



## A good start

### Principal of Inclusion:

It is binding on a welfare state to take care of every single citizen. Securing the wellbeing of everyone, particularly those unable to help themselves, irrespective of whether they constitute a critical mass or not, is important.

### Rare diseases:

1. The recent notification of the National Policy for Rare Diseases 2021 after various interventions, including the court, is pegged on this principle of inclusion.
2. A good start, it offers financial support for the one-time treatment of up to ₹20 lakh, introduces a crowdfunding mechanism, creates a registry of rare diseases, and provides for early detection.
3. 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.
4. WHO defines a rare disease as having a frequency of less than 6.5-10 per 10,000 people. As per an estimate, there are 7,000 known rare diseases with an estimated 300 million patients in the world; 70 million are in India.
5. 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).

Much of the effort in the sector, from the medical side, has been to evolve formal definitions, in the hope that it would support the development of and commercialisation of drugs for treatment, and improve funding for research on rare diseases.

The Centre can, however, still set aside a substantial corpus to fund life-saving treatments, even as it rolls out the policy. Doing so will not only complete a job well begun — even if not yet half done — but also cement its commitment towards the welfare of every single citizen in India.