

## India's Battle Against Sickle Cell Disease

*Mains Paper: GS Paper II - Issues relating to development and management of Social Sector/Health; Welfare schemes for vulnerable sections.*

### Why in News?

President of India Graces International Sickle Cell Day Commemoration at Omkareshwar, Madhya Pradesh.

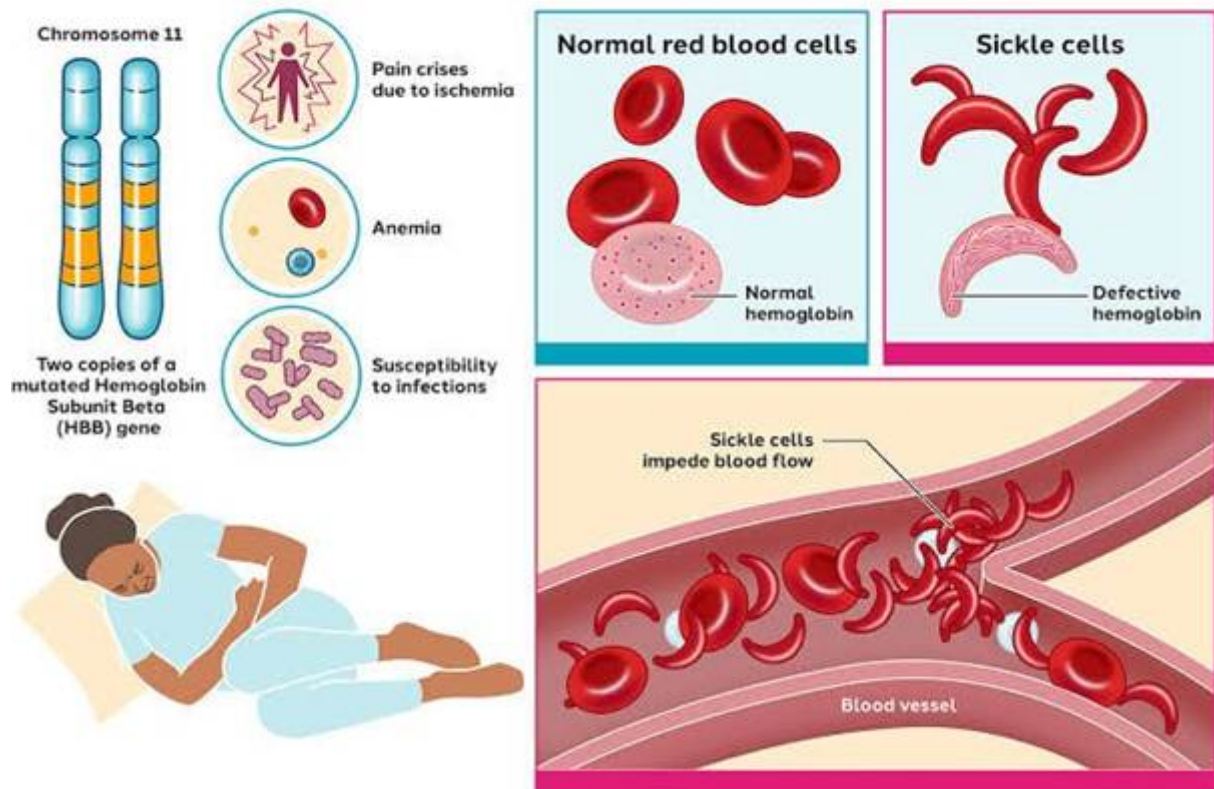
### What is Sickle Cell Disease (SCD)?

- **Definition** - Sickle Cell Disease is a **severe, inherited blood disorder** that alters the shape and function of red blood cells, leading to chronic health complications and significant morbidity.

### Cause (genetic Mutation)

- **Molecular Basis** - SCD is triggered by a point mutation in the **HBB gene on chromosome 11**, which dictates the production of the beta-globin chain in hemoglobin (the oxygen-carrying protein).
- **Structural Change** - This mutation creates abnormal hemoglobin known as Hemoglobin S (HbS). Under low oxygen, HbS polymerizes into rigid strands.
- **Cellular Transformation** - These strands warp normal, flexible red blood cells into stiff, "sickle" or crescent shapes, as illustrated above.
- **Inheritance** - It is an **autosomal recessive** condition.
- Inheriting **two defective genes** (one from each parent) causes the disease.
- Inheriting just one makes the person an **asymptomatic** carrier (Sickle Cell Trait).

# What is Sickle Cell Disease (SCD)?



## Clinical Manifestations

- **Vaso-Occlusive Crises (Pain Crises)** - The stiff cells get lodged in narrow capillaries, blocking blood flow to organs and causing sudden, debilitating pain.
- **Chronic Hemolytic Anemia** - While normal red blood cells live for 120 days, sickle cells break down in just 10-20 days.
- The bone marrow struggles to keep up, leading to persistent anemia and fatigue.
- **Vulnerability to Infection & Organ Damage**- The disease damages the spleen, critically impairing immune filtration and leaving patients prone to severe bacterial infections.
- Chronic vascular blockages can also lead to stroke, pulmonary hypertension, and acute chest syndrome.

## Treatment Framework

- **Symptomatic Relief**- Pain management (analgesics, hydration), infection prophylaxis (penicillin, pneumococcal vaccines), and regular blood transfusions to lower HbS levels.
- **Disease-Modifying Drugs**- Hydroxyurea (stimulates Fetal Hemoglobin production to prevent sickling) and targeted biologics like *Crizanlizumab*.
- **Curative Interventions** - Allogeneic Stem Cell Transplantation (bone marrow transplant) and cutting-edge CRISPR-Cas9 gene therapies (like *Casgevy*), which edit a patient's own stem cells to cure the disease without needing a donor.

## What are national initiatives associated with Sickle Cell?

### National Sickle Cell Anaemia Elimination Mission (NSCAEM)

- **Primary Target** - Eradicate SCD as a public health challenge by 2047, aligning with India's *Amrit Kaal* vision.
- **Joint Ministerial Synergy** - The mission is uniquely executed by integrating the Ministry of Health and Family Welfare (MoHFW) with the Ministry of Tribal Affairs (MoTA).

### Multi-Sectoral National Initiatives

- **Health & Screening Integration** - SCD tracking is embedded in the National Health Mission (NHM), the Rashtriya Bal Swasthya Karyakram (RBSK) for birth defect screening, and the PM Surakshit Matritva Abhiyan (PMSMA) for prenatal testing.
- **Digital Registries** - Status cards are synchronized with the Ayushman Bharat Health Account (ABHA) to create a portable, lifelong digital health record.
- **Legislative Backing** - Under the Rights of Persons with Disabilities (RPwD) Act, 2016, SCD is a recognized benchmark disability, granting patients access to affirmative action and institutional support.
- **State-Level Action** - Initiatives like Madhya Pradesh's "**Sickle Mitra**" deploy youth and community workers for targeted health outreach. Free treatment for acute crises is guaranteed under PM-JAY.

### What is the Key Progress and Statistical Milestones?

Metric Baseline	Cumulative Progress Achieved (As of Mid-2026)
Total Screenings Completed	Over 7.19 Crore individuals (Target exceeded)
Identified Patients (Diseased)	~2.46 Lakh individuals brought under active care
Identified Carriers (Trait)	Over 20 Lakh individuals mapped for genetic counselling
Genetic Cards Distributed	Over 4 Crore digital status cards issued

### What are the Major Challenges in Elimination?

- **Socio-Cultural Stigma** - In remote tribal pockets, deep-rooted apprehensions prevent people from getting screened or revealing their carrier status due to fears of marital or social exclusion.
- **Geographical & Logistics Barriers** - Reaching highly isolated hamlets (*padas* and *bastis*) across difficult terrains complicates the delivery of testing kits and medical supplies.
- **Operational Overhead** - Sustaining a lifelong supply chain of disease-modifying therapies (like Hydroxyurea), routine transfusions, and clinical monitoring strains rural health infrastructure.

### What is World Sickle Cell Awareness Day?

- **Context** - Recognized by the UN General Assembly in 2008, it is observed globally every **June 19** to destigmatize the disease and mobilize resources.

- **Global Theme (2026)** -“Closing the Survival Gap: Equity in Sickle Cell Disease”. The focus has shifted from mere awareness to demanding equitable access to advanced diagnostics and gene-editing therapeutics across geographies.
- **India's Stance-** India uses this platform to amplify localized, community-led interventions and celebrate the accelerated progress of its nationwide screening drive.

### **Ethical Dimensions of the National Sickle Cell Elimination Mission**

- **Distributive Justice and Health Equity:** Sickle Cell Disease disproportionately impacts India's Scheduled Tribes (ST) and marginalized socio-economic groups.
- Prioritizing resource allocation, advanced screening, and free therapeutics for these historically underserved populations corrects systemic health inequities, reflecting the ethical principle of **distributive justice**.
- **Autonomy vs. Social Exclusion (Stigma):** The introduction of "Genetic Status Cards" for pre-marital counseling creates an ethical tension between individual reproductive autonomy and the risk of **socio-cultural stigmatization**.
- Mismanaging this data could lead to involuntary marital boycott or social exclusion of carriers, making strict privacy and compassionate counseling a moral imperative.
- **Global Therapeutic Inequity:** While curative technologies like CRISPR-Cas9 (Casgevy) exist, their exorbitant costs make them virtually inaccessible to poor tribal families.
- Relying primarily on symptom management while advanced cures remain locked behind economic barriers raises profound ethical concerns regarding the **global right to equal health outcomes**.

### **What is the Way Forward?**

- To build on its early screening success and secure full eradication by 2047, India must expand its focus from broad testing to localized, community-led behavioral interventions.
- This requires integrating tribal leaders and youth corps (like 'Sickle Mitras') to dismantle social taboos and normalize pre-marital genetic counseling.
- Standardizing the supply chain for primary care medicines at village clinics and expanding localized prenatal diagnostic services will be critical to cutting transmission lines and securing a sickle-cell-free future.

### **Reference**

[PIB | INTERNATIONAL SICKLE CELL DAY COMMEMORATION](#)