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## National Policy on Rare Diseases

**Context:** Imported medicines and Food for Special Medical Purposes (FSMP) used to treat rare diseases under the National Policy for Rare Diseases, 2021, are now exempt from IGST when imported for personal use, as per the recent decision of the GST Council.

### Key Features

- The Ministry of Health and Family Welfare launched the National Policy for Rare Diseases (NPRD) in 2021 to provide treatment for rare disease patients.
- The policy aims to promote indigenous research and local production of medicines.
- It seeks to **lower the cost of treatment** for rare diseases.
- Early screening and detection of rare diseases is a key objective of the policy to aid in prevention.
- The policy categorizes rare diseases into three groups based on the type of treatment required:
  - **Group 1** consists of disorders amenable to one-time curative treatment.
  - **Group 2** includes diseases requiring long-term or lifelong treatment.
  - **Group 3** comprises diseases for which definitive treatment is available, but challenges include patient selection, high cost, and lifelong therapy.
- Financial support under the umbrella scheme of **Rashtriya Arogya Nidhi** is provided to rare disease patients listed under Group 1, with assistance of up to Rs. 20 lakhs.
- Rashtriya Arogya Nidhi is a scheme that offers financial aid to patients suffering from major life-threatening diseases, particularly those living below the poverty line (BPL).
- The financial assistance is not limited to BPL families but can be extended to approximately 40% of the population eligible under the norms of Pradhan Mantri Jan Arogya Yojana for treatment in government tertiary hospitals.
- **Centre of Excellence**
  - Patients can approach nearby Centre of Excellence (CoE) for rare disease treatment and financial aid.
  - Eight CoEs are designated for diagnosis, prevention, and treatment of rare diseases.
  - Each CoE receives a one-time grant of up to Rs. 5 crores for infrastructure development, including screening and treatment facilities.
- **Alternative Funding Mechanism:**
  - Voluntary crowdfunding is utilized as an additional funding avenue.
  - A digital platform is established for individuals and corporate donors to contribute voluntarily towards the treatment expenses of rare disease patients.
- **National Registry**
  - A national hospital-based registry for rare diseases will be established to provide comprehensive data and standardized definitions for researchers and developers.

### Rare Diseases

- There are 6,000-8,000 classified rare diseases, but less than 5% have available therapies.
- Examples of rare diseases include Lysosomal Storage Disorders (LSD), Pompe disease, cystic fibrosis, muscular dystrophy, spina bifida, and haemophilia.
- Approximately 95% of rare diseases lack approved treatments, and less than 1 in 10 patients receive disease-specific treatment.

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- About 80% of rare diseases have genetic origins.
- Rare diseases have varying definitions worldwide and prevalence ranges from 1 in 10,000 to 6 per 10,000 people.
- Broadly, rare diseases are health conditions with low prevalence that affect a small number of individuals compared to more common diseases.
- Many rare diseases are serious, chronic, and life-threatening.
- In India, around 50-100 million people are affected by rare diseases, with approximately 80% of them being children.
- High morbidity and mortality rates of these life-threatening diseases contribute to the low survival rates of affected children.

## Moderate Resolution Imaging Spectroradiometer (MODIS)

**Context:** Scientists analysing data from the Moderate Resolution Imaging Spectroradiometer have found that climate change has altered the colour of over half (56%) of the world's oceans.

- Tropical waters, including the southern Indian Ocean, have experienced a notable colour change, appearing greener.
- Changes in ocean colour indicate shifts in phytoplankton communities, which play a crucial role as the foundation of the marine food web.
- Human eyes cannot easily perceive subtle colour changes in the ocean.
- While oceans are commonly perceived as blue, the true colour can vary, encompassing shades from blue to green and even red.
- The green colour in the ocean is due to chlorophyll, a pigment utilized by phytoplankton for photosynthesis.
- Changes in phytoplankton population and colour can have an impact on organisms that rely on plankton as a food source.
- The colour trend observed in the southern Indian Ocean does not necessarily extend to the waters near India.

### MODIS

- The Moderate Resolution Imaging Spectroradiometer (MODIS) is a key instrument on the Terra (EOS AM-1) and Aqua (EOS PM-1) satellites.
- Terra and Aqua were launched by NASA in 1999 and 2002, respectively.
- Terra orbits the Earth in the morning, passing from north to south across the equator, while Aqua orbits in the afternoon, passing south to north over the equator.
- MODIS on Terra and Aqua captures data in 36 spectral bands, covering the entire Earth's surface every 1 to 2 days.
- These data contribute to our understanding of global processes in land, ocean, and the lower atmosphere.
- MODIS plays a crucial role in developing validated Earth system models for accurate global change predictions.
- The instrument's data assists policy makers in making informed decisions regarding environmental protection.

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## Nature Restoration Law

**Context:** MEPs recently voted in favour of the EU nature restoration law with 336 votes in favour, 300 against, and 13 abstentions.

### Objectives

- The law sets a target to restore 80% of European habitats in poor condition by 2050.
- Each Member State will have legally binding targets.
- By 2030, at least 20% of the EU's land and sea areas should be covered by nature restoration measures, with a long-term goal of extending restoration efforts to all ecosystems in need by 2050.

### Targets of the Law

- Aim to reverse the decline of pollinator populations by 2030 and ensure their continuous growth.
- No net loss of green urban spaces by 2030, with a target of 5% increase by 2050 and a minimum of 10% tree canopy cover.
- Increase overall biodiversity in agricultural ecosystems, with positive trends for grassland butterflies, farmland birds, and organic carbon.
- Restore and rewet drained peatlands used for agriculture and peat extraction.
- Increase biodiversity in forest ecosystems, with positive trends for forest connectivity, forest birds, and organic carbon stock.
- Restore marine habitats such as seagrasses and sediment bottoms, and conserve habitats of iconic marine species like dolphins, porpoises, sharks, and seabirds.
- Remove river barriers to achieve at least 25,000 km of free-flowing rivers by 2030.

### European Green Deal

- The programme aims to ensure that Europe becomes the first climate-neutral continent by 2050, simultaneously enhancing the competitiveness of European industry and facilitating a fair transition for affected regions and workers.
- List of initiatives (in random order):
  - Proposal to extend the EU Emissions Trading System
  - European Climate Law, legally establishing the 2050 climate-neutrality objective
  - Carbon Border Tax
  - New industrial strategy
  - Strategy for green financing and a Sustainable Europe Investment Plan
  - Comprehensive plan to increase the EU emissions reduction target for 2030 to 55%
  - 'Farm to Fork Strategy' focusing on sustainable food throughout the value chain
  - Biodiversity Strategy for 2030
  - New Circular Economy Action Plan addressing microplastics
  - New Just Transition Fund
  - Proposal to transform parts of the European Investment Bank into Europe's climate bank
  - European Climate Pact

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## NEWS IN BETWEEN THE LINES

### Chandrayaan-3



Today, India's third moon mission, Chandrayaan-3, is scheduled for lift-off at 2.35 p.m.

**Launch Location:** The Launch Vehicle Mark-III (LVM3) will take off from the second launch pad at the Satish Dhawan Space Centre in Sriharikota.

**Objective:** Chandrayaan-3 aims to achieve a soft landing on the lunar surface, following the unsuccessful attempt with the Chandrayaan-2 mission in 2019.

**Soft-landing:** Only three countries, the U.S., Russia and China, have successfully achieved a soft landing on the moon thus far.

**Components:** Chandrayaan-3 comprises an indigenous propulsion module (PM), a lander module (LM), and a rover. It aims to develop and demonstrate new technologies for interplanetary missions.

**Background:**

**Chandrayaan-1:** India's first lunar mission launched in 2008.

**Objectives:** Study the Moon's surface, search for water ice, and enhance understanding of lunar origin and evolution.

Discovered water molecules on the lunar surface and mapped various elements and minerals.

**Mission duration:** 312 days.

**Chandrayaan-2:** India's second lunar mission launched in 2019.

**Components:** Orbiter, lander (Vikram), and rover (Pragyan).

**Objectives:** Soft landing on the lunar south pole and rover exploration.

Lander experienced a hard landing and lost communication, but the orbiter remains operational.

### Bastille Day



Recently, the Prime Minister of India visited Paris to attend the French National Day celebrations, known as Bastille Day, as the Guest of Honour.

**Bastille Day:** The National Day of France, also known as Bastille Day or Fête nationale française, is observed on July 14 and features a grand military parade, dancing, and celebrations.

**Historical Significance:** July 14 commemorates the storming of the Bastille, a fortress in Paris, in 1789, which marked the beginning of the French Revolution and influenced democratic ideas worldwide.

**Fête de la Fédération:** July 14 is also the anniversary of Fête de la Fédération held in 1790 to celebrate the unity of the French people. It symbolized the end of the French monarchy and the establishment of a new order.

**Background:** The storming of the Bastille was preceded by social and economic tensions, including poverty, crop failures, and high food prices, which led to discontent among the commoners.

**Bastille Day Events:** On July 14, 1789, a large armed mob marched towards the Bastille, demanding its surrender. After initial resistance, the fortress was overrun, marking a significant victory for the revolutionaries.

**Indian Participation:** In 2009, Indian soldiers were invited to participate in the Bastille Day celebrations, with a contingent of 400 members from the Indian Army, Navy and Air Force leading the military parade.

### Condor's Passageway



Recently, the archaeologists in Peru discovered a 3,000-year-old sealed corridor known as the "condor's passageway" within the Chavin de Huantar archaeological site, located northeast of Lima.

**Condor Passageway:** A significant discovery in the sealed corridor includes a ceramic piece with a condor motif, symbolizing power and prosperity in ancient Andean cultures.

**Chavin Culture:** The Chavin culture, flourishing from 1,500-550 B.C., was known for advanced art featuring birds and felines. They existed over 2,000 years before the Inca Empire.

**Frozen in Time:** The sealed corridor reveals ancient artifacts and structures, offering a glimpse into the early days of the Chavin culture.



**Temple Complex:** The Chavin temple complex includes newly discovered passageways and terraces, with more excavation yet to be done.

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	<p><b>Historical Significance:</b> Chavin de Huantar, a World Heritage Site since 1985, gained prominence during the 1997 hostage rescue operation in Lima. The underground passageways of the site inspired the construction of tunnels by the Peruvian armed forces.</p> <p><b>Underground Passageways:</b> Chavin de Huantar features over 35 interconnected underground passageways, predating the temple's galleries. These passageways were built between 1,200 and 200 B.C. in the Andean foothills.</p>
<p><b>Indo-Pacific Economic Framework</b></p> 	<p>Recently, India has been considering its involvement in the trade pillar of the Indo-Pacific Economic Framework for Prosperity (IPEF), a 14-nation trade bloc.</p> <p><b>What is IPEF?</b> It is the US-led initiative that aims to enhance economic partnership and growth in the Indo-Pacific region, focusing on resilience, sustainability, inclusiveness, fairness and competitiveness.</p> <p><b>Members:</b> IPEF includes 14 countries, including India, Australia, Japan, South Korea, Singapore and the United States, representing 40% of the world's GDP.</p> <p><b>Pillars of IPEF:</b> The negotiations revolve around four pillars: supply-chain resilience, clean energy and infrastructure, taxation and anti-corruption and fair and resilient trade.</p> <p><b>India's Position:</b> India has joined three out of the four pillars of IPEF, excluding the trade pillar. India is cautious about conditionalities and conflicts with its interests in areas like digital governance, privacy and data regulations.</p>
<p><b>Place in News</b></p> <p><b>Ecuador</b></p>	<p>Recently, the port city of Guayaquil in Ecuador has been facing a severe crisis as criminal gangs fight for control, leading to a surge in violence.</p> <p><b>Capital:</b> Quito is the capital city of Ecuador, situated in the highlands of the country.</p> <p><b>Geographical Location:</b> Ecuador, located in South America, is bordered by Colombia and Peru. It has a diverse geography with the Andes, Amazon Rainforest and Galapagos Islands. Straddling the equator, it gets its name.</p> <p><b>Official Language:</b> The official language of Ecuador is Spanish. Indigenous languages such as Quechua and Shuar are also widely spoken.</p> <p><b>Currency:</b> The currency of Ecuador is the United States dollar (USD), which has been in circulation since the year 2000.</p> <p><b>Independence:</b> Ecuador gained independence from Spanish colonial rule on May 24, 1822, along with other South American countries under the leadership of Simón Bolívar.</p> <p><b>Biodiversity:</b> Ecuador is highly biodiverse, home to unique flora and fauna. The Galapagos Islands, a UNESCO World Heritage Site, are famous for their endemic species.</p> 

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