



HAEMOPHILIA CONCLAVE 2024

Organized By:

Haemophilia & Health Collective of North®

under the auspices of MAMC and Lok Nayak Hospital, Delhi

THEME

Policy and Protocols for Best Practices in Haemophilia Care
-enabling health equity under the changing landscape

PRE-CONFERENCE AGENDA

17 May 2024 | India Habitat Centre, New Delhi

Time	Session		
4:30 PM	Registration		
5:00 PM	Welcome to the Haemophilia Conclave 2024 & about the HHCN		Dr.Naresh Gupta
5:15 PM	Changing landscape of Haemophilia in India- taking cognizance and preparing to meet the challenges	Discussion- All Faculty	Moderator: Dr. KK Koul
5:45 PM	MAKING CHOICES IN DRUG PRODUCTS FOR HAEMOPHILIA - I Variables to consider in making the Best Choices - Hammer & Thrash a) For Haemophilia-A, with or without inhibitors b) For Haemophilia-B with or without inhibitors	A Panel Discussion Dr. Arun k Arya Dr. Tulika Seth Dr. Anupam Datta Dr. Sunita Aggarwal Dr. Meera V Dr. Lakshmi Mythili Mulam Dr. Sudhir Atri Col. Dr. Kundan Mishra All others	Moderator: Dr. R K Nigam
6:15 PM	MAKING CHOICES IN DRUG PRODUCTS FOR HAEMOPHILIA - II Practical considerations in making the Best Choices- Guidelines and Action Tables a) For Haemophilia-A, with or without inhibitors b) For Haemophilia-B with or without inhibitors	A Panel Discussion Dr. SA Mirza Dr. G Vikram Kumar Dr. Vandana Roy Dr. SP Verma Dr. Bobby Gulati Dr. Ankur Jain Dr. Ruby Khan Dr. KK Radhika All Others	Moderator: Dr. Sheikh Ahmad Bilal
6:45 PM	Strengthening the future of Haemophilia Care in India	Speaker: Dr. Kanjaksha Ghosh	Chair: Dr. Tulika Seth
	Haemophilia Conclave 2024 declaration	ALL	Chair: Dr. KK Koul
7:15 PM	HHCN Executive Meeting	All HHCN Members	
8:00 PM	Dinner		



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Agenda

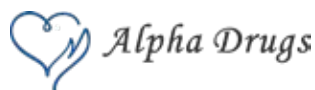
18 May 2024 | India Habitat Centre, New Delhi

Time	Session		
8:30	Registration		
9:25	Welcome to the Haemophilia Conclave 2024 & – setting the context	Speaker: Dr. Naresh Gupta	
9:45	Inauguration ceremony		
	about the HHCN	Chairperson, HHCN	
	Changing landscape of Haemophilia Care in India		Dr. Kanjaksha Ghosh
	HFI and evolution of Haemophilia Care in India:-	President, HFI	Mr. Premroop Alwa
	Address by Guest of Honour:	Guest of Honour	Mr. BS Bhalla, IAS
	Release of HHCN Policy Statement on Haemophilia Care in India		
10:30	A PERSPECTIVE Clotting Factors vs Factor Mimetics in Haemophilia Treatment – Contrasting Role	Speaker: Dr. Sunita Aggarwal	Chair: Dr. R K Nigam Co-Chair: Dr. Naresh Kumar Co-Chair: Dr. Praveen Bharti
11:00	ANOTHER PERSPECTIVE (Upcoming Products) Circulating Procoagulants and Anticoagulants – Complimentary roles in Haemophilia treatment	Speaker: Dr Arihant Jain	Chair: Dr. Arun K Arya Co- Chair: Dr. Sudhir Atri Co-Chair: Dr. Ankur Jain

Time	Session		
11:30	One Factor, Many Possibilities : Insights from Experience on use of EHLs <i>(Sponsored)</i>	Speaker: Dr. Meera V	Chair: Dr. Shubha Phadke Co- Chair: Dr. Alka Yadav Co- Chair: Dr. Kanwaljeet Kaur
12:00	MAKING BUDGETARY SENSE IN HAEMOPHILIA Practical approach to prioritize patient-subsets and resources: a) Scenario from Kerala b) Scenario from J&K c) Scenario from Karnataka	Speakers: a) Dr. Rahul R b) Dr. Sheikh Bilal Ahmed c) Dr. Cecil Ross <i>(10 minutes each)</i>	Chair: Dr. Tulika Seth Co-Chair Dr. Joseph John Co-Chair: Dr. Bobby Gulati
12:30	MANAGEMENT OF HAEMOPHILIA -Value of Emicizumab: From Bench to Bedside <i>(Sponsored)</i>	Speaker: Dr. Gerard Dolan	Chair: Dr. Cecil Ross Co-Chair Dr. Shubha Phadke Co- Chair: Dr. Sujata Mathews
13:15	Lunch Break		
13:45	OPTIMAL HAEMOPHILIA CARE IN INDIA: Where Emicizumab does play the role in improving Quality of Life? <i>(Sponsored)</i>	A Panel Discussion Panelists: Dr. Tulika Seth Dr. S P Verma Dr. Joseph John Dr. Cecil Ross Dr. Anupam Datta Dr. Pooja Dewan Dr. Ruby Khan Dr. Gerard Dolan	Chair: Dr. Sheikh Ahmad Bilal Moderator: Dr. Naresh Gupta
14:15	SURGICAL HAEMOSTASIS Managing hemostasis during surgeries on haemophilia A patients	Speaker: Dr. S P Verma	Chair: Dr. Arihant Jain Co- Chair: Dr. Harpreet Singh Co- Chair: Dr. Alok Hemal
14:45	EMERGING GENE THERAPIES The Future of Haemophilia Gene Therapies in India	Speaker: Dr. Savita Rangarajan (Virtually)	Chair: Dr. Kanjaksha Ghosh Co-Chair: Dr. KK Koul Co-Chair: Dr SA Mirza

Time	Session		
15:15	ACADEMIA, INDUSTRY and HCP Trends in Haemophilia treatment paradigms in India a) National Patient Group (HFI) b) Haemophilia providers c) Administrators/ Procurements agencies d) Industry - Novo Nordisk - Roche	A Panel Discussion Panelists: Mr. Premroop Alva Dr. Manudeep Kaushal Dr. Varun Kaul Dr. SP Verma Dr Joseph John Dr. Kanjaksha Ghosh Dr. Cecil Khakha Dr. Sheikh Ahmad Bilal Dr. Shakila Dr. Maya Sharma Dr. Monika Puri	Moderator: Dr Naresh Gupta
15:45	RARE FIND Clotting Factor X- the centerpiece - its Deficiencies and Therapeutic advancement (Sponsored)	Speaker: Dr. Tulika Seth	Chair: Dr. Arihant Jain Co- Chair: Dr. Anupam Datta Co- Chair: Dr. Pradeep Kumar
16:15	Tea Break		
16:30	NEED OF THE HOUR Developing uniform Treatment policy & protocols for Haemophilia Care	A Panel Discussion Panelists: Dr. Suresh Kumar Dr. Tulika Seth Dr. Joseph John Dr. Sheikh Ahmad Bilal Dr. Arun K Arya Dr. Varun Kaul Dr. Sudhir Atri Dr. Meera V Dr. Urmila Jhamb Dr Kusuma Dr. Jagdish Chandra	Moderator: Dr. Naresh Gupta
17:00	Role of FEIBA in OD & Surgery in CHAWI (Sponsored)	Speaker: Dr. Tulika Seth	Chair: Dr. KB Logani Co- Chair: Dr. Lakshmi MM Co- Chair: Dr. G Vikram Kumar
17:20	SUMMARY & CONCLUSION		Dr. Naresh Gupta
	Vote of Thanks		
	Valediction		

Scientific Partners:



Haemophilia & Health Collective of North®

In India, Haemophilia remained a rather neglected 'orphan disease' until the 2007-2008 when first fully comprehensive haemophilia care centre, HDCC, was established in Maulana Azad Medical College & Lok Nayak Hospital in Delhi under directions emanating from the directions of Hon'ble High Court of Delhi, mandated to Prof. Naresh Gupta as Network Coordinator of Haemophilia. Until that time, there was no institutional haemophilia care setup under any State/ UT Govt to provide free treatment for haemophilia.

The rapid progress that this Delhi initiative of free haemophilia care made was testimony to the deep vacuum that existed for adequate treatment of Haemophilia in India. With healthcare being a State subject, the Delhi initiative was getting overloaded. Soon, it overflowed into neighbouring and other States with Delhi's Advocacy and Capacity Building model. Within a decade almost all States and UTs were providing Haemophilia Care- a matter of great pride for Delhi.

Concurrently, the global developments in haemophilia care moved great strides with newer innovations, that improved the plight of haemophilia fraternity so gratifying. The rapidity of expansion in haemophilia care treatment modalities came with uncertainties and anxieties amongst not only patients but other stakeholders including the treaters, administrators and policymakers. Regular meetings of like-minded public-oriented experts were going on during the regular scientific meetings, and left much to be desired. And a felt need for more cohesive and consensus approach esp. in the changing landscape of expanding armamentarium to manage haemophilias was palpable from all corners. This is what led to the birth of *Haemophilia & Health Collective of North* in July 2023 with contribution from experts from across the country. It has been recognized as a National level organization by the Government of India.

Haemophilia & Health Collective of North (HHCN) is a body of senior experienced faculty staff largely from the Government medical colleges in different States of North India. These founder members have shown their mettle for improving the lot of haemophilia and other related blood disorders, and health in general in India. With their long experience and knowledge of ground realities and administrative functioning, the members have empowered the HHCN to think and recommend the best decisions in the interest of patients at large while keeping the situational constraints in mind.

1. In the short span since its foundation in July 2023, Haemophilia & Health Collective of North® has shown its dedication and capabilities by organizing the following.

In July 2023, **Haemophilia & Health Collective of North®** soon organized a highly participative and successful '**Haemophilia Conclave 2023**' on 20 July 2023 in New Delhi, striving to bring together the finest medical professionals and experienced caregivers, think tanks, leaders, administrators and policymakers, and other stakeholders from across the nation, playing vital role in haemophilia care. The objective being, inter alia, a Delhi consensus recommendation for protocols and policies for optimal haemophilia care resource-constraint settings.

2. In July 2023, the **Haemophilia Conclave 2023**, focussed sessions offering a deep dive into key issues that can potentially transform the future of haemophilia include Pharmacologic Treatment of Haemophilia, Non-Factor Therapy for Haemophilia, Are Newer Pharmacotherapy Really Worth the Money and Resources?, The Need for Uniform Treatment Policy & Protocols in India, Optimal Care in Haemophilia in India, Role of Physiotherapy & Occupational Therapy, Social Worker, and Psychology in Haemophilia Care, and more. The deliberations were intensive and of high quality as evident from the feedback and the ensuing recommendations.
3. In December 2023, **Haemophilia & Health Collective of North®** formally launched the print version of the **HHCN Recommendations on Policy & Protocols for selecting the right product for Optimal haemophilia care in India**.
4. In March 2024, **Haemophilia & Health Collective of North®** organized a core group Expert Meeting report on the "**Changing Landscape of Hemophilia Care: Unmet needs and solution**" in Dehradun, Uttarakhand. The focus was on deliberating on solutions for Improving adherence and confidence among PwH in the context of great inroads in treatment of haemophilia. The report is ready and will be incorporated in the next version of our National level guidelines on haemophilia care to be launched later this year.
5. In April 2024, **Haemophilia & Health Collective of North®** commemorates the **World Haemophilia Day 2024** along with Maulana Azad Medical College and Lok Nayak Hospital. The whole day programme on 20th April 2024 in the main auditorium on MAMC campus is geared to empower our Haemophilia Fraternity through their active participation and other day-long activities. This has been a regular annual celebration for more than a decade with a gathering of around 500 including patients, families, and other stakeholders including medical faculty.
6. In May 2024, **Haemophilia & Health Collective of North®** is organizing national **Haemophilia Conclave 2024** on the **Theme Policy and Protocols for Best Practices in Haemophilia Care in Developing Countries**

-Policy & Protocols for Enabling Best Haemophilia Treatments

Its proceedings will be incorporated in the next version of our National level guidelines on haemophilia care to be launched later this year.

While the expert founding Members (quod vide) of **Haemophilia & Health Collective of North®** are doing their best, we will surely benefit from constructive criticism. Meanwhile, it is our sanguine hope that these first national level recommendations on haemophile care will be perused by the different State administrations for optimizing health equity in haemophilia care. It is an expensive treatment but comes with unsurpassable benefits by 'resurrecting the dead children back to normal life longevity and quality'.

We soon hope to update these Recommendations on Best Practices in Haemophilia Treatment during second half of this year.

With Best Wishes!

Dr. Naresh Gupta