

RARE DISEASES POLICY

Relevant for: Developmental Issues | Topic: Health & Sanitation and related issues

National Policy for Rare Diseases, 2021 (the Policy) has been finalized and put in public domain.

The Policy can be accessed at website- <https://main.mohfw.gov.in/documents/policy>.

The Policy aims at lowering the incidence and prevalence of rare diseases based on an integrated and comprehensive preventive strategy encompassing awareness generation, premarital, post-marital, pre-conception and post-conception screening and counselling programmes to prevent births of children with rare diseases, and within the constraints on resources and competing health care priorities, enable access to affordable health care to patients of rare diseases.

Initiatives for treatment support for patients of rare diseases under the Policy are as follows: -

i. Financial support up to Rs. 20 lakhs under the Umbrella Scheme of Rashtriya Arogya Nidhi shall be provided by the Central Government for treatment, of those rare diseases that require a one-time treatment (diseases listed under Group 1). Beneficiaries for such financial assistance would not be limited to BPL families, but extended to about 40% of the population, who are eligible as per norms of Pradhan Mantri Jan Arogya Yojana, for their treatment in Government tertiary hospitals only.

ii. 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 (Diseases listed under Group 2).

iii. Keeping in view the resource constraints, and a compelling need to prioritize the available resources to get maximum health gains for the community/population, the Government will endeavour 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.

iv. Voluntary crowd-funding for treatment: Keeping in view the resource constraint and competing health priorities, it will be difficult for the Government to fully finance treatment of high-cost rare diseases. The gap can however be filled by creating a digital platform for bringing together notified hospitals where such patients are receiving treatment or come for treatment, on the one hand, and prospective individual or corporate donors willing to support treatment of such patients. The notified hospitals will share information relating to the patients, diseases from which they are suffering, estimated cost of treatment and details of bank accounts for donation/

contribution through online system. Donors will be able to view the details of patients and donate funds to a particular hospital. This will enable donors from various sections of the society to donate funds, which will be utilized for treatment of patients suffering from rare diseases, especially those under Group 3. Conferences will be organized with corporate sector companies to motivate them to donate generously through digital platform. Ministry of Corporate Affairs will be requested to encourage PSUs and corporate houses to contribute as per the Companies Act as well as the provisions of the Companies (Corporate Social Responsibility Policy) Rules, 2014 (CSR Rules). Promoting health care including preventive health care is included in the list in the Schedule for CSR activities.

Treatment cost of the patient will be first charge on this fund. Any leftover fund after meeting treatment cost can be utilized for research purpose also.

At present financial assistance to poor patients, living below threshold poverty line and also to the population, who are eligible as per norms of Pradhan Mantri Jan Arogya Yojana under Ayushman Bharat, suffering from specified rare diseases for their treatment at Government Hospitals or Institutes having super specialty facilities / Government tertiary hospitals is being provided under the Umbrella Scheme of Rashtriya Arogya Nidhi (RAN). The budget allocation for the current financial year 2021-2022 for rare diseases is Rupees 25 Crore.

National Policy for Rare Diseases, 2021 provides for National Consortium for Research and Development on therapeutics for Rare Diseases with an expanded mandate to include research & development, technology transfer and indigenization of therapeutics for rare diseases. It will be convened by Department of Health Research (DHR) with ICMR as a member.

The Union Minister of State for Health and Family Welfare, Dr. Bharati Pravin Pawar stated this in a written reply in the Lok Sabha here today.

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HFw/PQ-Rare Diseases Policy/23rdJuly2021/6

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