

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

**RAJYA SABHA
UNSTARRED QUESTION No. 435
TO BE ANSWERED ON 6th FEBRUARY 2024**

FINANCIAL ASSISTANCE TO PATIENTS SUFFERING FROM RARE DISEASES

435: SHRI JOSE K. MANI:

Will the **MINISTER OF HEALTH AND FAMILY WELFARE** be pleased to state:

- (a) whether Government has the details of the financial assistance provided to patients who are suffering from rare diseases in the country over the last three years;
- (b) if so, the details thereof, State-wise;
- (c) the details of additional support and facilities provided by Government to patients who are suffering from rare diseases;
- (d) whether Government has any plans to increase the quantum of financial assistance provided to patients who are suffering from rare diseases in the country; and
- (e) if so, the details thereof?

ANSWER

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

(a) & (b): Financial support up to Rs. 50 lakhs per patient is provided under National Policy for Rare Diseases (NPRD), 2021 for treatment of rare diseases. Financial assistance of Rs. 3.15 crore, Rs. 34.99 crore and Rs. 71.00 crore has been released to the Centers of Excellence (CoEs) in the financial years 2021-22, 2022-23 and 2023-24 respectively for the treatment of rare disease patients. The financial assistance is extended to CoEs and not to State Governments as per the provisions of NPRD. Hence, the State-wise details of financial assistance are not maintained. CoE-wise details are annexed.

(c): The Department of Revenue, Ministry of Finance, vide Notification dated 29.03.2023, provided full exemption from Basic Customs Duty (BCD) on Drugs or Medicines imported for persons suffering from rare disease and require these drugs or medicines or Food for Special Medical Purpose (FSMP) for the treatment of rare disease, if imported by an individual, for personal use or through CoEs, for treatment of rare disease. Further, vide Notification dated 26.07.2023, Integrated Goods and Services Tax (IGST) on medicines and FSMP used in the treatment of rare diseases enlisted under the NPRD, 2021 has been exempted when imported for personal use, subject to existing conditions.

(d) & (e): Financial assistance for treatment of rare diseases was enhanced from Rs. 20 lakhs to Rs. 50 lakhs from 19th May, 2022. Increase or decrease in financial assistance is dependent upon the treatment outcome of rare diseases and resource envelope available under the programme.

COE-WISE EXPENDITURE DETAILS**Financial Year 2021-22**

S. No.	Name of the CoE	Financial Assistance released in FY 2021-22 (In Rs.)
1.	CHG-IGI, Bengaluru	3,00,00,000
2.	AIIMS, New Delhi	15,00,000
Total		Rs. 3,15,00,000/- (Rs. Three Crore Fifteen Lakh Only)

Financial Year 2022-23

S. No.	Name of the CoE	Financial Assistance released in FY 2022-23 (In Rs.)
1.	CDFD-NIMS, Hyderabad	4,38,47,943
2.	KEM, Mumbai	1,99,70,876
3.	SGPGI, Lucknow	3,40,00,000
4.	PGIMER, Chandigarh	3,92,95,360
5.	ICH&HC, Chennai	4,94,63,018
6.	CHG-IGI, Bengaluru	5,38,45,000
7.	AIIMS, New Delhi	7,88,29,854
8.	IPGIMER, Kolkata	1,66,40,000
9.	MAMC, Delhi	1,40,10,000
Total		Rs. 34,99,02,051/- (Rs. Thirty Four Crore Ninety Nine Lakh Two Thousand Fifty One Only)

Financial Year 2023-24

S. No.	Name of CoE	Financial Assistance released in FY 2023-24 (In Rs.)
1.	AIIMS, New Delhi	35,00,00,000
2.	MAMC, Delhi	3,00,00,000
3.	SGPGI, Lucknow	3,00,00,000
4.	PGIMER, Chandigarh	3,00,00,000
5.	IPGMER, Kolkata	3,00,00,000
6.	KEM, Mumbai	3,00,00,000
7.	CDFD-NIMS, Hyderabad	3,00,00,000
8.	CHG-IGI, Bengaluru	9,00,00,000
9.	AIIMS, Jodhpur	3,00,00,000
10.	ICH&HC, Chennai	3,00,00,000
11.	SAT, Thiruvananthapuram	3,00,00,000
	Total till date	Rs. 71,00,00,000/- (Rs. Seventy One Crore Only)