

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

**LOK SABHA
UNSTARRED QUESTION NO. 2242
TO BE ANSWERED ON 28TH JULY, 2017**

THALASSEMIA PATIENTS

**2242. DR. K. KAMARAJ:
SHRI DIBYENDU ADHIKARI:**

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

- (a) whether the Government is planning for a National policy on thalassemia;
- (b) if so, the total number of patients suffering from thalassemia in the country;
- (c) whether it is also a fact that due to lack of access to treatment and the costs, a large number of people die across the country;
- (d) if so, the details of services in the hospitals and allocation of funds by the Government towards gene therapy process therein; and
- (e) whether the Government proposes to declare the patients of thalassemia as physically handicapped to give them access to various facilities like concession in rail/ bus fare etc. available to physically handicapped persons and if so, the details thereof?

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

(a): Public Health is a state subject. Under the National Health Mission (NHM), the Ministry has prepared and issued comprehensive guideline for Haemoglobinopathies (Thalassemia, Sick cell anemia and other variant anaemia) for prevention and management of Haemoglobinopathies.

(b) & (c): The exact number of patients is not known. The estimated number of patients in the country is 100000 with addition of approximately 1000 new cases every year. Data available on population screening by National Institute of Immunohaematology, Mumbai under Jai Vigyan Project is annexed. No published statistics regarding the annual deaths due to thalassemia is available.

(d): Public health and hospitals is a State subject. Government has not allocated any funds separately for gene therapy process.

(e): The Central Government has enacted the Rights of Persons with Disabilities Act, 2016 which came into force from 19.4.2017. Thalassemia has been included as a specified disability under the said Act. The Act provides for various rights and entitlements for persons with disabilities such as equality and non-discrimination, protection from cruelty and inhuman treatment, reproductive rights, access to justice etc. Further the Act mandates the appropriate Government to frame schemes and programmes to promote social security, health, rehabilitation and recreation of persons with disabilities.

Table 2. Prevalence of α -thalassemia trait reported in large studies

Region	Number of Individuals screened	Target groups	Technology used	Prevalence of α -thal trait (range)	Reference
Mumbai and Delhi	11,090	Secondary school students	CBC, Hb electrophoresis	4.05% (2.68-5.47%)	2
All Districts of Maharashtra	10,647	School and college students, pregnant women	CBC, HPLC	2.7% (1.0-6.0%)	16
All Districts of Gujarat	8004	School and college students, pregnant women	CBC, HPLC	3.5% (0-9.5%)	16
Bangalore, Kolkata, Ludhiana, Dibrugarh, Vadodara, Mumbai	56,780	College students, pregnant women	CBC, HPLC	2.78% (0.48-3.96%)	5
Districts of Gujarat	317,539	Tribal and non-tribal communities	CBC, HPLC	1.95% (1.74-2.18%)	17
South Gujarat	32,857	School and college students, community members	CBC and Hb electrophoresis, HPLC	4.4% (2.7-4.7)	18
Districts of Rural West Bengal	35,413	School and college students, married couples, pregnant women	CBC, HPLC	10.38% (8.96-11.21%)	19

CBC, complete blood count, Hb, hemoglobin; HPLC, high performance liquid chromatography.

Table 3. Case and tribal communities with a high prevalence of α -thalassemia carriers.

Group	Region	Prevalence of α -thalassemia carriers	Reference
Caste populations			
Sub castes of Sindhis	Nagpur, Maharashtra	8.0-17.0%	20
Bhatias	Mumbai, Maharashtra	5.9%	2
Khatri	Mumbai, Maharashtra	6.9%	2
Lohana	Mumbai, Maharashtra	5.6%	2
Brahmin	Delhi	5.3%	2
Jath	Delhi	6.9%	2
Kayastha	Delhi	5.3%	2
Kachhia Patels	Surat, Gujarat	6.0%	21
Modh Banias	Surat, Gujarat	6.2%	21
Muslim Fakirs	Surat, Gujarat	5.6%	21
Muslim Memons	Surat, Gujarat	7.2	21
Prajapati	Surat, South Gujarat	6.2	18
Ganchi	Surat, South Gujarat	6.2	18
Mayavanshi	Surat, South Gujarat	6.9	18
Lohana	Surat, South Gujarat	10.8	18
Sindhi	Surat, South Gujarat	10.2	18
Rajput	Bangalore, Karnataka	6.3	5
Jain	Bangalore, Karnataka	9.6	5
Muslim Shiya	Bangalore, Karnataka	6.3	5
Mondal	Kolkata, West Bengal	8.6	5
Brahmin	Dibrugarh, Assam	6.0	5
Arora	Ludhiana, Punjab	9.8	5
Vellala	Mumbai, Maharashtra	10.5	5
Lohana	Vadodara, Gujarat	7.4	5
Bhanushali	Gujarat	8.1	17
Bhakta	Gujarat	7.9	17
Lohana	Gujarat	6.5	17
Tribal populations			
Chaudhry	Surat, South Gujarat	12.6	18
Gamit	Surat, South Gujarat	15.9	18
Rohit	Surat, South Gujarat	6.3	18
Vasava	Surat, South Gujarat	13.6	18
Kokana	Surat, South Gujarat	14.7	18
Bhuyan	Sundargarh district, Orissa	6.5	22
Paik	Sundargarh district, Orissa	7.8	22
Paraja	Sundargarh district, Orissa	12.7	22
Dudh Kharia	Sundargarh district, Orissa	8.1	22

The following data from Maharashtra and Gujarat compiled by NIIH

Table 1. Prevalence of thalassemia carriers and expected annual births of thalassemia major babies in the districts of Maharashtra

District	Population (millions)	Crude birth rate	Total annual births	Number tested	Prevalence of heterozygotes no (%)	Marriages at risk per 1000 marriages	Expected annual births of homzygotes
Konkan Division							
Mumbai city	3.34	14.6	48 735	547	22 (4.0)	1.6	86.8
Mumbai suburbs	8.64	18.2	1 57 255				
Raigarh	2.21	21.8	48 132	578	30 (5.2)	2.7	34.2
Thane	8.13	23.4	1 90 285	233	11 (4.7)	2.2	111.3
Ratnagiri	1.70	20.5	34 783	1696	35 (2.1)	2.1	3.8
Sindhudurg	0.87	17.4	15 117	1070	11 (1.0)	0.1	0.4
Aurangabad Division							
Aurangabad	2.90	24.1	69 818	168	4 (2.4)	0.6	10.1
Bid	2.16	23.5	50 789	225	11 (4.9)	2.4	31.9
Jalma	1.61	24.6	39 679	77	1 (1.3)	0.2	1.7
Latur	2.08	24.1	50 134	112	3 (2.7)	0.7	9.2
Nanded	2.88	25.5	73 344	101	2 (2.0)	0.4	7.3
Osmanabad	1.49	23.2	34 488	86	1 (1.2)	0.1	1.2
Parbhani	1.53	25.2	38 498	38	1 (2.6)	0.7	11.4
Hingoli	0.99	26.1	25 764				
Nashik Division							
Ahmednagar	4.04	21.8	88 085	503	30 (6.0)	3.6	83.4
Dhule	1.71	22.5	38 429	128	5 (3.9)	1.5	29.3
Nandurbar	1.31	27.0	35 416				
Jalgaon	3.68	21.7	79 914	173	3 (1.7)	0.3	6.1
Nashik	4.99	25.0	1 24 844	316	13 (4.1)	1.7	55.1
Pune Division							
Kolkapur	3.52	19.3	67 997	452	11 (2.4)	0.6	10.3
Sholapur	3.85	22.2	85 459	400	7 (1.8)	0.3	6.7
Pune	7.23	20.6	1 48 990	807	11 (1.4)	0.2	7.0
Sangli	2.58	19.4	50 120	310	7 (2.3)	0.5	6.5
Satara	2.81	19.2	53 932	823	36 (4.4)	1.9	27.0
Nagpur Division							
Chandrapur	2.07	20.9	43 286	489	14 (2.9)	0.8	9.1
Gadchiroli	0.97	25.8	25 033	360	4 (1.1)	0.12	0.8
Bhandara	1.14	20.7	23 518	157	3 (1.9)	0.36	14.5
Gondiya	1.20	21.8	26 175				
Nagpur	4.07	20.2	82 166				
Wardha	1.24	19.2	23 745				
Amravati Division							
Akola	1.63	22.3	36 354	132	2 (1.5)	0.2	3.6
Washim	1.02	24.3	24 791				
Amravati	2.61	21.2	55 271	54	1 (1.9)	0.4	4.8
Buldana	2.23	23.5	52 463	72	2 (2.8)	0.8	10.4
Yavatmal	2.46	23.7	58 261	540	9 (1.7)	1.8	4.1
Total	96.9			10647	290 (2.7)		588

Table II. Prevalence of α -thalassemia and expected annual births of α -thalassemia major babies in the districts of Gujarat.

District	Population (millions)	Crude birth rate	Total annual births	Number tested	Prevalence of heterozygotes no (%)	Marriages at risk per 1000 marriages	Expected annual births of homzygotes
South Gujarat							
Valsad	1.41	22.7	32019	200	7 (3.5)	1.2	10.2
Dang	0.19	32.8	6124	141	4 (2.8)	0.8	1.3
Navsari	1.23	17.9	22007	137	3 (2.2)	0.5	2.7
Surat	5.0	23.2	115888	552	12 (2.2)	0.5	14.0
Central Gujarat							
Bharuch	1.37	22.3	30565	432	9 (2.1)	0.4	3.4
Narmada	0.51	24.6	12654	41	0	0	0
Anand	1.86	21.7	40294	300	10 (3.3)	1.4	11.8
Ahmedabad	5.82	20.5	119238	504	18 (3.6)	1.3	39.4
Vadodara	3.64	21.3	77570	2194	67 (3.1)	1	18.7
Kheda	2.02	23.1	46759	353	13 (3.7)	1.4	16.5
Gandhinagar	1.33	22.1	29491	51	1 (2.0)	0.1	2.9
Panchmahal	2.03	27.7	56100	258	10 (3.9)	1.5	21.9
Dahod	1.64	34.2	55966	119	4 (3.7)	1.4	16.4
Saurashtra							
Porbandar	0.54	21.8	11703	105	10 (9.5)	9.0	29.4
Jamnagar	1.82	21.7	39047	185	6 (3.3)	1.1	10.7
Rajkot	2.57	16.9	43433	309	16 (5.2)	2.7	30.7
Surendranagar	1.52	27.6	41818	92	5 (5.4)	2.9	32.7
Amreli	1.39	21.1	29411	144	9 (6.3)	4.0	30.7
Bhavnagar	2.47	25.3	62481	379	17 (4.5)	2.0	32.9
Junaghad	2.45	23.1	56553	304	25 (8.2)	6.7	104.4
Kuchchh	1.58	25.4	40214	603	27 (4.5)	2.0	21.1
North Gujarat							
Putan	1.18	26.1	30869	74	2 (2.7)	0.7	5.8
Banaskantha	2.50	31.3	78383	74	0	0	0
Mehsana	1.84	22.4	41169	307	4 (1.3)	0.2	1.8
Sabarkantha	2.08	25.1	52271	146	1 (0.7)	0	0.6
Total	49.9			8004	280 (3.5)		460