

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

**LOK SABHA  
UNSTARRED QUESTION NO. 1764  
TO BE ANSWERED ON 16<sup>TH</sup> DECEMBER, 2022**

**RARE DISEASES**

**1764. ADV. DEAN KURIAKOSE:**

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

- (a) Whether the Government has envisaged any scheme/plan to ensure timely treatment for children below 18 years of age suffering from rare diseases or diseases that require expensive treatment (above Rs. 5 lakhs);
- (b) If so, the details thereof;
- (c) Whether the Government has any plans to provide financial assistance to children below 18 years of age who require organ transplant;
- (d) If so, the details thereof;
- (e) Whether the Government has taken/proposes to take steps regarding upgradation of Trivandrum Medical College and Kozhikode Medical College as centres of excellence; and
- (f) If so, the details thereof and if not, the reasons therefor?

**ANSWER**

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

(a) & (b): The Government has launched National Policy for Rare Diseases (NPRD), 2021 in March, 2021 for the treatment of rare disease patients. Financial support 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.

(c) & (d): Under the Umbrella Scheme of Rashtriya Arogya Nidhi (RAN), financial assistance for life threatening diseases including organ transplant viz. heart/lung, liver, renal, kidney (ceiling cost upto CGHS rates) is provided to the poor patients living below State/UT-wise threshold poverty line and getting treatment at Government hospitals. In addition, financial assistance under National Organ Transplant Program is provided for post-transplant immune suppressant medicines to recipients belonging to Below Poverty Line (BPL) category and have undergone transplant in a Government hospital.

(e) & (f): As per the provision envisaged under para 9.1 of the policy, Centres of Excellence (CoEs) can be added for regional outreach based on recommendations of technical committee. An expert panel has inspected Trivandrum Medical College and Kozhikode Medical College, Kerala.

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