



# World Hemophilia Day

17 April, 2024

*Hemophilia is a genetic bleeding disorder that occurs when the blood does not clot normally.*



*Let's join hands to fight against the bleeding disorders on this day. Stay healthy and be safe*

# World Hemophilia Day -2024

**Bleeding disorders are not the end of the world; you could still lead a normal life**



In 1989, the World Federation of Hemophilia (WFH) started the first-ever World Hemophilia Day to raise awareness about hemophilia and other bleeding disorders. April 17 was chosen as the date in memory of Frank Schnabel, who was born on that day in 1942 and dedicated his life to improving the lives of people affected by bleeding disorders.

Hemophilia is sometimes referred to as “the royal disease,” because it affected the royal families of England, Germany, Russia and Spain in the 19th and 20th centuries. It is a rare and serious disease affecting approx 1 out of 10,000 people around the world. Many people with haemophilia are still undiagnosed or inadequately treated. Even when treated, people may suffer from chronic pain and limited mobility mainly due to bleeds in the joints, and if undertreated or not treated at all, risk dying at a young age.

This year 2024, World Hemophilia Day theme is “Equitable access for all: recognizing all bleeding disorders”. This theme emphasizes treatment for all and envisions a society in which every individual with inherited bleeding disorders has access to care, regardless of their kind of bleeding condition, gender, age, or location.

India is home to the second largest population of patients living with hemophilia. The poor availability of diagnostic and treatment facilities, along with the lack of awareness about hemophilia amongst primary care physicians and specialists is a major obstacle for the management of hemophilia.

Care of hemophilia has improved a lot in the last decade with an increase in hemophilia treatment centres and free factor injections, that help in blood clotting. In developed countries, majority of the patients are on regular replacement therapy which decreases or prevents bleeding.

Recently India have conducted the first human clinical trial of gene therapy for haemophilia A (FVIII deficiency) at Christian Medical College (CMC) Vellore. The trials involved deploying a novel technology of using a lentiviral vector to express a FVIII transgene in the patient’s own haematopoietic stem cell which will then express FVIII from specific differentiated blood cells. Hence there is a hope that manufacturing of this vector will commence soon in India and proceed with further clinical trials.

Let’s join people across the globe observing World Hemophilia Day to acknowledge volunteers, who support the hemophilia community and raise awareness about the condition.

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