

Ages 5–8

Guidelines for **Growing:**

An action plan for parents
of children with bleeding disorders



5 through 8 years of age



**Centers for Disease
Control and Prevention**
National Center on
Birth Defects and
Developmental Disabilities



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

5 through 8 years of age

Young children with bleeding disorders face a number of difficult and ongoing medical challenges as they mature and learn to manage their health. As a parent of a child with a bleeding disorder, it is important for you to be aware of what you can do to help your child as he or she moves through his or her life stages. This is the second age-specific brochure in the *Guidelines for Growing* series, adapted from the National Hemophilia Foundation's (NHF) Medical and Scientific Advisory Council (MASAC)* Transition Guidelines. Each brochure focuses on important milestones of your child's development as they relate to his or her bleeding disorder. This resource is designed to be used in conjunction with your hemophilia treatment center (HTC) provider team to guide you as you help your child grow and develop.

1. Social Support

- ✓ Continue to participate in your HTC and local bleeding disorders organization's programs and support groups, as well as national events. Encourage your child to make friends with other children there.
- ✓ Discuss with your HTC team your concerns about giving your child increased independence, as he or she goes to school, camp or other activities outside your home.
- ✓ Find age-appropriate activities that your child can participate in through school, camps, clubs, scouts or religious groups.

2. Health and Lifestyle

- ✓ Discuss with your HTC team the use of protective equipment and ways to safely adapt physical activities. Encourage physical fitness through family fun activities, such as swimming, walking, golfing and playing with a Frisbee®. Read the NHF publication “Playing It Safe: Bleeding Disorders, Sports and Exercise” available through HANDI, NHF’s Information Resource Center.
- ✓ Begin talking with your child about accepting his or her bleeding disorder and its effect on normal social development. Work healthy eating and physical fitness into your family’s routine. Avoid using unhealthy foods such as fast food or sweets as a reward for self-infusion or other healthy behaviors.
- ✓ Discuss the importance of dental hygiene and regular dental visits with your child, including its effect on his or her future health. Ask your HTC team for a list of dentists familiar with treating people with bleeding disorders.
- ✓ Be positive. Stress your child’s abilities, not disabilities, both with your child and with others with whom your child will interact.



3. Educational, Vocational and Financial Planning

- ✓ Help your child organize his or her schedule to include set times for homework, extracurricular activities and play. Begin to teach responsibility by giving your child age-appropriate chores and, if appropriate based on your philosophy and capability, an allowance.
- ✓ Introduce your child to a variety of activities so he or she can learn what interests him or her. Work with your child to set achievable goals and teach self-esteem so he or she will rely less on approval from others. As opportunities arise, discuss how his or her bleeding disorder might influence future goals and choices.
- ✓ At the beginning of each school year, get to know the adults your child will interact with at school (for example, the teachers, principal and school nurse.) The Steps for Living Web site (www.stepsforliving.hemophilia.org), your HTC or local bleeding disorders organization has brochures and forms that will help you understand how to partner with the school to create an inclusive yet safe learning environment. Most HTCs and local bleeding disorders organizations will offer to meet with the teachers or school administrators to explain bleeding disorders and the child's limitations or special considerations to prevent or deal with any problems.

4. Self-Advocacy and Self-Esteem

- ✓ Make sure that your child knows the name of his or her bleeding disorder and has a general understanding of how his or her treatment program works. There are many age-appropriate materials to help you

explain bleeding disorders to your child. For more information, contact HANDI by calling **1-800-42-HANDI/1.800.424.2634** or e-mail **handi@hemophilia.org**.

- ✓ Teach your child to recognize and report pain and symptoms of a bleed to the appropriate person, such as a teacher, club leader or coach. Help your child practice talking about any physical adaptations, accommodations or changes that he or she might need to participate in activities. Help your child learn how to explain his or her bleeding disorder and treatment to peers.
- ✓ Encourage your child to talk directly with the HTC team during visits. Coach your child on how to explain concerns to health care providers.
- ✓ Keep up-to-date with any changes in your health insurance and learn how those changes might affect your child's coverage. Understand what services are covered and if there are limits on coverage. Most HTCs and local bleeding disorders organizations can give you information about financial counselors and other patient assistance programs. Some states have insurance programs for eligible children with long-term medical needs.



- ✓ Learn about patient rights and responsibilities and about confidentiality laws related to health care. Consider keeping your own set of your child's medical records with clinic summaries, and laboratory and imaging reports.

5. Independent Health Care Behaviors

- ✓ Discuss treatment options with your HTC team. For example, if your child has a central venous access device (CVAD, a port or central line placed into a vein so that clotting factor can be given over a long time period), consider when it would be best for your child to begin learning venipuncture (placing the needle directly into the vein to give clotting factor) and start talking about it with your child. Begin teaching your child to build their skills and help with home treatment, such as mixing factor and keeping proper records.
- ✓ Discuss with your HTC team an appropriate timeline for your child to begin self-infusion therapy.

Keeping Your Child's Medical Records and Emergency Information Updated and Accessible

- ✓ Keep a list of important telephone numbers for emergencies. Include contact information for your pediatrician, HTC, factor provider, home health nurse, and local emergency room. Make sure it is in a place that is easy to access and your child and other family members know where to find it.

- ✔ Work with your health care providers to develop a summary of your child's medical history and treatments. This document provides information about your child's special health care needs in the event of an emergency.
- ✔ Protect your child with medical alert identification tags and emblems. That way, your child's bleeding disorder and emergency contact information can be identified in the event that your child is not conscious or old enough to tell medical personnel about his or her special needs. Discuss with your child the importance of wearing his or her medical alert tags and emblems, and keeping the information up to date at all times. HTC and local bleeding disorders organizations can provide you with information about medical alert identification programs.

Important HTC Information and Services

- ✔ Know how to find an HTC and obtain your child's clotting treatment when moving or traveling out of state. Contact HANDI or go to www.cdc.gov/ncbddd/hemophilia/HTC.html for listings of HTCs throughout the United States.
- ✔ You and your child should visit your HTC at least once a year for a comprehensive checkup, in addition to visiting a primary care doctor regularly. Provide your HTC with current contact information for your primary care doctor for consultation and coordination of care.
- ✔ Learn about the genetics of your child's bleeding disorder. Encourage family members who could be at risk of having a bleeding disorder or having a child with a bleeding disorder to get diagnostic testing.

The National Hemophilia Foundation (NHF) is dedicated to finding better treatments and cures for bleeding and clotting disorders and to preventing the complications of these disorders through education, advocacy, and research. Its programs and initiatives are made possible through the generosity of individuals, corporations, and foundations, as well as through a cooperative agreement with the Centers for Disease Control and Prevention (CDC).

The contents of this brochure are the sole responsibility of the authors and do not necessarily represent the official views of the CDC and other NHF funders.

The information contained in this publication is provided for your general information only. It is not intended as a substitute for visiting with your physician, nurse, or social worker. NHF does not give medical advice or engage in the practice of medicine. NHF under no circumstances recommends particular treatments for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

For more information or for help, please contact HANDI, NHF's informational resource center at **800.42.HANDI/800.424.2634** or e-mail **handi@hemophilia.org** or go to: **www.stepsforliving.hemophilia.org**.

Additional parenting resources can be found online: **www.cdc.gov/parents**.

Acknowledgements

This publication is adapted from the NHF MASAC Document #147: TRANSITION GUIDELINES for People with Bleeding Disorders. *MASAC: NHF's Medical and Scientific Advisory Council

NHF thanks the First Step Task Force for its input and contributions.

© 2011 National Hemophilia Foundation. Material in this publication may not be reproduced without written permission from the National Hemophilia Foundation.