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

LOK SABHA
UNSTARRED QUESTION NO. 2593
TO BE ANSWERED ON 17TH MARCH, 2017

RARE DISEASES

2593. SHRI PRAHLAD SINGH PATEL:

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

(a) whether the Government proposes to constitute a special research team to combat rare diseases in the country;

(b) if so, the details thereof and if not, the reasons therefor;

(c) the details of rare diseases discovered in the country and the number of people affected with such diseases, State/UT-wise and the progress achieved by the Government on treatment and medication of rare diseases in the country;

(d) whether the Government has evaluated the impact on the life of people affected by such diseases in the country and the outcome thereto; and

(e) the other steps taken/being taken by the Government in this regard?

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

(a) & (b): An expert group (Sub-committee) constituted by the Ministry of Health & Family Welfare, Government of India 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.

Department of Biotechnology (DBT), Ministry of Science & Technology, has a Task Force on Human Genetics and Genome Analysis under Medical Biotechnology programme, which targets towards preventing human diseases, early diagnosis and management of medical problems. The Task Force supports various projects on rare diseases like Sickle Cell Anaemia, Haemophilia and Thalassemia. DBT has instituted a joint collaboration with Japan to bear on clinical studies of brain and blood disorders under the venture titled "Accelerating the application of Stem Cell technology in Human disease".

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(c): Rare diseases include inherited Cancers, Autoimmune Disorders and Congenital malformations viz. Hemangiomas, Hirchsprung disease, Gaucher disease, cystic fibrosis, muscular dystrophies and Lysosomal Storage Disorders. Some other rare diseases include Alzheimers' disease, Hodgkin's disease, Leukemia, multiple sclerosis, etc. As informed by Public Health Division, Ministry of Health & Family Welfare, currently, there is no registry of rare diseases in India and therefore exact number of patients and their State/UTs-wise distribution are not known. The initial assessment for most of the rare diseases can be done at medical college hospitals and the suspected cases can be referred to super-specialty hospitals that have a functional medical genetics laboratory. As per report by the expert group (Sub-committee) constituted by the Ministry of Health & Family Welfare, Government of India, rare diseases are, in most cases, serious, chronic, debilitating and life threatening, often requiring long and specialised treatments. In addition, they often result in some form of handicap, sometimes extremely severe. At least 80% of rare diseases have an identified genetic origin and hence disproportionately impact children.

(d) & (e): Health being a State subject, it is the prerogative of the State Governments to provide comprehensive health care to the people including those suffering from rare diseases. The Central Government supports efforts of State Governments, financially and technically, in their endeavour to provide health care through their Programme Implementation Plan (PIP) under the National Health Mission.

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