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News: Rare Diseases

- Recently, the **Delhi High Court** has taken a proactive step to address the challenges faced by patients with rare diseases by establishing a five-member panel to implement the Centre's rare diseases policy effectively.
- The main objective of the Committee is to look after the implementation of **National Rare Disease Policy, 2020**.

Rare disease

- A rare disease, also referred to as an orphan disease, is any disease that affects a small percentage of the population.
- There are 6,000-8,000 classified rare diseases, but less than 5% have therapies available to treat them.
- Most rare diseases are genetic, and are present throughout a person's entire life, even if symptoms do not immediately appear.
- About 95% rare diseases have no approved treatment and less than 1 in 10 patients receive disease-specific treatment.
- 80% of these diseases have genetic origins.
- These diseases have differing definitions in various countries and range from those that are prevalent in 1 in 10,000 of the population to 6 per 10,000.

- However broadly, a 'rare disease' is defined as a health condition of low prevalence that affects a small number of people when compared with other prevalent diseases in the general population. Many cases of rare diseases may be serious, chronic and life-threatening.
- India has close to 50-100 million people affected by rare diseases or disorders, the policy report said almost 80% of these rare condition patients are children and a leading cause for most of them not reaching adulthood is due to the high morbidity and mortality rates of these life-threatening diseases.
- The most common rare diseases recorded in India are Haemophilia, Thalassemia, sickle-cell anaemia and primary immuno deficiency in children, auto-immune diseases, Lysosomal storage disorders such as Pompe disease, Hirschsprung disease, Gaucher's disease, Cystic Fibrosis, Hemangiomas and certain forms of muscular dystrophies.
- Globally, 8% of the population suffers from rare diseases. 75% of the survivors are children who make parents run from pillar to post for their treatment, exhausting their resources and emotionally draining themselves in the process.

National Policy on Rare Diseases, 2020

- Union Ministry of Health and Family Welfare recently released the National Policy for the treatment of 450 rare diseases.
- It intends to kickstart a registry of rare diseases, which will be maintained by the Indian Council of Medical Research (ICMR).
- India does not have a definition of rare diseases because there is a lack of epidemiological data on its incidence and prevalence. One of the immediate measures of this policy is to arrive at a definition of rare diseases suited to India.

Under the policy, there are 3 types of rare diseases

- Requiring one-time curative treatment.
 - Diseases that require long-term treatment, but where there is low cost.
 - Diseases that require both time and high cost.
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- As per the policy, an assistance of 15 lakh INR will be provided to patients suffering from rare diseases that are in the first category under RAN Scheme and Ayushman Bharat.

News: Indian Coffee

- Recently, the Statista site stated that India is the sixth largest producer of coffee in the world, after Brazil (largest producer of coffee), Vietnam, Colombia, Indonesia, Ethiopia and Honduras.

Coffee

- Coffee is a high – land plantation crop which is cultivated in regions having moderate temperature with heavy rainfall.
- It thrives well in Monsoon type of climate.
- India ranks 6th among the world's 80 coffee producing countries in a list topped by Brazil, with some of the finest robusta and some top-notch arabica cultivated.
- Brazil is followed by Vietnam, Colombia, Indonesia, Ethiopia and Honduras in terms of Coffee production.
- India cultivates 3.7% of entire coffee in the world. Nearly 70% of India's coffee is exported, largely to European and Asian markets.
- According to The Food and Agriculture Organization (FAO) statistics, India is the eighth largest exporter of coffee by volume.

- Coffee in India is traditionally grown in the **rainforests of the Western Ghats in South India**, covering Chikmagalur, Kodagu (Coorg), Wayanad, the Shevaroy Hills and the Nilgiris.
- **Karnataka accounts to nearby 3/4th of coffee production in India** followed by Kerala, Tamil Nadu, Andhra Pradesh and Odisha.

Climatic Conditions

- Coffee plant **requires hot and humid climate** with temperatures ranging between **15°C and 28 °C** and rainfall from **150 to 250 cm**.
- **Frost, snowfall, high temperature above 30°C and strong sun shine is not good for coffee crop** and is generally grown under shady trees.
- **Dry weather is necessary at the time of ripening** of the berries.
- **Stagnant water is harmful and the crop is grown on hill slopes at elevations from 600 to 1,600 metres above sea level**.
- **Well drained, loams containing good deal of humus and minerals like iron and calcium are ideal** for coffee cultivation.
- India is the **only country in the world where the entire coffee cultivation is grown under shade, hand-picked and sun dried**.
- **Two types of coffee varieties are produced in India; Arabica and Robusta. Robusta variety of coffee is produced more than Arabia variety in India.**