

Ministry of Health and Family Welfare

Free Treatment for Rare Genetic Diseases

Posted On: 28 JUL 2017 7:10PM by PIB Delhi

The Ministry of Health and Family Welfare has formulated a National Policy for treatment of Rare Diseases in India to progressively build India's capacity to respond comprehensively to rare diseases covering areas of: prevention, awareness generation, training of doctors, funding support for treatment on the parameters to be defined by a Central Technical cum Administrative Committee, promotion of research and development for drugs for treatment of rare diseases and diagnostics at affordable prices and measures for making the drugs for rare diseases more affordable, strengthening of laboratory networks, development of Centres of Excellence etc. On the whole, the Policy seeks to strike a balance between the interest of patients of Rare Diseases and health system sustainability. The Policy also recognizes and delineates the role of various Ministries and departments in the area of Rare Diseases.

Funding mechanism as given in the National Policy for treatment of Rare Diseases in India is as under:

- Setting up a corpus fund at Central level with the initial amount of Rs. 100 crore towards funding treatment of rare genetic diseases.
- Similar corpus at State level and contribution of funds by the Centre towards the state corpus to the ratio of 60:40 out of the central pool.
- It is up to the States to have a corpus of a larger amount. Requirement of funds by States is as per PIP process.

The Minister of State (Health and Family Welfare), Smt Anupriya Patel stated this in a written reply in the Lok Sabha here today.

MV/LK

(Release ID: 1497679) Visitor Counter: 331

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