World Sickle Cell Awareness Day

3.37 Crore screened under India's National Sickle Cell Anaemia Elimination Mission

(Ministry of Tribal Affairs)

June 18, 2024

Introduction

World Sickle Cell Awareness Day, observed annually on June 19th, serves as a crucial platform for raising awareness about sickle cell disease (SCD), a genetic blood disorder affecting millions worldwide. The day aims to highlight the struggles faced by those with SCD, promote understanding of the disease, and streamline efforts towards improving patient care and finding a cure. The international awareness day also seeks to increase public knowledge and understanding of the challenges experienced by patients, their families, and caregivers.

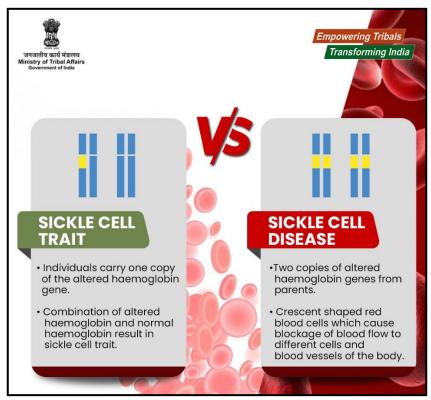
In 2024, the theme for World Sickle Cell Awareness Day is "Hope Through Progress: Advancing Sickle Cell Care Globally." This theme underscores the ongoing advancements in medical research and healthcare practices that bring hope to individuals and families affected by SCD. It also emphasizes the importance of global collaboration in enhancing treatment and care, ensuring that progress reaches every corner of the world.

Understanding Sickle Cell Disease

Sickle Cell Disease is a chronic, single-gene disorder that causes a debilitating systemic syndrome characterized by chronic anemia, acute painful episodes, organ infarction, and chronic organ damage, significantly reducing life expectancy. SCD is a genetic blood disorder affecting the entire life of the patient, as it leads to various severe health complications.



SCD causes red blood cells become to abnormally shaped like a crescent or sickle, instead of being round and flexible. These sickleshaped cells can block blood flow, leading to pain and other serious health complications. This genetic blood disease affects hemoglobin, the protein in red blood cells that carries oxygen throughout body, the resulting in a wide range of health issues significantly affecting the patient's quality of life.



Sickle Cell Disease is particularly prevalent in India, especially among the tribal population, though it also affects non-tribals. India has the largest tribal population density globally, with 8.6% of the population, or 67.8 million people, identified as tribal according to the 2011 Census. The Ministry of Health and Family Welfare (MoHFW) tribal health expert committee has highlighted SCD as one of the ten major health issues disproportionately affecting tribal communities.

National Sickle Cell Anaemia Elimination Mission

The National Sickle Cell Anaemia Elimination Mission, introduced in the Union Budget 2023, aims to address the significant health challenges Sickle Cell Disease (SCD) poses, particularly among India's tribal populations. This initiative was officially launched by Prime Minister Shri Narendra Modi from Madhya Pradesh on July 1, 2023, with the vision to eliminate sickle cell disease as a public health problem in India before 2047.

The mission aims to improve the care of all Sickle Cell Disease patients for a better future and to lower the prevalence of the disease through a multi-pronged coordinated approach towards screening and awareness strategies. Achieving this goal requires comprehensive efforts across diagnosis, treatment, and community engagement to effectively manage and eventually eradicate SCD's impact on public health in the country.

Objectives of the Mission:

- ❖ Provision of affordable and accessible care to all SCD patients
- ❖ To ensure quality of care for SCD patients
- ❖ To reduce the prevalence of SCD

These objectives are to be achieved through strategies spanning awareness generation, strengthening of screening and testing facilities, strengthening of laboratory services for diagnosis, facilitation of management & treatment, establishing linkages across levels of care, inter-sectoral convergence towards holistic approach and linkages with social security schemes/benefit packages.

Strategy

The strategy of the mission emphasizes three pillars:

- **Health promotion-** Awareness generation & pre-marital genetic counselling
- **Prevention** Universal screening and early detection
- ❖ Holistic Management & continuum of care- Management of persons with sickle cell disease at primary, secondary, and tertiary health care levels; treatment facilities at tertiary health care facilities, Patient support system and Community adoption.

Beneficiaries

The program is executed in a mission mode as part of the National Health Mission (NHM), showcasing a long-term commitment to eradicating the disease. Over a period of three years, spanning from the fiscal years 2023-24 to 2025-26, the program targets screening approximately 7 crore people. It focuses on universal population-based screening, prevention, and management of sickle cell anemia in all tribal and other highly prevalent areas States/UTs of India.

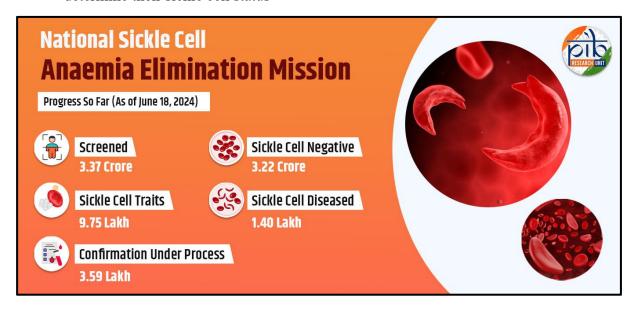
The programme aims to cover the entire population from birth to 18 years of age initially and shall incrementally include the entire population up to 40 years. While initially prioritizing high-prevalence states/UTs with significant tribal populations, the initiative plans to gradually expand its coverage to include all states/UTs in a phase-wise manner. This incremental

approach aims to ensure comprehensive screening, counseling for prevention, and extensive care for individuals affected by SCD across different age groups within three and a half years.

Progress So Far

As of June 18, 2024, the National Sickle Cell Anaemia Elimination Mission has made significant strides in screening and identifying cases of Sickle Cell Disease (SCD) across India. Here are the details of the progress made:

- ❖ A total of more than 3.37 crore individuals have been screened under the programme
- ❖ Out of those screened, more than 3.22 crore people have been confirmed negative for sickle cell disease
- ❖ A total of nearly 9.75 lakh individuals have been identified as carriers of the sickle cell trait
- ❖ More than 1.40 lakh people have been diagnosed with sickle cell disease based on the screening
- ❖ Currently, over 3.59 lakh individuals are undergoing further confirmation to determine their sickle cell status



Way Forward

In conclusion, the comprehensive efforts outlined through World Sickle Cell Awareness Day and the National Sickle Cell Anaemia Elimination Mission highlight a dedicated commitment to addressing the challenges posed by sickle cell disease (SCD) in India. Through increased awareness, strategic screening initiatives, and integrated healthcare approaches, significant progress has been achieved in identifying cases, providing care, and advancing toward the elimination of SCD as a public health concern by 2047. As these efforts continue to expand

across different states and age groups, they reinforce India's resolve to enhance healthcare outcomes and promote wellbeing among its diverse population, particularly in tribal and high-prevalence areas.

References:

- https://sickle.nhm.gov.in/home/about
- https://sickle.nhm.gov.in/home/guest_dashboard
- https://pib.gov.in/PressReleasePage.aspx?PRID=1936735
- ♦ https://pib.gov.in/PressReleasePage.aspx?PRID=1933456
- ♦ https://pib.gov.in/PressReleaseIframePage.aspx?PRID=1933580
- ♦ https://pib.gov.in/PressReleasePage.aspx?PRID=1942713
- ♦ https://pib.gov.in/PressReleasePage.aspx?PRID=1896039

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