

GOVERNMENT OF INDIA
(MINISTRY OF TRIBAL AFFAIRS)
LOK SABHA
UNSTARRED QUESTION NO. 3433
TO BE ANSWERED ON: 09.08.2021

SICKLE CELL DISEASE IN TRIBAL POPULATION

3433. SHRI PRATAP CHANDRA SARANGI:

Will the Minister of **TRIBAL AFFAIRS** be pleased to state:

- (a) whether it is a fact that sickle cell disease is found mostly among the tribal population;
- (b) if so, the incidence of sickle cell disease, State-wise; and
- (c) the details of the steps taken by the Government to eradicate the disease?

ANSWER

MINISTER OF STATE FOR TRIBAL AFFAIRS
(SMT. RENUKA SINGH SARUTA)

(a): Sickle Cell Disease is a genetic blood disorder affecting tribal population in Central, Western and Southern India.

(b): The Ministry of Tribal Affairs had given funds for screening of tribal students in collaboration with ICMR. Workshops have been conducted in States in collaboration with Department of Biotechnology for mapping of incidences of Sickle Cell Trait. Out of the 1,13,83,664 persons screened as reported by various States, about 8.75% (9,96,368) tested positive (Trait –949057, Disease – 47311). State wise details are at **Annexure 1**. However, State wise prevalence rate of sickle cell disease among the tribal population is not known in a definite manner as no such database is maintained centrally. There are certain studies undertaken by ICMR showing that the prevalence across the country is 5-34% (as per document on Sickle Cell Anaemia Control Program published by the state government of Gujarat).

(c): Public Health is a state subject and Ministry of Health and Family welfare is the sectoral ministry for all health issues, including sickle cell. National Health Mission has prepared a comprehensive guideline to control and prevent Haemoglobinopathies, including Sickle Cell Disease, and has disseminated the same to the states. This includes prenatal diagnosis ,counseling and setting up of early intervention centers to prevent and treat the complications arising from the disease. At present there is no permanent cure for the disease. However with good management of disease, severity and complications can be curtailed to improve the quality of life and life span of the people suffering with the disease. In consultation with Department of Health Research, Ministry of Tribal Affairs has circulated advisories on Sickle Cell Disease with a protocol for premarital counseling of people with sickle cell trait (carrier). A total of about Rs. 60.00 Crore has been released to the States seeking grants to tackle the Sickle Cell Anemia, including screening. State wise details for fund released is at **Annexure 2**.

Further, details of various projects undertaken by the Ministry of Tribal Affairs are as under:

(i) Sickle Cell Disease Support Corner (<https://scdcorner.in/>) has been developed in collaboration with Piramal Swasthya Management and Research Institute, to create a database of individuals with SCD or trait in the tribal populations; to connect these individuals to welfare schemes, disease-specific healthcare services and validated health information and to enable data-driven

policy insights and strategic inputs. The issue has been inter-alia taken up with Chief Secretary(s) vide D.O. letter dated 18.06.2021 regarding compilation of SCD data at state level.

(ii) TRI Division of MoTA has sanctioned a research study program to Sir Ganga Ram Hospital on sickle cell disease wherein the organization is required to prepare treatise on SCD for training of trainers in medical colleges and modules for training of medical officers at district hospitals and integrated center for hemoglobinopathies and hemophilia. Project will also cover 4-5 workshops for training of trainers. As on date, Sir Ganga Ram Hospital has prepared draft modules and these have been scrutinized by Technical Expert Group (TEG) comprising of experts in the field. Modules have now been forwarded to Directorate General Of Health Services (DGHS), Ministry of Health & Family Welfare for their comments.

(iii) Integrated Sickle Cell Anemia Research Program "I-SCARP" in Nandurbar district, Maharashtra : TRI Division has given this project to Swami Vivekananda Yoga Anusandhana Samsthana, S-Vyasa University, Bangalore and INFOMED, Ahmedabad. The project primarily aims to explore naturopathy and yogic methods for curing sickle cell anaemia disease and it is ongoing.

(iv) TRI Division has given a project of Mapping of Sickle Cell Anaemia in the Tribal Sub Plan Area among the Tribal Communities of the State and a Compendium of Empirical Studies & Its findings on Sickle Cell Anaemia among the Tribal Communities of ODISHA to TRI Odisha which is to be executed in collaboration with RMRC, Odisha.

(v) A project 'Diagnosis, IEC and Nutri support for sickle cell anaemia and Thalassemia affected patients' to TRI Telangana and it is to be done in consultation with Piramal Foundation and other organizations working with MoTA on SCD project.

(vi) A project entitled 'Mapping of Sickle Cell Anemia among the Tribal Communities, Collation of compilation of data, mapping of organisations working in Sickle Cell, Data base of master trainers on sickle cell in co-ordination with MoHFW, Data sharing mechanism and mapping of Blood Banks availability ' has been given to NTRI.

The Sickle Cell disease can be eliminated only if mass awareness campaign are started and there is participation of States, elected representatives, teachers and medical staff at schools and college level. Dedicated Health Cell has been established in Ministry for ensuring the STC component of Health is utilised effectively. Ministry has asked States to submit proposals for funding for basic Infrastructure- as per ready Reckoner and a letter from Secy Ministry of Tribal Affairs to Chief Secretaries of States. Ministry has also taken up the issue of disability certificate issued to SCD patients with Department of Empowerment pf person with disabilities, who have notified that Disability Certificate for than 80% disability would be valid for 3 years.

Annexure 1 referred to in reply to part (b) of the Lok Sabha Unstarred Question No. 3433 to be answered on 9th August 2021.

Update on Screening of Sickle Cell incidences in States

Name of the State	Total number of persons screened				
	Trait	Disease	Normal	Total	Percentage of Normal
Andhra Pradesh	57	-	94718	94775	99.94
Arunachal Pradesh	108	-	155923	156031	99.93
Assam	NR	NR	NR	0	
Bihar	03	00	2933	2936	99.90
Chhattisgarh	21267	590	151036	172893	87.36
Goa	NR	NR	NR	0	-
Gujarat	729561	29266	7886101	8644928	91.22
Himachal Pradesh	-	-	432	432	100.00
Jammu & Kashmir	NR	NR	NR	0	-
Jharkhand	09	03	288	300	96.00
Karnataka	NR	NR	NR	0	-
Kerala	2042		146138	148180	98.62
Madhya Pradesh	611	312	385365	386288	99.76
Maharashtra	169191	14141	1188426	1371758	86.64
Manipur	NR	NR	NR	0	-
Meghalaya	NR	NR	NR	0	-
Mizoram	NR	NR	NR	0	-
Nagaland		--	2700	2700	100.00
Odisha	25461	2999	102101	130561	78.20
Rajasthan		--	1800	1800	100.00
Sikkim	NR	NR	NR	0	-
Tamil Nadu	NR	NR	NR	0	-
Telangana	617	-	22775	23392	97.36
Tripura	68	0	245947	246015	99.97
Uttar Pradesh	0	0	105	105	100.00
Uttarakhand	0	0	282	282	100.00
West Bengal	62	-	226	288	78.47
Total	949057	47311	10387296	11383664	91.25

NR- Not reported.

Annexure 2 referred to in reply to part (c) of the Lok Sabha Unstarred Question No. 3433 to be answered on 9th August 2021.

Statement Showing funds Released to States for Tackling Sickle Cell Anemia including Screening

(Rs. in Lakh)

S. No.	Name of State	Fund sanctioned for Sickle cell					
		2014-15	2015-16	2016-17	2017-18	2018-19	2019-20
1	Andhra Pradesh	0.00	-	-	233.00	-	-
2	Assam	-	-	-	-	-	-
3	Arunachal Pradesh	100.00	150.00	-	-	-	-
4	Bihar	-	-	10.00	10.00	-	-
5	Chhattisgarh	249.60	-	300.00	-	-	90.00
6	Goa	-	-	-	-	-	-
7	Gujarat	-	-	-	-	-	-
8	Himachal Pradesh	-	25.00	-	-	-	-
9	Jammu & Kashmir	-	-	-	-	-	-
10	Jharkhand	200.00	-	-	-	-	-
11	Karnataka	200.00	51.00	-	-	-	-
12	Kerala	-	23.00	-	-	-	-
13	Meghalaya	300.00	-	-	-	-	-
14	Mizoram	-	80.00	-	3.00	-	-
15	Maharashtra	100.00	-	-	-	-	-
16	Madhya Pradesh	1000.00	350.00	-	-	56.5	-
17	Manipur	200.00	150.00	-	-	-	-
18	Nagaland	50.00	-	-	-	-	-
19	Odisha	-	700.00	-	-	-	-
20	Rajasthan	300.00	53.27	-	-	-	200.00
21	Sikkim	-	6.50	-	-	-	-
22	Tamil Nadu	-	-	27.20	-	-	-
23	Tripura	-	50.00	50.00	-	-	-
24	Telangana	100.00	126.87	-	-	-	-
25	Uttrakhand	-	-	-	-	-	-
26	Uttar Pradesh	20.00	-	-	-	-	-
27	West Bengal	-	250.00	150.00	-	-	-
	Total	2819.60	2015.64	537.20	246.00	56.5	290.00
