

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

**LOK SABHA
UNSTARRED QUESTION NO. 3887
TO BE ANSWERED ON 11.08.2023**

“DIAGNOSIS OF SICKLE CELL DISEASE IN TRIBAL AREAS”

3887. SHRI GAJENDRA SINGH PATEL:

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

- a. the details of various measures taken/proposed to be taken by the Government for the diagnosis of sickle cell disease in the tribal areas of the country;
- b. the details of places where sickle cell treatment centres have been set up in Madhya Pradesh;
- c. the steps taken/proposed to be taken by the Government for the treatment of sickle cell disease during the last three years, year-wise;
- d. whether awareness campaigns have been conducted by the Government in this regard at Panchayat level in the tribal dominated districts of the country and if so, the details thereof;
- e. the details of the efforts made by the Government for diagnosis of the said diseases in the Khargone-Baarwani Parliamentary Constituency of Madhya Pradesh; and
- f. the details of the programme being implemented by the Government to provide healthcare facility to women?

**ANSWER
THE MINISTER OF STATE IN THE MINISTRY OF HEALTH & FAMILY
WELFARE
(PROF. S. P. SINGH BAGHEL)**

(a) to (d): Sickle cell disease is a genetic blood disease which affects the whole life of patient. It is more common in the tribal population of India, but occurs in non tribals too. It not only causes anemia but also pain crisis, reduced growth and affects many organs like lungs, heart, kidney, eyes, bones and the brain.

To eliminate sickle cell disease, Sickle Cell Anemia Elimination Mission has been launched by Hon'ble Prime Minister from Madhya Pradesh on 1st July, 2023. The Objectives of the Mission are provision of affordable and accessible care to all Sickle Cell Diseased patients, quality of care for diseased and reduction in the prevalence of Sickle Cell Disease through

awareness creation, universal screening of 7 crore people in the age group of 0-40 years in affected 278 districts of tribal areas, and counseling through collaborative efforts of central ministries and state governments.

In order to provide facilities and treatment to the patients of hemoglobinopathy (sickle cell anemia, thalassemia and hemophilia) in 22 tribal dominated and 8 hub centers in Madhya Pradesh, budget has been allocated for the smooth operation of 29 Integrated Centers for Hemoglobinopathies & Hemophilia.

Sickle Cell Anemia Elimination Mission is a sub mission of NHM. Based on the proposal received from States, the funds have been approved by MoHFW under NHM. The amount approved for hemoglobinopathy screening under NHM during 2021-22 to 2023-24 is given at **Annexure**.

Under the National Sickle Cell Anaemia Elimination Mission, patients living with Sickle Cell disease are provided with the following services/ facilities for improving their quality of life through Ayushman Bharat-Health and Wellness Centres (AB-HWC);

- Regular follow-up of diseased individuals at frequent intervals.
- Counseling regarding lifestyle management.
- Nutritional supplementation support through distribution of folic acid tablets.
- Conducting yoga and wellness sessions.
- Management of crisis symptoms and referral to higher facilities.

Ministry of Health and Family Welfare has launched a National Sickle cell portal where progress of screening can be accessed at <https://sickle.nhm.gov.in>.

Through ministry of tribal affairs, awareness and counseling material have been developed. IEC and media activities are adopted for propagation of awareness of disease, screening and management. State Govts. have to play an important role in implementation of mission activities.

(e): As per the information received from State Govt. of Madhya Pradesh, after getting results of Pilot phase of Sickle cell screening in Jhabua & Alirajpur district, State Govt. of Madhya Pradesh decided to scale up the project in 89 tribal blocks that include Khargone & Baarwani district too. During the second phase total 2,93,642 beneficiaries screened for Sickle cell in Khargone & Baarwani district, out of that 6,282 Sickle cell trait (Carrier) and 1,775 Sickle cell diseased identified.

(f): Under NHM, the following healthcare facilities are provided including women;

- Teleconsultation services, through eSanjeevani, are available at functional AB-HWC to ensure specialist services closer to the people. As on 31st July 2023, more than 14.35 crore Teleconsultations have been provided via eSanjeevani portal. Screening of women is also being done at AB-HWCs for breast cancer, oral cancer and cervical cancer.

- **National Free Drugs Initiative:** States/UTs are supported to provide essential drugs based on the level of public health facilities free of cost to all who access these facilities.
- **Free Diagnostics Initiatives. (FDI):** Under the initiative, support provided to States/UTs to provide a set of essential diagnostics (14 tests at Sub Centre/ Health and Wellness Centre level, 63 tests at PHC/ PHC-HWC level, 97 tests at CHC level, 111 tests at SDH level and 134 tests at DH level) at various levels of care, free of cost.
- **National Ambulance Services (NAS)** - Under the NHM, technical and financial support is provided for emergency medical services in States/UTs through a functional National Ambulance Service (NAS) network linked with a centralised toll-free number 108/102.
- **National Mobile Medical Units (NMMU)** – are supported to facilitate access to public health care at the doorstep particularly to people living in remote, difficult, under-served and unreached areas to provide primary care services.

Apart from above mentioned schemes, Government has also implemented following schemes especially for pregnant women:

- **Surakshit Matritva Aashwasan (SUMAN)** provides assured, dignified, respectful and quality healthcare at no cost and zero tolerance for denial of services for every woman and newborn visiting public health facilities to end all preventable maternal and newborn deaths.
- **Janani Suraksha Yojana (JSY)**, a demand promotion and conditional cash transfer scheme for promoting institutional delivery.
- Under **Janani Shishu Suraksha Karyakram (JSSK)**, every pregnant woman is entitled to free delivery, including caesarean section, in public health institutions along with the provision of free transport, diagnostics, medicines, blood, other consumables & diet.
- **Pradhan Mantri Surakshit Matritva Abhiyan (PMSMA)** provides pregnant women a fixed day, free of cost assured and quality antenatal check up by a Specialist/Medical Officer on the 9th day of every month.
- **LaQshya** improves the quality of care in labour room and maternity operation theatres to ensure that pregnant women receive respectful and quality care during delivery and immediate post-partum.
- **Functionalization of First Referral Units (FRUs)** by ensuring manpower, blood storage units, referral linkages to improve the access to quality of care for pregnant women
- **Outreach camps** are provisioned for improving the reach of health care services especially in tribal and hard to reach areas. This platform is used to increase the awareness for the Maternal & Child health services, community mobilization as well as to track high risk pregnancies.
- **IEC/BCC campaigns:** One of the key focus areas of Maternal Health is to generate demand through Information Education & Communication (IEC), Inter-personal Communication (IPC) and Behaviour Change Communication (BCC) activities.

Amount approved for Hemoglobinopathy Screening

Rs. in Lakh				
Sl. No.	Name of States	2021-22	2022-23	2023-24
1	A&N Island	0	0.00	0.00
2	Andhra Pradesh	0	130.00	130.00
3	Arunachal Pradesh	2	9.98	10.48
4	Assam	0	24.96	31.20
5	Bihar	0	50.00	50.00
6	Chandigarh	0	17.50	17.50
7	Chhattisgarh	25	1536.36	1536.36
8	D&NH & D&D	0	0.00	0.00
9	Delhi	0	1202.00	933.00
10	Goa	0	0.00	0.00
11	Gujarat	12.51	445.50	505.68
12	Haryana	0	421.90	464.00
13	Himachal Pradesh	0	121.60	121.60
14	Jammu & Kashmir	501.25	0.00	0.00
15	Jharkhand	350	295.00	407.50
16	Karnataka	0	225.39	225.39
17	Kerala	59.42	5110.92	3848.40
18	Ladakh	0	0.00	0.00
19	Lakshadweep	0	2.00	2.10
20	Madhya Pradesh	1623	1100.00	1210.00
21	Maharashtra	294.31	2017.10	2017.10
22	Manipur	0	4.00	0.00
23	Meghalaya	21.5	0.00	0.00
24	Mizoram	0	0.20	0.20
25	Nagaland	0	0.00	0.00
26	Odisha	1842.11	87.50	87.50
27	Puducherry	0	22.50	22.50
28	Punjab	0	1311.00	961.00
29	Rajasthan	515	251.47	251.47
30	Sikkim	0	0.00	0.00
31	Tamil Nadu	9.24	6139.80	6139.80
32	Tripura	0	87.92	91.64
33	Telangana	264	239.25	0.00
34	Uttar Pradesh	4,405.95	7540.20	7540.20
35	Uttarakhand	15	472.39	482.19
36	West Bengal	0	125.40	132.50
	Total	9940.29	28991.84	27219.31