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

RAJYA SABHA
UNSTARRED QUESTION NO. 1386
TO BE ANSWERED ON 01ST AUGUST, 2023

FABRY DISEASE

1386. SHRI PRAMOD TIWARI:
SMT. RANJEET RANJAN:
DR. AMEE YAJNIK:

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

(a) whether not even a single patient with Fabry disease duly registered with Government has received treatment till date, despite availability of the therapy for the same for the past 20 years;
(b) whether it is a fact that, despite the declaration to release 50 lakh rupees for the treatment of rare diseases, not one of the 432 registered patients of rare diseases in the country has received these funds yet; and
(c) if so, the steps Government has taken to expedite the disbursement of the 50 lakh rupees?

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

(a) The patients suffering from Fabry disease are reportedly getting treatment at All India Institute of Medical Sciences, New Delhi; Maulana Azad Medical College, New Delhi; Institute of Post-Graduate Medical Education and Research, Kolkata; and Center for Human Genetics (CHG) with Indira Gandhi Hospital, Bengaluru, which are Centres of Excellence (CoEs) as designated under the National Policy for Rare Diseases (NPRD), 2021.

(b) & (c) The Government has launched NPRD, 2021 in March, 2021 for the treatment of rare disease patients. As per the amended provisions issued on 19.05.2022, financial support upto Rs. 50 lakhs is provided to the patients suffering from any category of the rare diseases, including Fabry disease. Eleven CoEs have been identified as on date. The financial assistance is provided to rare disease patients through CoEs for their treatment on the basis of the demand raised by the CoE. Financial assistance of Rs. 34.99 crore and Rs. 40 crore has been released to the CoEs in the financial year 2022-23 and 2023-24 respectively for the treatment of rare disease patients, including Fabry disease.

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