



INSIGHTSIAS
SIMPLIFYING IAS EXAM PREPARATION

FEB. 29, 2024

INSIGHTS INTO EDITORIAL



Editorial

ANALYSIS

- **A rough estimate suggests that about 8 crore-10 crore Indians** suffer from one rare disease or another;
 - over **75% are children**.

Issues associated:

- **These diseases** are largely overlooked.
- **Resource constraints**
- **India languishes near the bottom** on awareness, diagnosis, and drug development for rare diseases.
- **The Ministry of Health and Family Welfare formulated a national policy** to treat rare diseases in **2017** but withdrew it in 2018 owing to
 - “implementation challenges” and confusion regarding disease coverage
 - patient eligibility
 - cost-sharing.
 - **A revised policy, the National Policy for Rare Diseases (NPRD)**, was announced in 2021.
- **The policy attributes to a lack of sufficient data**, as if regular data collection and epidemiological assessments are not the government’s job.
- **Timely and accurate diagnosis is indispensable** for the robust management of any disease
 - **For rare disease patients**, it takes an average of seven years for their conditions to be diagnosed (if at all).
- **Physicians are generally unaware** of how to interpret the signs and symptoms
 - **healthcare professionals** must be trained to improve their diagnostic accuracy.
 - **Expectant mothers with a history of rare diseases** in their family must undergo mandatory prenatal screening and postnatal diagnosis and care.

- **Less than 50% of the 450-odd rare diseases** identified in India are treatable.
- **Treatments approved by the Drugs Controller General of India** are available for just about **20 rare diseases** and can be availed only from Centres of Excellence (CoEs).
 - **CoEs are few (12), unevenly distributed**, and uncoordinated
 - late diagnosis
 - inadequate therapies
 - Lack of timely availability are the norm.

Challenges:

- **The Budget’s allocation for rare diseases**, although increasing over the years, remains low at **₹93 crore for 2023-2024**.
- **Under the NPRD guidelines, up to ₹50 lakh is allowed per patient**, which will be disbursed to the concerned CoE.
 - **As chronic rare diseases usually require lifelong** management and therapy, this amount is woefully inadequate.
- **The CoEs are wary of beginning any treatment** that they may need to suspend later, leaving them vulnerable to judicial action from patients and their kin.
- **Confusion in the fund utilization: More than ₹47 crore of the ₹71 crore financial assistance** allocated to the **11 CoEs** for the current year remains unused.
 - **There is no parity** between CoEs
 - **Mumbai exhausted** all its funds (while treating only **20 of 107 patients**)
 - **Delhi utilizing** less than **20%**.
- **NPRD has urged the CoEs** to crowdfund to treat rare disease patients.
 - **A portal with over 1,400 registered patients** has collected less than ₹3 lakh in three years.

Way Forward

- **It is imperative for the Central government to frame** a standard definition of rare diseases, increase budgetary outlays, dedicate funding for drug development and therapy, and increase the number of CoEs
 - **Ensure better coordination and responsible** utilization of funds.
- **State governments must introduce social assistance programmes** and develop satellite centers under the CoEs.
- **Public and private companies** could be co-opted for funding; CSR initiatives and partnerships can be leveraged to meet shortfalls.
- **The issue of exorbitant drug prices** and availability must be addressed.
 - **Last year, the government waived off GST and customs duty** on medicines for rare diseases.
 - **This exemption applies only to drugs** which are to be “imported for personal use” and not to the ones commercially available in India.
- **The government must incentivise domestic manufacturers** under the **Production-Linked Incentive Scheme**, reduce clinical trial requirements in appropriate cases, and look into options such as **repurposed drugs and bulk-import**.
- **Government must withdraw the GST** on life-saving drugs.

QUESTION FOR PRACTICE

Q. Besides being a moral imperative of the Welfare State, primary health structure is a necessary precondition for sustainable development.” Analyze. (UPSC 2021)

(200 WORDS, 10 MARKS)