
NATIONAL HAEMOPHILIA CARE MEETING (NHCM)

Improving Haemophilia Care Through
Awareness, Education and Advocacy

Bengaluru, India
23rd – 24th February, 2013



HEMOPHILIA FEDERATION INDIA
Healing Hemophiliacs in India Since 1983



Maulana Azad Medical College
New Delhi, India



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National Haemophilia Care Meeting (NHCM)

- Summary of Discussions



The National Haemophilia Care Meeting (NHCM) was held to discuss the burden of haemophilia in India and the barriers in providing adequate healthcare to people with haemophilia (PWH) in the country.

The presentations reviewed the current burden of PWH in the country, status of care that they are receiving, both through the private hospitals system, as has been the pattern in most parts of the country for many years in the past and the increasing involvement of the Government hospitals in many states more recently. The challenges faced in providing adequate care through private hospitals were discussed as also successful examples of good treatment centres within the Government system, particularly at the State level. Specifically, it was recognized that sustained care for PWH can only come through the Government system and so the barriers to its successful development needed to be identified and resolved. In particular, this would include systems for regular procurement and equitable distribution of adequate clotting factor concentrates (CFC) of good quality as well as establishing appropriate resources at designated medical institutions in every state for care of PWH. The role of the Hemophilia Federation, India (HFI) in this rapidly evolving situation was also discussed. Apart from disseminating information about the Government programs to PWH and supporting them to reach these institutions for their care, the National Hemophilia Registry, maintained by the HFI, could also be of immense value in ensuring proper planning of the care program. A critical requirement is the training of health care personnel in Government institutions. This could be achieved through partnership with key institutions in the country that have the expertise to provide such training to these health care personnel in different aspects of care of PWH.

The first National Haemophilia Care meeting, 2013 therefore was a unique event that brought together state healthcare administrators, physicians involved in care of PWH and representatives of the national and international

patient organisations to discuss barriers to effective care of PWH. This is particularly critical at this time in the country when several State Governments have allocated specific budgets for procuring CFCs for PWH and developing other services for them. Without such discussion and planning there is a significant chance that these resources may not be appropriately utilized. On the other hand collaboration between the different stakeholders could become a model of public private partnership (PPP) for the management of treatable genetic disorders in India.

The reason why haemophilia can be a good example to start with is because this is one hereditary genetic disorder for which there is a well established replacement therapy that is widely available and with which excellent long term results can be achieved in this disease, if used properly.

Challenges and strengths:

Challenges

1. Of the estimated more than 60,000 patients with severe haemophilia in the country, only about 15,000 are accounted in the NHR. Many more are certainly registered with different treatment centres in the country but may not have been systematically documented.
2. Awareness among in the community and even among medical personnel of bleeding disorders in general is limited. The result is that not just haemophilia and other hereditary bleeding disorders but even the more common acquired bleeding conditions are not adequately diagnosed or treated leading much avoidable morbidity and even mortality.
3. Diagnostic facilities for these bleeding disorders very limited in the country. There are many states in India where the diagnosis of haemophilia and similar bleeding cannot be confirmed.
4. Even though effective treatment with replacement therapy with CFCs has been well established in the world for several decades, this has not been possible to implement in any significant way in India. Furthermore, the concept of comprehensive care through a team of healthcare personnel with different expertise is also not widely understood.
5. Given the relatively small market for CFCs in India at present compared to many other countries, there are very limited numbers of suppliers for these products. Currently, there are also no Indian manufacturers of these products with acceptable data on their quality that can meet the demands of the country.
6. Use of blood bank plasma based therapies also results to many PWH developing transfusion transmitted infections.
7. The result of the above is that many PWH do not survive childhood and those who do often develop many musculoskeletal or other

complications that seriously limit their ability to live normally unable to partake in education or vocation.

Strengths

1. A few centres of excellence with all necessary expertise for comprehensive haemophilia care that can guide the establishment of care programs in the country.
2. Developing support from several state governments for haemophilia in their health budgets along with participation and enthusiasm of the medical personnel in key government institutions to develop good facilities for haemophilia and other hereditary blood diseases.
3. A well coordinated patient network that has been working in this field for over 25 years and has a good database of patients in the country.

Roles of Key Stake Holders

Government

1. Allocate specific budget for haemophilia care including purchase of adequate quantities of CFC as well establishment of appropriate infrastructure in designated Government medical institutions.
2. Recognize that biological products such as CFCs have specific requirements for definitions of quality which must be recognized when procuring such products to ensure safety and efficacy of these treatments. Establish a system of tender for consolidated purchase of CFCs in the state that includes all stakeholders with appropriate experts for the purchase of CFCs. Given the relatively small volume of purchase in each state by international standards at present, consider the possibility of combined tenders between several states to attract more vendors. This will increase competition and could reduce prices.
3. Different states may use various schemes to fund these initiatives – combine with existing programs such as the NHRM or through specific

allocations for certain diseases within the state health budget. Good inventory management of CFCs and ensuring regular and constant supply is indeed a must for this program to be successful.

4. Designate specific Government medical institutions in each district for developing different levels of expertise and infrastructure for basic or comprehensive haemophilia care. Only then will such care reach all PWH in India.
5. Identify suitable healthcare personnel in each of these institutions to be trained in different aspects of haemophilia care- physicians / paediatricians / laboratory personnel / orthopedicians / psychiatrists / physiotherapists / occupational therapists and other experts as needed including surgeons, as needed depending on the level of care being established.
6. Special attention may also be given in select institutions to developing genetic diagnosis facilities for carrier detection and counselling towards prevention.
7. Ensure sustained support for these centres on an annual basis for providing care to PWH and other hereditary blood diseases.

Patient organizations – Hemophilia Federation of India (HFI) and its chapters

1. Work with Government to identify more PWH in the country and help maintain a good national registry.
2. Inform and educate PWH about modern management of haemophilia and the different government and other programs available in each state for their care.
3. Assist PWH in reaching the designated institutions for their care.
4. Provide other forms of social support for PWH and their families including assistance with education and vocation, if possible.
5. Increase awareness of bleeding disorders in the community and lobby for support for it.
6. Leverage its affiliation with the World Federation of Hemophilia to get international expertise in this work wherever necessary.

Key Medical Institutions for Specialized Care of PWH

1. It will be important to recognize that while the Government system develops, the expertise for special care for PWH, particularly with regard to difficult surgical procedures will need to be done in those centres which have the requisite expertise. A system of partnership will need to evolve with Government institutions so that over a period of time, even these treatments can be offered at the Government institutions, as much as possible.

Centres of Excellence in Haemophilia Care

1. Critical to the goal of ensuring appropriate utilization of the funds allocated by the different state Governments is the training of appropriate health care personnel in each of the designated institutions. This is huge task and will need a systematic plan for its execution. A few centres in the country that have the requisite expertise to train people in different aspects of comprehensive care should partner with the Government to provide training in all aspects of care of PWH.
2. These centres should also work with the Government in creating protocols for management of haemophilia in each state in accordance with the budgets allocated and also for monitoring outcomes of these treatments. The aim should be to gradually move towards optimal treatment of all PWH in line with international recommendations.
3. Also work with the Government to see how facilities developed for haemophilia and other hereditary bleeding disorders can also be utilized for even acquired bleeding conditions which are not uncommon in any general hospital as well as other common hereditary blood diseases such as thalassemia and sickle cell diseases.

If all stakeholders work together then haemophilia care can indeed become a great example of public private partnerships in different ways and establish a model for other treatable chronic diseases in the country. What is also very important to note is that the facilities established for these relatively rare bleeding disorders will immensely help improve the management of patients with many other much more common bleeding conditions such after surgical or obstetric procedures and thus be of great help beyond these diseases in many general hospitals.

List of Participants

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- Dr. Rabindra Kumar Jena, Head of the Dept. of Haematology - SCB Medical College, Bhubaneswar, Odisha,
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- Dr. Vikas Sinha, Dean - M.P.. Shah Medical College, Jamnagar, Gujarat,
- Dr. Milind Dighe, In-charge of Blood Bank, S S G Medical College, Vadodara, Gujarat,
- Dr. Rajiv N. Daveshwar, Medical Superintendent, SSG Hospital, Vadodara, Gujarat,
- Dr. Amrit T Leuva, Dean - SSG Medical College, Vadodara, Gujarat
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- Dr. M.K. Vadel, Medical Superintendent, New Civil Hospital, Surat, Gujarat
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- Dr. Naresh Gupta, Director & Professor - L.N.J.P.H. Hospital, Delhi;
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