

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

**RAJYA SABHA
UNSTARRED QUESTION No. 604
TO BE ANSWERED ON 25th July, 2023**

APPLICATIONS RECEIVED FOR SEEKING FUNDS TO TREAT RARE DISEASES

604. SHRI K. R. N. RAJESHKUMAR:

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

- (a) the details of the applications received for seeking funds to treat rare diseases;
- (b) the status and decision taken on those applications, State-wise;
- (c) the details of the funds disbursed and the current status of the treatments, State-wise; and
- (d) if not, the reasons therefor?

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

- (a) to (d) The Government implemented National Policy for Rare Diseases (NPRD) with effect from 30th March 2021. Eleven (11) Centres of Excellence (CoEs) have been identified. The financial support for rare diseases patients has been increased from up to Rs. 20 lakhs to up to Rs. 50 lakhs per patient. Details of funds released to CoEs under NPRD, 2021 is tabulated below:

Financial Year	Amount (in Rs.)	No. of Patients/beneficiary
2021-22	3.15 crore	Rs. 3 crore to 22 patients through Registry of Hon'ble High Court of Karnataka and Rs. 15 lakh for one patient to AIIMS, New Delhi.
2022-23	34.99 crore	203

Treatment of the patients starts immediately after their registration in the Centres of Excellence.
