
Prelims and Mains focus: about the draft policy and its features; its criticisms

News: After being directed by the Madras High Court, on January 6, to consider the issue of providing medical care to those suffering from the rare Lysosomal Storage Disorders (LSD) as a “national emergency”, the Centre informed the court of having notified a draft national policy on rare diseases.

About the draft policy

- It proposes to set up a registry under the Indian Council of Medical research (ICMR) to create a database.

- To provide financial assistance of up to Rs 15 lakh to Ayushman Bharat beneficiaries for rare diseases that require a one-time treatment in tertiary hospitals only.

- It also suggests voluntary crowdfunding as an alternate means of financial support and notifying government hospitals to facilitate treatment.

- Alternatively, the draft proposes to set up a digital platform for voluntary crowdfunding.

- The draft policy also categorises rare diseases under three categories based on clinical experiences and treatment availability. The policy also states that in the absence of data to clearly define rare diseases, such diseases in India will construe the three categories as identified in the policy.

Criticism of the policy
Public health groups have criticised the policy on following grounds:

1. It appears the entire policy is drafted to justify that government cannot provide treatment due to high cost as it is resource constrained.
2. The policy has adopted a **very narrow scope limited to only 3 categories**, while ignoring those where treatment is yet to be developed and R&D is required.

**Rare diseases**

- According to the government, so far only about **450 diseases have been recorded in India** from tertiary care hospitals that are globally considered as rare diseases.

- The **most commonly reported diseases** include Haemophilia, Thalassemia, Sickle-cell Anaemia and Primary Immuno Deficiency in children, autoimmune diseases, Lysosomal storage disorders such as Pompe disease, Hirschsprung disease, Gaucher’s disease, Cystic Fibrosis, Hemangiomas and certain forms of muscular dystrophies.

- There are **7,000 - 8,000 rare diseases**, but **less than 5% have therapies available**. About 95% rare diseases have no approved treatment and less than 1 in 10 patients receive disease specific treatment. Where drugs are available, they are expensive.