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

LOK SABHA UNSTARRED QUESTION NO. 3153 TO BE ANSWERED ON 13.12.2024

TREATMENT OF SICKLE CELL ANEMIA

3153. SHRI SANJAY UTTAMRAO DESHMUKH:

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

- (a) the total number of registered patients of sickle cell anemia in Maharashtra particularly in the Parliamentary Constituency of Yavatmal-Washim alongwith the steps taken as on date to assess their condition;
- (b) whether medicines and facilities for the treatment of sickle cell disease in Primary Health Centres of Yavatmal-Washim are insufficient and if so, the details thereof;
- (c) the steps taken/proposed to be taken by the Government to make these available immediately;
- (d) whether there is any scheme to organise free camps for the treatment of sickle cell disease in rural areas;
- (e) if so, the details thereof and if not, the reasons therefor alongwith the time by which these are likely to be organized;
- (f) the time by which special wards and specialist doctors are likely to be appointed for the affected patients in district and tehsil hospitals; and
- (g) whether the Government is contemplating to launch any such financial assistance scheme for the relief of the poor and needy patients keeping in view its costly treatment and if so, the details thereof?

ANSWER THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY WELFARE (SMT. ANUPRIYA PATEL)

(a) to (g): To eliminate sickle cell disease (SCD), National Sickle Cell Anaemia Elimination Mission (NSCAEM) has been launched by Hon'ble Prime Minister from Madhya Pradesh on 1st July, 2023. The objectives of the Mission are provision of affordable, accessible and quality care to all Sickle Cell Diseased patients, reduction in the prevalence of SCD through awareness creation, targeted screening of 7 crore people till year 2025-26 in the age group of 0-40 years in affected districts of tribal areas and counselling through collaborative efforts of central ministries and State governments. Details of individuals screened, confirmed as carrier, diseased and patients under treatment in the State of Maharashtra and in the Districts

of Yavatmal-Washim Parliamentary Constituency (as on 10.12.2024) are as follows:

Sr. No	State/District	Total no. of individuals screened	Total no. of sickle cell carriers	Total no. of sickle cell Diseased	Total no. of sickle cell disease patients under Treatment
1	Maharashtra	50,81,086	1,46,335	18,893	3,887
2	Washim	1,98,925	142	13	1
3	Yavatmal	2,82,531	9,481	1,486	628

To ensure availability of essential drugs and reduce the OOPE of the patients including sickle cell diseased, visiting the public health facilities, Government has rolled out the Free Drugs Service Initiative under NHM. This includes financial support to States/UTs for 106 drugs at SHC level, 172 at PHC level, 300 at CHC level, 318 at SDH level and 381 drugs at district Hospitals. Hydroxyurea, drug for SCD patients, has been included in NHM Essential Drugs List at SHCs, PHCs /Urban PHCs, CHCs and District Hospitals to address the issue of access to medicine.

This Ministry also supports 'Free Diagnostics Service Initiative' programme under National Health Mission (NHM) with the aim to provide accessible and affordable pathological and radiological diagnostics services closer to the community, which in turn reduces the Out-of-Pocket Expenditure (OOPE). Diagnostics services for all including Sickle cell Anemia patients are provided free of cost at all levels of public health facilities [14 tests at SHCs, 63 at PHCs, 97 at Community Health Centres (CHCs,) 111 test at Sub District Hospitals and 134 tests at District Hospitals].

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. Awareness activities are also provided in each sickle cell screening camp. State Governments play an important role in implementation of mission activities including awareness drive.

This Ministry has directed all States/UTs to organize monthly fixed-day outreach services, namely Ayushman Arogya Shivir to deliver healthcare services closer to the community and reduce out-of-pocket expenditure. This initiative envisages holding health camps at the AAM (SHC & PHC) with the presence of Medical officers in SHC and specialist medical camps at PHC and CHCs once each month.

This Ministry provides technical and financial support including support for recruitment of health human resource (Specialists Doctors and other health workers), to the States/UTs to strengthen the public healthcare system, based on the proposals received in the form of Programme Implementation Plans (PIPs) under NHM. Government of India provides approval for the proposals in the form of Record of Proceedings (RoPs) as per norms & available resources.

Under NSCAEM, screenings are conducted at all health facilities from District Hospitals upto Ayushman Arogya Mandir (AAM) level. Patients living with SCD are provided with the following services/ facilities for improving their quality of life through AAM- Sub Health Centres (SHC) and AAM- Primary Health Centres (PHCs):

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