

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

RAJYA SABHA
UNSTARRED QUESTION No. 260
TO BE ANSWERED ON 5th DECEMBER, 2023

RARE DISEASES AND OTHER INHERITED DISORDERS

260. SHRI NARAYANA KORAGAPPA:

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

- (a) whether it is a fact that 2950 patients have been enrolled from Karnataka on the National Registry for rare and other inherited disorders;
- (b) the efforts being made by Government to help these patients who have been suffering from rare diseases;
- (c) the details of Centres of Excellence identified in Karnataka, district-wise, for diagnosis, prevention and treatment of rare diseases; and
- (d) the details of financial and other support given by Government to the above patients suffering from rare diseases?

ANSWER

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

(DR. BHARATI PRAVIN PAWAR)

(a) As per the data available with Indian Council of Medical Research (ICMR), 3001 patients have been enrolled from Karnataka on the portal of National Registry for Rare and Other Inherited Disorders (NRROID) as on October, 2023.

(b) & (c) 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 Karnataka namely, Center for Human Genetics with Indira Gandhi Hospital, Bengaluru, have been identified, which are premier Government tertiary hospitals with facilities for diagnosis, prevention and treatment of rare diseases. Public Health is a State subject, however, the Central Government encourages and supports the States in their endeavor towards screening and prevention of rare diseases through CoEs. Financial support up to Rs. 50 lakhs per patient is provided under NPRD, 2021 for treatment of rare diseases. As envisaged in the policy, Department of Health Research has established the National Consortium for Research and Development on Therapeutics for Rare Diseases (NCRDTRD) for streamlining the research activities for rare diseases.

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.

(d) Financial assistance of Rs. 3.15 crore, Rs. 34.99 crore and Rs. 40 crore has been released to the CoEs, including CHG-IGI, Bengaluru, in the financial years 2021-22, 2022-23 and 2023-24 respectively for the treatment of rare disease patients. The CHG-IGI, Bengaluru was provided Rs. 3 crore, Rs. 5,38,45,000 and Rs. 3 crore during the financial years 2021-22, 2022-23 and 2023-24 respectively.
