

## 29th Feb 2024

by saurabh pandey





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#### International Relations

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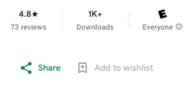
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### Topic-Article 371 A

 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. Speci□c 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 di □usely throughout the CNS.
- The CNS is involved in the release of various neurotransmitters, including dopamine, noradrenaline, and serotonin. CB1 is like a tra□c 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.





 According to the Organization for 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 Byearold child actress Suban Blatmagar from dermatomyosits, a rare disorder that causes inflammation in muscles, came in the same month as Rare Disease Day, which is marked 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 stigmatistic.

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. Most patients typically receive only basic treatment that alleviates symptoms. Some require exorbitantly priced antidotes and supportive medication throughout

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 Spiral Muscular Atrophy and Gaucher's disease to lesser-known ones such a bester-known ones such a property of the control of the control lesser known ones such a present the control of the control lesser known ones such a Whipple's disease. Roughly about 8 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 Thiruvananthapuran in the Lok Sabha and the Sahitya Akadem Award-winning auth of 25 books



Shashank Shekhar

Hittley and accurate tagglooss is indispensable for the robust management of any disease, yet for rare disease patients, it takes an average of seven years for their conditions to be diagnosed (fd at al). Physicians are generally unaware of how to interpret the signs and symptoms, healthcare professionals must be trained to Expectant mothers with a history of rare diseases in their family training the control of properties of the control of properties of the control of properties of properties of the control of properties properties of properties of properties properties of properties pro

must undergo mandatory
pre-natal screening and post-natal
diagnosis and care.
Less than four of the 450 odd.
rare diseas. Article with title: India

rare diseas Afficie with the: 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 (CoSa). Since CoSa are few (12), unevenly distributed, and uncoordinated, late diagnosis, inadequate therapies and lack of timely availability are the norm

Funds are a major chailenge too. The Budget's allocation for rare diseases, although increasing over the years, remains low at 293 crore for 2023-2024, with previous years having seen reductions of up to 75% from the Budget Estimates and an even worse reduction of 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 '\( 3 \) 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

's fight against rare diseases, increase budgetary outlays, dedicate funding for drug development and therapy, and increase the number of CoEs whill also ensuring better coordination and responsible utilisation of funds. State governments must introduce social assistance programmes and develop satellite centres under the CoEs. Public and private companies could be

leveraged to meet shortfalls.
Finally, the issue of exorbitan
drug prices and availability must
be addressed. Last year, the
government waived off GST and
customs duty on medicines for
rare disease. But this exemption

#### The nagging problem of Katchatheevu

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

STATE OF PLAY

L. Srikrishna srikrishna kitthehindu.co.

part of Sri Lanka located about 14 m ical miles from Rameswa in Tamil Nadu, is back in the melight for the wrong reas On February 17, fishers associations in Ramanthe

associations in Fama ram district announ they were boycottin nual two-day festiv duled for February 2 at the St. Authony's C. the uninhabited isle year, this event bring et the people from b of the Palk Bay sepan dia and Sri Lanka. TI folk also announced would observe an is strike. These decision mark of protest again mark of protest again uning arrests of India

Shift in approach

Though the response of the sr Lankan authorities is not new there seems to be a shift in the way 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.

it has been a practice for the Church authorities to extend an invitation to the Verkodu parish, which, in turn, seeks applications from pilgrims. On producing valid documents, pilgrims are allowed to cross the Palk Strait using trawlers. Their actions are monitored by Central and State asencies and legal assistance to the imprisoned fishermen and work towards their early release. towards their early release. lombo to treat the fishermen issue as "a purely humanitarian and livelihood concern." It says both sides should ensure that force is not used under any circumstance. Deen circumstance. Deen tities release the fishermen as a matter of routine, they do not return the impounded fishing vessels. The Ramanathapurram fishermen believe that time too, vessels were impounded and not returned.

Resolving the issue For about 10 years, the

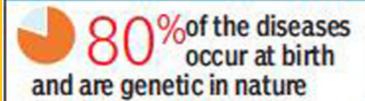
For about IO years, the fishermen have been hoping that their issue will get resolved. Sushma Swaraj, as External Affairs Minister, had even organised a high-level meeting of fishermen from both the countries to work out a solition. "But this could not deliver results fully due to various political developments,"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

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



## THE SCENARIO IN INDIA

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



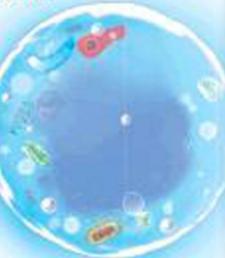
50%babies born with rare diseases die within a year of birth

#### 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

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#### On irregularities in vertical devolution







# 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

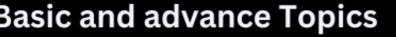




- But the amendment in 2000 provided a constitutional basis for it. Presently, the net proceeds consists of the gross tax revenue after the deduction of cesses, surcharges and the cost of collection of taxes.
- Over the past decade or more, several cesses and surcharges were introduced by the Union government.
- 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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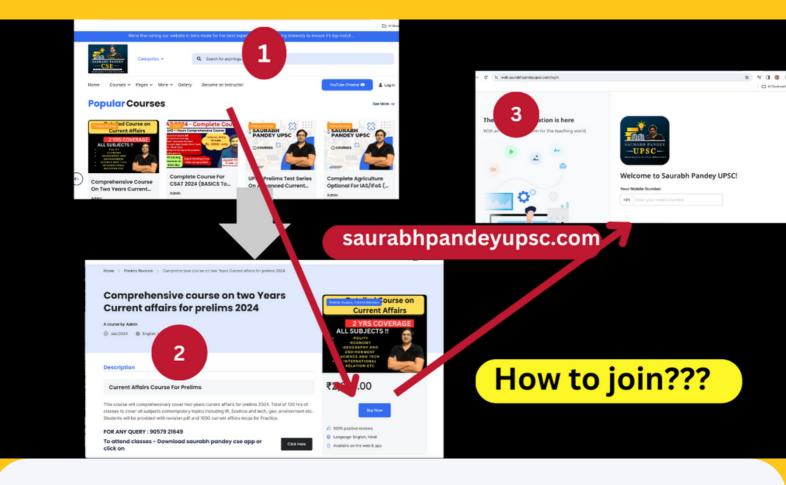
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