



S. P. E. A. K. U. P. Handling Abuse Allegations

WALKING THROUGH A MALL, GROCERY SHOPPING, GOING TO CHURCH OR DROPPING YOUR CHILD OFF AT DAY CARE OR SCHOOL ARE UNEVENTFUL SITUATIONS FOR MOST PARENTS. HOWEVER, PARENTS OF CHILDREN WITH HEMOPHILIA MAY DISCOVER THAT WHEN THEIR CHILD HAS VISIBLE BRUISING, MEETING PEOPLE AT THESE EVENTS CAN QUICKLY BECOME SOME OF THE MOST DIFFICULT MOMENTS OF PARENTING. IN THE LAST 30 YEARS WE HAVE ALL BECOME MUCH MORE AWARE OF CHILD ABUSE AND OUR RESPONSIBILITY TO CHILDREN WHO MAY BE THE VICTIMS OF SUCH CRUELITIES.

BY SUE DU TREIL, DCSW, ACSW

Police, physicians, medical personnel, clergy, teachers and day-care center staff are all mandated by criminal law to report suspected child abuse and neglect. Thus, they do not have to have conclusive evidence in order to report. Other citizens, though, are now much more aware of the problem because of television and other forms of mass media and, consequently, report more frequently than in the past. When parents of a child with hemophilia engage in activities with their child who is bruised, there is a possibility that they will be reported for child abuse.

So, what can a parent of a child with hemophilia do to prevent reports or convince child protection that no abuse is involved once a report is made? The good news is that there is much that can be done. The following acronym can help parents remember what they can do:

- S** PEAK UP.
- P** REPAIR yourself by carrying a letter from a hemophilia treatment center (HTC).
- E** DUCATE others about hemophilia.
- A** LERT tag.
- K** NOWLEDGE about hemophilia.
- U** NDERSTAND that others are trying to help your child.
- P** AUSE and breathe.

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Speak up. The best tool is communication. It is important to tell day-care center staff, teachers, clergy, medical personnel and other professionals about the child's disease. An HTC can help parents with this task by sending literature, such as the pamphlet published by NHE entitled *Inherited Bleeding Disorders and Child Abuse Investigations* (Johnson & Christie, 1998). In addition, learning how to calmly and directly address a person who might be staring at a bruise is truly the most effective method to prevent a report. Simply say, "My child has hemophilia. It is a bleeding disorder, so he/she bruises easily." This can be very helpful in two ways. First, it gives the person some very important information about the cause of the bruising. Second, when parents speak matter-of-factly about a child's hemophilia, the child will learn that parents are able to speak up for him, and it serves as a model for the child.

Prepare by carrying a letter from your HTC. Ask the HTC to write a letter that gives the child's diagnosis and states that he/she may easily bruise along with the HTC's contact information. Parents should carry this letter with them at all times. This document is very substantial evidence of the child's condition and is particularly useful when going to an emergency room where the ▶

▶ child is not known, when the child enters day care or school or if a child protection worker contacts the parents.

Educate others about hemophilia. Since hemophilia is such a rare illness, few people have a true understanding of it. Therefore, one of the most important roles a parent of a child with hemophilia has is to educate others about hemophilia. This can be a very helpful way to prevent inappropriate referrals to child protection. Parents will have to be able to explain the child's disease to family, friends, other parents, the child's playmates, day-care center staff, teachers and even some medical professionals. The physicians, nurses and social workers at an HTC are the first who will educate parents about the child's hemophilia and they are consistently available to answer any questions. Another excellent resource is a recent publication by the Centers for Disease Control and Prevention entitled *Basic Concepts of Hemophilia: A Self-Study and Planning Workbook for Families with a New Diagnosis of Hemophilia* (Butler, Crudder, Riske, & Toal, 2001). This book allows parents to have a written resource about hemophilia and it also has wonderful information about parenting a child with hemophilia. The nurse and social worker at the HTC can also help educate day-care center staff and teachers by visiting them with the parents (when necessary) to describe the child's hemophilia and what can be expected. However, what do parents do when they have to educate medical professionals, especially when they have to go to an emergency room? Physicians and nurses in emergency rooms do not often have exposure to children with hemophilia, so it is very impor-



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tant for parents to be able to explain their child's disease. An excellent tool to help parents when visiting an emergency room is the guide written by the Nursing Group of Hemophilia Region VI entitled, *Emergency care for patients with hemophilia: An instructional manual for medical professionals* ([2nd Edition] [Wulff, Zappa, & Womack, 1999]). This guide is available at every HTC in the United States and Canada. HTCs have distributed copies to local emergency departments that care for persons with hemophilia. Be sure to bring a copy along at each emergency room visit to assist in educating the ER staff.

Alert tag. Making sure that the child wears a MedicAlert® tag every day is one of the best ways to prevent a report. It alerts people to the fact that the child has a medical condition, and often this is sufficient to ward off a report.

Knowledge about hemophilia. The more parents know about their child's disease, the more expert they become. Parents will be able to quickly explain their child's condition with confidence. There are several sources of information about hemophilia that are available through an HTC, NHP's HANDI ([800] 42-HANDI or handi@hemophilia.org) and Web sites that specifically address hemophilia (listed at the end of this article).

Understand that others are trying to help the child. Every year children in our society grow in importance. Consider that it is only recently that there has been open acknowledgement that children were abused and neglected. In the 1970s the first child protection reporting laws were written. Keeping this in mind might shift a parent's viewpoint. If parents are in the position of having

been reported for child abuse, they will be more able to give the investigator the information he/she needs to invalidate the report. The information the investigator will need is a clear statement from the parents that their child has hemophilia and medical documentation of the child's condition. Parents might be asked to sign a release of medical information or give permission for the physician from child protection to examine the child.

Parents might think, "Why would that doctor need to see my child?" The physician from child protection is an expert in the area of child abuse and neglect. Sometimes children with hemophilia are physically abused or neglected, so even if you can explain bruising as the result of hemophilia, this physician will look at the bruises to ensure that they were not inflicted through abuse. Bruises from abuse often have the shape of the object that was used to abuse the child (a belt, extension cord, hairbrush, hand, hot iron or curling iron, etc). Additionally, the child protection physician will look for signs of neglect, such as malnutrition, poor hygiene, etc. While cooperating with child protection, parents may feel the need to have their own attorney present if it becomes apparent that the investigation might go beyond the initial contact. Legal counsel is a right that can help parents focus on how best to present their case if a court becomes involved.

Pause and breathe: Taking a minute to reflect on what to say and how

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to say it is always helpful in difficult situations. Breathing also relaxes the body by giving it the oxygen it needs when under stress. Parents may need to practice this several times until they are able to give the information requested. Courage and encouragement need to be present in order for parents to deal effectively in these situations. By adopting this mode of behavior, parents teach children through example. Additionally, parents should accept the support of spouses, parents, children, friends, colleagues and spiritual advisors. Having supportive people present will lessen the burden and give parents greater insight into how to cope.

In conclusion, the acronym SPEAK UP can be a tool to help parents remember all the resources they have available regarding possible allegations of child abuse. The most important of these resources, of course, is the ability of parents and children to speak up about hemophilia. ☺

REFERENCES

- 1 Aagard, IS. The charge: Child abuse. *Hemalog* 11(2):27-29, April 2000.
- 2 Merritt, D. They're saying I hurt my child. *Belonging*, 5-7, 11, Summer 1999.

HELPFUL WEB SITES

- www.hemophilia.org
- www.wfh.org
- www.hemophiliagalaxy.org
- www.hemophilia.net
- www.hemophilavillage.com
- www.mmhc.com
- www.web-depot.com/hemophilia
- www.medicalert.org