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National Policy for Rare Diseases 2021

Why in news?

The Union Health and Family Welfare ministry recently approved the National Policy for Rare Diseases 2021.

What are rare diseases?

- Rare diseases are broadly defined as diseases that infrequently occur in a population; three markers are used:
    1. the total number of people with the disease
    2. its prevalence
    3. the availability/non-availability of treatment options
- WHO defines rare disease as often debilitating lifelong disease or disorder with a prevalence of 1 or less, per 1000 population.
- However, different countries have their own definitions.
- It is defined in a way to suit their specific requirements and in context of their own population, health care system and resources.
- As per an estimate, there are 7,000 known rare diseases with an estimated 300 million patients in the world.
    - Of this, 70 million are in India.
- They include inherited cancers, autoimmune disorders, congenital malformations, Hirschsprung's disease, Gaucher disease, cystic fibrosis, muscular dystrophies and Lysosomal Storage Disorders (LSDs).

What are the key provisions in the policy?

- **Objective** - The policy intends at lowering the cost of treatment of rare diseases (diseases listed under Group 1 in the rare disease policy).
- It also aims at increasing the focus on indigenous research and local production of medicines.
- **Support** - Those who are suffering from rare diseases that require one-time treatment will have the financial support of up to Rs 20 lakh under the umbrella scheme of Rashtriya Arogya Nidhi.
- Financial assistance will not be limited to just the BPL families.
- Around 40% of the population covered under the Pradhan Mantri Jan Arogya Yojana will benefit from the policy.
- **Funding** - The policy will make use of a crowdfunding mechanism to cover

the cost of treatment of rare diseases.

- As part of it, corporates and individuals will be encouraged to extend financial support through a robust IT platform.
- **Registry** - A national hospital-based registry of rare diseases will be created.
- This is to ensure that adequate data and comprehensive definitions of such diseases are available for those interested in research and development.
- **Detection** - The policy aims to screen and detect rare diseases at early stages, which will in turn help in their prevention.
- It aims to achieve this through the help of Health and Wellness Centres, District Early Intervention Centres and counselling.

What is the significance?

- Rare diseases are difficult to research upon.
- Also, availability and accessibility to medicines are important in the process of treatment.
- Fund support from government is vital for continual treatment of those with rare diseases.
- The Supreme Court and various high courts had expressed concern about the lack of a national policy for rare diseases.
- The policy thus aims to help the nation overcome these fundamental challenges.

What are the shortcomings?

- Much of the effort in the rare diseases sector, from the medical side, has been to evolve formal definitions.
- This is because it would support the development of and commercialisation of drugs for treatment, and improve funding for research on rare diseases.
- The Policy meets much of the demands, but falls short of delivering the complete mandate.
- As per the Policy, diseases such as LSD for which definitive treatment is available, but costs are prohibitive, have been categorised as Group 3.
- However, no funding has been allocated for the immediate and lifelong treatment needs, for therapies already approved by the Drugs Controller General of India.

What can be done?

- Experts point out that the costs to help already-diagnosed patients might be in the range of Rs. 80-100 crore annually.
- To note, the Centre has worked out cost-sharing agreements with Kerala, Tamil Nadu and Karnataka.

- If it can extend this with other States too, its share of the annual costs will be halved.
- The Centre can, however, still set aside a substantial corpus to fund life-saving treatments, even as it rolls out the policy.

Source: The Hindu, Hindustan Times