

# National Rare Disease Policy 2021

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## **National Rare Disease Policy 2021**

### **Aim**

- Increase focus on indigenous research and local production of medicines.
- Lower the cost of treatment of rare diseases.
- Screen and detect rare diseases early for prevention.

### **Major Provisions**

- Group 1: Disorders amenable to one-time curative treatment.
- Group 2: Diseases requiring long-term or lifelong treatment.
- Group 3: Diseases with available treatment but challenges in patient selection, high cost, and lifelong therapy.

### **Centres of Excellence**

- naming of eight health care establishments as "Centres of Excellence."
- Support in one-time amounts of up to Rs. 5 million dollars for enhancing diagnostic facilities.

### **Financial Support**

- Up to Rs. 500 in financial assistance is available. 50 lakhs to the patients experiencing any classification of the Uncommon Sickneses and for therapy in any of the Focal point of Greatness (CoE) referenced in NPRD-2021, outside the Umbrella Plan of Rashtriya Arogya Nidhi.

### **National Registry**

- Establishment of a rare disease registry at a national hospital.
- Ensuring that all definitions and data are complete for purposes of research and development.

### **Concerns Raised**

- Lack of sustainable funding for patients with Group 3 disorders.
- Prohibitive costs of drugs for rare diseases.
- Limited global and domestic manufacturers of drugs for rare diseases