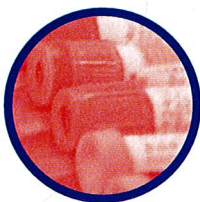


# INHERITED BLEEDING DISORDERS AND CHILD ABUSE INVESTIGATIONS



*A resource for emergency  
medical providers, healthcare  
workers, day care and school  
personnel, child protection  
advocates and the community.*



**NATIONAL HEMOPHILIA FOUNDATION**  
*for all bleeding disorders*

## BACKGROUND

Many children are diagnosed with an inherited bleeding disorder after an investigation or report of suspected child abuse.

Inherited bleeding disorders should be considered a possibility when investigating these cases.

When a child exhibits frequent bruising, swelling or pain in a joint or bleeding from the mouth, an expert in bleeding disorders should be consulted to assist mandated professionals assessing suspected child abuse.

It is extremely important for affected families to inform daycare and school personnel of the child's diagnosis. Additionally, daycare/school/emergency medical personnel and child protection staff should take complete medical (including bleeding) and incident histories from a family when a child does exhibit these symptoms. Consultation with a hematologist familiar with hemophilia and other bleeding disorders is strongly recommended for help with management of bleeding symptoms as well as long-term care.

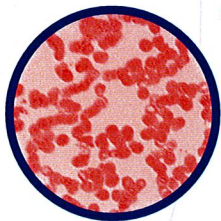
By educating people about bleeding disorders, the trauma associated with such investigations might be reduced.

An inherited bleeding disorder is a lifelong, chronic condition. It is characterized by the inability to form a stable clot and results in prolonged bleeding. The two most common inherited bleeding disorders are hemophilia and von Willebrand disease.



## WHAT IS HEMOPHILIA?

Hemophilia is an inherited bleeding disorder in which the affected individual lacks or has a deficiency of one of the proteins needed for blood to clot properly. Hemophilia occurs in one out of every 5,000 males; there are about 17,000 affected individuals nationwide. The disorder is X-linked and therefore rare in females. In about a third of all cases, there is no family history of the disease, and hemophilia occurs as the result of a spontaneous genetic mutation.



The severity of hemophilia ranges from mild (bleeding only with significant trauma or surgery) to severe (spontaneous and/or traumatic bleeding). Joint and muscle bleeding are typical symptoms in people with hemophilia. Bleeding can also occur in almost any location, such as the mouth, nose and inside the head and the abdomen.

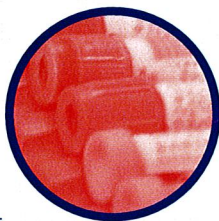
Bruising is often seen and can be quite dramatic. In a person with severe hemophilia, bleeding and bruising can occur without evidence of trauma. Children with a bleeding disorder often develop hemorrhages in joints or bruises from normal, age-appropriate activities (eg, falling when learning to walk, receiving immunizations, etc.). In children with the severe form of the disease, the bleeding can be spontaneous, occurring with no prior trauma. Some typical patterns of bruising or bleeding in the pediatric population include:

- finger marks on the chest wall
- bruising on buttocks
- lumps or bruising on the forehead
- large bruising with lumps on arms and legs
- mouth bleeding
- muscle bleeding
- joint bleeding

Treatment consists of treating the affected area and infusing the missing clotting protein into a vein. However, most superficial bruising does not require treatment and gradually goes away.

## WHAT IS VON WILLEBRAND DISEASE?

von Willebrand disease (VWD) is an inherited bleeding disorder in which the affected individual has a decreased amount or decreased function of von Willebrand factor, a protein necessary for clotting. This occurs in up to 1% – 2% of the population and is inherited in an autosomal dominant fashion, affecting males and females equally. Because the majority have mild disease, this disorder is generally less severe than hemophilia, although severe bleeding can occasionally occur. Children can have bruising, mouth bleeding or nosebleeds. In contrast to those associated with hemophilia, joint bleeds occur rarely, if at all. Typical symptoms are:



- nose and mouth bleeding
- easy bruising
- in females, heavy menstrual bleeding

Treatment may consist of a specific nasal spray that increases the clotting protein or intravenous infusion of the clotting factor.

## DIAGNOSIS

Diagnosis of hemophilia or von Willebrand disease is made by measuring clotting protein levels in the blood. This is usually performed at birth if there is a family history. (Of course, in children with no family history, parents and physicians may not know to ask for testing.) Tests to rule out a bleeding disorder may also be done if a person has excessive or prolonged bleeding (with or without trauma or surgery) or if there is unexplained bruising or bleeding.





## **ABOUT NHF**

The National Hemophilia Foundation is dedicated to finding the cures of inherited bleeding disorders and to preventing the complications of these disorders through education, advocacy, and research.

This material is provided for your general information only. The National Hemophilia Foundation (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

## **ACKNOWLEDGMENTS**

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## **COMPREHENSIVE CARE**

Many people with inherited bleeding disorders receive their medical care, information and education from a nationwide network of hemophilia treatment centers, the National Hemophilia Foundation and local chapter affiliates. These providers are also available to educate people in the community about bleeding disorders.

## **WHERE TO GET MORE INFORMATION**

For further information about inherited bleeding disorders, please call the hemophilia treatment center nearest you.

To identify the hemophilia treatment center nearest you, call HANDI, the information center of the National Hemophilia Foundation, at (800) 42-HANDI. HANDI information specialists can send you general information on inherited bleeding disorders, connect you with the hemophilia treatment center nearest you and provide contact information for NHF chapters.



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