

Haemophilia & Health Collective of North[®]
POLICY STATEMENT on
The Turnaround in Haemophilia Care in India

18 May 2024

at Haemophilia Conclave 2024, India Habitat Centre, New Delhi

Founders of the *Haemophilia & Health Collective of North*[®] are witness to the rapid progress in Haemophilia Care in India, having laid down the groundwork over previous decades.

Prior to circa 2007-2008, haemophilia care in developing countries was unfortunately suboptimal and the mandate befell on a compassionate physician in New Delhi, whose initial efforts combined with widespread advocacy & capacity building, along with generous financial support from the governments played a pivotal role in turning around the Quality of Life for the haemophilia community in India.

With the ushering in of a '*thinking haemophilia*' mindset, the diagnostics and therapeutics including the supportive pillars of physiotherapy, rehabilitation, sociology, psychology, improved diet, nutrition and vaccination took it to a higher plane. The multipliers prospered from the active involvement, engagement, and empowerment of the haemophilia community.

With current availability of a wide range of drug products for haemophilia treatment, the expectations and aspirations of the individual stakeholders are soaring high, albeit mixed with caution of uncertainty and some anxiety.

In such *milieu*, the *Haemophilia & Health Collective of North*[®] was initiated in 2023 with prime mandate to lay down the guide for policies, procedures and protocols for haemophilia care in India.

Haemophilia & Health Collective of North[®] firmly believes in

- a) no gainsaying on the unparalleled benefits in medical science from treating haemophilia, and that there is no justification to deny treatment to any person with haemophilia.
- b) the treatment allows haemophilia patients to live a normal life, thus contributing to personal and social well-being, and enriching the national economy, and fulfilling several SDGs.
- c) There is a dire need to have uniform Policies, Procedures and Protocols in haemophilia treatment for optimal use of resources and health equity in the diversity of India
- d) the need and necessity of developing and disseminating such recommendations as available on the Policies, Procedures and Protocols widely for betterment and consensus application*.
- e) the need for expansion of diagnostic services to enable patients to benefit from the treatments available
- f) empowering the young women to make informed decision about prenatal testing.
- g) the huge collateral benefits of improved 'haemophilia-diagnostic' infrastructure will bring down morbidities & mortalities with improved care across many a specialty and lower the maternal mortalities from postpartum haemorrhage.
- h) the health equity in haemophilia care is more realizable now than ever before, with the wide spectrum of treatment products and modalities available.

* ***Haemophilia & Health Collective of North*[®] recommendation on Policy & Protocols for selecting the right product for optimal haemophilia care in India (14 December 2023)** are the first national guidelines, and freely available on our website www.hhcn.in

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