

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

**RAJYA SABHA  
UNSTARRED QUESTION NO. 1381  
TO BE ANSWERED ON 1<sup>ST</sup> August, 2023**

**COMBATING SICKLE CELL ANEMIA**

**1381. SHRI SYED NASIR HUSSAIN:**

**DR. AMEE YAJNIK:**

**SHRI PRAMOD TIWARI:**

**SMT. RANJEET RANJAN:**

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

- (a) the progress made by the Council of Scientific and Industrial Research (CSIR) in its efforts to combat Sickle Cell Anemia using CRISPR CAS-9 therapy;
- (b) the budgetary allocation and expenditure for research on Sickle Cell Anemia by Government from 2020, year wise;
- (c) details of work done so far on Sickle Cell Anemia by the gene therapy advisory and Evaluation Committee (GTAEC), Department of Biotechnology (DBT) and National Apex Committee for Stem Cell Research and Therapy (NAC-SRT ); and
- (d) the steps taken by the Government to achieve the target of elimination Sickle Cell Anemia from the country by 2047, given the high cost and initial stage of development of cure involving gene therapy and stem implants?

**ANSWER**

**THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY  
WELFARE**

**(PROF. S.P. SINGH BAGHEL)**

(a) 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.

(b) The details of funds allocated and expenditure for research on Sickle Cell Anemia Mission as per Council of Scientific & Industrial Research (CSIR) are as under;

Rs. in lakh

| Budget        | FY 2020-21 |             | FY 2021-22 |             | FY 2022-23 |             |
|---------------|------------|-------------|------------|-------------|------------|-------------|
|               | Released   | Expenditure | Released   | Expenditure | Released   | Expenditure |
| Non Recurring | 577.00     | 577.00      | 190.50     | 52.20       | 50.50      | 50.49       |
| Recurring     | 681.01     | 619.51      | 920.40     | 668.14      | 920.39     | 837.12      |
| Total         | 1258.01    | 1196.51     | 1110.90    | 720.35      | 970.89     | 887.61      |

[Beside above, Rs. 4317.6 lakh has been budget and spent by ICMR on Research Projects for Sickle Cell Anemia since 2020]

(c) NAC-SCRT National Apex Committee for Stem Cell Research (NAC-SCRT) and Gene Therapy Advisory and Evaluation Committee (GTAEC) was constituted as an independent body of experts and stakeholders and same were notified by the Department of Health Research, Ministry of Health and Family Welfare, Govt. of India in 2009 and 2017 respectively to oversee the activities in the field of stem cell research and gene therapy research in India to provide a hand holding for the investigators/ industry and also give pre-Investigational New Drug (IND) consultations. However, no specific research work/guidelines related to sickle cell anemia was allocated/conducted by NACSCRT and GTAEC till March 2023.

(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 Anaemia 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 SCD patients 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 counselling through collaborative efforts of central ministries and state governments.

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.

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.