

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

**LOK SABHA
UNSTARRED QUESTION No. 3830
TO BE ANSWERED ON 25th March, 2022**

FUNDS FOR TREATMENT OF RARE DISEASES

3830. SHRI RAVNEET SINGH BITTU:

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

- (a) whether the Government is cognizant of the reduction in donations leading to delay in treatment of children suffering from rare diseases in the country and if so, the details thereof;
- (b) the total amount mobilised by the Government in this regard during the last three years, year-wise;
- (c) whether the Government proposes to extend the benefits of the Rashtriya Arogya Nidhi (RAN) scheme to Group 3(a) patients too;
- (d) if so, the details thereof and if not, the reasons therefor; and
- (e) the other measures being taken by the Government to ensure availability of sufficient funds for timely treatment of the children suffering from rare diseases in the country?

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

(a) to (e) The National Policy for Rare Diseases (NPRD), 2021 was published on 30.03.2021. As per provisions envisaged in the policy, for the diseases/disorders amenable to one time curative treatment (listed under Group-I), financial support under umbrella scheme of RAN, an amount upto Rs. 20 lakh for entitled beneficiaries is provided by the Central Government. The diseases requiring long term/ lifelong treatment having relatively lower cost of treatment (listed under Group 2), the financial support is envisaged to provide by the State Governments. The diseases for which definite treatment is available but involves very high cost and lifelong therapy (listed under Group 3), the

policy provides assistance to the patients through Digital Platform inviting voluntary donations from individuals and corporate donors. Donors have a choice to make donations to different Centres of Excellence (CoEs) and for the patients treated by these CoEs.

The total amount released by the Government for treatment of Rare Disease Patients during the last three years, is as follows:

- (i) Year 2019-20 – Rs. 1.30 Crore
- (ii) Year 2020-21 – Rs. 10 Crore
- (iii) Year 2021-22 – Rs. 03 Crore