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Issues in the treatment of 'rare diseases', and what the govt can do

In August 2024, the government told Parliament that financial assistance of Rs 24 crore had been released to CoEs for treating rare disease patients until August in the current financial year.

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Therapies are available for less than 5% of rare diseases, leading to less than 1 in 10 patients receiving disease-specific care.

The Delhi High Court last week issued directions aimed at improving the availability of so-called “orphan drugs”, which are medications used to treat “rare diseases” — defined by the World Health Organization (WHO) as a debilitating, lifelong condition that affects 1 or fewer people in 1,000.

Around 55 medical conditions — including Gaucher’s disease, Lysosomal Storage Disorders (LSDs), and certain forms of muscular dystrophy — are classified as rare diseases in India. The National Registry for Rare and Other Inherited Disorders (NRROID) started by the Indian Council of Medical Research (ICMR) has the **records of 14,472 rare disease patients in the country.**

Therapies are available for less than 5% of rare diseases, leading to less than 1 in 10 patients receiving disease-specific care. Existing treatments are often very expensive. While the Centre provides financial assistance to various Centres of Excellence (CoE) for treatment, stakeholders have gone to court to highlight challenges in accessing funds.

Categories of rare diseases

In India, rare diseases are categorised into three groups based on the nature and complexity of available treatment options.

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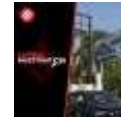


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Group 1 includes diseases that can be treated with a one-time curative procedure. Group 2 diseases require long-term or lifelong treatment which are relatively less costly and have shown documented benefits, but patients need regular check-ups. Group 3 diseases are those for which effective treatments are available, but they are expensive and must often continue lifelong. There are challenges in selecting the right beneficiaries for these treatments.

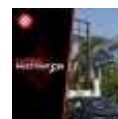
Current funding policy

In 2021, the National Policy for Rare Diseases (NPRD) was launched, under which financial assistance up to Rs 50 lakh is provided to patients receiving treatment at an identified CoE. The CoEs include AIIMS in Delhi, PGIMER in [Chandigarh](#) and the Institute of Postgraduate Medical Education and Research at Kolkata's SSKM Hospital.

The following year, the Health Ministry opened a Digital Portal for Crowdfunding & Voluntary Donations with information about patients and their rare diseases, the estimated cost of treatment, and bank details of the CoEs. Donors can choose the CoE and patient treatments they wish to support. Each CoE also has its own Rare Disease Fund, which is used with approval from its governing authority.

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In August 2024, the government told Parliament that financial assistance of Rs 24 crore had been released to CoEs for treating rare disease patients until August in the current financial year. Before that, Rs 3.15 crore, Rs 34.99 crore, and Rs 74 crore was released in 2021-22, 2022-23, and 2023-24 respectively. Further, Rs 35 crore has been released for purchasing equipment to improve patient care services.

Cost of orphan drugs

* Many medicines and therapies for rare diseases are patented, which makes them very expensive. The market for these drugs is small and the development costs are high, so pharmaceutical companies often don't find it profitable to produce them, pushing up prices.

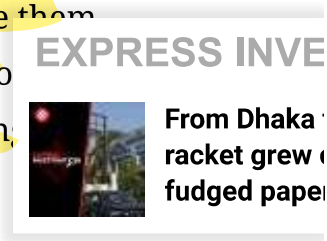
* Developing and manufacturing these drugs in India could help bring down prices, but the government will have to offer incentives such as tax breaks to companies.

* Import of rare disease medicines by patients does not attract customs duty, but companies that bring these drugs to India still pay 11% customs duty and 12% GST. Delhi High Court has now set a deadline of 30 days to process the necessary exemptions for these medicines under the customs, GST, and Income Tax laws.

* On January 3, 2019, the Department of Pharmaceuticals under the Union Ministry of Chemicals and Fertilisers issued an order freeing orphan drugs from price controls. The High Court expressed concern over this exemption, saying "the position cannot continue in this manner".

* If treatments or medicines for rare diseases are not available, the government can, under the Patents Act of 1970, allow a third party to manufacture them against

payment of a royalty to the patent holder. The government can also acquire patents to ensure the availability of medicines if the patent holder does not provide them. The court said there wasn't enough research and development in the field of rare diseases, and stressed that negotiating with pharma companies and boosting domestic efforts could help lower costs of treatment.



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* Delays and red tape in decision making is another problem. The National Rare Diseases Committee meeting in June 2023 discussed the delay in getting approval from the Drug Controller General of India (DCGI) for US-based Sarepta Therapeutics to sell its medicines in India. AIIMS and other CoEs were importing the drugs through distributors for patients, and the delay was impacting treatment.

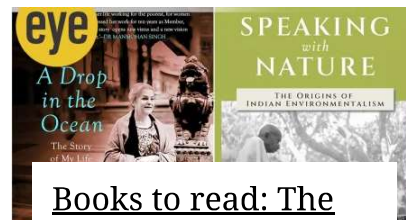
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