Centres of Excellence for Rare Disease

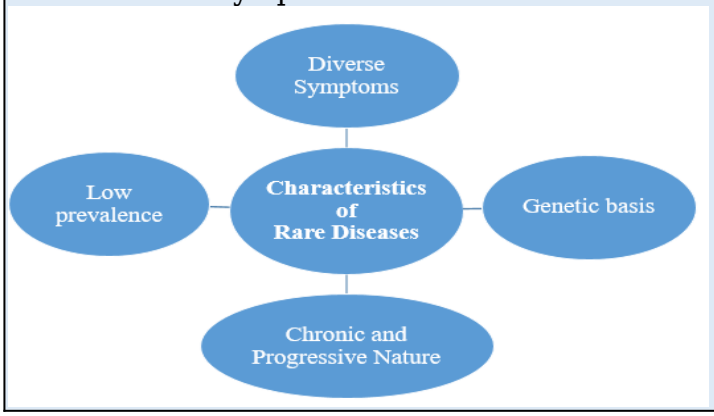
Why in news?

The Union Ministry of Health and Family Welfare is discussing adding more Centres of Excellence (CoEs) to its network of centres to improve access to diagnosis and treatment for patients suffering from rare diseases.

- **Centres of Excellence** – They are institutions *identified by the central government* under the National Policy for Rare Diseases (NPRD), 2021.
- **Aim** – To treat patients suffering from rare diseases actively.

Rare disease

• **Definition –** According to WHO, Rare disease is a *lifelong disease* with a prevalence of ***10 or fewer per 10,000 population***.
• According to Organization of Rare Diseases India (ORDI) defined rare disease as a disease when it *affects 1 in 5,000 people.*
• **Spread** – It affect approximately *3.5% to 5.9% of the population.*
• **Causes** – *72% of rare diseases are genetic*, with over 7000 characterized by diverse disorders and symptoms.



- **Numbers** – There are ***12 such centres***.
- **Coverage** – These centres cover with a quota of 2,420 rare disease patients from 6 categories ***across 3 groups*.**

Categories of Rare Disease - NPRD

• **National Policy for Rare Diseases (NPRD)** – It was launched by Ministry of Health & Family Welfare launched in *2021*.
• There are 3 groups *based on the type of treatment* they require.
• **Group 1** – Diseases that can be cured with a one-time treatment.
• **Group 2** – Diseases that require long-term or lifelong treatment, but are relatively inexpensive.
• **Group 3** – Diseases that have a definitive treatment, but are expensive and require lifelong therapy.

*Currently, **63** **rare diseases** are included under NPRD on recommendation of Central Technical Committee for Rare Diseases (CTCRD).*

- **Tax exemption** – GST and Basic Customs Duty on drugs imported for Rare Diseases for individual use and through CoE.
- **Challenges** – It has *lack of institutional care* at CoEs to the *exhaustion of the one-time fund* of Rs 50 lakh given to patients.
- It fails to support sustained treatment for chronic conditions like Lysosomal storage disorders (LSDs).

Most common rare disease in India
• Lysosomal Storage Disorders • Pompe disease (Glycogen storage disease type II) • Anderson–Fabry disease • Mucopolysaccharidosis • Severe Combined Immunodeficiency (SCID) • Phenylketonuria • Cystic Fibrosis • Duchenne Muscular Dystrophy

***Rare Disease Day** was observed on the last day of February i.e., 28th February (or 29 in leap years).*

Reference

PIB | National Policy for Rare Diseases

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