NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

HEMOPHILIA FACT SHEET

What is hemophilia?
Hemophilia is a genetic bleeding disorder that prevents the blood from clotting normally. The two main forms are hemophilia A (factor VIII deficiency) and hemophilia B (factor IX deficiency). Depending on the amount of clotting factor in the blood, hemophilia can be characterized as mild, moderate, and severe.

What causes hemophilia?
Hemophilia is largely an inherited disorder which primarily affects men while women may carry the gene. Some women who are carriers also have bleeding symptoms. Hemophilia results from the deficiency of one or more proteins known as blood clotting factors. Everyone inherits two sex chromosomes, X and Y, from his or her parents. The gene that causes hemophilia is located on the X chromosome.

If a man with hemophilia has a daughter, she will be a carrier of hemophilia, as her father contributed his X chromosome. A son of a man with hemophilia will not have the disorder, as his father contributed his Y chromosome, which does not have the gene that causes hemophilia.

With each pregnancy, if a woman who is a carrier has a son, he has a 50% chance of having hemophilia. Sometimes, a baby will be born with hemophilia when there is no known family history. This means either that the gene has been "hidden" (that is, passed down through several generations of female carriers without affecting any male members of the family) or the change in the X chromosome is new (a "spontaneous mutation").

What are the symptoms of hemophilia?
Symptoms of hemophilia include uncontrolled, often spontaneous bleeding. A person with hemophilia does not bleed harder or faster than a person without hemophilia, he bleeds longer. Internal bleeding into the joints can result in pain, swelling and, if left untreated, can be life threatening or cause permanent damage and disability. Women who carry the gene may experience bleeding symptoms.

How many people are affected by hemophilia?
Hemophilia occurs in 1 in 5,000 live male births in the United States; of these cases 80 percent are hemophilia A and 20 percent are hemophilia B. There are approximately 20,000 individuals affected with hemophilia in the United States. The number of people affected worldwide by hemophilia is estimated at more than 400,000 people.

Is there a cure for hemophilia?
Currently, there is no cure for hemophilia. This is a lifelong condition.

What treatment is available?
Treatment typically requires frequent intravenous injections of replacement clotting factor that is manufactured either from human plasma or using recombinant technology. In cases of severe hemophilia, doctors sometimes recommend giving a regimen of regular factor replacement treatments, also called prophylaxis, to prevent bleeding episodes before they happen. The Medical and Scientific Advisory Council of the National Hemophilia Foundation recommends prophylaxis as optimal therapy for individuals with severe hemophilia A and B.

For more information about hemophilia visit the National Hemophilia Foundation's website at www.hemophilia.org or the Centers for Disease Control and Prevention hemophilia website at http://www.cdc.gov/ncbddd/hemophilia/.