Vigyan Samachar/DBT News
15/01/2020

National Policy for Treatment of Rare Diseases (NPTRD) 2020

Rare diseases are low prevalence health conditions which affect small number of people compared to much prevalent diseases. It is estimated that about 6000 to 8000 rare diseases exist with new rare diseases being reported frequently around the world. However, 80% of all rare disease patients are affected by approximately 450 plus rare diseases.

Indian government formulated the National Policy for Treatment of Rare Diseases (NPTRD) in the year 2017. The policy was reviewed to address new challenges and to incorporate new information and updates available for further improvisation and effective implementation. The state governments can consider supporting patients with rare diseases by providing them with special diets, hormonal supplements or other relatively low cost interventions.

According to draft of rare diseases policy 2020, Government of India has proposed a financial support of up to Rs 15 lakh under the *Rashtriya Arogaya Nidhi* (RAN) Scheme for one time treatment of patients with rare diseases. Draft has also proposed setting up a digital platform for individuals and corporate donors to contribute to the treatment cost of patients with rare diseases.

The scheme aims at providing interventions to ensure more years of healthy life to poor people who cannot afford healthcare. The three important objectives of the NPTRD Policy 2020 are:

1. A financial support up to Rs. 15 lakhs from Central Government for treatment of rare diseases that require a one-time treatment.
2. State Governments can consider supporting patients of such rare diseases that can be managed with multiple low cost interventions.
3. Creation of an alternate funding mechanism through setting up a digital platform for voluntary individual and corporate donors to contribute to the treatment cost of patients of rare diseases.

Some globally considered rare diseases include haemophilia, thalassemia, sickle-cell anaemia and primary immuno deficiency in children, auto-immune diseases, lysosomal storage disorders like pompe disease, hirschsprung disease, Gaucher's disease, cystic fibrosis, hemangiomas and multiple muscular dystrophies.

The policy is an attempt to reduce the burden of astronomically high treatment costs of such disease; however, it still remains to see whether or not the one time treatment is sufficient for patients suffering from muscular dystrophies, thalassemia, sickle cell anaemia etc. furthermore, there is a need to creating awareness among primary care physicians, and to facilitate adequate screening and diagnostic facilities in resource constrained health settings of India.

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