



The Haemophilia Society
Calcutta Chapter



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Organization Overview

What Is Hemophilia?

Hemophilia is a life-threatening bleeding disorder. In persons with hemophilia (PWH) blood does not clot normally due to deficiency or absence of clotting proteins called Factors.

1 in 10,000 Births

Is effected globally with these genetic bleeding disorder.

Approx. 120,000

Persons & Children with Hemophilia (P&CwH) live across India

Hemophilia is an inherited genetic disorder, transmitted through the **X chromosome**. Since women have two X chromosomes, if one X chromosome has the hemophilia gene, there is a chance it can get transferred during child birth. Women who have the hemophilia gene are called carriers. When the mother is a carrier and the father is normal, for each child there is a **50% chance** that a son will have hemophilia and a **50% chance** that a daughter will carry the gene. In some cases, there may be no family history, meaning that the change in the X chromosome is a new one (known as a "**Gene Mutation**").



Life With Hemophilia

With Hemophilia, recurrent & prolonged bleeding into joints and muscles can lead to permanent disability. Bleeding from the sensitive organs can lead even to death.

In persons & children with hemophilia all the XIII clotting factors which form the blood clot are not present, out of these XIII clotting factors, factor VIII or IX are either deficient or totally missing, there is one more category that is deficiency of factor XI which is very rare.

The lack of the Factors can cause continued bleeds and slow to no clotting,, which can lead to disability & death for the affected person especially children when left untreated.

Management of hemophilia requires continuous supply of blood clotting products like Anti-Hemophilic Factor (AHF), which is not produced in India and hence very expensive & out of reach of the **19,240 poor patients** registered with us so far.



Long Term Effects of Hemophilia

Disability & Death

Prolonged internal bleeding into joints and muscles, if not treated properly and in time, can permanently damage them leading to disability, and internal bleeding from sensitive parts of the body like the brain, intestines, stomach etc. lead to immediate death.

AIDS and Hepatitis Infection

Due to the high cost of AHF, most hemophiliacs in India tend to depend on infusions of unsafe, wet blood products such as Fresh Frozen Plasma (FFP) or lyophilized cryoprecipitate. These risks exposing patients to blood borne infections such as HIV/ AIDS and Hepatitis Infections

Mental Stress

Prolonged internal bleeding into joints and muscles, if not treated properly and in time, can permanently damage them leading to disability, and internal bleeding from sensitive parts of the body like the brain, intestines, stomach etc. lead to immediate death.

Financial Crisis

Prolonged internal bleeding into joints and muscles, if not treated properly and in time, can permanently damage them leading to disability, and internal bleeding from sensitive parts of the body like the brain, intestines, stomach etc. lead to immediate death.

What Is The Hemophilia Federation India?



Since 1983, Hemophilia Federation India (HFI) is the only national umbrella organization in India working for the welfare of the PwH through a network of 87 chapters spread over four regions of North, South, East and West Regions.

The organization aims to reach out to P&CwH and provide total quality care, education, make treatment available at affordable cost, psycho-social support, and economic rehabilitation and thus help them in improving the quality of life without disability and free of pain.



The Role Of HFI in Hemophilia

The HFI with the financial aid of BHEL was able play the following role in the lifes of P&CwH



Provide regular and increased supply of sponsor free Anti Hemophilic Factor (AHF) to persons & children with Hemophilia (P&CwH) for impoverished families.

Reduce the hassle of searching for new donors for the treatment, of Hemophilia once the sponsored quantity of AHF gets exhausted

Reduce the risk of blood borne diseases like HIV, HCV, and Hepatitis, by avoiding high-risk treatments like plasma and cryo-precipitate transfusion.

Focusing on other issues related to Hemophilia, like education, physiotherapy, psycho-social support, awareness, etc.

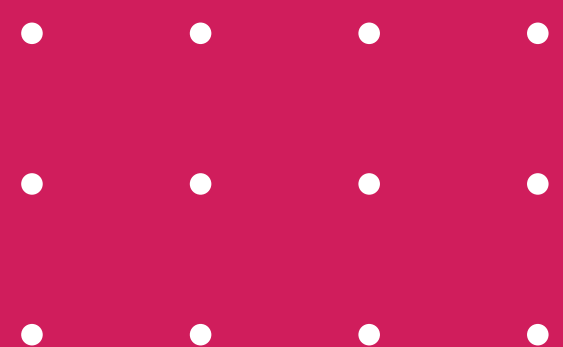
Provide free AHF to HIV+ persons with hemophilia to assist them with difficulties brought on by HIV and Hepatitis infection.

Reduce the sense of insecurity, helplessness & self-pity amongst the impoverished P&CwH patients across the country.

Key Differentiator Of HFI

- Established a network of 87 chapters (74 affiliated and 13 Non-affiliated chapters) spread across India.
- The only organization in India that provides structured training to our medical and paramedical practitioners.
- Established two International Hemophilia Training Centers at CMC Vellore and KEM Hospital Mumbai. Physiotherapy College in Pune trains physiotherapists for Hemophilia care and St. Stephens Hospital in Delhi trains laboratory technicians in running standardized Hemophilia tests.
- Enforced WHO standardized diagnostic tests available to our PWH. In addition, all Chapters are attached to diagnostic facilities locally.
- Special Needs Cell for HCV/ HIV positive PWH supports them by providing lifelong subsidized treatment including Anti-Retroviral Therapy Drug.
- Established the National Hemophilia Registration (Record) to locate undiagnosed persons and children with Hemophilia. and have been able to update records of support to more than 21,800 persons with Hemophilia in our national Hemophilia records.





The Haemophilia Society Calcutta Chapter

The **Haemophilia Society Calcutta Chapter (HSCC)** was established on 11th September 1983. The chapter made it their mission to find a better treatment and care for patients with hemophilia. Currently, we provide Anti-Hemophilic Factor(AHF) treatment at the chapter premises and our executive committees and patient coordinators manage and visit all district and sub-district hospitals in West Bengal to host seminars on the advocacy of Hemophilia and procure AHF treatment in every district. The determination we have to create a better future for all hemophilia patients both current and future, fuels the work we do every day.



The Mission Of **HSCC**

Initially, the **Haemophilia Society Calcutta Chapter (HSCC)** started functioning with the motto to provide care to the hemophiliacs of the neighboring districts as HSCC was easily accessible and the nearest chapter from all these districts. Subsequently, hemophiliacs also enrolled as members of The Haemophilia Society Calcutta Chapter.

The HSCC also aims to locate undiagnosed “Persons with Hemophilia (PWH)” and educate and provide them proper information on Hemophilia Care to both Persons with Hemophilia, their families and the medical fraternity along with medical treatment at affordable cost



Initiatives Taken By HSCC

Treatment

- Giving 24*7 treatment for emergencies
- OPD by DR. Amal Kumar Saha/ Week
- Physiotherapy OPD By Juliet Ekka.

Education

- (Through SOL (Save one Life) project) provide financial support to the patient till his 25 years.

Career

Through SPONSORSHIP Program & MEG (Micro Enterprise Grant).

- **Sponsorship** : Guide patients to choose professional courses and aid them financially for it.
- **MEG** : A Hemophilia patient's mother or a patient can get financial grants for establishing a small business.



Major HSCC Activities

Swasthya Bhavan Advocacy

COVID 2nd Vaccination Drive

Awareness Program On
Virtual Platform



Mental And Psychological
Health Awareness

Home Based Therapy at
Diamond Harbour Govt.
Medical College & Hospital

Demonstration and Infusion
training at Uluberia Sub
Division






Closing Note

By donating to HSCC not only provides you with taxations benefits but also makes you part of a noble endeavour to bring a smile to the more under previlaged hemophiliac members of our society and allow to them live an equal and healthy life.

We at team HSCC, extend our sincerest gratitude for your donations and we hope you will continue a help us in our endeavour for creating a brighter and equal life for hemophiliac paitents



Thank You