

# NATIONAL HAEMOPHILIA CARE MEETING

Improving Haemophilia Care Through  
Awareness, Education and Advocacy

Bengaluru, India  
5<sup>th</sup> - 6<sup>th</sup> April, 2014



**HEMOPHILIA FEDERATION INDIA**  
*Healing Hemophiliacs in India Since 1983*



Maulana Azad Medical College  
New Delhi, India



CHRISTIAN MEDICAL COLLEGE  
VELLORE  
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# National Haemophilia Care Meeting 2014

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The National Haemophilia Care Meetings (NHCM) are being organized to bring together health planners from different states in India to discuss an area of health care that is unique in its requirements and needs a model that has a strength and flexibility to be uniformly successful across India. Care of people with bleeding disorders is an unmet need in the country. This not only affects those with hereditary bleeding diseases like haemophilia but also many more with acquired causes of bleeding. Some of these lead to significant morbidity and mortality. The first NHCM meeting held in 2013 was extremely successful in achieving these aims where participants from 15 states participated. In many ways it was a unique meeting of this kind on the country. It helped everyone learn about the plans made in different states and resources allocated by them for haemophilia care and learn from one another's experiences in the challenges faced and successes in their implementation. As more states continue to allocate resources for haemophilia care, it was considered necessary and important to continue this process. The second NHCM meeting was therefore conducted in April, 2014 to discuss the burden of haemophilia in India, the barriers in providing adequate healthcare to people with haemophilia (PWH) and potential ways of overcoming them. It involved the different stakeholders in haemophilia care viz. state healthcare administrators, expert physicians involved in care of PWH and representatives of the national patient organizations. The program included discussions on organization of comprehensive hemophilia care as well as presentations from different states on their own plans and experiences.

## Haemophilia Care in the States – Govt support

State Health care administrators from various states – Tamil Nadu, Maharashtra, West Bengal, Jammu & Kashmir, Haryana, Kerala shared respectively their State Govt's support, challenges they face and future opportunities for provision of Haemophilia care.

### Tamil Nadu

Aim: To provide treatment facilities to people with Haemophiliain all Medical College Hospitals, thereby helping to have access for appropriate treatment.

#### Initiatives:

1. Separate budget allocation for Haemophilia by Government of Tamil Nadu.
2. Conducted state level seminar, CME activities in various Medical Colleges for Health Care Professionals about Haemophilia disease and its management.
3. Maintenance of patient log book and hospital register to update the data of PWH in Government Medical College Hospitals in Tamil Nadu.

### Maharashtra

Aim: To provide diagnostic and treatment services for Haemophilia, Thalassemia, & Sickle cell diseases by establishing day care centers, physiotherapy clinics and strengthening existing supportive departments like blood bank

### Initiatives:

1. Budget allocation: 4.96 crores (Inclusive of infrastructure provision, salary & training)
2. Approval of 'Haematology programme', under National Rural Health Mission (NRHM) and successful implementation in four centres in Maharashtra viz. the district hospitals in Thane, Nasik, Satara, and Amravati.
3. Establishment of 'Day care centres' (under 'Haematology programme') for investigation and treatment of Haemophilia, Thalassemia, & Sickle cell diseases.

## **West Bengal**

Aim: To provide affordable, accessible and sustainable high-quality essential healthcare for all in 5 years by focusing on the poor, mother, child and elderly, and those living in underserved areas and to emphasise and develop the maintenance of standards of service in hospitals and healthcare facilities.

### Initiatives:

1. Initiate and establish Special Hemophilia Clinic (Day Care) for comprehensive care and follow up in four centres in West Bengal.
2. Establish diagnostic services like coagulation assay, correction study, factor assay and inhibitor assay in Institute of Haematology and Transfusion Medicine.
3. Provide on demand, factor replacement at Day Care supplied by Govt. of West Bengal free of cost for patients in need (approx. 60,000 unit F-VIII used / month)
4. Provide prophylactic Factor VIII/ IX support (only for small proportion of patients in reimbursable sector and through clinical trials)
5. Provide FFP/ Cryo-precipitate for acute bleeding episodes, if factor not available

### Challenges:

1. Under reporting of cases
2. Non-affordability due to high cost of treatment
3. Only 5% of PWH received F-VIII while 85% received FFP and 10% received cryoprecipitate
4. Very few centers have complete diagnostic facilities
5. Inadequate supply of factor concentrate

### Opportunities:

To integrate and involve Haemophilia care along with Thalassemia control and treatment programme at each of the District Head quarters which is currently going on in the state. This could be particularly leveraged for awareness generation and treatment.

## **Jammu and Kashmir**

### Initiatives:

1. Establishment of Haemophilia care in the Medical Colleges at Jammu & Srinagar.
2. Separate ward has been set up for PWH

### Opportunities:

1. Up gradation of the laboratories facilities has been planned

### Challenges:

1. Lack of policy consensus on source of funding for haemophilia care in J & K.
2. Intermittent shortages of factors mostly due to procedural delays/financial constraints in procurement.
3. Significant lack of resource allocation to provide prophylactic factor support for PWH and additional cost burden for treatment of complications and Hepatitis.

## **Haryana**

### Initiatives:

1. Designation of specialized treatment centres for Haemophilia by upgrading facilities at five general hospitals, i.e., Ambala, Karnal, Rohtak, Hisar and Gurgaon as Primary Specialized Treatment Centres (STCH) and the PGIMS (Rohtak) as a referral unit for secondary/tertiary care treatment of haemophilia
2. Provision of F-VIII at these centres to treat bleeding episodes and any associated complications.
3. Free transport facility for all PWH and free education facilities for PWH up to Class-X.
4. Budget allocation - Rs.3.24 crores approval in the State NRHM PIP for free treatment of haemophilia patients and additional Rs. 0.12 crore approval by the State Government for free transportation of PWH.
5. Issue of ID cards for total of 278 PWH for comprehensive care.

### Opportunities:

1. To establish four additional centres in Haryana at Sirsa, Kaithal, Panchkula and Faridabad, for the management of haemophilia in Haryana.

### Challenge:

1. Funding resource allocation to provide AHFs covering all the bleeding episodes of all the patients.

## **Kerala**

### Initiatives:

1. Establishment of primitive haemophilia treatment facility in 2005 with a well-functioning NABH accredited blood bank and a cryoprecipitate preparation unit.
2. Inauguration of a Haemophilia Treatment Centre on 20/2/2014 by Kerala Chief Minister
3. Fully automated coagulation lab with facility for platelet aggregation and TTI screening
4. Establishment of fully functional, state-of-the-art physiotherapy unit;

5. Capacity building of medical and paramedical staff towards establishment of comprehensive care with the help of CMC Vellore
6. Unique aspects of implementation: Through Panchayati raj and decentralisation, Public Private Partnership, Inter-sectoral co-ordination (Lottery, Labour) & NHM.

#### Challenges:

1. Lack of awareness regarding disease, its burden in the state, complication and management at various levels
2. Lack of infrastructure in terms of Lab diagnosis, trained personnel & team work
3. Budgetary constraints for provision of free factor support
4. Lack of political and bureaucratic will

#### Opportunities:

1. Need to create a database in association with all Haemophilia Society in Kerala.
2. Inclusion of CFC in the essential drug list of government procurement
3. Capacity building including skill assessment to enhance efficiency
4. Need to establish centre of Excellence for management of Haemophilia and other bleeding disorders.

## **One Country One Treatment**

India is a country of varied diversity. Different state governments provide varying services for management of PWH with no uniform standards. Hence there is a need to understand the unique support required for diagnosis and treatment of PWH at national level and stream line the diverse services offered by various State Governments, ultimately aiming at “One country one treatment for hemophilia”.

Hemophilia is a unique among genetic diseases in several ways – the complications are bleeding immediately and repeatedly painful leading to serious physical disabilities and loss of life and unlike many other genetic diseases there is very effective factor replacement therapy available that can completely transform the lives of these patients. There is extensive experience in the world with the effectiveness of such replacement therapy. As different state governments allocate resources for care of people with haemophilia, it is necessary that all the other components of an effective program for the care of people with haemophilia also be developed so that there is the optimal utilization of allocated resources. These include clearly defining the role that all stakeholders will need to play in this process. These have been identified in the report of the first NHCM meeting. In addition, national guidelines on the management of haemophilia will need to be developed keeping in line with the principles described in international guidelines. Establishing an effective registry, complete at each state level would also be critical for effective implementation of any care plan in each state. Collaboration between the local chapters of the Hemophilia Federation (India), which has been maintaining a registry for over 15 years and the local health authorities could help achieve this rapidly.

Designating treatment centers within the state hospitals and developing some of them as comprehensive care centres and arranging for training for all involved health care personnel would be the other important components of this process. Centres in India that have such expertise will provide the necessary training. Such a partnership will help develop the necessary care for people with haemophilia. It should be mentioned that these services will not only help better care for people with hemophilia but the diagnostic services developed will help improve care for other patients with major bleeding such as obstetric and surgical complications. Such a public-private partnership and inter-sector co-operation could become a new paradigm for developing health care support for chronic diseases.

Funding resources should be identified for Hemophilia care not only for free treatment support (including Clotting factor concentrates) but also for diagnostic and non-medical support needed for PWH.

### **Establishing a Haemophilia Treatment Centre -What does it Require?**

Health care delivery for PWH has to be done at three levels viz. primary, secondary and tertiary care as in other diseases. Designation of Hemophilia Treatment Centre (HTC) is essential to focus on the development of multidisciplinary expertise at different levels for providing comprehensive care for PWH. This can be done by enhancing existing infrastructure and other components / facilities as needed and having local health care personnel trained in different aspects of haemophilia management.

In India, we can therefore plan for three levels of care.

1. Primary care (Emergency management) – Any hospital where a patient can get urgent assessment and treatment with CFC for bleeding
2. Haemophilia Treatment Centre – A designated centre with expertise in clinical assessment as well as haematological and non-surgical management of common musculoskeletal (MSK) problems.
3. Comprehensive care centre – A centre fulfilling the criteria for CCC as defined in the WFH guideline and as described below.

The core team usually consists of the following members:

- i. a medical director (preferably a pediatric and/ or adult hematologist, or a physician / pediatrician with interest and expertise in haemostasis)
- ii. a nurse coordinator who coordinates the provision of care educates patients and their families acts as the first contact for patients with an acute problem or who require follow-up is able to assess patients and institute initial care where appropriate
- iii. a musculoskeletal expert (physiotherapist, occupational therapist, physiatrist, orthopedist, rheumatologist) who can address prevention as well as treatment
- iv. a laboratory specialist or technologist capable with expertise in diagnosis of haemostasis disorders.
- v. a psychosocial expert (preferably a social worker, or a psychologist) familiar with available community resources and able to engage with PWH to address their problems as best as possible.

As the center advances, the comprehensive care team should also include or have access to, among others: chronic pain specialist, dentist, hepatologist, infectious disease specialist, immunologist, gynecologist/obstetrician, geneticist and vocational counselor.

## **Training in Haemophilia Care: What are the Requirements and Opportunities?**

A major need in the country apart from resources for infrastructure and clotting factor concentrates is to develop the trained manpower for HTC. For this, it is best that the haemophilia nurse be the first point of contact. Unfortunately, this practice is almost non-existent at present in many centres. This needs to be addressed with a specialised nurse training programme. Standardized training modules and programs are also essential for laboratory technicians and pathologists in the diagnostic aspects and for physical therapists / orthopaeds / physiatrists in the musculoskeletal aspects to be able to provide quality care to PWH in India.

## **Conclusion**

NHCM 2014 thus highlighted the various measures that could be practised in order to achieve better care for PWH on both regional and community levels.

- There is a dire need to strengthen the diagnostic services for haemophilia to cover the population across the country. The sustained provision of the clotting factors needs to be a priority by the Government.
- All relevant stakeholders should work on a common goal of delivering comprehensive care for PWH with an urgent need to provide accepted standards of care and services across the country.
- Innovations and investment in continued education and faculty development will also play major role in effective management of PWH.
- Apart from governmental resources, public-private partnerships could further assist in this process.

## List of Participants

Name	Designation	Place
Mr K. H. Govinda Raj	Commissioner (Family Welfare) & Mission Director (NRHM)-Government of Maharashtra	Maharashtra
Dr. Biswaranjan Satpathi	Director of health services, Directorate of health services	Kolkata
Dr. Gopal chandra Biswas	Deputy Director central medical stores, Central medical Stores	Kolkata
Dr. Sikha Banerjee	Medical Superintendent, Calcutta Medical College Hospital	Kolkata
Dr. R S Aswal	Principal & Medical Superintendent, Doon Hospital	Dehradun
Dr. H K Agrawal	Joint Director Medical Care, Swasthya Sewa Maha Nideshalaya	Lucknow
Dr. N.V.Kamat	Director of health services, Directorate of health services	Delhi
Dr. Girish Choudhari	Assistant Director, Directorate of health services	Mumbai
Dr. Kanjaksha Ghosh,	President Haemophilia Federation India	Delhi
Dr. Saleem Ur Rehman	Director Health Services, Directorate Health Services	Srinagar
Dr. D K Pal	Medical Superintendent, Hamidia Hospital	Bhopal
Dr. B S Ohri	Deputy Director & Technical Board member of State procurement unit DHS	Bhopal
Dr. P N Remani	Additional Director of health services, Directorate of health services	Trivandrum
Dr. Vijayakumar K	Blood Bank Officer and Head of Hemophilia treating centre	Aluva, Angamally
Dr. Geethanyamagowdar	Director Health & Family Welfare Govt of Karnataka	Bangalore
Dr. Anand Naik	District Surgeon-Udupi District Hospital	Udupi
Dr. Parashuramappa	District Surgeon-CG Hospital	Davengere
Dr. Rajeswari Devi H R	District Surgeon-Wenlock Hospital	Mangalore



## List of Participants

<b>Name</b>	<b>Designation</b>	<b>Place</b>
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Dr. Shashikant Apte	Head of Department-Haematology,Sahyadri Hospital	Pune
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Mr. Sathyanarayana	Secretary haemophilia federation India Chennai Chapter	Chennai

## **Organizers**

1. Dr. Alok Srivastava, Professor of Medicine ,Department of Haematology ,Christian Medical College , Vellore, Tamilnadu
2. Dr. Naresh Gupta, Director-Professor - L.N.J.P.H.. Hospital, Delhi
3. Dr. Cecil Ross, Professor & Head of Haematology Dept., - St. John's Medical College & Hospital, Bangalore.