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MINISTRY OF SCIENCE AND TECHNOLOGY



MK Yadav Sir

Table of Contents

1. India’s Transplant Law
2. 106th Amendment Act
3. Global River Cities Alliance
4. India-Oman Relationship
5. National Energy Conservation Day
6. Article 356
7. CEC And Other ECs Bill 2023
8. Multi Modal Logistics Park
9. India’s Industrial Production
10. Pompe Disease

INDIAN EXPRESS

Page 12

INDIA'S TRANSPLANT LAW

(Syllabus: GS Paper 2 - Governance)

Kidney transplants in India: the law, the demand, the alleged rackets

ANONNA DUTT
NEW DELHI, DECEMBER 12

THE GOVERNMENT has ordered a probe into the findings of an investigation by *The Telegraph* published earlier this month, alleging that poor Myanmarese villagers were being lured into giving their kidneys to rich patients from that country, with the involvement of Delhi's Apollo hospital.

Organ donations and transplants in exchange for money are forbidden in India in order to protect poor and vulnerable donors from potential exploitation. Apollo has maintained that the transplants were performed only after receiving go-aheads from the authorisation committee, and a certificate from the Myanmar embassy certifying the donors as relatives.

Allegations of "kidney scams" have surfaced earlier too. Most alleged rackets rely on forged documents to establish a relationship between the donor and recipient.

India's transplant law

A transplant can be either from a pool of organs of deceased persons donated by their relatives, or from a living person the recipient knows. The Transplantation of Human Organs and Tissues Act, 1994 allows living donations, in most cases, from close relatives such as parents, siblings, children, spouse, grandparents, grandchildren. Altruistic donations from distant relatives, in-laws, or long-time friends are allowed after additional scrutiny to ensure there is no financial exchange.

For living donations from close relatives, involving Indians or foreigners, documents establishing their identities, family tree, documents, and pictures proving the donor-recipient relationship, and documents to show the financial standing of the donor have to be submitted. Donors and recipients are interviewed to establish the relationship.

YEAR-BY-YEAR IN THE COUNTRY

Year	Deceased	Living
2022	1,541	10,164
2021	830	8,275
2020	516	4,970
2019	1,138	8,613
2018	1,164	6,772

(Source: NOTTO)

For donations from unrelated persons, documents and photographic evidence showing their long-term association or friendship have to be submitted along with all other documents. Such cases are examined by an external committee to guard against illegal dealings.

Offering to pay for organs or to supply organs for payment, initiating/ negotiating/ advertising for such an arrangement, looking for a person to supply organs, and abetting in preparing false documents is punishable by jail up to 10 years and a fine of up to Rs 1 crore.

EXPLAINED HEALTH

Kidney among most targeted

One, the demand is very high. Every year, an estimated 2 lakh Indians reach end-stage kidney failure. All of them need either a transplant or regular dialysis, but only around 12,000 kidney transplants take place in the country every year.

It is also the transplant with the least risk to the donor.

Two, it is the cheapest and most accessible. A kidney transplant costs about Rs 5 lakh, which increases the pool of people who can undergo the procedure. More than 500 centres in India are trained to harvest or transplant kidneys, which provide more opportunities to people who want to undergo the surgery by getting around the law.

Three, the kidney is the organ that can survive the longest outside the body — 24-36 hours. In comparison, lungs remain viable only for 4-6 hours, and the liver for 8-12 hours.

Addressing supply gap

The pool of organs in India can be significantly increased by promoting deceased donations. Organs of only a small fraction of brain deaths are donated, even though they are the ideal candidates for organ donation.

To improve this percentage, the government has rolled out an Aadhaar-linked registry of donors so that their family members can be assured that it was their wish to donate if they die. Only 16% of the total transplants in the country use deceased organs. This, experts say, can be increased several-fold by increasing awareness.

There is also a need to reduce the number of people who require organ transplants.

Context: Recently, the government has ordered a probe into the findings of an investigation alleging that poor Myanmarese villagers were being lured into giving their kidneys to rich patients from that country.

India's Transplant Law

- **Source of Transplants**: A transplant **can originate from a pool of organs** donated by deceased persons' relatives or from a living person known to the recipient.
- **Regulation**: The Transplantation of Human Organs and Tissues Act, 1994 permits living donations, primarily from close relatives like parents, siblings, children, spouse, grandparents, and grandchildren.
  - Altruistic donations from distant relatives, in-laws, or long-time friends are allowed after additional scrutiny, ensuring no financial exchange.
- **Documentation for Living Donations**: In cases of living donations from close relatives, whether Indian or foreign, various documents including identity proofs, family tree, pictures, and documents proving the donor-recipient relationship must be submitted.
- **Unrelated Living Donations**: Donations from unrelated individuals require submission of documents and photographic evidence demonstrating a long-term association or friendship.
  - An external committee thoroughly examines such cases to prevent illegal dealings.
- **Legal Consequences**: Initiating or participating in transactions involving payment for organs, advertising such arrangements, seeking organ suppliers, and aiding in the creation of false documents are punishable offenses.
- **Penalties**: Imprisonment for up to 10 years and fines up to Rs 1 crore.

THE HINDU

Page 1

Lok Sabha passes Bills for women's quota in J&K, Puducherry

The Hindu Bureau
NEW DELHI


Nityanand Rai

The Lok Sabha on Tuesday passed two Bills to extend the provisions of the Constitution (106th Amendment) Act, which grants 33% reservation to women in the Lok Sabha and State Assemblies, to the Union Territories of Puducherry and Jammu and Kashmir. The debate in the House was, however, dominated by Supreme Court's verdict on Monday on Article 370.

Minister of State for Home Nityanand Rai introduced the Jammu and Kashmir Reorganisation (Second Amendment) Bill and the Government of Union Territories (Amendment) Bill in the Lok Sabha.

"Provisions for providing reservation for women in the Legislative Assembly of the Union Territory of Jammu and Kashmir are also required to be made by Parliament by amending the Jammu and Kashmir Reorganisation Act, 2019," said the Bill. The provisions for providing reservation for women in the Puducherry Assembly also need to be made by Parliament, the statement read.

National Conference's Hasnain Masoodi pointed out that while there was talk of representation, Jammu and Kashmir had no MLA since the last six years and that "four officers" were running the Union Territory.

106TH AMENDMENT ACT

Syllabus GS Paper 2 - Polity)

Context: Recently, the **Lok Sabha passed two Bills** to extend the provisions of the Constitution (106th Amendment) Act**, which grants 33% reservation to women** in the Lok Sabha and State Assemblies, to the Union Territories of Puducherry and Jammu and Kashmir.

The Constitution (106th Amendment) Act

- **About**: The Constitution (106th Amendment) Act, 2023, mandates the reservation of one-third of all seats for women in the Lok Sabha, State legislative assemblies, and the Legislative Assembly of the National Capital Territory of Delhi.
  - **This includes seats reserved for SCs and STs.**
- **Duration**: The reserved seats' implementation will take effect after the publication of the census conducted following the commencement of the Act.
  - The **reservation will endure for a 15-year period**, and any potential extension will be determined by parliamentary action.
- **Rotational Allocation of Reserved Seats**: The rotation of seats allocated for women will be governed by parliamentary legislation after each delimitation process, ensuring a fair and systematic distribution.
- **Current Representation Statistics**: Approximately 15% of the total members in the 17th Lok Sabha (2019-2024) are women. In state legislative assemblies, women, on average, constitute 9% of the total members.

PIB

Dec 12

GLOBAL RIVER CITIES ALLIANCE

(Syllabus: GS Paper 2 – IR)

NMCG Launches Global River Cities Alliance at the United Nations Climate Change Conference in Dubai

Context: "The Global River Cities Alliance (GRCA) was recently launched at COP28, the United Nations Climate Change Conference in Dubai."

Global River Cities Alliance (GRCA)

- **About:** GRCA is a unique alliance covering 275+ global river-cities in 11 countries, international funding agencies and knowledge management partners and is first of its kind in the world.
- **Led by**: National Mission for Clean Ganga (NMCG) under the Ministry of Jal Shakti
- **Global Expansion of RCA**: The GRCA extends the River Cities Alliance, initially established by NMCG with 142 Indian river cities, by incorporating river cities from Den Haag (Netherlands), Adelaide (Australia), and Szolnok (Hungary).
- **International Collaboration for River Conservation**: The alliance is dedicated to promoting global cooperation in river conservation and sustainable water management practices.
- **Memorandum of Common Purpose with US Initiative**:
- Previously, the RCA formalized a Memorandum of Common Purpose with the Mississippi River Towns and Cities Initiative in the United States.
- **Emphasis on Mainstreaming Rivers in Urban Planning**: The Director General of NMCG underscores the significance of integrating rivers into urban planning for overall environmental health.

Significance of RCA

- Enhancing **river basin cities to be water-sensitive, leading to improved** river health.
- Strengthening the **governance of river cities and enhancing their liveability** to attract external economic investments.
- **Advocating for Urban River Management Plans** and developing city-specific sectoral strategies to ensure sustainable urban river management.
- **Supporting member cities in the implementation of SDG6,** focusing on Clean Water and Sanitation.

National Mission for Clean Ganga (NMCG)

- **About**: It is formed to act as implementation arm of National Ganga River Basin Authority (NGRBA) which was constituted under the provisions of the Environment (Protection) Act (EPA),1986.
- **Established**: Year 2011 as a registered society under Societies Registration Act,1860.

FINANCIAL EXPRESS

Page 2

INDIA-OMAN RELATIONSHIP

(Syllabus: GS Paper 2 – IR)

Oman deal to boost India's presence in West Asia

FE BUREAU
New Delhi, December 12

INDIA HAS STARTED talks with Oman on a broad trade agreement. Apart from the immediate benefit of lower duties, the proposed pact also has the potential to open doors for India to have a larger presence in West Asia, according to a report.

While Oman's economic size and population limits the benefits that can be directly derived from the Comprehensive Economic Partnership Agreement (CEPA), its true value lies in fostering economic and strategic ties in the region of critical importance, says the report by trade policy think-tank Global Trade Research Initiative (GTRI).

"The CEPA is not just a trade agreement but a stepping stone towards a more robust and influential presence for India in West Asia," it said.



■ The negotiations for the India-Oman CEPA are advancing quickly, with India aiming for a swift conclusion

Oman's population is 5 million as compared to India's 1.4 billion. The West Asian country's economy is $115 billion as compared to $3.5-trillion Indian economy. Local opportunity for India's exports comes from the high per capita income in Oman which stands at $25,060.

The negotiations for the India-Oman CEPA are advancing quickly, with India aiming for a swift conclusion, replicating its successful fast-track negotiation strategy used with the UAE, Australia, the UK and the European Free Trade Association that includes Switzerland, Norway, Iceland and Liechtenstein.

With the UAE, the negotiations took just about a year while with Australia, the deal was concluded in six months.

"The India-Oman CEPA is expected to be a comprehensive agreement, building upon the terms India offered to the UAE, and will encompass a wide range of subjects, including goods, services and intellectual property," GTRI's co-founder Ajay Srivastava said.

Over 83.5% of India's goods exports, valued at $3.7 billion, currently face a 5% import duty in Oman. With the new Free Trade Agreement (FTA), products like gasoline, iron, steel and electronics will benefit from duty elimination. Petroleum products account for 49% of India's exports to Oman.

Around 16.5% of Indian exports to Oman worth $800 million already enjoy zero tariffs. These include wheat, basmati rice, fruits and vegetables, medicines, fish, tea and coffee.

India's imports from Oman were $7.9 billion last year, of which petroleum products accounted for $4.6 billion and urea $1.2 billion. The FTA will give an opportunity to Oman to diversify its economy to address the vast market offered by India.

In 2022, India's service exports to Oman were worth about $2.8 billion, while its imports were $200,000. India could seek increased access to the Omani market for business services and computer and information services, which Oman regularly imports. India might also negotiate for priority visas for its professionals on short-term assignments in Oman.

Context: "Recently, **India initiated discussions with Oman on a comprehensive trade** agreement, **aiming not only for immediate advantages such as reduced duties** but also foreseeing the potential to expand its influence in West Asia, as stated in a report."

- India and Oman are negotiating a comprehensive economic partnership agreement (CEPA), under which the two countries could significantly reduce or eliminate customs duties on the maximum number of goods agreed between them.

India-Oman Relations

- **Political Relations**: India considers Oman a crucial ally in the Gulf, serving as a strategic partner in various forums including the Gulf Cooperation Council (GCC), Arab League, and the Indian Ocean Rim Association (IORA).
- **Defence Cooperation**: India and Oman conduct regular biennial bilateral exercises between all three services. **Army exercise: Al Najah, Air Force exercise: Eastern Bridge and Naval Exercise: Naseem Al Bahr.**
- **Economic Relations:** India is among Oman's top trading partners. India is the 2nd largest market for Oman's crude oil exports for the year 2022 after China.
- India is also the **4th largest market for Oman's non-oil exports** for the year 2022 after UAE, US and Saudi Arabia and **2nd largest source of its import after UAE**.

Oman

- **About:** Oman, country occupying the southeastern coast of the Arabian Peninsula at the confluence of the Persian Gulf and Arabian Sea.
- **Bounded by**: Southwest - Yemen, South and East - Arabian Sea, North - Gulf of Oman, Northwest - United Arab Emirates West - Saudi Arabia.
- **Capital**: Muscat
- **Mountain Ranges**: North (Al-Hajar) and southeast coast (Qara or Dhofar Mountains)
- **Gulf of Oman**: It also known as the Gulf of Makran or Sea of Makran, forms the only entrance to the Persian Gulf from the Indian Ocean.
- **Bordering Countries**: It is bordered by Pakistan and Iran in the north, by the United Arab Emirates in the west and by Oman in the south.

PIB

Dec 12

NATIONAL ENERGY CONSERVATION DAY

(Syllabus: GS Paper 3 – Env and Eco)

National Energy Conservation Day 2023 to be celebrated on December 14, 2023

Context: "Recently, The President of India graced the National Energy Conservation Day 2023 function held at Vigyan Bhawan, New Delhi.

National Energy Conservation Day 2023

- **Celebrated:** On December 14 every year
- **Objective**: To raise awareness about global warming and climate change while encouraging initiatives to conserve energy resources. Additionally, it showcases the nation's accomplishments in the realms of energy efficiency and conservation.
- **Organized By**: The Bureau of Energy Efficiency (BEE), under Ministry of Power
- **Main Attractions:**
  - **National Energy Conservation Awards 2023**: To raise awareness about energy efficiency and its conservation, recognizes and encourages endeavours of industrial units, institutions, and establishments in reducing energy consumption by felicitating them>
  - **National Energy Efficiency Innovation Awards (NEEIA) 2023**: To recognize outstanding work and innovative minds of India in the area of Energy Efficiency, NEEIA was started in the year 2021.

Bureau of Energy Efficiency (BEE)

- **Set up**: On March 1, 2002 under the provisions of the Energy Conservation Act, 2001.
- **Mission**: To assist in developing policies and strategies with a thrust on self-regulation and market principles, within the overall framework of the Energy Conservation Act, 2001
- **Objective**: Reducing the energy intensity of the Indian economy.

ARTICLE 356
(Syllabus: GS Paper 2 – Polity)

Supreme Court: Irreversible changes can be made under Article 356

Context: The Supreme Court recently held that the declaration of State emergency under Article 356 and the subsequent actions of the President should have a "reasonable nexus".

Article 356

- **About:** In India, President's (or Governor's) rule is the suspension of state government and imposition of direct Union government rule in a state.
- **Under Article 356**: If a **state government is unable to function** according to Constitutional provisions, the Union government can take direct control of the state machinery.
- **Imposed in a State**: On recommendation of Governor in case of failure of constitutional machinery.
- **Duration**: 6 Months, A maximum of 3 years by approval of Parliament after every 6 months
- **Termination**: By President, any time (s)he deems fit; does not need Parliament's approval.
- **Parliament's Role**: Every such proclamation must get Parliament's approval within two months from date of issue.
- **New Provision**: The 44th Constitutional Amendment 1978 states that the President's Rule can't be imposed in any state beyond 1 year unless.
  - A Proclamation of National Emergency is in operation
  - The Election Commission certifies that the continuance of President Rule is necessary to hold Assembly elections.

Emergency provisions in India

- **National Emergency (Article 352):** An emergency due to war, external aggression or armed rebellion.
- **Presidents' rule (Article 356):** An Emergency due to the failure of the constitutional machinery in the states. It is also known by two other names–'**State Emergency' or 'constitutional Emergency**'. However, the Constitution does not use the word 'emergency' for this situation.
- **Financial Emergency (Article 360):** Financial Emergency due to a threat to the financial stability or credit of India.

ALL INDIA RADIO

Dec 12

CEC AND OTHER ECS BILL 2023
(Syllabus: GS Paper 2 – Polity)

RS passes bill regarding appointment and term of office of Chief Election Commissioner and other Election Commissioners

Context: The Rajya Sabha recently passed the Chief Election Commissioner and other Election Commissioners (Appointment, Conditions of Service and Term of Office) Bill, 2023."

The CEC and Other ECs (Appointment, Conditions of Service and Term of Office) Bill, 2023

- **Background:** In March of this year, the Supreme Court issued a ruling stating that a committee, **consisting of the Prime Minister, Leader of the Opposition in the Lok Sabha, and the Chief Justice of India**, should be responsible for appointing the CEC and ECs.

Major features of the New Bill

- **Committee Composition:** Prime Minister, the Leader of the Opposition in the Lok Sabha, and a Cabinet Minister nominated by the Prime Minister.
- **Qualifications for Appointment**: They should have held or currently hold a post equivalent to the rank of secretary.
- **Appointments Process**: The Selection Committee, consisting of the Prime Minister, the Leader of the Opposition in the Lok Sabha, and the nominated Cabinet Minister, will appoint the CEC and ECs from the prepared panel.
- **Search Committee**: It will consist of two other members not below the rank of Secretary to the government, knowledgeable in matters related to elections.

Election Commission India

- **About:** It is an autonomous constitutional body responsible for administering Union and State election processes in India.
- **Establishment:** 25th January 1950.
- **Appointment**: Under Article 324 (2), the President appoints the CEC and other
- **Tenure**: 6 years or until they reach the age of 65 years, whichever is earlier
- **Removal**: Similar to that of a Supreme Court judge
- **Aim**: To define and control the process for elections conducted at various levels: Parliament, State Legislatures, and the offices of the President and Vice President of India

LIVEMINT Page 11

MULTI MODAL LOGISTICS PARK

(Syllabus: GS Paper 3 – Economy)



NHAI inks pact for logistics park

The National Highways Authority of India (NHAI) has signed an agreement with DC Multi Modal Park (Nagpur) Ltd, a special purpose vehicle of DeltaBulk Shipping India Pvt Ltd, for the development of multi modal logistics park (MMLP) at Nagpur.

The MMLP will be developed in an area of 150 acres under the public private partnership model at an estimated cost of ₹673 crore.

This will be first MMLP in Maharashtra under the PM Gati Shakti National Master Plan. The MMLP will be developed in three phases. The phase-I with an investment of ₹137 crore is expected to be completed in two years. MMLP will cater to about 9.47 million tonnes (MT) cargo in the horizon period of 45 years and will give huge boost to the industrial zones in the catchment region such as Nagpur, Wardha, Chandrapur and Gondiya.

It will create a lot of employment opportunities and bring in economic development in the region, NHAI said in a statement.

SUBHASH NARAYAN

Context: NHAI has signed an agreement with M/s. DC Multi Modal Park (Nagpur) Limited, a SPV of M/S. DeltaBulk Shipping India Pvt. Ltd., for the development of Multi Modal Logistics Park (MMLP) at Nagpur.

- This **project is poised to be the first MMLP in Maharashtra under the PM Gati Shakti National Master Plan**, making it a significant milestone in the country's development.

Key Points

- The **multi-modal logistics park (MMLP)** will undergo **development in three phases**.
- **Phase-I of the Project**: It involves an investment of ₹137 crore and is anticipated to be completed within two years.
- The MMLP is designed to handle approximately 9.47 million tonnes (MT) of cargo over a span of 45 years.
- The **logistics park is expected to significantly enhance industrial activity** in the surrounding areas, benefiting regions such as Nagpur, Wardha, Chandrapur, and Gondiya.

Multi-Modal Logistics Park (MMLP)

- **About**: MMLP as an inter-modal freight-handling establishment comprising warehouses, dedicated cold chain facilities, freight or container terminals and bulk cargo terminals.
  - It eases and optimizes merchandise movement via road, rail, waterway and air.

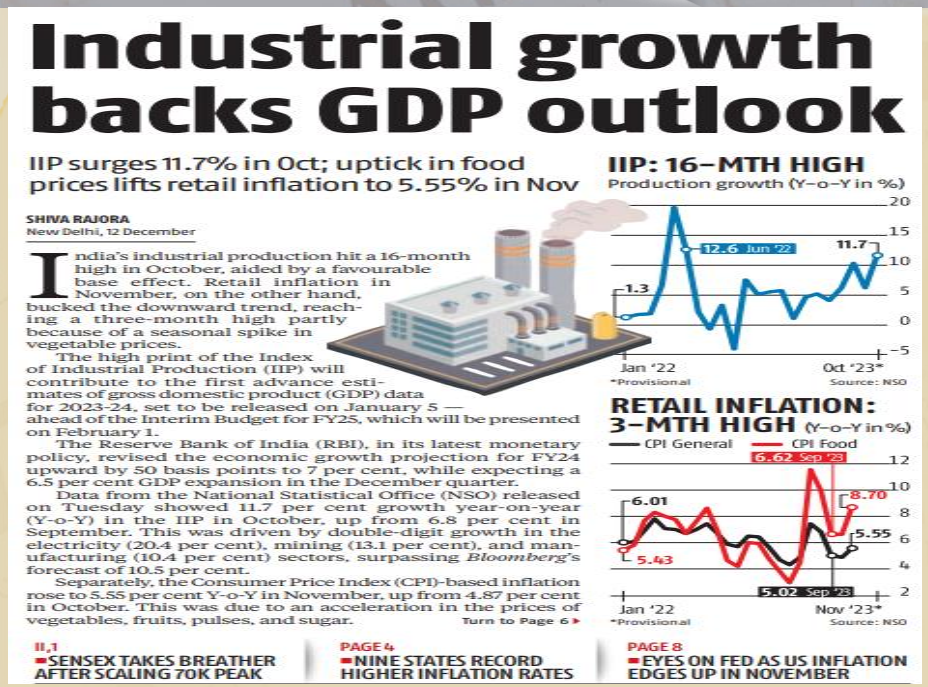
Significances of MMLP

- **Minimise Costs of Logistics**: It aims to reduce India's logistics costs from the current about 14% of GDP to less than 10% of GDP, on par with international standards.
- **Efficient Inventory planning:** Regional logistics parks can provide end-to-end visibility of inventory, collaboration, agility and optimization.
- **Maximise Utilisation of Assets**: It helps in the proper utilisation of assets as the transit time is less and the goods vehicles and the other hardware are free to use for the other business or purposes.
- **Environment Friendly**: Increased freight movement on higher sized trucks and rail will enable in reduction in CO_2 emissions.

BUSINESS STANDARD Page 1

INDIA'S INDUSTRIAL PRODUCTION

(Syllabus: GS Paper 3 – Economy)



Industrial growth backs GDP outlook

IIP surges 11.7% in Oct; uptick in food prices lifts retail inflation to 5.55% in Nov

SHIVA RAJORA
New Delhi, 12 December

India's industrial production hit a 16-month high in October, aided by a favourable base effect. Retail inflation in November, on the other hand, bucked the downward trend, reaching a three-month high partly because of a seasonal spike in vegetable prices.

The high print of the Index of Industrial Production (IIP) will contribute to the first advance estimates of gross domestic product (GDP) data for 2023-24, set to be released on January 5 — ahead of the Interim Budget for FY25, which will be presented on February 1.

The Reserve Bank of India (RBI), in its latest monetary policy, revised the economic growth projection for FY24 upward by 50 basis points to 7 per cent, while expecting a 6.5 per cent GDP expansion in the December quarter.

Data from the National Statistical Office (NSO) released on Tuesday showed 11.7 per cent growth year-on-year (Y-o-Y) in the IIP in October, up from 6.8 per cent in September. This was driven by double-digit growth in the electricity (20.4 per cent), mining (13.1 per cent), and manufacturing (10.4 per cent) sectors, surpassing *Bloomberg*'s forecast of 10.5 per cent.

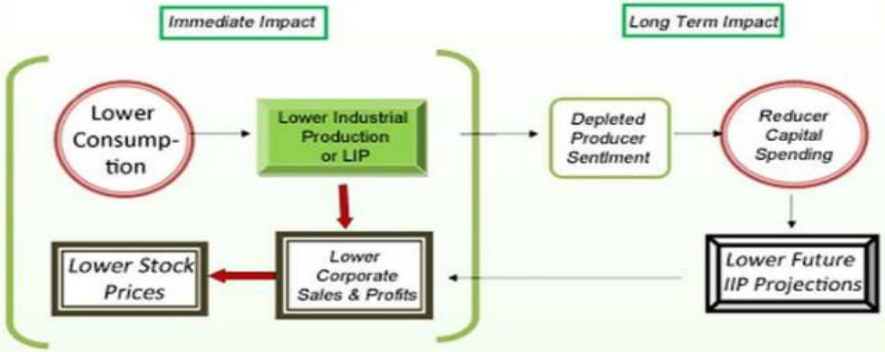
Separately, the Consumer Price Index (CPI)-based inflation rose to 5.55 per cent Y-o-Y in November, up from 4.87 per cent in October. This was due to an acceleration in the prices of vegetables, fruits, pulses, and sugar. Turn to Page 6 ▸

IIP: 16-MTH HIGH
Production growth (Y-o-Y in %)

RETAIL INFLATION: 3-MTH HIGH (Y-o-Y in %)

II,1 ■SENSEX TAKES BREATHER AFTER SCALING 70K PEAK
PAGE 4 ■NINE STATES RECORD HIGHER INFLATION RATES
PAGE 8 ■EYES ON FED AS US INFLATION EDGES UP IN NOVEMBER

IMPACT OF IIP ON INDIAN ECONOMY



Context: Recently, India's industrial production reached a 16-month high in October, benefiting from a favorable base effect.

India's Industrial Production

- **About**: IIP is an indicator that measures the changes in the volume of production of industrial products during a given period.
- **Published by**: National Statistical Office (NSO), Ministry of Statistics and Programme Implementation.
  - It is a composite indicator that measures the growth rate of industry groups classified under:
- **Broad Sectors**: Mining, Manufacturing, and Electricity.
- Use-based sectors: Basic Goods, Capital Goods, and Intermediate Goods.
- **Base Year**: 2011-2012.
- **Significance of IIP**: It is used by government agencies including the Ministry of Finance, the Reserve Bank of India, etc, for policy-making purposes.
- IIP remains extremely relevant for the calculation of the quarterly and advance GDP (Gross Domestic Product) estimates.

INDIAN EXPRESS

Page 12

POMPE DISEASE

(Syllabus: GS Paper 3 – Sci and Tech)

POMPE DISEASE

A rare genetic disorder that can impact mobility and everyday functions

RUPSA CHAKRABORTY
MUMBAI, DECEMBER 12

NIDHI SHIROL, India's first Pompe disease patient, passed away last month at the age of 24 after battling the disease for years. Nidhi spent the last six years of her life in a semi-comatose state.

In 2010, Nidhi's father Prasanna Shirol started the Organisation for Rare Diseases India, the first NGO in the country for rare diseases.

Rare genetic disorder

Also called the Glycogen Storage Disease Type II, Pompe disease is a rare genetic disorder caused by a deficiency of the enzyme acid alpha-glucosidase (GAA). This enzyme is crucial for breaking down glycogen into glucose within the lysosomes of cells.

The prevalence estimates of the disease range from 1 in 40,000 to 1 in 300,000 births. The age of onset and severity can vary, leading to a spectrum of clinical presentations.

Key symptoms

Muscle weakness: Progressive muscle weakness is a primary feature of Pompe disease. Weakness in the respiratory muscles can result in breathing difficulties, even while lying down.

Motor skill delay: Children with the disease may experience delays in achieving motor milestones such as sitting, crawling, and walking.

Respiratory complications: The weakening of respiratory muscles, can lead to shortness of breath, respiratory infections, etc.

Hypertrophic cardiomyopathy: It is characterised by the thickening of the heart muscle walls. This can lead to impaired heart functions.



Nidhi in a wheelchair, due to mobility issues. *Express*

The diagnosis

Enzyme assays are conducted to measure the activity of the deficient enzyme, GAA. Genetic testing identifies mutations in the responsible GAA gene. Genetic analysis confirms the presence of specific mutations associated with the disease. A diagnosis can help in timely intervention and symptoms management.

Is there a cure?

Not at the moment, but some treatment options can help improve the patient's quality of life. Enzyme Replacement Therapy, a standard treatment, involves the infusion of the missing enzyme to alleviate glycogen buildup.

Context: India's first Pompe disease patient, passed away last month at the age of 24 after battling the disease for years. Nidhi spent the last six years of her life in a semi-comatose state.

Pompe Disease

- **About:** It (also known as acid-maltase disease and glycogen storage disease II) is a rare genetic disorder that causes progressive weakness to the heart and skeletal muscles.
- **Caused by**: Mutations in a gene that makes an enzyme called acid. alpha-glucosidase (GAA), which the body uses to break down glycogen, a stored form of sugar used for energy.
  - Pompe disease happens **when your body can't make a protein that breaks down** a complex sugar, called glycogen, for energy. Too much sugar builds up and damages your muscles and organs.
- **Types**: **Onset** - First few month of Life, **Late Onset** - Any Age
- **Symptoms**: **Muscle weakness**: Progressive muscle weakness is a primary feature of Pompe.
- **Treatment**: Not at the moment, **but some treatment options can help improve the patient's quality of life**. Enzyme Replacement Therapy, a standard treatment, involves the infusion of the missing enzyme to alleviate glycogen buildup.

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