NATIONAL SICKLE CELL ANAEMIA ELIMINATION MISSION: SCIENCE & TECHNOLOGY

PM shares an article on landmark initiative aiming for a Sickle Cell Disease-free India by 2047

Launched in 2023, the National Sickle Cell Anaemia Elimination Mission aims to stop the genetic transmission of the disease by 2047 by screening 70 million people, primarily in tribal areas. The mission focuses on early detection, free treatment with drugs like hydroxyurea, and genetic counselling to prevent high-risk marriages.

National Sickle Cell Anaemia Elimination Mission (NSCAEM)

The Union government is making significant strides with its National Sickle Cell Anaemia Elimination Mission (NSCAEM), which was launched in July 2023. The mission is a focused effort to address the high prevalence of Sickle Cell Disease (SCD), particularly within India's tribal communities, with a long-term vision for its elimination.

Key Aspects of the Mission

Primary Goal

The mission's overarching objective is to eliminate the genetic transmission of sickle cell disease by the year 2047.

Screening Target

A core component of the mission is a massive screening drive aiming to test 70 million people under the age of 40 by the financial year 2026.

Progress Report (as of July 2024)

Screened Population

Over 60.7 million individuals have been screened across 17 states identified as high-prevalence zones.

SCD Patients Identified

The screening has diagnosed 216,000 people with Sickle Cell Disease.

Carriers Identified

A total of 1.69 million people have been identified as carriers of the sickle cell trait.

Geographic Concentration

The disease burden is highly concentrated, with 95% of all cases in India being reported from five states: Odisha, Madhya Pradesh, Gujarat, Chhattisgarh, and Maharashtra.

Interventions and Strategies

Comprehensive Healthcare

Providing free healthcare services, diagnostics, and access to essential medicines like hydroxyurea.

Prevention and Awareness

Implementing widespread genetic counselling, running public awareness campaigns, and distributing genetic status cards to individuals to inform them of their carrier status and help in making informed marriage choices.

Capacity Building

Establishing Centres of Excellence in 15 premier medical institutions to serve as hubs for advanced diagnosis, management, and research.

Training and Development

Rolling out Training of Trainers (ToT) programs to equip community health workers with the necessary skills for screening and counselling.

Technological Deployment

Using cost-effective, portable Point-of-Care (PoC) diagnostic devices to enable rapid and accessible screening in remote areas.

Collaborative Approach

The mission employs a "whole-of-government" strategy, ensuring convergence between multiple ministries. The involvement of the Ministry of Tribal Affairs is particularly crucial. The mission's success is also highlighted through community-based success stories, such as that of Meena from Chhattisgarh.

Future Focus

The path forward involves intensifying efforts in genetic counselling, expanding awareness campaigns to reach the last mile, and leveraging digital tools and platforms to track and support every carrier and patient.

Understanding Sickle Cell Anaemia (SCA)

Sickle Cell Anaemia is a hereditary blood disorder (a genetic disease) caused by a mutation in the HBB gene. This mutation leads to the production of an abnormal form of haemoglobin called haemoglobin S (HbS).

Mechanism

The abnormal HbS causes red blood cells (RBCs) to become distorted into a rigid, sickle-like or crescent shape, especially under low oxygen conditions. These misshapen cells have a reduced oxygen-carrying capacity, are fragile, and can block blood flow in small vessels, leading to tissue and organ damage.

Inheritance

It is an autosomal recessive disorder. This means that for a child to have the disease, they must inherit the defective gene from both parents. If a child inherits the gene from only one parent, they will be a "carrier" (have the sickle cell trait) but usually won't have the disease symptoms.

Symptoms

1. Anaemia and chronic fatigue.
2. Episodes of extreme pain, known as pain crises.
3. Swelling in hands and feet.
4. Frequent infections due to a damaged spleen.
5. Delayed growth and development in children.
6. Vision problems.

Complications

If left unmanaged, SCD can lead to severe complications such as stroke, organ damage (spleen, kidneys, liver), pulmonary hypertension, and chronic leg ulcers.

Prevalence in India

The disease is particularly common in the tribal communities of central, western, and southern states, including Chhattisgarh, Madhya Pradesh, Maharashtra, Odisha, and Gujarat.

Diagnosis

Blood tests such as Haemoglobin Electrophoresis or High-Performance Liquid Chromatography (HPLC) to detect HbS. Newborn screening to identify the disease at birth. Genetic testing to confirm the mutation.

Treatment and Management

Medicines

Hydroxyurea (to reduce the frequency of pain crises), pain relievers, antibiotics (to prevent infections), and folic acid supplements (to help produce new RBCs).

Procedures

Blood transfusions to treat severe anaemia and bone marrow transplant, which can be curative in some, particularly younger, patients.

Supportive Care

Maintaining adequate hydration, prompt management of infections, and oxygen therapy during crises.

Prevention

The primary strategy for preventing the transmission of the disease involves:

1. Premarital and genetic counselling.
2. Carrier screening to identify individuals with the sickle cell trait.
3. Educating carriers to avoid high-risk marriages (i.e., marriage between two carriers).

Other Government Initiatives

Supporting the mission's goal, the government has included the key drug hydroxyurea in the National Essential Drug List, ensuring its availability and affordability.

Source: https://www.pib.gov.in/PressReleasePage.aspx?PRID=2155384