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DAILY NEWS ANALYSIS

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1. New rare disease policy is a chance to create an inclusive public health imagination.

- What is a rare disease?
- Why do we need nationwide policy to treat rare diseases?
- How should new and inclusive rare disease policy be framed?

GS paper 2 (Issues related to health, education and human resources)

DAILY NEWS ANALYSIS

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What is the context about?

- Recent developments have not given the rare disease community much to celebrate as India suspended the National Policy for the Treatment of Rare Diseases.
 - The suspension of the National Policy for the Treatment of Rare Diseases was a rude shock, particularly for those patients who were relying on the money allotted through the policy for life-saving treatments.
 - Government has announced a 'one-time financial assistance' for Rare diseases. The standing finance committee has approved a proposal for adding a sub-component under the umbrella scheme of Rashtriya Arogya Nidhi (RAN) .
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What is a rare disease?

- A rare disease, also referred to as an orphan disease, is any disease that affects a small percentage of the population. Most rare diseases are genetic, and are present throughout a person's entire life, even if symptoms do not immediately appear.
- Rare diseases are characterised by a wide diversity of symptoms and signs that vary not only from disease to disease but also from patient to patient suffering from the same disease. Relatively common symptoms can hide underlying rare diseases, leading to misdiagnosis.

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Why do we need nationwide policy to treat rare diseases?

- State has responsibility for providing affordable, accessible and reliable health-care services to every citizen. In fact constitution also mentions importance of health-care services under articles like 21, 38 and 47 and thus state cannot evade this responsibility under the pretext of non-justifiability of articles.
- Given the low volumes at which the drugs needed to treat such diseases would be consumed, pharmaceutical companies have little commercial incentive to produce them. Thus, a nationwide policy on orphan drugs could incentivize these players.

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● Even if pharmaceutical companies are incentivized to develop drugs to treat rare diseases, pharmaceutical companies remain beholden to the laws of economics and, given the low demand for orphan drugs, price these drugs as high as they choose to. Hence there has to be regulation of the government in restricting the exorbitant prices of the drugs.

● Although proportion of rare diseases is much less than the other diseases, it does not reduce the importance of the life of person affected by rare diseases. Thus national policy would remove this adverse distinction and would make government committed equally to all people.

How should new and inclusive rare disease policy be framed?

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● A new and inclusive rare disease policy should allocate substantial resources to research for the development of new platform therapies that could commonly treat different rare diseases, with the additional possibility of simultaneously bringing down the costs of current treatments.

● The government must not abandon the rare disease community to the market mechanism. Low incidence makes rare diseases “unprofitable” and companies are reluctant to invest in them..

● Giving incentives to pharmaceutical companies to develop treatments for rare diseases has resulted in treatments being priced so exorbitantly that even the government cannot afford to procure them for the economically weaker sections of society.
