



Haemophilia & Health Collective of North®

Registered under the Society Registration Act XXI, 1860
hcnindia@gmail.com

Policy Statement 2026 of Haemophilia & Health Collective of North®

(Sequence 04)

सत्यम् शिवम् सुन्दरम्

16 May 2026

@National Haemophilia Conclave 2026 - Policy, Protocols, Procedures, Roadmap ahead

Mainstreaming Haemophilia: Integrating Care into Health

Venue: Hotel Radisson Blu Plaza, New Delhi, India

Founders of the *Haemophilia & Health Collective of North®* along with renowned experts and advisors thereto, and all the delegates from across the country attending *National Haemophilia Conclave 2026*, are witness to the expeditious advancements in Haemophilia Care and are also witness to the notable contributions of *Haemophilia & Health Collective of North®* in ushering their benefits for haemophilia care in India.

Prior to circa 2007-2008, haemophilia care in developing countries including India were suboptimal and the mandate befell on a compassionate physician in New Delhi, pursuant to an Order from Hon'ble High Court of Delhi. 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 *Quality of Life* for the haemophilia community in India.

With this evolution of a '*thinking haemophilia*' mindset, the diagnostics as also the therapeutics including the supportive pillars of physiotherapy, rehabilitation, sociology, psychology, improved diet & nutrition and the vaccinations catapulted the benefits to greater heights. The multipliers prospered from the altruistic engagement and participation from the large community of like-minded compassionate health experts, and thus empowering the haemophilia community all across.

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

In this milieu, *Haemophilia & Health Collective of North®* published the first national *Guidelines and Recommendation on Policy & Protocols for selecting the right product for optimal haemophilia care in India (14 December 2023)*- available free on HHCN website www.hhcn.in

Under advocacy thrust, haemophilia welfare received further boost when Haemophilia was recognized and included the under the *Rights of Persons with Disabilities (RPWD) Act, 2016* for disability benefits. Thalassaemia and Sickle Cell Anaemias- that were also included- received renewed boost in circa 2023 from Government of India under 'elimination' of the latter two genetic blood disorders.

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

- Haemophilia encompasses abundant scientific knowledge for their basic, clinical understanding, and treatment and preventive modalities for precise and personalized management.
- A precise and detailed diagnosis of haemophilia is *sine qua non* to avail and benefit from the modalities of treatment and prevention- these are available free of cost from the State Government institutions.

- c) There is no gainsaying the unparalleled benefits of the treatment of haemophilia. However, these accrue only when the diagnosis is clear and precise.
- d) Thus, it is vital to propagate wider screening and diagnostic programmes- to be made available, accessible and acceptable to all the suspected individuals from across the country, including difficult and mountainous terrains akin to the Ladakh union territory.
- e) Medical treatment of haemophilia would warrant urgent and/ or point-of-care access to specific scientifically proven treatments as standard of care.
- 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 different stakeholders.
- g) There is a dire need to update the Guidelines for Policies, Protocols and Procedures for managing different presentations, complications, and preventions. Uniform application of such guidelines would go a long way in optimizing the use of resources and bringing health equity across the diversity in India.
(* HHCN published the first national such guidelines on Haemophilia in December 2023, and HHCN is in the process of its update)
- h) With the remarkable and unparalleled benefits of scientific treatment & prevention and care, there is no justification to deny access to treatments for haemophilia.
- 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 including newborns is utmost import, to minimize early age morbidity and mortality.
- k) There is need for empowering each and every haemophilia, to boost their self-confidence & productivity by engaging psychosocial interventions.
- l) Young girls and women too suffer silently from haemophilia. Empowering them through improved diagnosis and therapeutic interventions awaits a big boost. And, also their focussed needs on heavy menstrual bleeds and on prenatal diagnosis, to facilitate making informed decision, warrants priority. These would go with national move on women empowerment.
- m) Indeed, remarkable breakthroughs and such array of landmarks in haemophilia with- the defined screening protocols, the diagnostics spectrum based on functional/ physical/ antigenic/ immunological/ molecular genetics, the innovative therapeutics using the most up-to-date technologies for creating extended half-life clotting factors, recombinant DNA factors, bispecific antibodies as factor mimetics, factor antibodies and siRNA products using RNAi to rebalance haemostasias, the gene and cell therapies and the prevention and supportive care protocols... Time is now ripe for the haemophilia to take a lead in providing guide and solutions for other rare diseases under the prevailing health systems.
- n) The infrastructure development for haemophilia are already providing collateral benefits, with potential to bring down morbidities and mortalities in several other specialties by improving their care, and lowering the maternal mortalities from postpartum haemorrhage.
- o) 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, released on 14 December 2023 are available free on our HHCN website www.hhcn.in**

[doctornaresh](mailto:doctornaresh@hhcnindia@gmail.com)
hhcnindia@gmail.com