NATIONWIDE CHILDREN'S
*When your child needs a hospital, everything matters.*℠

Helping Hand™

# Hemophilia Carrier

A hemophilia (Hee-mo-FEE-lee-ah) carrier is a female who has the gene that causes hemophilia A (Factor VIII) or hemophilia B (Factor IX) deficiency. Factor VIII (8) and Factor IX (9) are needed for the blood to clot normally.

The genes for Factor VIII and Factor IX are on the X chromosome (CROW mo sohm). Males have one X and one Y chromosome. Females have two X chromosomes. A male gets an X chromosome from his mother and a Y chromosome from his father. A female gets two X chromosomes - one from each parent. The Y chromosome cannot help to make the Factor VIII or Factor IX for the blood to clot normally. Therefore, boys with a change in the Factor VIII or IX gene on their X chromosome will have hemophilia.

Carriers are females who have one working hemophilia gene and one non-working hemophilia gene. The working gene can produce Factor VIII or Factor IX. For this reason, many carriers will have Factor VIII or Factor IX levels in the normal range. Sometimes a carrier's factor levels are too low and the person may have bleeding symptoms. This person is called a symptomatic (sim toe MAT ick) carrier.

## Signs and Symptoms

About 1 out of 4 hemophilia carriers will have symptoms. For those with symptoms, bleeding can be mild or severe. Bleeding may happen as:

- nosebleeds
- easy bruising
- heavy menstrual periods
- bleeding after childbirth or surgery
- bleeding after injury
- bleeding into the joints

The severity of bleeding depends on the level of Factor VIII or Factor IX in the blood.

## Diagnosis

There are two blood tests that can be done to find out if you are a hemophilia carrier.

- A test for factor levels. People who have a low-normal Factor VIII or Factor IX level may be hemophilia carriers.
- A genetic test. This test can confirm if either you or your child is a hemophilia carrier. For the most accurate genetic test, a male relative with hemophilia should have a genetic test to find the gene change in the family.

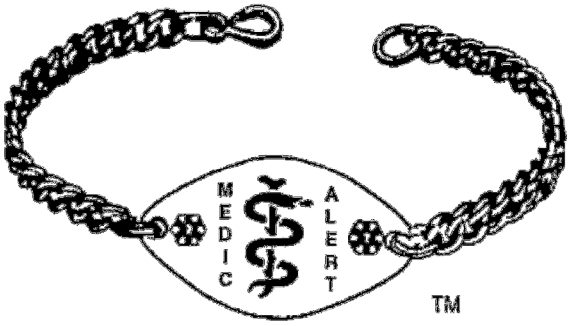
## Treatment and Prevention

If you are a symptomatic carrier, be sure to tell your doctors and dentist (especially surgeons and your gynecologist). Adult women receive care at The Ohio State University Hemophilia Treatment Center (HTC). Children are seen at Nationwide Children's Hospital.

Treatment for symptomatic carriers may include medicine such as desmopressin acetate (DDAVP; see HH-V-120 DDAVP for bleeding disorders) and/or Recombinant Factor VIII or IX.

Symptomatic carriers need to:

- Avoid contact sports, like football, boxing, wrestling and hockey.
- Wear a medical alert bracelet or necklace at all times (Picture 1). This helps in an emergency if the person is not able to speak. Purchase ID bracelets and necklaces at your local drugstore or homecare company.



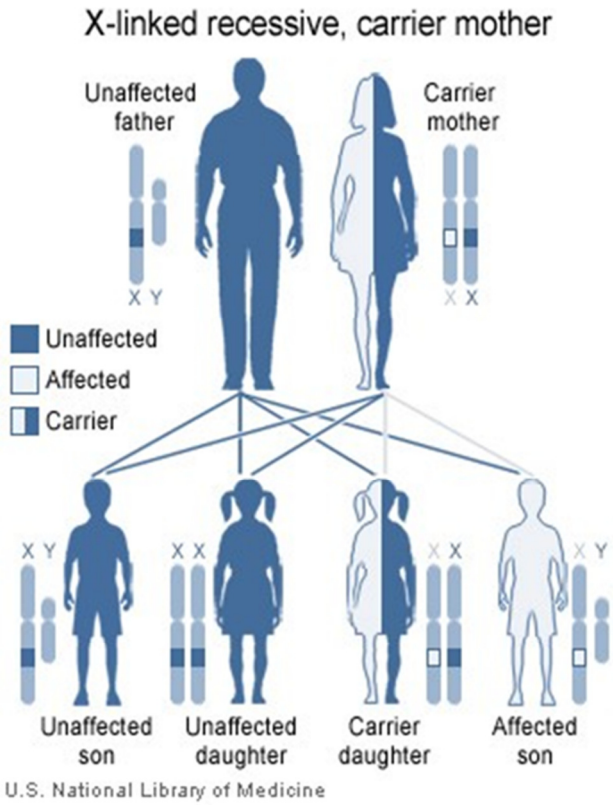

**Picture 1** Symptomatic carriers should wear a medical ID necklace or bracelet.

- Avoid aspirin or products that contain aspirin. Tell the doctor about any herbal remedies or over-the-counter medicines your child takes. Some of these products may be harmful.

## How Hemophilia Is Inherited

- Most, but not all, mothers who have a son with hemophilia are carriers.
- A female who is a carrier has a 50 - 50 chance that each male child will have hemophilia. There is a 50 - 50 chance that each female child will be a carrier (Picture 2).

**Picture 2** How hemophilia is inherited



## When to Call the Doctor

If you or your child is a hemophilia carrier, call the doctor for:

- Nosebleeds that last more than 10 minutes or happen more often
- Menstrual periods that last more than 7 days
- Prolonged bleeding after the loss of a tooth or dental surgery
- Minor cuts that bleed for a long time or do not stop with normal pressure
- Swollen, tender, warm, painful or stiff joints
- Severe stomach pain with no explained cause
- Severe back pain
- A raised bump under the skin
- A planned procedure or surgery
- Blood in the urine or stool

## Other Information

- Your child will have regular appointments in the Hemophilia Treatment Center (HTC) every 6 to 12 months.
- Specialists in dentistry, genetics, social work, nursing and physical therapy will see your child.
- You will learn about current and new treatments.
- If you have any questions, please contact the HTC at 614-722-8876.