

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

**LOK SABHA
UNSTARRED QUESTION No. 5022
TO BE ANSWERED ON 31st March, 2023**

LIFESTYLE AND GENETIC DISEASES

5022. SHRIMATI SUMALATHA AMBAREESH:

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

- (a) whether the Government has noticed the rise in lifestyle and rare genetic diseases in the country;
- (b) if so, the details regarding the steps and measures taken for spreading awareness on the same;
- (c) the steps taken to prevent rare genetic disorders;
- (d) whether the Government has observed that medicines for rare genetic diseases are very costly;
and
- (e) if so, the details of steps taken to decrease the price?

**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) National Registry for Rare and Other Inherited Disorders (NRROID), a total of 9076 patients suffering from rare diseases have been enrolled since November, 2019.

(b) & (c) The Government has launched National Policy for Rare Diseases (NPRD), 2021 in March, 2021. The policy aims at lowering the incidence and prevalence of rare diseases based on an integrated and comprehensive preventive strategy encompassing awareness generation, premarital, post-marital, pre-conception and post-conception and post-conception screening and counselling programmes to prevent births of children with rare diseases, and within the constraints on resources and competing health care priorities, enable access to affordable health care to Patients of rare diseases. Eleven (11) Centres of Excellence (CoEs) have been identified, which are premier Government tertiary hospitals with facilities for diagnosis, prevention and treatment of rare diseases.

(d) & (e) Specific treatments like gene therapy and antisense molecules etc. are quite expensive. In order to help the patients in terms of affordable medicines, Department of Pharmaceuticals has initiated the implementation of Production Linked Incentive Scheme for Pharmaceuticals. The

Scheme provides for financial incentives to manufacturers selected under the Scheme for domestic manufacturing of various product categories, which also include Orphan drugs. The Guidelines for the Scheme are available on the website of the Department of Pharmaceuticals under the tab 'Schemes'

Department of Revenue, Ministry of Finance vide their Notification No. 46/2021-Customs dated 30.09.2021 gives full waiver of Basic Customs Duty (BCD) and Integrated Goods and Services Tax (IGST) to drugs imported (personal use only) for treatment of Spinal Muscular Atrophy (SMA) rare disease, thereby making the medicines for SMA rare disease more affordable. Subsequently, Department of Revenue, Ministry of Finance vide their Notification No. 02/2022-Customs dated 01.02.2022 has given exemption from Basic Customs Duty to drugs or medicines, which are used in the treatment of Rare Diseases when imported by Centres of Excellence (CoEs) as specified in NPRD, 2021 or any person or institution on recommendation of any Centre of Excellence listed in NPRD, 2021, certifying that the person (by name) for whom the drugs or medicines are imported, is suffering from a rare disease (to be specified by name) and requires the drugs or medicines for the treatment of said rare disease.
