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National Policy for Rare Diseases 2020: Patient Groups express dejection

14 January 2020 | News

The Government reviewed the policy in order to improve and effectively implement it

NATIONAL POLICY FOR RARE DISEASES

2020

Government of India had formulated a National Policy for Treatment of Rare Diseases (NPTRD) in the year 2017. However, the Government decided to review the policy due to implementation challenges and in the light of new information and updates available/received for its further improvement and effective implementation.

Policy 2020:

1. Financial support up to Rs. 15 lakhs under the Umbrella Scheme of Rashtriya Arogaya Nidhi (RAN) shall be provided by the Central Government for treatment, of those rare diseases that require a one-time treatment
2. State Governments can consider supporting patients of such rare diseases that can be managed with special diets or hormonal supplements or other relatively low-cost interventions
3. The Government will endeavor to create 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

In response to this, patient groups are expressing their dejection on the draft National Policy for Rare Diseases 2020.

"The policy is good in terms of thinking and long-term direction. But it is far from reality and genuine interest in providing the much-needed treatment to the treatable Rare Diseases. There is no clarity, financial commitments, the group 3 Diseases where we were eagerly waiting, the plan is a mockery such as creating a digital platform for Crowd Funding. How can you design a policy based on donations by the government? The policy is just another piece of paper" - Prasanna Shirol, Founder of the Organization for Rare Disease India (ORDI).

"This is not even draft policy document, it is like reading a document on Rare Diseases, more like a definition to layman - an illusion. Even the Draft makers could not comprehend in line. Most pages refer to definitions to rare Diseases, why so? A disease is a disease, why tag it with adjectives and phrases and nouns and pronouns. If there is definite cure, care to manage that. The best part of the document refers to add extensive diseases, which is appropriate and appreciable part texted by our experts Medical and Geneticists of India’s Prime Government medical institutions like AIIMS, Delhi, PGI Lucknow, PGI Chandigarh, KEM Mumbai and MAMC Delhi. But sadly, the government has not and had no intentions to make this policy workable. Most of the diseases will not be covered in one-time solution of upto Rs. 15 lacs. or excuse of Crowd Funding and stressing the states to do their best. No patient of Lysosomal Storage Disorders (LSDs) will be eligible. The Ministry and Brooding ill-will political intention of people at helm aka bureaucratic delays and their hands bound, there doesn't seem to be any way forward. It's just an eye wash" - Manjit Singh, President, Lysosomal Storage Disorders Support Society.