

## 29th Feb 2024

by saurabh pandey





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### **IRUPSC**

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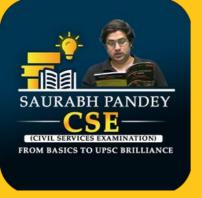
**Basics and current affairs** 

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### Topic-Article 371 A

• .Article 371A of the Constitution of India has been the major hurdle in the Nagaland government's efforts to regulate small-scale illegal coal mining activities in the State. Special to Nagaland, Article 371A has special provisions guaranteeing the protection of land and its resources apart from the Naga customary law and procedure.





Article No.	Subject-matter
371	Special provision with respect to the states of
	Maharashtra and Gujarat.
371 – A.	Special provision with respect to the state of
	Nagaland.
371 – B.	Special provision with respect to the state of Assam
371 – C.	Special provision with respect to the state of Manipur
371 – D.	Special provisions with respect to the state of Andhra
	Pradesh or the state of Telangana
371 – E.	Establishment of Central University in Andhra Pradesh
371 – F.	Special provisions with respect to the state of Sikkim
371 – G.	Special provision with respect to the state of Mizoram
371 – H.	Special provision with respect to the state of Arunachal
	Pradesh
371 – I.	Special provision with respect to the state of Goa
371 – J.	Special provisions with respect to the state of Karnataka





#### Article 371 – A → Special Provisions for Nagaland

- Act of parliament relating to following matters would not apply to Nagaland unless state assembly so decides:
- Religious & social practices of Nagas
- Nagas customary law & procedure
- Administration of civil or criminal justice involving decisions according to Naga customary law
- Ownership & transfer of land & its resources
- Special responsibility of governor wrt law & order in the state (after consulting COMs, but his decision will be final) regarding internal disturbances occurring in Naga hills mainly in Tuesang area (Special responsibility ceases if President directs so)





# Jacaranda and climate change

- Jacaranda mimosifolia is a subtropical tree native to southcentral South America that has been widely planted elsewhere because of its attractive and longlasting violet-colored flowers.
- It is also known as the jacaranda, blue jacaranda, black poui, Nupur or fern tree













- Local scientists have begun investigating how widespread the early-bloom phenomenon is, but they point to climate change as the first culprit.
- "They are starting to flower in January, February, which is winter, when it is not yet their time.

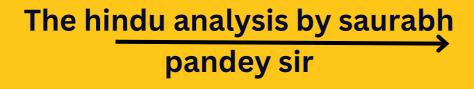






# Medicinal properties of canabis

- The cannabis plant (Cannabis sativa) has long been of interest to psychiatrists for its perceived effects on mood and cognition.
- There is currently significant research interest in using cannabis-based compounds to manage and/or treat schizophrenia and cannabisuse and heroin-use disorders.







- The major psychotomimetic agent in C. sativa is a compound called delta-9-tetrahydrocannabinol (THC).
- There is growing interest in another cannabinoid, cannabidiol (CBD), which may have antipsychotic, anti-inflammatory, and neuroprotective properties.
- The plant's flowering parts are more potent than its leaves.







### The cannabinoid system

- The human cannabinoid system has two cannabinoid receptors, called CB1 and CB2.
- The naturally occurring substrate of the CB1 receptor is anandamide, a compound whose name comes from the Sanskrit word 'ananda', meaning bliss.
   CB2 is found in the spleen and testes and to a lesser extent in the central nervous system (CNS).
- CB1 is found diusely throughout the CNS.
- The CNS is involved in the release of various neurotransmitters, including dopamine, noradrenaline, and serotonin. CB1 is like a trad cop: it controls the level





- The endocannabinoid system (ECS) comprises a dense network of chemical signals and cellular receptors.
- The cannabis plant works its effect by hijacking this machinery.
- The cannabinoid system
   modulates a host of bodily
   functions, including pain,
   memory, psychomotor control,
   sleep, and appetite







## Rare diseases

- According to the World Health Organization, rare diseases afflict 1 or less per 1,000 population.
- Barely 5% of the over 7,000 known diseases worldwide are treatable.
- India accounts for one-third of the global rare disease incidence, with over 450 identified diseases.







- Rare diseases are broadly defined as diseases that infrequently occur in a population, and three markers are used the total number of people with the disease, its prevalence, and the availability/non-availability of treatment options.
- WHO defines rare disease as having a frequency of less than 6.5-10 per 10,000 people.







Rare Diseases India, these include inherited cancers, autoimmune disorders, congenital malformations, Hirschsprung's disease, Gaucher disease, cystic fibrosis, muscular dystrophies and Lysosomal Storage Disorders (LSDs)







# Editorial special Rare diseases

#### India's fight against rare diseases

he tragic death of 19-year-old child active Suhani Bhatmagar from demandramyositis, a rare disorder that causes inflammation in muscles, came in the same month as Bare Disease Day, which smarked today. The last day of February every year is consecrated to support crores of individuals who, because of their rare medical conditions, have long been neglected and stignatised. According to the World Heiath Calculation of the Control of the Co

sarely 5% of the over 7,000 known liseases worldwide are treatable. Most patients typically receive only basic treatment that alleviates symptoms. Some require exorbitantly priced antidotes and supportive medication throughout heir lives, which they can't afford. Rare diseases in India

Rare diseases in India 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 Mucopolysacchardosis typ. 1 and S crore 10 crore Indians suffer from one rare disease or another; over 75% are children. Yet these diseases are largely overlooked.



Shashi Tharoor is third-term MP (Congress) for Thiruvananthapuram in the Lok Sabba and the Sabtya Akademi Award-winning autho of 25 books

Shashank

Shashank Shekhar is his Legislative and not the government's job. Timely and accruate diagnosis is indispensable for the robust management of any disease, yet for rare disease patients, it takes an average of seven years for their an average of seven years for their all. Physicians are generally unaware of how to interpret the signs and symptoms; healthcare professionals must be trained to improve their diagnostic accuracy. Expectant mothers with a history of rare diseases in their family pre-natal screening and post stands.

rare diseas Article with title: India are treatable. Worse, treatments approved by the Drugs Controller General of India are available for just about 20 rare diseases and can be availed only from Centres of Excellence (CoFa), Since CoFs are few (12), unevenly distributed, and uncoordinated, late diagnosis, inadequate therapies and lack of timely availability are the norm.

runas are a major chainenge too. The Budget's allocation for rare diseases, although increasing over the years, remains low at 193 crore for 2023-2024, with previous years having seen reductions of up to 75% from the Budget Estimate stage to the Revised Estimates and an even worse reduction 90% in actual expenditure. Under the than 20%. And in a classic case of abdication of governmental responsibility, NPRD has urged the COEs to crowdfund to treat rare disease patients. A portal with over 1,400 registered patients has collected less than 33 lakh in three years. Can crowdfunding ever be a sustainable national policy?

The way forward

Admittedly, the situation is not easy for the government, and to it credit, India has at least recognised rare diseases.

However, the efforts are far from easificatory. It is impossible force, it is impossible for the same force of the same force.

35 light against rare diseases diseases, increase budgetary outlays, dedicate funding for drug development and therapy, and therapy and increase the number of Colfs with and responsible utilisation of funds. State governments must introduce social assistance programmes and develop satellite centres under the CoRs. Public and private companies could be co-opted for funding. CSR

Finally, the issue of exorbitans.
Finally, the issue of exorbitan
drug prices and availability mus
be addressed. Last year, the
government waived off GST and
customs duty on medicines for
rare diseases. But this exemptio

#### The nagging problem of Katchatheevu

Though fisherfolk want to resume fishing in the islet, India cannot allow it

STATE OF PLAY

L. Srikrishna

part of Sri Lanka an located about 14 nau ical miles from Rameswara in Tamil Nadu, is back in the melight for the wrong reason On February 17, fisherme

On February I, fishemes associations in Rumanuthapu ram district announced that hey were boxcotting the an nual two-day festival, softe at the St. Anthony's Church in the uninhabited islet. Every year, fishe event brings together the people from both side of the Pails Bay separating in of the Pails Bay separating in of the Pails Bay separating for folk also amounced that they would observe an indefinite strike. These decisions were a midefinite and the painting and the paints the ST Lankan government's continuing arrests of indian fisher

Shift in approach

Though the response of the Sr Lankan authorities is not new there seems to be a shift in thway the island nation's judici



the original shrine of the Church was built by the Ramnad Diocese more than 100 years ago. As per the Sri Lankan Navy records, it was constructed in 1901. Though it was taken over by the Jaffna diocese after India ceded Katchatheevu to Sri Lanka in 1974, the two countries organise the festival together. In recent years, people from other States such as Karnataka have also been attending it.

Over the last Is-odd years, it has been a practice for the Church authorities to extend an invitation to the Verkodu parish, which, in turn, seek applications from pilgrims. On producing valid documents, pilgrims are allowed to cross the Palk Strati using trawlers. Their actions are monitored by Central and State agencies

and legal assistance to the imprisoned fisherme and work towards their early release. New Delhi abs been asking Colombo to treat the fishermen sisse as "a purely humanitarian and livelihood concern". It as says both sides should ensure that force is not used under any circumstance. Exen though the Srl Lankan authortics release the fishermen as a second to the control of the control

Resolving the issue

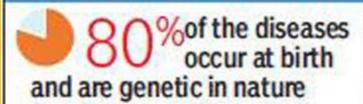
For about 10 years, the fishermen have been hoping that their issue will get resolved. Sushma Swaraj, as External Affairs Minister, had even organised a high-level meeting of fishermen from both the countries to work out a solution. "But this could not deliver results fully due to various political developments," Mr. Jesu Raja said.

Now, sections of the fisherfolk expect the Indian government to impress upon the Sri



## THE SCENARIO IN INDIA

FROM OVER 7,000 IDENTIFIED RARE DISEASES, 95% DO NOT HAVE ANY FDA APPROVED ORPHAN DRUGS



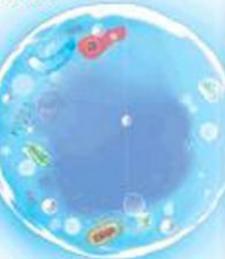
50%babies born with rare diseases die within a year of birth

#### ESTIMATES

9-10 crore | No. of people in India who suffer from rare diseases, which is 25% of global patients

#### 5.4 to 6.5 lakh

No, pf people in Hyderabad, of a population of 90 lakh, who suffer from rare diseases



40% | Chances of error in diagnosis during a patient's first visit

4.8 years | Average time taken for diagnosis

20 years | Maximum time taken to detect



#### SOME RARE DISEASES

- ➤ Thalassemia
- Sickle cell anaemia
- ➤ Ataxia
- Lysosomal storage disorder
- ➤ Congenital insensitivity to pain (rarest of rare)
- Acquired aplastic anaemia
- Muscular dystrophy
- Multiple sclerosis
- Sweet syndrome
- ➤ Paediatric cardiomyopathy

### **HOW INDIA CATEGORIZES** RARE DISEASES



#### Group 1

Disorders amenable to one-time curative treatment:

Treated with stem cell transplantation transplantation

Treated with organ

#### **Group 2**

Diseases requiring long term or lifelong treatment with relatively low cost

Managed with special dietary formulae or food for special medical purposes

Amenable to hormones or specific drugs

#### Group 3

Diseases for which definitive treatment is available but challenges are to make optimal patient selection for benefit, very high cost and lifelong therapy

# What is Dermatomyositis?

Dermatomyositis is a condition that affects the muscles, skin, and blood vessels, and it is both inflammatory and degenerative. Inflammatory myopathies are a category of disorders that cause the body's immune system to target healthy muscle tissue.





- There are fundamental challenges in the research and development for the majority of rare diseases as relatively little is known about the pathophysiology or the natural history of these diseases particularly in the Indian context.
- Rare diseases are also difficult to research upon as the patients pool is very small and it often results in inadequate clinical experience.
- Availability and accessibility to medicines are also important to reduce morbidity and mortality associated with rare disease.







# National Policy for Rare Diseases 2021 approved



- Provides for financial support upto Rs 20L to individuals with certain rare diseases that require one-time treatment.
- Assistance to be extended to not just BPL families, but to about 40% of the population who are covered under Pradhan Mantri Jan Arogya Yojana
- The financial support will be provided under the umbrella scheme of Rastriya Arogya Nidhi & not PM-IAY





# Editorial special text category

secture is estimated to be between 12,200 and 12,000 crore in the market. m

Item 15,30, while ustan consuments will pay a facebook.com/thehindu twitter.com/the\_hindu instagram.com/the\_hindu

On irregularities in vertical devolution

Agitations by different State governments in New Delhi bave highlighted many disquieting issues in the practice of fiscal federalism in India. In light of this the 16th FC must take initiative to correct historical wrongs in vertical devolution through compensations to the States

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# vertical devolutionand fiscal fedralism

- The net divisible pool, or net proceeds, is that part of the gross tax revenue from which a share would have to be vertically devolved by the Union to all States.
- Such shares are assigned by each FC for a five-year period.
- Earlier, all corporation taxes and customs duties were fully absorbed by the Union, and only income taxes and excise duties were shared with the States.

•





- However, with changes over the years, culminating in a constitutional amendment in 2000, all taxes of the Union were added to the net proceeds.
- But there was a catch cesses and surcharges under Article 270 and Article 271 were kept out of the net proceeds.
- In the past, such exclusion of cesses and surcharges were based on specific FC recommendations







- But the amendment in 2000 provided a constitutional basis for it. Presently, the net proceeds consists of the gross tax revenue after the deduction of cesses, surcharges and the cost of collection of taxes.
- Over the past decade or more, several cesses and surcharges were introduced by the Union government.
- When the Goods and Services Tax (GST)
   was initiated in 2017, the expectation was
   that many cesses and surcharges would be
   discarded and subsumed into the GST
   system.
- On the contrary, new cesses and surcharges continued to be introduced, and many old cesses and surcharges remained outside the GST system.











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Q "Without transparent vertical devolution, fiscal fedralism cannot be established" examine

प्रश्न ''पारदर्शी ऊर्ध्वाधर हस्तांतरण के बिना, राजकोषीय संघवाद स्थापित नहीं किया जा सकता है'' परीक्षण करें

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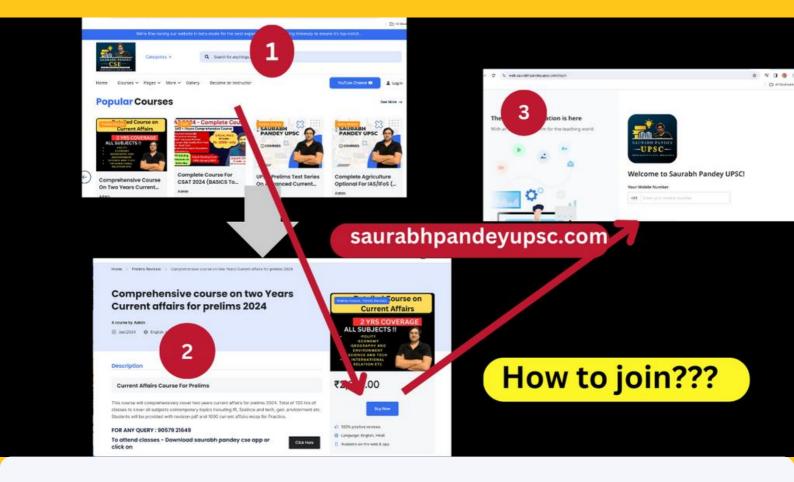
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