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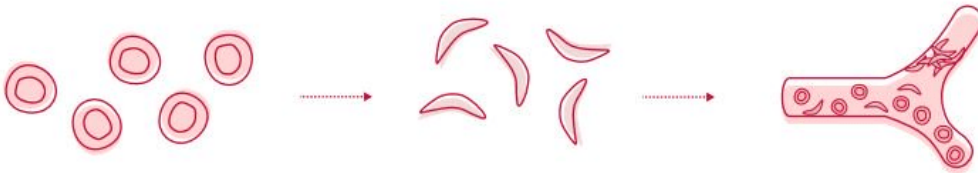
No Newborn With Sickle Cell Disease By 2047, PM To Launch Elimination Mission Next Week: Munda

Prime Minister Narendra Modi is scheduled to launch a mission to eliminate Sickle Cell Anaemia by 2047 from Shahdol in Madhya Pradesh on June 27. On World Sickle Cell Day (June 19), Union Tribal Affairs Minister ARJUN MUNDA details his Ministry's action plan to tackle the menace that is prevalent amongst tribals and is endemic in over 15 States with a significant ST population.

June 18, 2023



What is Sickle Cell Disease?



SCD is a blood disorder

Sickle Cell Disease (SCD) is an inherited blood disorder that affects red blood cells. Normal red blood cells are round and flexible, which lets them travel through small blood vessels to deliver oxygen to all parts of the body.

Causing misshapen blood cells

SCD causes red blood cells to form into a crescent shape, like a sickle.

Creating painful complications

The sickle-shaped red blood cells break apart easily, clump together, and stick to the walls of blood vessels, blocking the flow of blood, which can cause a range of serious health issues.

Know The Sickle Cell Disease

New Delhi

Sickle Cell Disease (SCD), a genetic condition, is widespread among the tribal population in India where about 1 in 86 births among Scheduled Tribes (ST) have it. The disease is prevalent among the States like Gujarat, Jharkhand, Madhya Pradesh, Chhattisgarh, Maharashtra, Odisha, Rajasthan, Tamil Nadu, Telangana, Karnataka, Kerala, Uttarakhand, West Bengal, Andhra Pradesh, Uttar Pradesh and Bihar.

The first description of sickle haemoglobin in India was by Lehman and Cutbush in 1952, among the tribal population in the Nilgiri Hills of south India. In the same year, Dunlop and Mazumder also reported the presence of sickle haemoglobin in Upper Assam's tea garden workers who were migrant labourers from tribal groups in Bihar and Odisha. Since then, many population groups have been screened.

In Numbers

49.4%

Female Literacy rate of Scheduled Tribes

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Update

Karnataka tribals register protest against broken footbridge in unique way

This Independence Day, inhabitants of an Yerava tribal settlement in South Kodagu in Karnataka adopted a unique way to register their protest against the lack of a proper approach road. Members of the 15 tribal families have to struggle daily to reach their settlement as the footbridge connecting the main road to their habitations got washed off for the third time during last year's monsoons and has since been thus till now. They said the panchayat constructed a 20-feet footbridge to the settlement nearly three times, but it gets washed off every year during incessant rainfall. However, the Government has not taken any steps to resolve the issue. It has been over a year now that the tribals have laid a broken electric pole

The view holds that mass screening and management of SCD is important to ensure greater life expectancy and quality of life for the tribal people. Largely, the requirement is to have the focus on screening with a view to identifying carriers and couples in their reproductive years, and providing counselling to prevent the spread of the disease.

At the Ministry of Tribal Affairs (MoTA), during the review meeting taken by the Prime Minister on January 20, 2015, the Ministry was asked to work out guidelines/draft protocol for counselling (pre-marital) people with sickle cell trait and disease.



Tribal Affairs Minister Arjun Munda

In 2018, the Abhay Bhang Committee, an expert committee in its report on Tribal Health, listed Sickle Cell Disease as one of the 10 special problems in tribal health. The Committee suggested the establishment of a Tribal Health Cell and National Tribal Health Roadmap for dealing with tribal health issues.

The Tribal Health Cell at MoTA has taken several initiatives on the suggestions in the expert committee report including the launch of a Tribal Health Collaborative with the Ministry of Health and Family Welfare (MoHFW), NITI Aayog and NGOs working together in 50 aspirational districts to start with.

MoTA in coordination with MoHFW, State Governments, Organizations working on SCD and NGOs has been working proactively for devising strategies for prevention, care and management of SCD. It strives to innovate and improve care delivery for people living with Sickle Cell Disease through engagement of multiple stakeholders. Ministry has also developed Sickle Cell Disease Support Corner and strives to ensure data-based planning and management so as to bridge the gap between patients and health care services in tribal areas.

The Ministry has also been providing funds to different States for screening and testing as per requirement of the States.

**Based on the learnings from different States, the Ministry has prepared a roadmap for prevention, management and elimination of Sickle Cell Disease with a target that no baby should be born with Sickle Cell Disease by 2047. The strategic roadmap initiated at MoTA and prepared by experts and DGHS, ICMR describes the building blocks around various aspects associated with SCD, be it awareness, screening, referral centers, adequate collaboration between patients, Central and State Government, medical research and research centres and NGOs. The Ministry with the help of top Hematologists and experts also prepared a training module to train medical and paramedical staff.**

MoTA has spearheaded the demand for revision of the disability guidelines. These benefits are needed

as a makeshift footbridge which they use risk their lives. Hence, on August 15, they stood on the broken footbridge and waved the tricolour to highlight their problems.

### PM pays tribute to Birsa Munda on Independence Day

Addressing the nation from the ramparts of the Red Fort, Prime Minister Narendra Modi said, "The country remains forever indebted to Birsa Munda for the selfless sacrifice and service to the nation." He emphasized Munda's significant role in the fight for freedom, who at a young age of 22, shook the foundations of the British Raj. "The period of freedom movement has been one of struggle. Youngsters, farmers, women, and tribals, everyone fought continuously against slavery."



**चम्पाई ने जेएमएम से अलग होने का निर्णय सार्वजनिक किया, हेमंत द्वारा अपमानित होना वजह बताई**

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खुली चिट्ठी में चम्पाई ने गिनाये अपमानित होने वाले वाक्ये। पूछा कि क्या लोकतंत्र में इससे अपमानजनक कुछ हो सकता है कि एक मुख्यमंत्री के कार्यक्रमों को कोई अन्य व्यक्ति (हेमंत) रद्द करवा दे? पार्टी की कार्यशैली पर भी बातों ही बातों में सवाल खड़े किये। सभी [...]



जनता से किये हर वादे को पूरी संजीदगी से निभाने का प्रयास कर रहे हैं: हेमंत सोरेन

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MoTA has spearheaded the demand for revision of the disability guidelines. These benefits are needed

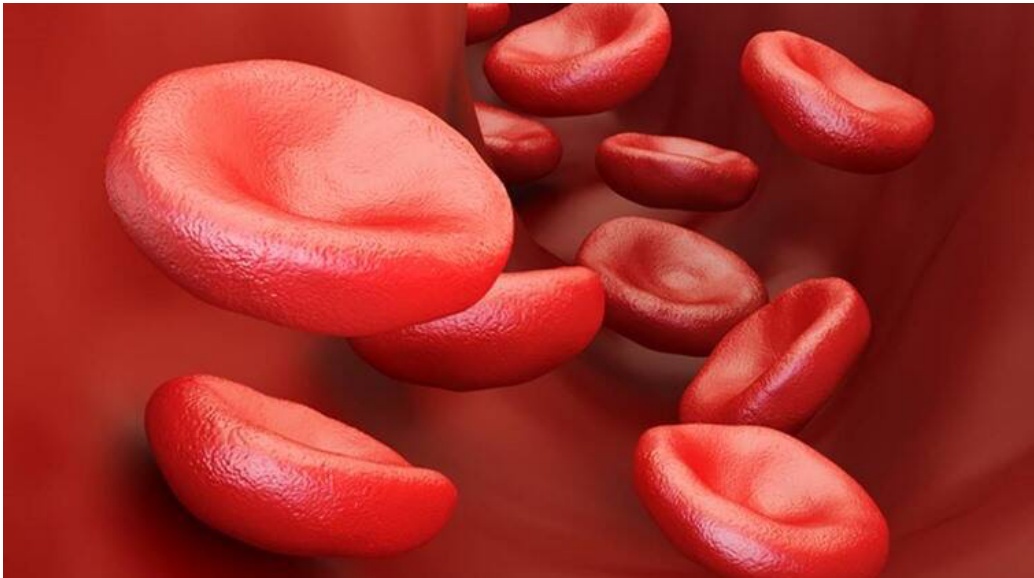
by many patients of hemophilia, thalassemia and SCD to participate in society on an even-playing field. Synergistic efforts of government, health care providers and civil society can improve the quality of life and extend the survival of these Hematology patients.

MoTA has created a Swasthaya portal along with SCD Corner and App. It has a repository of SCD patients and traits. It also consists of the latest technologies and guidelines from national and international field.

We all know that health comes by evolution and must meet the need of the people, as they perceive them. Faith healing has always been a part of the traditional treatment in the Tribal Health Care System, which can be equated with rapport or confidence building in the modern treatment procedure. Our cultural roots of Ayurveda and traditional medicine have time-tested wisdom. These are being evaluated with modern research methods to bring them forward to help our patients.

An action research project has been sanctioned by MoTA to understand the efficacy of Yoga based life-style intervention (YBLI) in reducing oxidative stress and its related complications at different organ and systems level. This pilot project in Nandurbar district of Maharashtra has shown promising results. Based on the outcomes, Ministry of AYUSH would be asked to facilitate and fund similar research.

Health is widely linked with development. MoTA encourages research and innovation for finding evidence base solutions to health problems.



**Sickle Cells (Representational)**

MoTA supported The Council for Scientific and Industrial Research (CSIR), IGIB, which is working on CRISPR CAS-9 therapy on cells or Sickle Cell Disease. The breakthrough success of CRISPR-CAS (Clustered Regularly Interspaced Short Palindromic Repeats- CRISPR Associated) methods for correcting genetic diseases in patients has fueled significant scientific investment into bringing such methods to the clinic.

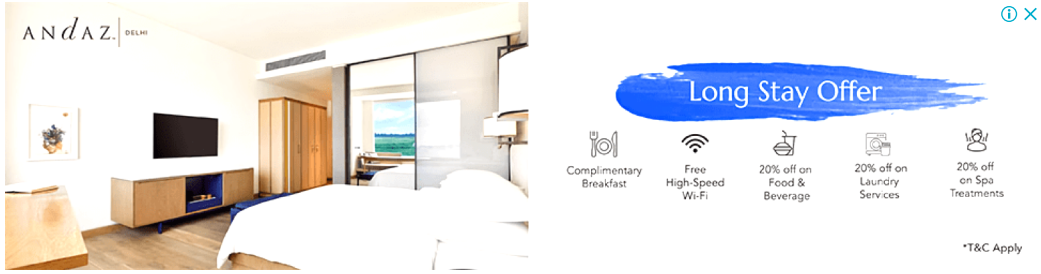
**This technology (which won the Noble Prize in Chemistry in 2020) has the potential to be a single dose cure for blood disorders like Sickle Cell Anemia. To implement this program towards a possible first trial within the next 3 years (2021-2024) a total estimated budget of Rs 60 cr (10 cr per year) has been ensured under STC funds. This will be independent of local support extended towards the partnering institutes for the Research and Development going into the gene-editing pipeline.**

The Ministry has provided funds through the scheme of Centre of Excellence, and has facilitated funding of these research projects through STC funds available with the Department of Science and

Technology.

The Prime Minister is scheduled to launch a mission to eliminate Sickle Cell Anaemia by 2047 from Shahdol in Madhya Pradesh on June 27. It entails awareness creation, universal screening of 7 crore people in the age group of 0-40 years in affected tribal areas, and counselling through collaborative efforts of Central Ministries and State Governments.

MoTA's role is to focus on prevention strategies. Awareness and counselling modules have been prepared and the strategic plan has been developed with regard to awareness campaigns in a mission mode. Strong referral mechanisms are being made through development of the competency centers throughout the country. However, all this can be achieved in a better manner when people from different walks of life join hands together to attain this common goal.



**Tags:** Adivasi Arjun Munda Ministry of Tribal Affairs Narendra Modi Prime Minister Scheduled Tribes Sickle Cell Mission The Indian Tribal Tribals World Sickle Cell Day

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