Hemophilia Society of Tanzania for Bleeding Disorders

TANZANIA

About Us

The Hemophilia Society of Tanzania is a non-governmental society, formed in 2009 to create awareness and education about bleeding disorders, to improve diagnosis, care and treatment of these conditions. As a member of the World Federation of Hemophilia, the Society shares the vision of, "Treatment for All". In Tanzania, patients should have access to accurate diagnosis, treatment and care provided by trained personnel, as well as access to an adequate supply of safe blood products. This information brochure is intended to answer basic questions about these disorders as well as to point out some of the complications. For further information, please feel free to contact the Society.

What is Hemophilia?

Hemophilia is a disorder of the blood in which the blood proteins called clotting factors are deficient, causing people with hemophilia to bleed for a longer time than a person without hemophilia. A person is born with hemophilia and will have it for life. With adequate treatment, the condition can for the most part, be chronic in nature, and may not be outwardly visible. The most common forms are Hemophilia A and Hemophilia B. The incidence of Hemophilia A is 1 in 10,000 while the incidence of Hemophilia B is lower at 1 in 50,000 people. Hemophilia is found in all populations worldwide.

Hemophilia, a genetically inherited disorder, is passed from the parent to the child. However, in 30% of cases, hemophilia can occur when there is no previous family history. It affects mostly males, although under some circumstances, a female can be affected.

The severity of Hemophilia depends on the amount of Factor 8 or Factor 9 in the blood. There are three levels of severity: severe, moderate, and mild:

- People with severe hemophilia usually bleed frequently, about one or two times per week, often into their muscles or joints. Bleeding can be spontaneous, which means it happens for no obvious reason. Their factor level is less than 1%.

- People with moderate hemophilia bleed less often, usually after an injury but they can also bleed spontaneously. Their factor level is 1% to 5%.

- People with mild hemophilia usually bleed only as a result of surgery or major injury. Their factor levels are 5% to 40%.

The level of Factor 8 or Factor 9 usually stays the same throughout the person's life. Other clotting disorders such as von Willebrand Disease can affect both women and men - this condition follows a different inheritance pattern.

What are the Signs of Hemophilia A and B?

The signs of Hemophilia A and B include:

- Bruising
- Prolonged bleeding after getting a cut, removing a tooth or having surgery, such as circumcision
- Bleeding into muscles, causing swelling in affected muscle
- Bleeding into joints, possibly causing a reduction in mobility
- Sudden bleeding inside the body for no clear reason
- Bleeding for a long time after an accident, especially after an injury to the head

Where Does Bleeding Occur?

Bleeding can occur outside the body, but most bleeding occurs internally in muscles and joints and at times in vital organs. Here are some examples of where bleeding can occur, but all internal bleeds should be checked by your doctor or hematologist.

- External bleeding: large cuts, mouth bleeds, nosebleeds
- Internally into muscles: upper arm and forearm, the iliopsoas muscle, the thigh and calf
- Internally into joints: knee, ankle and elbow most commonly
- Internal serious muscle bleeds: iliopsoas muscle, the forearm and the calf
- Internal life-threatening bleeds: the head, throat, digestive tract and iliopsoas muscle

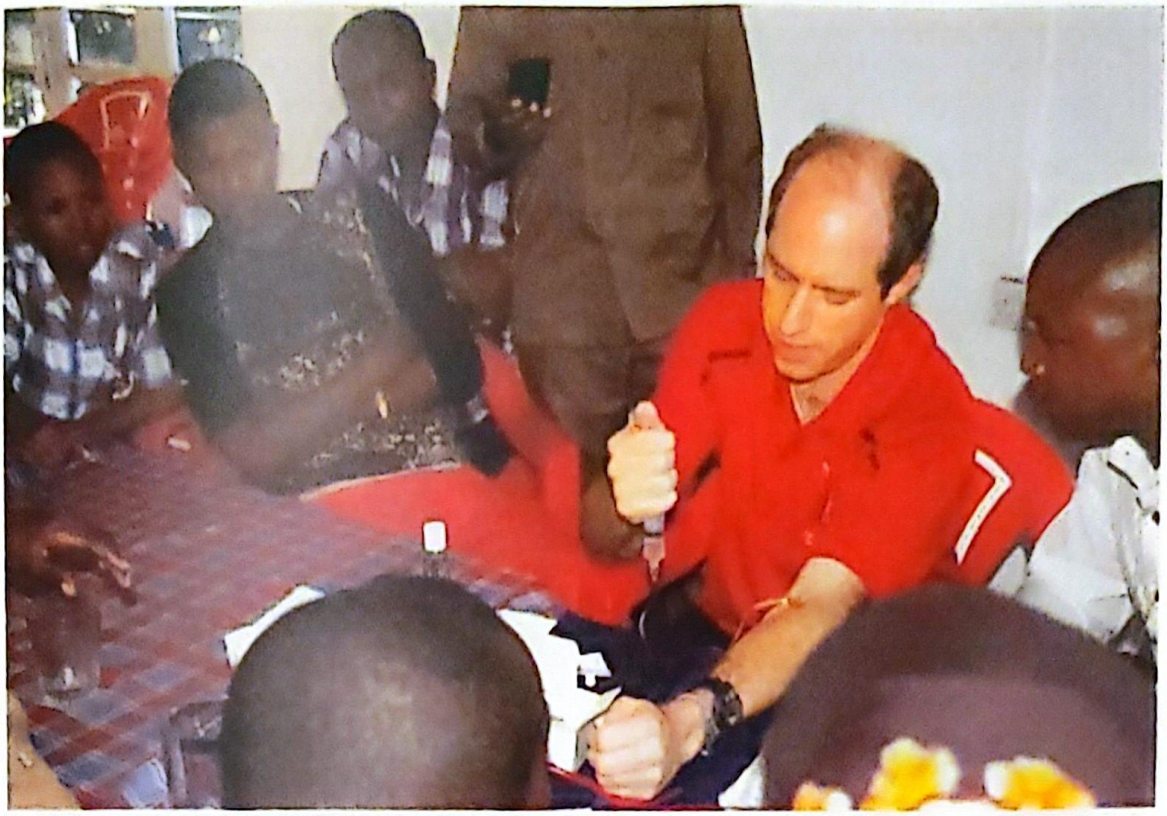
How is Hemophilia Diagnosed?

Hemophilia is diagnosed by taking a blood sample and measuring the level of factor activity in the blood. If Factor 8 activity is determined to be lower than normal, the person is diagnosed with Hemophilia A. Similarly, if Factor 9 activity is found to be lower, then the person is diagnosed with Hemophilia B. These diagnostic tests can be done at Muhimbili Hospital, the National Hospital located in Dar Es Salaam.

Muhimbili National Hospital

How is Hemophilia Treated?

Treatment for hemophilia is very effective today.



In order to stop the bleeding, the missing clotting factor is injected into the bloodstream using a needle and syringe. Bleeding should be treated as quickly as possible. If bleeding is treated quickly, less product is needed to stop the bleeding. Damaging complications to surrounding tissue can also be limited by prompt treatment although repeated bleeding into the same joint without prompt treatment can damage the cartilage and bone in a joint leading to chronic arthritis and disability.

With an adequate quantity of treatment products and proper care, people with hemophilia can live perfectly healthy lives. Without treatment, most children with severe hemophilia will die young.

Factor concentrates are the treatment of choice for hemophilia. Limited supplies of factor concentrates may be available at the Muhimbili National Hospital in Tanzania through humanitarian aid donations from the World Federation of Hemophilia or other donors.

When factors are not available, fresh frozen plasma (FFP) may be used as an alternative treatment. In fresh frozen plasma, the red cells have been removed leaving behind blood proteins which would include clotting Factors 8 and 9. However, this treatment is less effective than factor concentrates for those with Factor 8 deficiency because inadequate amounts of factor are available in a single dose and a higher dose places the patient at risk of circulatory overload. The risk of viral contamination is greater with the use of FFP than with the use of plasma derived factor concentrates which are heat treated. Treatment with FFP is available in Tanzania.

Global research continues to widen the range of products available for treatments as we continue to strive for the ultimate goal of treatment for all, in every country around the world.

What are Inhibitors?

Inhibitors are a complication that can occur when a person with hemophilia has an immune response to treatment with clotting factor concentrates.

Sometimes a person's immune system reacts to proteins in factor concentrates as if they were harmful foreign substances because the body has never seen them before. When this happens, inhibitors (also called antibodies) form in the blood to fight against the foreign factor proteins. This stops the concentrates from being able to correct the bleeding problem.

Pain Medication - Aspirin should be Avoided

People with hemophilia should not take aspirin (ASA or Acetylsalicylic Acid) or anything containing aspirin or NSAID's, because it interferes with the clotting factor process. Paracetamol is a perfectly safe alternative to aspirin to relieve pain.

Other Important Considerations

TREATMENT: Treat bleeding into joints, muscles, injury to the neck, mouth, tongue, face or the eyes. Treat blows to the head or strong headaches and any heavy or persistant bleeding from any site, all open wounds requiring stitches, and before surgery or work on the teeth. Always treat bleeding quickly - for example, never wait until a joint is hot, swollen or painful.

EXERCISE: Decreases the risk of spontaneous bleeds and builds stronger muscles and healthy bones as well as helping to maintain a healthy weight. When choosing activities, choose those with a low risk of injury such as walking, swimming, bicycling, or weight lifting (not power lifting).

NUTRITION: Eat foods rich in iron such as meats, leafy green vegetables, dried beans and grains. - Avoid unhealthy weight gain as this places added stress on joints.

SCHOOL: Discipline for children with hemophilia should not include beatings or other forms of physical punishment.

WORK AT HOME: Knowledge is Power - Learn all you can about your condition so that you can be your own best advocate!!

Contact Information >>>

The Hemophilia Society of Tanzania is a membership driven organization. If you wish to join the Society and learn more about our educational activities and events, or perhaps you have further questions, feel free to contact us:

Richard Minja

Email: richardmazingira@gmail.com

Phone: +255754541517