



Message from the Chair, **Haemophilia & Health Collective of North**[®]

Greetings!

It gives me immense pleasure in welcoming you to our initiatives and pioneering milestones in promoting and furthering the cause of Haemophilia Care in India.

Haemophilia remained largely neglected '*orphan disease*' until the 2007-2008, when the first fully comprehensive *Haemophilia DayCare Centre*, HDCC, was established in the New Delhi's premier Maulana Azad Medical College and Lok Nayak Hospital, under a mandate given to the undersigned as Network Coordinator for Haemophilia. Hitherto, haemophilia fraternity was feeling & suffering the deprivation of a free, institutionalized care for haemophilia.

The grand success of this *HDCC* initiative was indeed a matter of great pride for Delhi Government. However, it came with its own barriers and challenges in providing free and skilled treatments to the surging number of patients coming to Delhi State from outside.

And our focus shifted to advocacy and capacity building towards replicating similar haemophilia care beyond Delhi. This would accrue similar benefits to all haemophiliacs irrespective of where they reside and without loss of the *Golden Hour* in emergency bleeds.

It was heartening to see this replication of our *Haemophilia DayCare Centre*, HDCC model in the neighbouring and far-off States and UTs providing free Haemophilia Care under government institutions- indeed another matter of great pride for Delhi!

Concurrently, the burgeoning global research and developments in haemophilia were heralding innovative modalities for better management of haemophilia, with further improvements in quality of life amongst the haemophilia fraternity. India did not remain untouched, has its success stories in haemophilia- which sets an example of success transformation in *Quality of Life* for a rare/ hereditary/congenital disease.

The rapidity of expansion in haemophilia treatment modalities came with uncertainties and anxieties amongst not only patients but also other stakeholders including the treaters, administrators and policymakers.

With this expanding armamentarium, there was a felt need for more cohesive and consensus approach and Policy & Protocol Guidelines for haemophilia care in India and other developing countries.

This is what led to the birth of **Haemophilia & Health Collective of North**[®] registered in July 2023 as national academic Society under Registered under the Society Registration Act XXI, 1860. Its founding members comprised of highly qualified senior experienced faculty drawn largely from the government medical colleges and institutions from across different States of India.

In December 2023 itself, **Haemophilia & Health Collective of North** fulfilled the felt need (*vide supra*) by coming out with the print version of the **HHCN Recommendations on Policy & Protocols for selecting the right product for Optimal haemophilia care in India**. These

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were distributed free to the delegates attending our annual *National Haemophilia Conclaves* since 2023. A soft .pdf version has been available on this website www.hhcn.in

In a short span since its foundation in July 2023, **Haemophilia & Health Collective of North**® has shown its dedication, capabilities and achievements- as highlighted in the document *HHCN- The Foundation* - also available on our website www.hhcn.in


We at indeed feel proud of *HHCN's* achievements- all credit goes to the untiring efforts of our *HHCN Executive Members*, supported by selfless haemophilia & health *External Eminent Experts of Repute*.

We look forward to hearing from you- your constructive feedback and support.

Wishing the Very Best for Haemophilia & Health!

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20 March 2024



Prof. Naresh Gupta

Chairperson
Haemophilia & Health Collective of North



&
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