

**GOVERNMENT OF INDIA
MINISTRY OF SCIENCE AND TECHNOLOGY
DEPARTMENT OF BIOTECHNOLOGY**

**LOK SABHA
UNSTARRED QUESTION NO. 2014
TO BE ANSWERED ON 29.11.2019**

UMMID

2014. SHRI RAMALINGAM S.:
SHRI SHRIRANG APPA BARNE:
DR. HEENA GAVIT:
SHRI VINAYAK RAUT:
DR. KALANIDHI VEERASWAMY:
SHRI A. RAJA:
DR. DNV SENTHILKUMAR S.:
SHRI MANNE SRINIVAS REDDY:
SHRI HEMANT SRIRAM PATIL:

Will the Minister of SCIENCE AND TECHNOLOGY विज्ञान और प्रौद्योगिकी मंत्री be pleased to state:

- (a) whether Government is aware that congenital and hereditary genetic diseases are becoming a significant health burden in India, if so, the details thereof and the corrective action taken in this regard;
- (b) the estimated number of children that are born with hereditary diseases every year in the country, State/UT-wise;
- (c) whether the Government has launched “Unique Methods of Management and treatment of Inherited Disorder (UMMID)” initiative to tackle the menace of genetic disease in newborns, if so, the details thereof along with the aims, objectives and the features thereof;
- (d) the details of the targets set, funds sanctioned/released and number of National Inherited Diseases Administration (NIDAN) Kendras/training centres likely to be established under the First Phase of the said initiative including in rural areas, State/UT-wise including Tamil Nadu;
- (e) whether Government has identified the number of districts in the rural areas where these Kendras are likely to be started, if so, the details thereof along with the number of people who are likely to be the beneficiaries in this initiative; and
- (f) the further steps taken by the Government to help the future generation in treating and preventing these diseases caused by genetic disorders?

ANSWER

**MINISTER FOR HEALTH AND FAMILY WELFARE; MINISTER FOR SCIENCE
AND TECHNOLOGY; AND MINISTER OF EARTH SCIENCES
(DR. HARSH VARDHAN)**

- (a) & (b)** Yes, congenital and hereditary genetic diseases are a significant health burden in India. Based on the data published in the journal ‘Community Genetics’ (2002; 5 (3):

192-6), an estimated 495,000 infants with congenital malformations, 390,000 with G6PD deficiency, 21,400 with Down syndrome, 9,000 with β -thalassaemia, 5,200 with sickle cell disease, and 9,760 with amino acid disorders are born each year in the country. Considering these facts, National Policy for Treatment of Rare Diseases was announced in June 2017 by Ministry of Health & family Welfare, Govt. of India. However, in the light of new information and updates available for further improvement and effective implementation, Central Govt. has decided to review this policy and through Gazette notification dated 18.12.2018 kept this policy in abeyance till the revised policy is issued by the Central Govt. or till further order whichever is earlier.

(c) Yes, the Department of Biotechnology (DBT), Govt. of India has recently launched Unique Methods of Management of Inherited Disorders (UMMID) initiative with the objectives i) to establish Genetic Diagnostic Units in Government Hospitals wherein the influx of patients is more, ii) to produce skilled clinicians in the area of Human Genetics, and iii) to do pilot scale screening of pregnant women and new born babies for diagnostics of inherited genetic diseases in some aspirational districts to provide comprehensive clinical care (diagnosis, management, multidisciplinary care, counselling, prenatal testing).

(d) & (e) Under UMMID initiative, following projects have been sanctioned as a pilot initiative:

(i) Five Genetics Labs- NIDAN Kendras (National Inherited Disorders Administration Kendras) have been sanctioned to provide comprehensive clinical care including diagnosis, management, multidisciplinary care, counseling, prenatal testing at following Government hospitals

S. No.	State	Implementing Institution	Sanctioned cost (Rs. in Crores)	Released amount (Rs. in Crores)
1.	West Bengal	NRS Medical College, Kolkata	1.50	0.81
2.	Rajasthan	AIIMS Jodhpur	1.47	1.15
3.	Delhi	Army Hospital Research & Referrals, New Delhi	1.41	1.08
4.	Delhi	Lady Harding's Medical College, New Delhi	4.58	2.19
5.	Telangana	NIMS, Hyderabad	1.58	1.19

(ii) Seven Training Centres at following institutions/ hospitals have been supported to provide training in Biochemical Genetics, Cytogenetics, Molecular Genetics, Clinical Genetics and Comprehensive clinical care to the clinicians working in Government hospitals

S. No.	State	Implementing Institution	Sanctioned cost (Rs. in Crores)	Released amount (Rs. in Crores)
1.	Tamil Nadu	Madras Medical Mission, Chennai	0.48	0.28
2.	Uttar Pradesh	SGPGIMS, Lucknow	3.95	1.48
3.	Telangana	CDFD, Hyderabad	3.95	1.48
4.	Delhi	AIIMS, New Delhi	4.41	1.68
5.	Delhi	MAMC, New Delhi	4.41	1.55
6.	Maharashtra	NIIH, Mumbai	3.95	1.48

7.	Tamil Nadu	CMC, Vellore	3.93	1.73
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- (iii) Under the program, seven Aspirational Districts namely Mewat, Haryana; Yadgir, Karnataka; Haridwar, Uttarakhand; Washim & Nandurbar, Maharashtra; Ranchi, Jharkhand; Shrawasti, Uttar Pradesh have been identified for screening of 10,000 pregnant women and 5000 new born babies per year in each districts for diagnostics of inherited genetic diseases to provide comprehensive clinical care including diagnosis, management, multidisciplinary care, counseling, prenatal testing.
- (f) Nidan Kendras established and clinicians trained through UMMID initiative will cater to the need of treating and preventing diseases caused by genetic disorders across the country.
