



HAEMOPHILIA

“Access for all: Prevention of bleeds as the global standard of care”

An uncommon genetic condition called haemophilia impairs the blood's capacity to clot properly. Haemophiliacs are susceptible to internal bleeding that occurs suddenly, which can harm joints, and organs, and possibly kill them. Despite improvements in treatment, obtaining care remains difficult for those with haemophilia and other bleeding diseases.

The annual World Haemophilia Day is observed on April 17 and is intended to increase public awareness of haemophilia and associated bleeding diseases. The emphasis of this year's (2023) theme, "Access for all: Prevention of bleeds as the global standard of care," is on the value of offering preventative care to everyone who has a bleeding disease. Therefore, preventative care for people with bleeding disorders has become the foremost priority for healthcare providers, decision-makers, corporations and other stakeholders – this can lessen the frequency of bleeding episodes and enhance quality of life.

Unfortunately, not everyone has access to preventive care. Access to clotting factor concentrates is frequently restricted or non-existent, putting people with bleeding disorders at risk for haemorrhagic crises that could be fatal. Cost and illiteracy can keep people from seeking preventative care even in nations where clotting factor concentrates are accessible.

It is critical to recognise the strides that have been made in the treatment of bleeding disorders as well as the work that has to be done to guarantee universal access to care. People with bleeding disorders must have access to the preventive care they require in order to live healthy.

The World Federation of Haemophilia (WFH) is trying to reduce these inequalities and enhance access to preventive care. In collaboration with its national affiliates, the WFH aims to advocate for policies that will increase access to care while also educating and supporting people who have bleeding disorders.

In conclusion, universal standards of care for all people with bleeding problems should include access to preventive care. It is crucial to keep spreading the word about haemophilia and other bleeding diseases and fighting for laws that facilitate access to healthcare. Together, we can make sure that people with bleeding disorders have the chance to lead active, healthy lives.

“Stand committed and serve as a platform to increase awareness and provide education about Haemophilia and other bleeding disorders”

Dr. Somnath Singh
Deputy Director
UN Global Compact Network India