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

LOK SABHA
UNSTARRED QUESTION NO. 1724
TO BE ANSWERED ON 27th JULY, 2018

LYSOSOME STORAGE DISEASE

1724. 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 Disease among people;

(b) if so, the details thereof including types of diseases identified so far;

(c) whether the Government has formulated a national policy that recommends genetic counseling and preconception and ante-natal screening to parents and if so, the details thereof;

(d) whether the Government proposes to make budgetary allocations for patients suffering from rare genetic diseases;

(e) whether the Government proposes for a mandatory screening of rare genetic diseases such as Phenylketonuria that warrants immediate diagnosis; 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) & (b): Government is aware about common Lysosomal Storage Disease (LSD). Exact prevalence in India is not known as there are no prevalence studies on Lysosomal Storage Disorder from India. Gaucher's disease, MPS-I, MPS-II, MPS-IV, MPS-VI, Pomp's disease, Fabry disease etc. are primarily the LSDs reported in India.

(c): Government of India has formulated a "National Policy for treatment of Rare Diseases" which includes genetic counseling.

It envisages as a preventive strategy, explore feasibility of a plan for providing and progressively scaling up pre-conception and antenatal genetic counselling 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.

(d): Government of India has already made budgetary allocations for certain identified genetic diseases for which the State Governments are assisted through the Programme Implementation Plans.

(e) & (f): No. There is no National Newborn Screeing (NBS) program presently for Rare Diseases. Some States Governments have State programs for Newborn Screening (NBS) primarily for Congenital hypothyroidism, Congenital adrenal hyperplasia, and G6 PD deficiency. Phenylketonuria is included in State of Kerala NBS program.

All inborn errors of metabolism are not being screened. Congenital hypothyroidism screening is also proposed under Rashtriya Bal Swasthya Karyakarm.