Hemophilia and von Willebrands are inherited bleeding disorders resulting in a deficiency or absence of a protein in the blood that helps to form a clot. This protein is called Factor VIII (Hemophilia A) or Factor IX (Hemophilia B) for those with hemophilia. If the deficiency is found in the von Willebrand protein it is called von Willebrands. These bleeding disorders are characterized by delayed clotting of the blood.

*Children with Hemophilia or von Willebrands do not bleed any faster but may have prolonged oozing after some injuries.*

Hemophilia is carried on the X chromosome. In general, females are carriers and males are affected. Sisters will not have hemophilia but brothers may or may not be affected. Von Willebrands is carried on an autosomal chromosome, similar to the chromosomes that determine eye and hair color. Von Willebrands occurs in both males and females.

**Severity**

The severity of the bleeding disorder can vary greatly. Some children have an average of one bleeding episode a week while others may go a whole year or more without a significant bleeding episode.

There are three levels of severity for hemophilia:

- **Mild** - usually bleeds only after major injury, surgery, or tooth extractions
- **Moderate** - bleeding is usually caused by injury
- **Severe** - bleeding can be caused by injury but can also be spontaneous

There are three types of von Willebrands: common areas of bleeding are in the mucosa (i.e. mouth, nose, gastrointestinal tract and heavy periods)

- **Type 1** - usually mild bleeding seen primarily only after injury, surgery or tooth extractions and other mucosal bleeding
- **Type 2** - usually moderate bleeding caused by moderate injury, surgery and tooth extractions and other mucosal bleeding
- **Type 3** - usually severe bleeding, can be caused by injury and can also be spontaneous

**Types of Bleeds**

**Life-threatening**

- **Head injuries** - signs and symptoms to look for include nausea, vomiting, headache, lethargy (abnormal drowsiness), confusion, visual changes or loss of consciousness. All head injuries must be reported to parents immediately. Initially there may be no symptoms but all head injuries should still be treated as life threatening.
- **Neck and Throat** - symptoms include acute pain, swelling, breathing problems or difficulty swallowing.
- **Abdominal** - symptoms include acute abdominal tenderness, pain, heat or swelling.

*No matter how significant the injury, proceed with first aid as for any other child.* If it is a head, throat or abdominal injury, the parent should be called immediately. If he/she cannot be reached, call the hemophilia treatment center or physician on call.

**FIRST AID FOR SCRAPES AND MINOR CUTS:**

Administer first aid as you would for any other child; put on gloves, clean the area, and apply a Band-Aid. For cuts that require stitches, apply pressure by hand or a pressure dressing and then call the parents.

**Joint or Muscle Bleeding** - the child may report tingling or a bubbling sensation or stiffness. There may be warmth, pain or decreased motion. Often the first sign is a limp or protecting a limb or joint. Have the child rest and call the parents.

**Mouth Bleeds** - mouth bleeds seldom stop without treatment. You can try having the child apply ice or cold compresses to the bleeding area but if it hasn’t stopped in 20 minutes, call the parents.
Types of Bleeds continued

Nose Bleeds - put on gloves, head upright, and apply continuous pressure for twenty minutes. Most children can do this themselves. If not stopped, call the parents.

*Any observed bleeding at the school and how it was managed should be reported to the parents. This exchange of information is important so that the parent knows what has been done and can observe the child for any re-bleeding and subsequent need for treatment.

Physical Activity

Each child should maintain an appropriate level of physical activity to maintain strong muscles and good joint mobility. The level of participation of a child with a bleeding disorder in physical education class is highly variable and is based on each individual’s abilities.

A physical education program should:

1. Follow the recommendations determined by the hemophilia treatment center.
2. Encourage activities such as swimming, calisthenics, ball games such as softball and tennis, dancing, and modified gymnastics.
3. Discourage contact sports with a high risk of injury such as football, hockey and boxing.
4. Promote the spirit of participation, involvement and encourage self-esteem.

* As is true for all children, proper instruction on a given activity, including rules and utilization of appropriate gear (helmets, pads, guards, etc.) are critical to safe participation.

School Attendance and Performance

There is no reason for the student with Hemophilia and other bleeding disorders to be unsuccessful at school. Communication between the hemophilia treatment center, family and student should be ongoing when health care concerns interfere with performance. Prolonged illness resulting in frequent absences may alter social development as well.

The student’s right to privacy must be respected. Many students prefer that their friends not be aware of their condition. To prevent the child from feeling different than his or her peers, giving preferential treatment and overprotecting the student should be avoided.

The child's limitations should be taken into consideration. Children may at times attend school using splints, slings, crutches or a wheelchair. Arrangements for assistance in carrying books, use of an elevator (if available) and time to safely change classes may be needed. These accommodations should be arranged between the parents and the school ahead of time.

For more information

UW Hospital and Clinics Comprehensive Program for Bleeding Disorders
2704 Marshall Court, Madison, WI 53705
866-737-6707, Fax: (608) 262-8539
uwhealth.org
Karmin Enge, RN (608) 890-9493
Jeff Amond, MSSW (608) 890-9495
Paulette Drozdowicz, RN (608) 890-9494

Eliot Williams, MD, PhD, Adult Hematology
Dr. Carol Diamond, MD, Pediatric Hematologist
UWHC ON CALL PEDIATRIC HEMATOLOGIST (608) 262-2122