-2686.



Haemophilia World

Published quarterly by the World Federation of Hemophilia. Includes information on hemophilia treatment around the world with a special emphasis on countries in the Developing World. Free with WFH membership. Contact WFH, 1425 René Levesque Boulevard West, Suite 1010, Montreal, Québec, Canada H3G 1T7 or by E-mail: wfh@wfh.org.



Web sites**Hemophilia Organizations**

Canadian Hemophilia Society	www.hemophilia.ca
National Hemophilia Foundation	www.hemophilia.org
World Federation of Hemophilia	www.wfh.org
Kelley Communication	www.kelleycom.com

National Transfusion Services

Canadian Blood Services	www.blood.ca
Héma-Québec	www.hema-quebec.qc.ca

Manufacturers of Clotting Factor Concentrates

Baxter	www.hemophiliagalaxy.com
Bayer HealthCare	www.bayer.ca
CSL Behring	www.cslbehring.ca
Novo Nordisk	www.novonordisk.ca
Octopharma	www.octopharma.com
Pfizer	www.pfizer.ca www.embracelife.ca

Other Useful Organizations

MedicAlert Foundation
2005 Sheppard Avenue East, Suite 800
Toronto, Ontario M2J 5B4
Tel: 1-800-668-1507
www.medicalert.ca

This foundation offers 24-hour medical information services and provides medical identification bracelets and necklaces.

www.bebeccino.com

Online shopping destination* for parents of a child with a bleeding disorder including protective items such as helmets and knee pads.

*The CHS is providing this online source for information only and does not endorse any of the resources available on the site.

Test Your Knowledge... Answers

Page 2-16

None of your son's children will have hemophilia. However, all of his daughters will be carriers. This means that your grand-daughters' sons (your great-grandsons) each have a 1-in-2 chance of having hemophilia. Your grand-daughters' daughters (your great-grand-daughters) each have a 1-in-2 chance of being carriers.

Page 4-24

R - Rest
I - Ice, Immobilization
C - Compression
E - Elevation

Page 4-31

a, b, d, f, g

Page 5-26

The correct dose is 400 to 600 IU.

At the first sign of a joint bleed, a boy with factor VIII hemophilia should raise his level to 20 to 30% of normal. This requires 10 to 15 IU per kilogram. As he weighs 40 kg, you need to infuse 400 IU (10 IU/kg times 40 kg) to 600 IU (15 IU/kg times 40 kg).

Page 5-28

The correct answer is less than 1 percent.

After infusion, his factor level is 40%.

After 12 hours, it is 20% (40% times 1/2).

After 24 hours, it is 10% (20% times 1/2).

After 36 hours, it is 5% (10% times 1/2).

After 48 hours, it is 2.5% (5% times 1/2).

After 60 hours, it is 1.25% (2.5% times 1/2).

After 72 hours, it is less than 1% (1.25% times 1/2).

Page 6-1

The correct answer is Sweden.

Page 6-6

Short-term prophylaxis

Long-term prophylaxis

Primary prophylaxis

Secondary prophylaxis

Page 8-23

All of them.

Page 15-23

a, b, c, d, and e. However, reading a Harry Potter book to him is not a bad idea, either.