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

LOK SABHA
UNSTARRED QUESTION NO. 4390
TO BE ANSWERED ON 12TH AUGUST, 2016

RARE GENETIC DISEASES

4390. SHRIMATI BUTTA RENUKA:

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

(a) whether crores of people in the country suffering from life threatening genetic diseases including progeria;

(b) if so, the details of such rare diseases prevailing in the country;

(c) whether Indian Society for Clinical Research (ISCR) has conducted any detailed study in this regard, if so, the details and outcome thereof;

(d) whether the Government has prepared any action plan to combat and cover such rare disease under the National Health Mission and set up a panel to frame a policy, in this regard; and

(e) 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): Prevalence rate in India for rare genetic diseases is not clearly available. Medical literatures give an incidence of 1:428 million population for Progeria and 1:40000 for Gaucher's and Pompe disease. The Department of Health Research (DHR) is supporting research on genetic diseases. Research in these diseases is limited due to lesser availability of the number of patients. Research is widely initiated in other diseases like Lysosomal Storage diseases, Sickle Cell anaemia, Thalassemia, Haemophilia, etc.

(c): The Indian Society for Clinical Research has not conducted any research/study for life threatening genetic diseases in the country.

Source: Indian Society for Clinical Research, Mumbai

(d) & (e): The Government of India is implementing a comprehensive National Health Mission Programme to strengthen health delivery system, which also covers important life threatening diseases including rare and genetic diseases under it.

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Health being a State subject, the Government of India provides financial support to the States to strengthen their health care delivery system, including screening, as well as treatment of other important diseases including life threatening rare diseases (thalassemia, haemophilia, sickle cell anemia and other genetically inherited disorders/diseases).

The Government of India also provides technical support to state governments under the National Health Mission Programme to deal with such life threatening diseases and genetically inherited disorders.

The Department of Health Research is also supporting research on such disorders/diseases in its on-going research projects. A National Task Force study on Lysosomal Storage Disorders (LSD's) which is a group of rare genetic disorders, at 10 centres in India is also under way. This study will enable setting up of clinical, biochemical and molecular diagnostics for these conditions. Research is initiated in other genetic diseases like sickle cell anemia, thalassemia, haemophilia, etc. Prenatal counselling and setting up of early intervention centres to prevent the transmission/transfer of such diseases is also done under the National Health Mission.

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