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**OUR GOALS**

1. Encouraging health insurance companies to invest in patient education.
2. Advocating information therapy.
3. Setting up a national network of patient education centers.
4. Developing patient educational materials in Indian Languages for the web.

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Understanding Hemophilia  
World Hemophilia day- 17th April'10
Hemophilia

Haemophilia is a genetic disorder that affects human body's capability to form blood clots or coagulation, which is an important factor to stop bleeding.

Haemophilia is: mostly a genetic disorder, prevents the blood from clotting, more prevalent in males than in females, incurable but controllable.

With proper treatment, those suffering from hemophilia may lead a relatively normal life, which is why it is so important to identify symptoms of hemophilia early.

Causes: Blood clotting factors are substances in the blood that help form a clot. When one or more of these clotting factors are missing, there is a higher chance of bleeding. In most cases, the disorder is passed down through families (inherited). It most often affects males.

Symptoms:

- Excessive Bleeding;
- Easy bruising. Bleeding – internally and externally;
- Bleeding in the knees, elbows, or other joints without any obvious injury;
- Internal bleeding in the brain is a very serious complication of haemophilia that can happen after a simple bump on the head or a more serious injury.

Exams and Tests:

Human blood comprises of about 13 clotting factors that helps to stop bleeding. People with Hemophilia (PWH) have absence of one of these clotting factors in their blood. Commonly, a deficiency of factor VIII and IX is found in the hemophiliacs.

Below is the range of Hemophilia basis the clotting factor available in human body:

- Normal range: 50-150%   
- Mild hemophilia: 5-40%   
- Moderate hemophilia: 1-5%   
- Severe hemophilia: Less than 1%

In severe cases, even a minor injury could result in blood loss lasting days, weeks, or not even healing completely. In cases of internal bleeding in areas such as the brain or inside joints, this can be fatal or permanently debilitating.

Over a period of time, bleeding into joints and muscles can cause permanent damage and chronic pain.

Hemophilia can be controlled by:

- Proper diagnosis
- Access to trained healthcare
- Replacing the missing clotting factor in the blood
- By injecting the needed factor into a vein

The ultimate goal is to offer a cure for the disease. The challenge is to transfer normal genes into a patient so that they will produce the normal clotting protein.

Outlook (Prognosis):

Most people with hemophilia are able to lead relatively normal lives. However, some patients have significant bleeding events, most commonly chronic bleeding into the joint spaces.

A small percentage of people with hemophilia may die from severe bleeding.