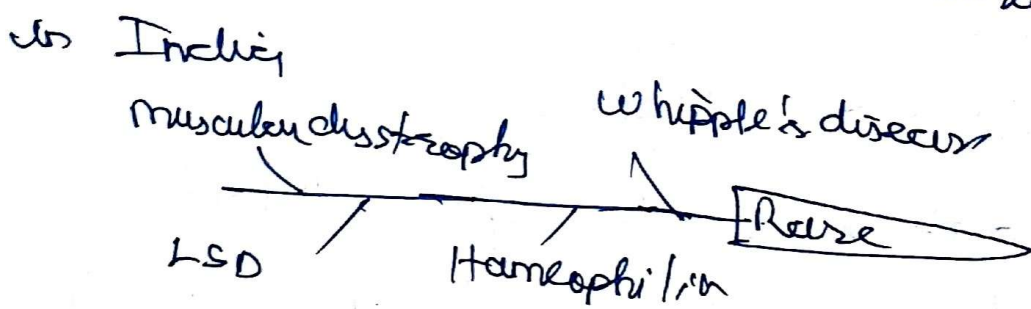


Rare diseases pose a significant health challenge affecting many. In this, discuss situation of RD in India & government strategies to address.

The World Health Organization defines rare diseases as one that affects 1 in 1000 population. India has been paying a silent price due to the burden of rare diseases.

Situation in India

* Rare diseases number in India is more than 450 affecting 8 to 10 crore people. But, less than 50% of rare diseases have treatment in India.



* Lack of funding - the National Policy of rare diseases allocates ₹50 lakh per patient which is

insufficient as the treatment cost exceeds costs in some diseases,

② Inadequate entry - the Drug Controller General of India has treatment for only 20 rare diseases in its entire of expenditure. These too, 50% of funds are unutilised because the legal issues.

③ No proper definition of rare diseases as present in India which hampers the treatment to the needy.

strategies to address

* First, is to define what constitutes a rare disease in the Indian context and develop a disease repository statute.

Second, Improve the funding to the scheme via CSR funds, private public partnership and enhanced grants

Third, exempt customs duty and GST for scarce drug imports for commercial purpose too as presently it is exempt for personal use.

Fourth, a new production linked incentive scheme for the production of scarce diseases drugs can be thought of.

where it can go,

As health is a state subject, states can take NAIP - provision against scarce diseases initiative to comprehensively address scarce disease synergised by similar policy from the centre can bring changes in law (9:50)