GOVERNMENT OF INDIA MINISTRY OF TRIBAL AFFAIRS LOK SABHA UNSTARRED QUESTION NO- 802 TO BE ANSWERED ON- 07/02/2022

SICKLE CELL DISEASE AMONG TRIBAL POPULATION

802. SHRIMATI RITA BAHUGUNA JOSHI: SHRI SHYAM SINGH YADAV:

Will the Minister of TRIBAL AFFAIRS be pleased to state:

- (a) whether the Government has conducted nationwide screening for Sickle Cell Disease (SCD) among the tribal population of the country;
- (b) if so, the details thereof;
- (c) the steps taken by the Government for the preventive measure and its treatment in the tribal population;
- (d) whether the Government will promote more affected tribal persons to get voluntarily registered on SCD support centre to get information about the disease and resources to get help and if so, the details thereof?
- (e) the number of tribal women suffering from sickle cell anaemia in Uttar Pradesh; and
- (f) the steps which the Government is taking to eliminate sickle cell anaemia amongst tribal women?

ANSWER

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

- (a) & (b) Ministry of Tribal affairs has conducted screening of tribal population in collaboration with ICMR and Department of Biotechnology. Out of the 1,13,83,664 persons screened in different States, about 8.75% (9,96,368) tested positive (Trait –949057, Disease 47311).
- (c) to (f): 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 pre-natal 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 1**.

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 to create awareness about SCD and 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. In collaboration with organisation like Pirmal Swasthya, USAID and Novartis, Ministry has started "Unmukt" program on pilot basis in 2 districts one in Chattisgarh and the other In Jharkhandd to create awarenes about the disease.
- (ii) This Ministry in consultation with Ministry of Health and Family Welfare is developing a treatise on SCD for training of trainers in medical colleges and modules for training of medical officers at District hospitals and integrated centers.
- (iii) The Ministry has sanctioned a research project which aims to explore naturopathy and yogic methods for curing sickle cell anaemia disease.
- (iv) The Ministry has sanctioned a project to Tribal Research Institute (TRI) Odisha 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.
- (v) A project 'Diagnosis, IEC and Nutri support for sickle cell anaemia and Thalassemia affected patients' has been sanctioned to TRI Telangana.
- (vi) A project entitled 'Mapping of Sickle Cell Anemia among the Tribal Communities, Collation and compilation of data, mapping of organizations 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 National Tribal Research Institute (NTRI).
- (vii). States have been asked to seek funds under Grants under article 275(1) for infrastructural requirements related to diagnostic facilities and testing.

Dedicated Health Cell has been established in Ministry to focus upon health issues holistically including Sickle Cell Anemia among ST population including tribal women.

Department of Empowerment of person with Disabilities has issued notification for considering SCD as disability and issuing disability certificate more than 80% disability valid for 3 years.

State-wise details of screening of Sickle Cell Disease in tribals is at **Annexure 2**. Gender specific information is not maintained by the Ministry.

Annexure 1 referred to in reply to part (c) of the Lok Sabha Unstarred Question No. 802 to be answered on 07.02.2022

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		

Annexure 2 referred to in reply to part (e) of the Lok Sabha Unstarred Question No. 802 to be answered on 07.02.2022.

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.
