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

LOK SABHA
UNSTARRED QUESTION NO.2002
TO BE ANSWERED ON 29TH NOVEMBER, 2019

DIAGNOSTIC FACILITIES FOR GENETIC DISEASES

2002. SHRIMATI KESHARI DEVI PATEL:

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

(a) the details of diagnostic facilities being provided in Government hospitals to diagnose the genetic diseases among infants;

(b) the number and names of hospitals in Uttar Pradesh which are equipped with the aforesaid facilities and the time by which rest of hospitals are to be provided these facilities;

(c) number of children found affected with the genetic diseases and the steps taken to treat them since year 2015 to 2019 along with the details thereof;

(d) the annual budget being spent in UP to diagnose genetic diseases among infants; and

(e) whether such diseases are on rise day by day among children, if so, the details thereof from 2014 to 2019?

ANSWER
THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY WELFARE
(SHRI ASHWINI KUMAR CHOUBEY)

(a) to (e): The Government of India under National Health Mission is implementing Rashtriya Bal Swasthaya Karyakram. Under this programme 30 selected health conditions have been identified for screening including specific genetic diseases among newborn namely Congenital hypothyroidism and Congenital adrenal hyperplasia, Down Syndrome, glucose-6-phosphate dehydrogenase (G6PD) defficiency.

In Financial Year 2019-20, under National Health Mission as proposed by State/UT, proposals for newborn screening for selected genetic diseases were approved for Maharashtra, Himachal Pradesh, Rajasthan, Karnataka, Kerala, Tamil Nadu and Delhi.

In Uttar Pradesh, Department of Medical Genetics, Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow has a lab for conducting screening for inborn error of metabolism including specific genetic diseases. From Dec 2015 to March 2019, as reported by State, more than 66,750 samples have been screened under this program from district hospitals of Barabanki, Raebareli and other public hospitals of Lucknow like King George Medical University, Rani Laxmibai Hospital, Veerangana Jhalakari Bai Mahila Hospital, Avantibai Mahila Hospital. Babies diagnosed with the disorders are being provided management and follow up.

There is no centralised information available on occurrence of genetic diseases in children. However, Indian Council of Medical Research (ICMR) has recently initiated steps to set up rare disease registry which will include selected genetic diseases.