

**GOVERNMENT OF INDIA
MINISTRY OF HEALTH AND FAMILY WELFARE
DEPARTMENT OF HEALTH AND FAMILY WELFARE**

**RAJYA SABHA
UNSTARRED QUESTION No. 1551
TO BE ANSWERED ON 20th DECEMBER, 2022**

FINANCIAL ASSISTANCE TO THE PATIENTS WITH RARE DISEASES

1551. SHRI K.R.N. RAJESHKUMAR:

Will the Minister of **HEALTH AND FAMILY WELFARE** be pleased to state:

- (a) whether it is a fact that, the Ministry is providing financial assistance to the patients who are suffering from rare diseases in the country;
- (b) if so, the details of the applications received in last three years;
- (c) the quantum of funds released in last three years, State-wise;
- (d) the details of advanced treatments available in the country for the treatment of rare diseases, State-wise and specialty-wise; and
- (e) the details of support rendered to those patients, if treatments are not available in the country?

**ANSWER
THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY
WELFARE
(DR. BHARATI PRAVIN PAWAR)**

(a) to (c): The Government has launched National Policy for Rare Diseases (NPRD), 2021 for the treatment of rare disease patients. Financial assistance upto Rs. 50 lakhs is provided to the patients suffering from any category of the rare diseases and getting treatment in any of the Centre of Excellence (CoE) identified under NPRD-2021. Ten (10) CoEs have been identified as on date.

Financial assistance to rare disease patients is released to the treating CoE only for the treatment of rare diseases identified and categorized under NPRD, 2021. Therefore, State-wise and specialty-wise data is not maintained. A total of Rs. 21.63 Crore (Rs. Twenty One Crore Sixty Three Lakh Only) has been released by the Government for the treatment of patients suffering from rare diseases under the Umbrella Scheme of Rashtriya Arogya Nidhi

(RAN) [upto March 2021] and in accordance with the provisions of NPRD, 2021 (from 1st April 2021 onwards).

(d): Some advanced treatments available in the country for the patients suffering from rare diseases are as below:

- (i) Enzyme replacement therapy for Lysosomal storage disorders e.g. Gaucher's disease, Mucopolysaccharidosis, Pompe disease, Fabry disease etc.
- (ii) Spinal Muscular Atrophy: Gene therapy (Zolgensma), Nusinersen, Risdiplam.
- (iii) Haematopoietic stem cell transplantation (HSCT) for various disorders like Inborn errors of Immunity.
- (iv) Small molecule diseases (e.g. Urea cycle defects, Organic acidemia, Aminoacidopathies etc): Emergency management and Dietary therapy {Foods for Special Medical Purpose (FSMP)}.

(e): Supportive therapy including physiotherapy, assistive devices, behavioral therapy, nutritional rehabilitation, respiratory support and symptomatic treatment is provided as per need at the CoEs for the patients with Rare Diseases.
