Haemophilia & Health Collective of North®
Policy Statement 2025
Quod Verum Tutum

18 May 2025
@ ***National Hemophilia & Haemoglobinopathy Conclave 2025***: Emerging Paradigms in Haemophilia and Haemoglobinopathy Care in India-Time to realign
Venue : Holiday INN Aero city, New Delhi, India

Founders of the *Haemophilia & Health Collective of North*® and all the renowned experts & advisors thereto, and all delegates from across the country attending this ***NHH Conclave 2025,*** are witness to the recent expeditious advancements in Haemophilia Care globally and also witness to the noteworthy role played by the *Haemophilia & Health Collective of North*® in adopting them in India for larger public benefits.

Prior to circa 2007-2008, haemophilia care in developing countries including India was suboptimal and the mandate befell on a compassionate physician in New Delhi *vide* an Order from Hon'ble High Court of Delhi. And with widespread advocacy & capacity building initiatives, supported by generous financial and logistics support from the governments and other stakeholders, 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 altruistic participation and engagement of the large community of like-minded medical experts, and went on to empower the haemophilia community at large.

With current availability of a wide range of treatment modalities, the expectations and aspirations of the individual stakeholders are soaring high, albeit mixed with caution and anxiety.

This haemophilia public welfare programme received further boost in circa 2023 from Government of India's renewed thrust on the 'elimination' of two other genetic blood disorders namely, Thalassaemia and Sickle Cell Anaemias, though the on-going recognition was there ever since the recognition of these three disorders under the *Rights of Persons with Disabilities (RPWD) Act, 2016.*

In such *milieu*, the *Haemophilia & Health Collective of North*® places on record its mandate to lay down the guide for policies, procedures, protocols and practices for the comprehensive and holistic care of these three blood disorders- Thalassaemia, Sickle Cell Anemia and Haemophilia- and the allied ones.

Haemophilia & Health Collective of North® reposes trust as under:

a) The three genetic blood disorders namely, Haemophilia, Thalassaemia, and Sickle Cell Anemia are medically and clinically diverse. However, each possess abundant scientific knowledge for their basic, clinical understanding, and treatment and preventive modalities for their individual management.
b) The diagnosis of each disorder is precise and detailed, and paramount to avail the benefits of the modalities of its respective treatment and prevention- available free of cost from the State institutions.
c) There is no gainsaying the unparalleled benefits of the treatment of haemophilia, thalassaemia and sickle cell anaemias. However, these accrue only when the diagnosis is precise and detailed.

d) Thus, it is vital to propagate wider screening and diagnostic programmes- access to which may be available to all from far and wide.

e) Medical treatment of each would warrant immediate or urgent access to specific treatment and support.

f) There is a rapid progress in newer therapeutic modalities, going upto gene and cell therapies. The role and place of each modality can at times be intimidating to the stakeholders.

g) There is a dire need to come out with consensus uniform Policies, Procedures and Protocols and Practices for managing different presentations, complications, and preventions. Such guidelines would go a long way in optimizing the use of resources and bringing health equity across the diversity in India
(HHCN published such guidelines on Haemophilia in December 2023*)

h) With the remarkable and unparalleled benefits of scientific treatment & prevention and care, there is no justification to deny access to treatments for haemophilia, thalassemia, or sickle cell anaemia.

i) The treatments in haemophilia has transformed the quality of life to practically normal, thereby advancing and upgrading their personal and social life, and enriching the national economy, and fulfilling several SDGs.

j) Newer modalities to empower these young children is utmost import, to boost their confidence and productivity.

k) Empowering the young women on prenatal diagnosis, to facilitate making informed decision.

l) The infrastructure development for these diseases have collateral benefits, with potential to bring down morbidities & mortalities in other specialties by improving their care and lowering the maternal mortalities from postpartum haemorrhage.

m) The health equity in haemophilia care is more realizable now than ever before, with the wide spectrum of treatment products and modalities available. The key decisions relate to availability, accessibility, acceptability, adoptability and applicability of the treatment modalities along with outcome assessment and an audit.

* ***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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