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Half of world's haemophilia patients in India, experts seek govt's attention

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According to the survey conducted by the World Federation of Hemophilia in 2011-12, almost half of the world's Hemophilia population lives in India and around 70 percent of PwH do not have adequate knowledge or access to treatment. Thus, it remains a concern that the risk of death from lack of basic knowledge and untreated Hemophilia is very high in the country.

Therefore, to mark the occasion of World Hemophilia Day on April 17, Hemophilia Federation (India) under the patronage of ministry of health and family welfare and National Health Mission, organized a sensitization programme on Hemophilia and its management at New Delhi. The program was aimed towards addressing Hemophilia as a disease and discussed the initiatives undertaken by the society and the government for treatment and management of this blood disorder. This event provided sensitization on the disease for policy makers; both at national and state level drawing references from Hemophilia management status in India vis a vis other developing countries.

Ruling BJP's member of parilament, Mrs Meenakshi Lekhi was present as chief guest and Dr Jagdish Prasad, directorate general of health services was the guest of honor with Dr Majoj Jhalani, joint secretary, national policy, health ministry.

The program kicked off with the welcome address by Dr Kanjaksha Ghosh, President, Hemophilia Federation India who talked about the state of Hemophilia in the country and the need of the hour to take appropriate initiatives in collaboration with the government. The programme drew participation from high profile personnel including all the state's Principal Secretaries of Health and the Mission Directors - NHM in addition to secretaries of the Ministry of Health and Family Welfare, Government of India.

Discussing the current state of Hemophilia in India, Dr Kanjaksha Ghosh, President, Hemophilia Federation India said, "At present, only 15 percent of the total Hemophilia population has been identified in India and the rest lay undiagnosed. There are about 16,000 patients registered with Hemophilia in the country as yet, however, we suspect that the number of people suffering with Hemophilia in India could be ranging 7 times more than the current registered patients"

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The panel discussed the need to have a policy intervention for making diagnosis, screening and comprehensive care for Person with Hemophilia (PwH) more accessible. This can be achieved by developing more treatment centers equipped to handle PwH, increasing number of coagulation labs, training medical for practitioners and developing regional 'Centre of Excellence-Hemophilia Treatment Centres'.

Talking about the disease management in Delhi region and his mission of 'One Country, One Treatment' that focusses on providing treatment to patients in their vicinity, Dr Naresh Gupta, head, Department of Medicine, LNJP Hospital said, "In Delhi, there are 2,000 registered patients suffering from Hemophilia and the state is also witnessing cases coming from other states as they do not have basic facilities and management care in their region. Through this initiative, we are proposing to build more treatment and care centers in regions which would create effective mechanism for diagnosis, treatment and bringing timely comprehensive care for Hemophiliacs within their reach"

The program also witnessed sessions on Hemophilia disease in females, role of physiotherapy in reducing musculoskeletal morbidities among PwH in India, Government's intervention and role in addressing Hemophilia management.