

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

**RAJYA SABHA
UNSTARRED QUESTION NO. 1392
TO BE ANSWERED ON 01.08.2023**

“ELIMINATION OF SICKLE CELL ANAEMIA”

1392 SMT. SUMITRA BALMIK:

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

- a. the steps taken up Government towards elimination of sickle cell anaemia in the country;
- b. the tally of total number of patients suffering from the disease, State-wise;
- c. the details of the recently launched programme for eradication of sickle cell anaemia in Madhya Pradesh; and
- d. whether any medicines or medical interventions have been researched upon for mitigation of the disease?

ANSWER

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

(a) to (c): 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. The State-wise screening target is given at **Annexure**.

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. State Governments are doing screening by scheduling outreach campaign in villages and schools/hostels. The preventive measurement and management of disease is also an important component of the mission.

Ministry of Health and Family Welfare has launched a National Sickle cell portal where all States update the progress of screening and test results.

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.

(d) Council of Scientific & Industrial Research (CSIR), through its constituent laboratories namely, CSIR-Institute of Genomics and Integrative Biology (CSIR-IGIB), Delhi and CSIR-Indian Institute of Chemical Technology (CSIR-IICT), Kolkata has engaged in Research & Development for gene editing approaches for sickle cell anemia therapy under CSIR Sickle Cell Anemia Mission. Under this Mission, CSIR-IGIB along with CSIR-IICB has provided proof-of-concept correction of sickle cell anaemia mutation in patient-derived cells and the increase in Fetal hemoglobin (HbF) production through Hereditary Persistence of Fetal Hemoglobin (HPFH) editing [publication in Proceedings of the National Academy of Sciences, 2019]. CSIR leads are now taken forward towards a dedicated Phase-I clinical trial with funding from Department of Science and Technology and the Ministry of Tribal Affairs..

Annexure

State-wise Screening Targets

S.N.	State/UT	Three years Target	FY (2023-24) Target	FY (2024-25) Target	FY (2025-26) Target
1	Andhra Pradesh	1857526	668833	668833	519860
2	Assam	2973667	1070718	1070718	832231
3	Bihar	559818	201572	201572	156674
4	Chhattisgarh	17314950	6164532	6164532	4985886
5	Gujarat	6413295	2279212	2279212	1854871
6	Jharkhand	5831719	2069807	2069807	1692105
7	Karnataka	328696	118352	118352	91992
8	Kerala	196314	70686	70686	54942
9	Madhya Pradesh	10384000	3698930	3698930	2986140
10	Maharashtra	6906335	2456740	2456740	1992855
11	Odisha	6314772	2263737	2263737	1787298
12	Rajasthan	3889858	1396607	1396607	1096644
13	Tamil Nadu	538764	193991	193991	150782
14	Telangana	1122195	404065	404065	314065
15	Uttar Pradesh	241976	87127	87127	67722
16	Uttarakhand	701715	252664	252664	196387
17	West Bengal	4462261	1602427	1602427	1257407
	Total	70,037,861	25,000,000	25,000,000	20,037,861