Rare Diseases in India

Why in News?

Recently, a 19-year-old child actress, Suhani Bhatnagar, died due to dermatomyositis, a rare disease

Dermatomyositis

- It is an ***uncommon inflammatory*** disease marked by muscle weakness and a distinctive skin rash.
- The condition can affect adults and children, affects more females than males.
- There's ***no cure*** for dermatomyositis.

Rare disease

- A disease is considered rare if it affects fewer than 200,000 people in the U.S. and fewer than 1 in 10,000 people in the European Union.
- **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.

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

- **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.

Status in India

- India lacks a standard definition for rare diseases.
- Estimate suggests that about 8 crore-10 crore Indians suffer from one rare disease or another, over 75% are children.
- India accounts for one-third of the global rare disease incidence, with over 450 identified diseases.
- These range from widely known ones such as Spinal Muscular Atrophy and Gaucher's disease to lesser-known ones such as Mucopolysaccharidosis type 1 and Whipple's disease.
- **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.
- Currently, ***63 rare diseases*** are included under NPRD on recommendation of Central Technical Committee for Rare Diseases (CTCRD).

Reference

[The Hindu | Rare diseases]