

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

LOK SABHA

UNSTARRED QUESTION No. 1135

TO BE ANSWERED ON 8th DECEMBER, 2023

NATIONAL POLICY FOR RARE DISEASES, 2017

1135. SHRI SUDHAKAR TUKARAM SHRANGARE:

SHRI NARANBHAI KACHHADIYA:

SHRI BIDYUT BARAN MAHATO:

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

(a) whether the Government has prepared any institutional framework for the implementation of the National Policy for Rare Diseases, 2017 along with the treatment of such rare diseases particularly with regard to Maharashtra;

(b) if so, the details thereof and if not, the reasons therefor;

(c) whether any steps have been taken by the Government to ensure that the benefits of the said policy reach upto the last mile patients suffering from such rare diseases; and

(d) if so, the details thereof?

ANSWER

**THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY
WELFARE**

(DR. BHARATI PRAVIN PAWAR)

(a) to (d) Ministry of Health and family Welfare, Government of India had formulated a National Policy for Treatment of Rare Diseases (NPTRD) in July, 2017. Implementation of the policy, however, faced certain challenges. Based on consultation and recommendations, a decision was taken to reframe the National Policy for Treatment of Rare Diseases and an Expert Committee was constituted. Based on the report of the Expert Committee, the Government launched National Policy for Rare Diseases (NPRD) in March 2021 which aims at lowering the incidence and prevalence of rare diseases based on an integrated and comprehensive preventive strategy, constraints on resources and access to affordable health care to patients of rare diseases which are amenable to one-time treatment or relatively low

cost therapy. Twelve (12) Centres of Excellence (CoEs) with one CoE in Maharashtra namely, King Edward Medical Hospital, Mumbai, have been notified. These are premier Government tertiary hospitals with facilities for diagnosis, prevention and treatment of rare diseases. In order to ensure that the benefits of the said policy reach up to the last mile patients, financial support up to Rs. 50 lakhs is provided under NPRD, 2021 to all the patients without discrimination for treatment of rare diseases. Further, the number of CoEs are also being enhanced for coverage of more areas geographically. The present list of 12 CoEs is as below:

- i. All India Institute of Medical Sciences, New Delhi
- ii. Maulana Azad Medical College, New Delhi
- iii. Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow
- iv. Post Graduate Institute of Medical Education and Research, Chandigarh
- v. Centre for DNA Fingerprinting & Diagnostics, Hyderabad
- vi. King Edward Medical Hospital, Mumbai
- vii. Institute of Post-Graduate Medical Education and Research, Kolkata
- viii. Center for Human Genetics (CHG) with Indira Gandhi Hospital, Bengaluru
- ix. All India Institute of Medical Sciences, Jodhpur, Rajasthan
- x. Institute of Child Health & Hospital for Children, Chennai, Tamil Nadu
- xi. Sree Avittam Thirunal Hospital, Government Medical College, Thiruvananthapuram, Kerala.
- xii. All India Institute of Medical Sciences, Bhopal, Madhya Pradesh

Vide Notification dated 29.03.2023, Department of Revenue provides full exemption from Basic Customs Duty (BCD) on Drugs or Medicines imported for persons suffering from rare disease and requires these drugs or medicines or Food for Special Medical Purposes (FSMP) for the treatment of said rare disease, if imported by an individual, for personal use, 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.

Financial assistance of Rs. 3.15 crore, Rs. 34.99 crore and Rs. 40 crore has been released to the CoEs in the financial years 2021-22, 2022-23 and 2023-24 respectively for the treatment of rare disease patients. The KEM, Mumbai was provided Rs.1,99,70,876/- and Rs.3.00 crore during the financial year 2022-23 and 2023-24 respectively.
