

National Policy for Rare Diseases 2021

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National Policy for Rare Diseases Latest News

Several rare disease patients across India, including many children, are facing a life-or-death struggle due to delays in implementing the National Policy for Rare Diseases (NPRD) 2021, patient advocacy groups said recently.

About National Policy for Rare Diseases

- The **Ministry of Health & Family Welfare** launched the National Policy for Rare Diseases (NPRD) in March 2021.
- Currently, **63 rare diseases are included** under the National Policy for Rare Diseases on the recommendation of the Central Technical Committee for Rare Diseases (CTCRD).

National Policy for Rare Diseases Features

- The rare diseases have been identified and **categorized into 3 groups.**
 - **Group 1: Disorders amenable to one-time curative treatment.**

- **Group 2:** Diseases **requiring long-term/lifelong** treatment with relatively **lower cost of treatment**.
- **Group 3:** Diseases for which **definitive treatment is available** but challenges are to make optimal patient selection for benefit, **very high cost**, and **lifelong therapy**.
- **Financial support of up to Rs. 50 lakhs per patient** is provided for the **treatment at the notified Centres of Excellence (CoEs) for Rare Diseases**.
- **12 Centres of Excellence (CoEs) have been identified** so far, which are premier Government tertiary hospitals with facilities for diagnosis, prevention, and treatment of rare diseases.
- In order to receive financial assistance for treatment of rare disease, the patient may approach a nearby or any CoE to get registered.
- **Treatment** of patients **starts immediately after registration with the CoEs**.
- **Nidan Kendras** have been set up **for genetic testing and counselling** services.
- The Ministry of Health and Family Welfare has obtained **exemption from the** Department of Expenditure on Goods & Services Tax (**GST**) **and Basic Customs Duty on drugs imported for Rare Diseases** for individual use and through CoE.
- As envisaged in the policy, the Department of Health Research has **established the National Consortium for Research and Development on Therapeutics for Rare Diseases (NCRDTRD)** for streamlining the research activities for rare diseases.
- It has **provisions for the promotion of research and development** for diagnosis and treatment of rare diseases; promotion of **local development and manufacture of drugs**; and creation of a conducive environment for indigenous manufacturing of drugs for rare diseases at affordable prices.

National Policy for Rare Diseases FAQs

Q1. What is the national database for rare diseases?

Ans. This database from the National Organization for Rare Disorders contains reports on more than 1,200 rare disorders.

Q2. What are some examples of rare diseases in India?

Ans. Some examples of rare diseases in India include Osteopetrosis, Laron's Syndrome, Fabry disease, Prader Willi Syndrome, Cystic Fibrosis etc.

Q3. What are the causes of rare diseases?

Ans. The causes of rare diseases include genetic mutations, environmental factors, infections, immune system disorders, metabolic abnormalities, and sometimes chromosomal abnormalities or unknown factors.

Source: IT

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