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Rare Diseases Policy 2021 focuses on indigenous research for treatment

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The Rare Diseases Policy aims to lower the high cost of treatment for rare diseases

Dr Harsh Vardhan, Union Health & Family Welfare Minister approved the “National Policy for Rare Diseases 2021” on 30th March 2021. For quite some time different stake holders have been demanding for a comprehensive policy for prevention and management of rare diseases.

The Rare Diseases Policy aims to lower the high cost of treatment for rare diseases with increased focus on indigenous research with the help of a National Consortium to be set up with Department of Health Research, Ministry of Health & Family Welfare as convenor.

Increased focus of research and development and local production of medicines will lower the cost of treatment for rare diseases. The policy also envisage creation of a national hospital based registry of rare diseases so that adequate data is available for definition of rare diseases and for research and development related to rare diseases within the country.

The Policy also focuses on early screening and prevention through primary and secondary health care infrastructure such as Health and Wellness Centres and District Early Intervention Centres (DEICs) and through counselling for the high-risk parents. Screening will also be supported by Nidan Kendras set up by Department of Biotechnology.

Policy also aims to strengthen tertiary health care facilities for prevention and treatment of rare diseases through designating 8 health facilities as Centre of Excellence and these CoEs will also be provided one-time financial support of up to Rs 5 crores for upgradation of diagnostics facilities.

A provision for financial support up to Rs. 20 lakhs under the Umbrella Scheme of Rastriya Arogya Nidhi is proposed for treatment, of those rare diseases that require a one-time treatment (diseases listed under Group 1 in the rare disease policy). Beneficiaries for such financial assistance would not be limited to below poverty line (BPL) families, but the benefit will be extended to about 40% of the population, who are eligible under Pradhan Mantri Jan Arogya Yojana.

Besides, the Policy also envisages a crowd funding mechanism in which corporates and individuals will be encouraged to extend financial support through a robust IT platform for treatment of rare diseases. Funds so collected will be utilized by Centres of Excellence for treatment of all three categories of rare diseases as first charge and then the balance financial resources could also be used for research.