

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

**LOK SABHA
UNSTARRED QUESTION NO. 1843
TO BE ANSWERED ON 06TH DECEMBER, 2024**

PREVALENCE OF GENETIC DISORDERS

1843. SHRI G LAKSHMINARAYANA:

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

- (a) the number of children (below 18 years) and adults suffering from genetic disorders in the country during the last five years, State-wise;
- (b) the types of genetic disorders most prevalent among children, specifically mentioning thalassemia, sickle cell anaemia, down syndrome, and cystic fibrosis, State-wise;
- (c) the number of Nidaan Kendras established under the Unique Methods of Management and Treatment of Inherited Disorders (UMMID) scheme, including their locations and the type of genetic disorders in the country, State/UT-wise;
- (d) the number of genetic screenings conducted and individuals trained in each State, particularly through Nidaan Kendras, State/UT-wise;
- (e) whether the Government plans to establish additional Nidaan Kendras in States with high genetic disorder prevalence, including Andhra Pradesh for new centers or clinical training in the country, State/UT-wise; and
- (f) the current status and expected time by which the said project is likely to be completed in Andhra Pradesh?

ANSWER

**THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY WELFARE
(SHRI PRATAPRAO JADHAV)**

(a): Indian Council of Medical Research (ICMR) has informed that the National Registry for Rare and Other Inherited Disorders (NRROID) was initiated in November 2019 to document prospectively the data of various patients suffering from rare genetic diseases who visit the hospital OPDs. The age and state-wise data of 13,186 patients suffering from rare genetic diseases is available in the registry. The state-wise distribution of children (below 18 years) and adults suffering from genetic disorders, enrolled in the registry is given at Annexure 'A'.

(b): As on 24.11.2024, a total of 4,75,42,776 individuals have been screened under the National Sickle Cell Anaemia Elimination Mission (NSCAEM). The State-wise details of screenings conducted and

diseased Sickle Cell Anaemia individuals identified through screening in the affected States is given at Annexure-B.

The National Registry for Rare and Other Inherited Disorders collects information on Thalassemia patients which are enrolled from 24 centres across the country. The State-wise distribution of Thalassemia patients enrolled in the registry is given at Annexure C.

Additionally, ICMR funded Centre for Advanced Research on Childhood Respiratory Disease collected information on cystic fibrosis patients from 4 institutes across the country. The state-wise distribution of cystic fibrosis patients which were enrolled (through hospitals) in the above-mentioned project is given at Annexure D.

(c): Department of Biotechnology (DBT) has informed that it has undertaken Unique Methods of Management and Treatment of Inherited Disorders (UMMID) scheme initiative to address the burden of genetic disorders in the country through establishment of three components: DBT-UMMID-NIDAN Kendras (Genetic diagnosis centres), outreach to aspirational districts for antenatal & newborn screening, and training centres for capacity building among Government doctors. Initially DBT-UMMID-NIDAN Kendras were set up in five major hospitals, across India as part of the first phase. Currently, in phase two of UMMID Initiative, the DBT-UMMID-NIDAN Kendras Network has been expanded to 26 Centers nationwide across 15 States/UTs, including institutes from varied geographical locations.

The state wise list of DBT-UMMID-NIDAN KENDRA is given at Annexure E.

DBT-UMMID-NIDAN Kendras undertake Prenatal testing for genetic disorders such as Beta thalassemia, sickle cell disease, and other hemoglobinopathies, Down syndrome and other aneuploidies, Congenital malformations such as neural tube defects and other genetic disorders prevalent at a relatively higher rate in the region. Newborn Screening is undertaken for relatively common treatable genetic metabolic disorders including, Congenital hypothyroidism, Congenital adrenal hyperplasia, Galactosemia, Biotinidase deficiency, Glucose-6-phosphate dehydrogenase (G6PD) deficiency and other treatable genetic metabolic disorders prevalent at a relatively higher rate in the region.

(d): Initially DBT-UMMID-NIDAN Kendras were set up in five major hospitals, across India as part of the first phase. The number of genetic screenings conducted and individuals trained in each state, particularly through Nidan Kendras, State/UT-wise is provided below:

NIDAN Kendra	Institute/ State	No. of genetic screenings	No. of Manpower trained
Delhi	-Army Hospital Research and Referral, Delhi	7500	4
	-Lady Hardinge Medical College, Delhi	7255	11
Rajasthan	-All India Institute of Medical Sciences (AIIMS), Jodhpur, Rajasthan	27618	22
Telangana	- Nizam's Institute of Medical Sciences, Hyderabad, Telangana	28284	7
West Bengal	-Nil Ratan Sircar Hospital Medical College and Hospital, Kolkata, West Bengal	28041	7

Apart from the above 60 clinicians have been trained throughout India under the training component.

(e) and (f): Currently, in phase two of UMMID Initiative, the DBT-UMMID-NIDAN Kendras Network has been expanded to 26 Centers nationwide across 15 States/UTs, including institutes from varied geographical locations.

In the State of Andhra Pradesh, DBT- UMMID-NIDAN Kendra has been sanctioned at Sri Venkateswara Institute of Medical Sciences, Tirupati, Andhra Pradesh on 14th November, 2024 for a period of three years.

Annexure-A

State-wise distribution of children (below 18 years) and adults suffering from genetic disorders, enrolled in the National Registry for Rare and Other Inherited Disorders (NRROID)

States/UTs	Above 18 years	Below 18 years
Andaman Nicobar	0	2
Andhra Pradesh	92	497
Arunachal Pradesh	3	20
Assam	278	716
Bihar	70	536
Chandigarh	35	87
Chhattisgarh	7	59
Dadra Nagar Haveli	0	1
Daman Diu	1	1
Delhi	158	788
Goa	2	3
Gujarat	55	301
Haryana	97	441
Himachal Pradesh	28	113
Jammu Kashmir	12	84
Jharkhand	18	150
Karnataka	285	833
Kerala	41	167
Ladakh	0	4
Lakshadweep	0	1
Madhya Pradesh	79	357
Maharashtra	287	913
Manipur	2	6
Meghalaya	1	1
Mizoram	0	1
Nagaland	2	6
Odisha	15	82
Puducherry	3	17
Punjab	115	353
Rajasthan	24	212
Sikkim	0	7
Tamil Nadu	213	902
Telangana	82	630
Tripura	0	22
Uttar Pradesh	324	1927
Uttarakhand	16	67
West Bengal	81	453
Total	2426	10760

Annexure-B

State-wise details of screenings conducted and diseased Sickle Cell Anaemia individuals identified through screening in affected States

State Name	Total Screened	Total No. of Diseased
Andhra Pradesh	9,29,380	1706
Assam	8,47,274	258
Bihar	11,976	1
Chhattisgarh	1,44,11,035	25378
Gujarat	35,58,702	5740
Jharkhand	21,98,507	2149
Karnataka	2,18,069	564
Kerala	1,06,753	1167
Madhya Pradesh	84,69,811	25307
Maharashtra	49,91,803	19296
Odisha	47,62,739	89324
Rajasthan	36,24,600	2947
Tamil Nadu	2,58,162	495
Telangana	4,33,449	836
Uttar Pradesh	6,48,371	18
Uttarakhand	1,64,532	2
West Bengal	1,907,613	5422
Total	4,75,42,776	1,80,610

Annexure-C

State-wise distribution of Thalassemia patients enrolled in National Registry for Rare and Other Inherited Disorders (NRROID)

State/UT	No. of patients suffering from Thalassemia
Andhra Pradesh	43
Arunachal Pradesh	7
Assam	544
Bihar	159
Chandigarh	26
Chhattisgarh	7
Dadra Nagar Haveli	1
Daman Diu	1
Delhi	237
Gujarat	31
Haryana	129
Himachal Pradesh	31
Jammu Kashmir	3
Jharkhand	25
Karnataka	155
Kerala	4
Madhya Pradesh	96
Maharashtra	383
Manipur	1
Meghalaya	0
Odisha	12
Puducherry	2
Punjab	130
Rajasthan	19
Tamil Nadu	313
Telangana	71
Tripura	4
Uttar Pradesh	493
Uttarakhand	13
West Bengal	53
Grand Total	2993

Annexure-D

State-wise distribution of Cystic Fibrosis patients enrolled (through hospitals) in ICMR funded Centre for Advanced Research on Childhood Respiratory Disease project

State/UT	No. of patients suffering from Cystic Fibrosis
Delhi	143
Jammu Kashmir	64
Rajasthan	34
Tamil Nadu	50
Grand Total	291

Annexure-E

The number of genetic screenings conducted and individuals trained in each state, particularly through Nidan Kendras, State/UT-wise.

NIDAN Kendra	Total	Institute/ State
Andhra Pradesh	1	- Sri Venkateswara Institute of Medical Sciences, Tirupati, Andhra Pradesh
Assam	1	- Assam Medical College & Hospital, Dibrugarh, Assam
Bihar	1	- All India Institute of Medical Sciences (AIIMS), Patna, Bihar
Chandigarh	1	- Government Medical College & Hospital, Chandigarh
Chhattisgarh	1	-All India Institute of Medical Sciences (AIIMS), Raipur, Chhattisgarh
Delhi	2	-Army Hospital Research and Referral, Delhi -Lady Hardinge Medical College, Delhi
Jharkhand	1	-Rajendra Institute of Medical Sciences (RIMS), Ranchi, Jharkhand
Jammu & Kashmir	2	-Government Medical College, Srinagar, J&K -Sher-i-Kashmir Institute of Medical Sciences, (SKIMS), Srinagar, J&K
Karnataka	2	-Bangalore Medical College and Research Institute, Bangalore, Karnataka -Command Hospital Air Force Bangalore, Bangalore, Karnataka
Kerala	2	-Government Medical College, Kozhikode, Kerala -Government Medical College, Thiruvananthapuram, Kerala
Mizoram	1	-Civil Hospital Aizawl, Mizoram
Madhya Pradesh	1	-All India Institute of Medical Sciences (AIIMS), Bhopal, Madhya Pradesh
Maharashtra	4	-All India Institute of Medical Sciences (AIIMS), Nagpur, Maharashtra -Mahatma Gandhi Institute of Medical Sciences, Sevagram, Maharashtra -Armed Forces Medical College, Pune, Maharashtra -National Institute for Research in Reproductive and Child Health (ICMR- NIRRH), Mumbai, Maharashtra
Odisha	1	-All India Institute of Medical Sciences (AIIMS), Bhubaneswar, Odisha
Rajasthan	2	-Sawai Man Singh Medical College, Jaipur, Rajasthan - All India Institute of Medical Sciences (AIIMS), Jodhpur, Rajasthan
Telangana	1	- Nizam's Institute of Medical Sciences, Hyderabad, Telangana
Uttar Pradesh	4	-King George Medical University, Lucknow, UP -All India Institute of Medical Sciences (AIIMS), Gorakhpur, UP -Aligarh Muslim University, UP -Institute of Medical Sciences (IMS), BHU, Varanasi, UP
Uttarakhand	1	-All India Institute of Medical Sciences (AIIMS), Rishikesh, Uttarakhand
West Bengal	1	-Nil Ratan Sircar Hospital Medical College and Hospital, Kolkata, West Bengal
TOTAL	30	
