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

## RAJYA SABHA STARRED QUESTION NO. 154 TO BE ANSWERED ON THE 6<sup>TH</sup> AUGUST, 2024

#### NATIONAL SICKLE CELL ANAEMIA ELIMINATION MISSION

#### **154 DR. ASHOK KUMAR MITTAL:**

Will the Minister of Health and Family Welfare be pleased to state:

- (a) the current status of implementation of the National Sickle Cell Anaemia Elimination Mission launched in 2023, including details of screening conducted and counselling provided in affected tribal regions;
- (b) the steps being taken to improve access to modern medications, including hydroxyurea and other disease-modifying therapies, for patients with Sickle Cell Disease (SCD), particularly in tribal and rural areas;
- (c) whether Government is considering initiatives to promote research in gene therapy and other advanced treatments for SCD in the country, if so, the details thereof; and
- (d) the measures being implemented to strengthen healthcare infrastructure, improve early diagnosis and enhance community engagement to combat SCD?

# ANSWER THE MINISTER OF HEALTH AND FAMILY WELFARE (SHRI JAGAT PRAKASH NADDA)

(a) to (d) A Statement is laid on the Table of the House.

# STATEMENT REFERRED TO IN REPLY TO RAJYA SABHA STARRED QUESTION NO. 154 \* FOR 6<sup>TH</sup> AUGUST, 2024

(a) 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 Sickle Cell Disease (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. Ministry of Health and Family Welfare (MoHFW) has launched a National Sickle cell portal i.e. https://sickle.nhm.gov.in where achievement of screening can be accessed. As on 31.07.2024, a total of 3,85,09,466 population in the 17 identified States have been screened and uploaded on the portal by States.

Under NSCAEM, screenings are conducted at all health facilities from District Hospitals upto Ayushman Arogya Mandir (AAMs) level. Patients living with SCD are provided with the following services/ facilities for improving their quality of life through AAMs;

- > 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.

Through Ministry of Tribal Affairs (MoTA), awareness and counseling material have been developed. IEC and media activities are adopted for propagation of awareness of disease, screening and management. State Governments have to play an important role in implementation of mission activities.

(b) & (c) Hydroxyurea has been included in National Health Mission (NHM) Essential Drugs List at Sub-Health Centres, Primary Health Centres (PHC)/ Urban PHC, Community Health Centres (CHC) and District Hospitals to address the issue of access to medicine. Under NHM, financial support is provided for the procurement of Hydroxyurea, to reduce the out-of-pocket expenditure borne by sickle cell anaemia patients.

Council of Scientific and Industrial Research (CSIR) has been actively promoting research in gene editing therapies for advanced treatment options for SCD through its program on Sickle Cell Mission which was undertaken at one of the constituent laboratories of CSIR namely CSIR-Institute of Genomics and Integrative Biology (IGIB), Delhi from 2017-2023.

(d) For early diagnosis, facilities for screening for age 0-40 years as well as counselling are available at all level of health facilities from district hospitals till AAMs. NHM supports towards establishment of Integrated Center for Hemoglobinopathies & hemophilia (ICHH) in District Hospitals in co-ordination with state Health Departments, procurement of screening kits and SCD cards.

MoHFW has devised the cost norms for establishment of Centres of Excellence on SCD funded by MoTA in various states.

ICMR-National Institute of Research In Tribal Health (NIRTH), Jabalpur has provided training to master trainers on diagnosis of SCD in states where SCD is prevalent.

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