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

LOK SABHA
UNSTARRED QUESTION NO. 2029
TO BE ANSWERED ON 29th DECEMBER, 2017

RARE DISEASES

2029. SHRI ADHALRAO PATIL SHIVAJIRAO:
SHRIMATI MAUSAM NOOR:

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

(a) whether the Government is aware of the prevalence of rare genetic disorders collectively identified as Lysosome Storage Diseases and if so, the details thereof;

(b) whether the Government has formulated a scheme that recommends genetic counseling, pre conception and antenatal screening to parents, if so, the details thereof;

(c) whether the Government has decided to formulate a comprehensive policy regarding the prevention and free of cost treatment for rare disorders and if so, the time by which final decision is likely to be taken in this regard;

(d) whether the Government proposes to make budgetary allocations for patients suffering from rare genetic diseases and if so, the details thereof;

(e) whether screening for rare genetic diseases such as Phenylketonuria is mandatory at present; and

(f) if so, the details thereof and if not, the reasons therefor?

ANSWER
THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY WELFARE
(SMT. ANUPRIYA PATEL)

(a): An expert group constituted by the Ministry of Health & Family Welfare in March 2016 suggested that amongst the estimated 7000 different rare diseases in the world, the Lysosomal storage diseases (LSDs) and the Inborn errors of metabolism (IEMs) are of immediate relevance in India. Currently, India doesn't have epidemiological data on rare diseases and consequently no comprehensive data on burden and prevalence of rare diseases and the associated morbidity and mortality.

(b): No.

(c): The Ministry of Health and Family Welfare has formulated a National Policy for treatment of Rare Diseases in India to progressively build India's capacity to respond comprehensively to rare diseases covering areas of: prevention, awareness generation, training of doctors, funding support for treatment on the parameters to be defined by a Central Technical cum Administrative Committee, promotion of research and development for drugs for treatment of rare diseases and diagnostics at affordable prices and measures for making the drugs for rare diseases more affordable, strengthening of laboratory networks, development of Centres of Excellence etc. On the whole, the Policy seeks to strike a balance between the interest of patients of Rare Diseases and health system sustainability. The Policy also recognises and delineates the role of various Ministries and departments in the area of Rare Diseases.

(d): Funding mechanism as given in the National Policy for treatment of Rare Diseases in India is as under:

- Setting up a corpus fund at Central level with the initial amount of Rs. 100 crore towards funding treatment of rare genetic diseases.
- Similar corpus at State level and contribution of funds by the Centre towards the state corpus to the ratio of 60:40 out of the central pool.
- It is up to the States to have a corpus of a larger amount. Requirement of funds by States is as per PIP process.

(e) & (f): No. The National Policy calls for exploring the feasibility of a plan for providing and progressively scaling up pre-conception and antenatal genetic counseling and screening in a targeted manner, or otherwise, to provide option to parents to prevent conception or birth of a child with a rare genetic diseases.