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

LOK SABHA UNSTARRED QUESTION NO. 303 TO BE ANSWERED ON 21ST JULY, 2023

ERADICATION OF SICKLE CELL ANEMIA

303. SHRI SUSHIL KUMAR SINGH:

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

- (a) the specific details of the Sickle Cell Anemia Elimination Mission, including the mission's goals, key strategies and planned timelines for implementation;
- (b) the measures that are being implemented/to be implemented by the Ministry to create awareness about Sickle Cell Anemia, particularly among the vulnerable communities;
- (c) the details regarding the role of the State/UT Governments in the implementation of the said mission, including any collaborations with Non-Governmental Organizations (NGOs), private healthcare institutions, and international agencies;
- (d) the estimated budget allocated for the said mission, its disbursement, and the challenges faced in this regard;
- (e) the initiatives and programmes that have been planned as part of the mission to improve the quality of life of the patients already living with Sickle Cell Anemia; and
- (f) the research initiatives and partnerships, if any, to support the development of a more effective treatments?

ANSWER THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY WELFARE (PROF. SATYA PAL 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 Anaemia Elimination Mission has been launched by Hon'ble Prime Minister from Madhya Pradesh on 1st July, 2023. The Objectives of the Mission is provision of affordable and accessible care to all SCD patients, quality of care for SCD patients and reduction in the prevalence of SCD 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 counselling through collaborative efforts of central ministries and state government.

Through ministry of tribal affairs, awareness and counseling material has been developed. IEC and media activities are adopted for propagation of disease, screening and management. State Govt. have to play an important role in implementation of mission activities. State Government doing screening by scheduling outreach campaign in villages and schools/hostels. The preventive measurement and management of disease is also an important component of mission.

- (d): 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.
- (e): Under the National Sickle Cell Anaemia Elimination Mission, patients living with Sickle Cell disease 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.
- (f): The breakthrough success of CRISPR(Clustered Regularly Interspaced Short Palindromic Repeats)-CAS (CRISPR Associated) methods by Council for Scientific and Industrial Research (CSIR), Institute of Genomics and Integrative Biology (IGIB) for correcting genetic diseases in patients has fuelled significant scientific investment into bringing such methods to the clinic.
- An action research project has been sanctioned by Ministry of Tribal Affairs to understand the efficacy of Yoga based life-style intervention (YBLI) in reducing oxidative stress and its related complications at different organ and systems level for the management of sickle cell anemia.
- Central Council for Research in Ayurvedic Sciences (CCRAS) an autonomous body of the Ministry of AYUSH has developed two coded formulations, AYUSH-RP and AYUSH-SC3 for managing sickle cell disease through systemic drug development process. The M/o Ayush, Govt of India and M/o Tribal afairs, Govt. of India have entered into Memorandum of Understanding (MoU) on 23rd October 2022 and one of the Areas of Cooperation in the MoU is "work on public health research initiative for tackling endemic & genetic disease like sickle cell anemia, TB, Malaria and Malnutrition".
