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New guidelines for haemophilia treatment to empower policymakers in India

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These guidelines mark the first set of local directives aimed at guiding and optimising the path of haemophilia treatment in India



The Haemophilia & Health Collective of North (HHCN), a registered body of India's leading healthcare professionals working in the domain of haemophilia care for over two decades, in collaboration with National Health Mission (NHM) representatives from 16 states, has proposed a first-of-its-kind Indian guidelines for treatment of Persons with Haemophilia (PwH).

The new guidelines recommend use of prophylaxis as standard of care (SOC) in haemophilia patients to prevent them from bleeding, and clearly articulates the need for comprehensive care including significance of timely diagnosis, physiotherapy and multidisciplinary care for PwH.

First time a separate category for Non-factor replacement (currently available as Emicizumab) is incorporated in the selection criteria. The real world experience bears out the rapid switchovers to non-factor products and which remains the drug of choice.

The new guidelines also recommend budgetary calculation for payers and/or policymakers to understand the budgetary requirements of each state and central reimbursement bodies. Optimal deployment of resources for severe Hemophilia A patients including high bleeders, pediatric population, patients with inhibitors is also suggested.

Current treatment modalities in India primarily focus on on-demand therapy – FVIII replacement to address bleeding episodes as they occur. However, exposure to exogenous Factor VIII could lead to development of inhibitors. This renders treatment with Factor VIII ineffective.

The new guidelines recommend adoption of advanced care to tackle bleeding incidents and reduce disability and improve quality of life for haemophilia patients.

Worldwide, countries are moving towards advanced non-replacement therapy or prophylaxis care because breakthrough bleeds remain an issue with the levels of protection offered by current FVIII concentrates.

In India, prophylaxis adoption is estimated at about 4%, whereas in most other developing countries it is over 20% and in developed countries 80-90% haemophilia patients are on prophylaxis.