

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

**LOK SABHA
UNSTARRED QUESTION No. 1247
TO BE ANSWERED ON 9th FEBRUARY, 2024**

ENROLLMENT OF RARE DISEASE PATIENTS

1247. DR. SHASHI THAROOR:

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

- (a) the number of Rare Diseases Patients enrolled within the Centres of Excellence across the country;
- (b) the details of the allocation and utilisation of funds by the different Centres of Excellence across the country during the last three years and the current year till date, year-wise;
- (c) whether regular meetings have been conducted by the National Rare Diseases Commission ever since its constitution by the Delhi High Court in 2023; and
- (d) 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) Rare Disease patients, who are amenable to treatment, are enrolled with Centres of Excellence (CoEs). As per the data maintained by 12 CoEs, there are 2420 patients enrolled as on date.
- (b) The National Policy for Rare Disease, 2021 was launched on 30.03.2021. The details of financial assistance released to the different Centres of Excellence across the country for treatment of patients during the last three years and the current year till date, year-wise, is annexed.
- (c) & (d) In compliance with the Order dated 15.05.2023 of the Hon'ble High Court of Delhi in the matter of WP No. 5315/2020 and other connected petitions, a National Rare Diseases' Committee (NRDC) under the Chairmanship of Secretary, Department of Health Research & DG, ICMR was constituted by the Ministry of Health and Family Welfare (MoHFW). As of now, twelve(12) NRDC meetings have been held since constitution of the Committee.

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

S. No.	Name of the CoE	Financial Assistance released in FY 2021-22 (In Rs.)	Funds Utilized (In Rs.)
1.	Center for Human Genetics (CHG) with Indira Gandhi Hospital, Bengaluru	3,00,00,000	3,00,00,000
2.	All India Institute of Medical Sciences, New Delhi	15,00,000	8,93,993

Financial Year 2022-23

S. No.	Name of the CoE	Financial Assistance released in FY 2022-23 (In Rs.)	Funds Utilized (In Rs.)
1.	Centre for DNA Fingerprinting & Diagnostics with Nizam's Institute of Medical Sciences, Hyderabad	4,38,47,943	6,21,690
2.	King Edward Medical Hospital, Mumbai	1,99,70,876	1,67,45,652
3.	Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow	3,40,00,000	3,40,00,000
4.	Post Graduate Institute of Medical Education and Research, Chandigarh	3,92,95,360	1,04,20,101
5.	Institute of Child Health and Hospital for Children (ICH & CH), Chennai	4,94,63,018	3,98,60,000
6.	Center for Human Genetics(CHG) with Indira Gandhi Hospital, Bengaluru	5,38,45,000	5,38,45,000
7.	All India Institute of Medical Sciences, New Delhi	7,88,29,854	7,55,98,991
8.	Institute of Post-Graduate Medical Education and Research, Kolkata	1,66,40,000	1,63,28,822
9.	Maulana Azad Medical College, New Delhi	1,40,10,000	Nil*

*The financial assistance of Rs.1,40,10,000/- was released to MAMC, Delhi vide Sanction Order dated 20.03.2023, which was reflected in their account on 24.03.2023. As the financial year closes by 31st March, the CoE carried forward the whole amount to the next financial year i.e. 2023-24.

Note : Unspent balance of Financial Year 2022-23 has been carried forward by the CoEs for continuing treatment of the patients. Only ICH&HC, Chennai had surrendered the unspent balance of Rs. 96,03,018/- in CFI.

Financial Year 2023-24

S. No.	Name of CoE	Financial Assistance released in FY 2023-24 (In Rs.)	Funds Utilized (In Rs.) As on date	Available Balance for continuing treatment (In Rs.) As on date
1.	All India Institute of Medical Sciences, New Delhi	35,00,00,000	7,25,76,446	28,12,60,424
2.	Maulana Azad Medical College, New Delhi	3,00,00,000	77,56,644	3,62,53,356
3.	Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow	3,00,00,000	2,51,84,272	2,13,23,307
4.	Post Graduate Institute of Medical Education and Research, Chandigarh	3,00,00,000	2,75,51,952	24,48,048
5.	Institute of Post-Graduate Medical Education and Research, Kolkata	3,00,00,000	2,73,48,738	29,62,440
6.	King Edward Medical Hospital, Mumbai	3,00,00,000	3,00,00,000	28,29,968
7.	Centre for DNA Fingerprinting & Diagnostics with Nizam's Institute of Medical Sciences, Hyderabad	3,00,00,000	27,20,726	7,05,05,527
8.	Center for Human Genetics(CHG) with Indira Gandhi Hospital, Bengaluru	9,00,00,000	1,61,96,912	7,38,03,088
9.	All India Institute of Medical Sciences, Jodhpur	3,00,00,000	91,17,801	2,08,82,199
10.	Institute of Child Health and Hospital for Children (ICH & CH), Chennai	3,00,00,000	3,00,00,000	Nil
11.	Sree Avittam Thirunal Hospital (SAT), Government Medical College, Thiruvananthapuram	3,00,00,000	53,00,000	2,47,00,000