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Early diagnosis and access to treatment critical for children with Hemophilia

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Fear of heavy-bleed and mortality takes an emotional toll on children with Hemophilia

On World Hemophilia Day, healthcare practitioners and caregivers have reiterated the critical need for early diagnosis, access to treatment, and physiotherapy for people with Hemophilia to lead a near-normal life. With easy access to factor replacement therapy and physiotherapy, Hemophilia patients, especially children can fight this life-threatening blood disorder. The risk of death from a lack of basic knowledge and untreated Hemophilia is very high. They also laid strong emphasis on Government support to ensure availability of diagnosis facility, factor replacement therapy and physiotherapy at Government centers. According to Hemophilia Federation (India), there are over 20,000 registered patients with it. However, this number would be much higher, considering the population of India.

According to Dr. Savita Rangrajan, Haematologist, J J hospital, Mumbai “On World Haemophilia Day, I would like to highlight the critical role of early diagnosis and access to adequate treatment in to give these children a near normal childhood and a pain-free life for the future. Pre-emptive Physiotherapy plays an important part in ensuring that the joints remain healthy. The society and the Government need to work together to fight this condition, which can sometimes be fatal in the absence of adequate knowledge about the disease and lack of appropriate and adequate treatment. Just as the Government has a responsibility to provide adequate factor concentrates, the patients have an equal responsibility in managing their condition and therefore all patients should be seen by hematologists with experience in managing patients with Bleeding disorders on a regular basis. Whilst Haemophilia bleeds can be treated with on-demand factor therapy, it is time to move towards prophylactic infusions of clotting factors for all patients to prevent bleeds.”

Children with Hemophilia

Children are innocent victims of Hemophilia. The fear of bleeding episodes and mortality prevents them from having a normal childhood and takes a heavy emotional toll on their lives and those of their parents and family. Since Hemophilia is a life-long medical condition, without access to proper treatment, children frequently miss school and have to always be alert to injuries.

While there are government facilities available for factor replacement therapy and disease identification, these are not spread uniformly across the county. However, a few centers in Uttar Pradesh and Gujarat provide personalized prophylaxis – the most optimized care for Hemophilia. On the other hand, what is also urgently needed are trained doctors and government support to extend access to factor replacement therapy at government centers across India. It is important for the

government and for every Indian to come forward in support of Hemophilia patients. They can lead a near-normal and productive life with easy access to the required factor replacement therapy and physiotherapy.

What is Hemophilia?

Hemophilia is a hereditary genetic blood disorder that impairs the body's ability to control blood clotting. People with this disease do not bleed any faster than normal but can bleed for a longer time. Their blood does not have enough clotting factor. Clotting factor is a protein in blood that controls bleeding. A serious disorder, it puts the patient at risk of death due to excessive bleeding. Awareness about the blood disorder and its management can make accessibility of appropriate treatment a reality for patients and save their lives.

Hemophilia is usually of two types first one is called Hemophilia A and another one is Hemophilia B. The most common type of Hemophilia is called Hemophilia A. This means the person does not have enough clotting factor VIII (factor eight). Hemophilia B is less common. A person with Hemophilia B does not have enough factor IX (factor nine). The result is the same for people with Hemophilia A and B; that is, they bleed for a longer time than normal.

Symptoms

The signs of Hemophilia A and B are the same: big bruises, prolonged bleeding after getting a cut, removing a tooth, or having surgery; spontaneous bleeding (sudden bleeding inside the body for no clear reason), bleeding into muscles and joints. Bleeding into a joint or muscle causes swelling, pain, and stiffness in the joints, and difficulty using a joint or muscle.

Treatment

Treatment for Hemophilia today is very effective. The missing clotting factor is injected into the bloodstream using a needle. Bleeding stops when enough clotting factor reaches the spot that is bleeding. Bleeding should be treated as quickly as possible. Quick treatment will help reduce pain and damage to the joints, muscles, and organs. If bleeding is treated quickly, less blood product is needed to stop the bleeding.

While Hemophilia cannot be cured, patients can lead a near normal life through prophylaxis treatment. Prophylaxis, essentially replacement of clotting factor on a regular basis, helps the blood to clot normally in case of an injury or bleed. The treatment prevents bleeding and joint destruction, helping children with Hemophilia be more active, attend school, go for outdoor games and above all, follow a routine life which every child wants to live.