World Sickle Cell Day 2020

Why in News

Recently, **World Sickle Cell Day 2020** was observed in India to increase awareness about the Sickle Cell Disease (SCD) at the national level.

- The day is recognised by the United Nations and celebrated every year on **19th June.**
- The United Nations General Assembly adopted a resolution recognising sickle cell disease as a public health problem on 22th December, 2008.

Key Points

- **Sickle Cell Disease**

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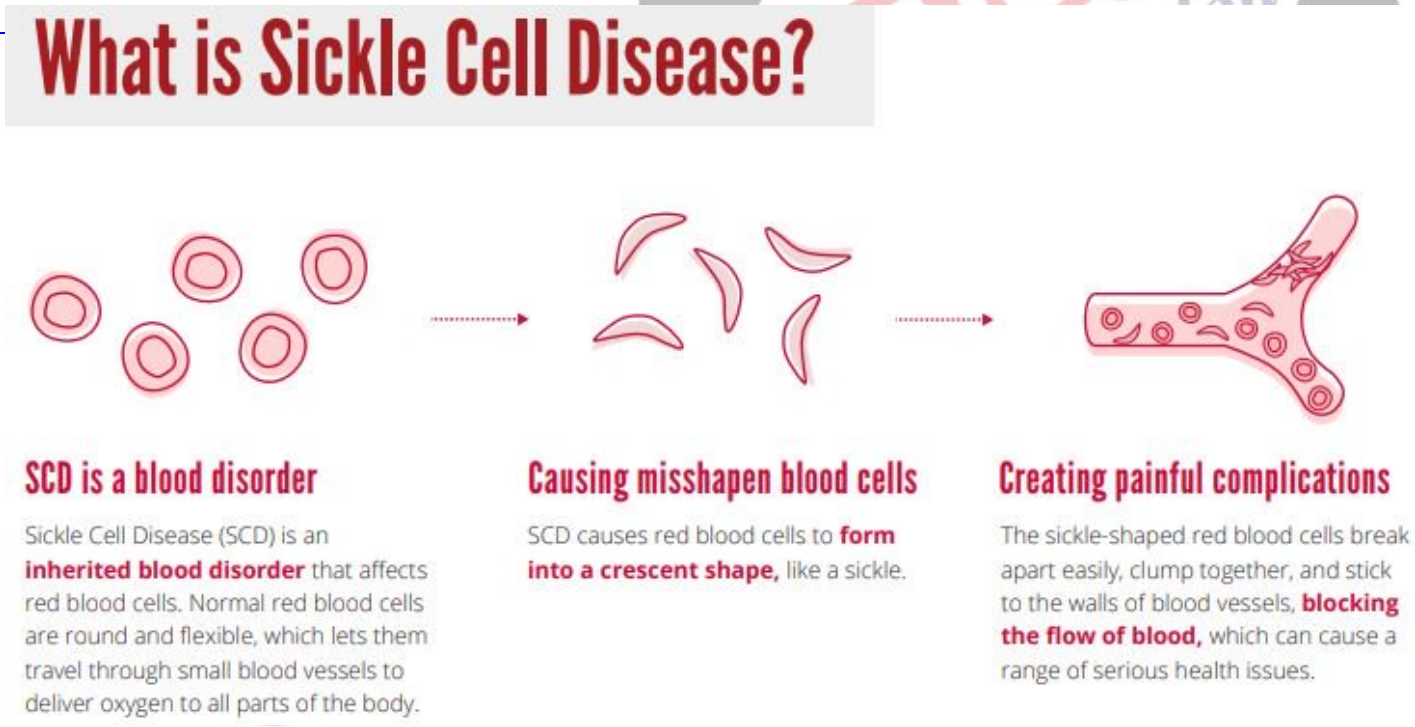

  - It is an **inherited blood disease** which is most common among people of African, Arabian and Indian origin.
  - It is a **group of disorders that affects hemoglobin,** the molecule in red blood cells that delivers oxygen to cells throughout the body.
  - People with this disease have atypical hemoglobin molecules called hemoglobin S, which can distort red blood cells into a sickle, or crescent shape. This blocks blood flow and oxygen from reaching all parts of the body.
  - **Symptoms:** It can cause severe pain, referred to as sickle cell crises. Infections and fatigue are other symptoms.

        - People with sickle cell disorders are also at a risk of complications such as stroke, acute chest syndrome, blindness, bone damage, etc.
        - Over time, people with sickle cell disorders can experience damage to organs including the liver, kidney, lungs, heart and spleen. Death can also result from complications of the disorder.
    - **Treatment:** Medication, blood transfusions and rarely a bone-marrow transplant.
- **Related Data:**
    - According to **Global Burden of Disease (GBD)—**a global research programme that estimates mortality and burden from major diseases across the globe— the prevalence and incidence of sickle cell disease in India in 2017 and 2018 was **1,104,634 and 195,166,** respectively.
    - The disease in India occurs predominantly in eastern Gujarat, Maharashtra, Madhya Pradesh, Chhattisgarh, western Odisha and in pockets of the Nilgiri Hills in north Tamil Nadu and Kerala.
        - The disease is prevalent among tribal communities (including children).
- **Challenges:**
    - **Social Stigma:** It reduces the effectiveness of screening programmes as people don't want to go to health authorities.
    - **Prevalence among Tribal Population:** Access to care for SCD in the tribal regions of India is limited.
    - **School Drop Out:** Children with sickle cell disease often have to drop out from school.
    - **Policy Issue:** The delayed implementation of the **2018 draft policy on haemoglobinopathies.**
        - The policy aims to provide evidence-based treatment for patients and reduce the number of new-born children with sickle cell disease through initiatives such as the **Sickle Cell Anaemia Control Program,** screening and prenatal diagnosis.
- **Initiatives by India:**
    - **Initiative by the Ministry of Tribal Affairs:** In order to collect real time data and provide relevant information related to Sickle Cell, the government has **launched a new portal** which will act as a catalyst in creating awareness.
        - The portal will have real time data through a dashboard along with registration facility, information about the disease and various government initiatives undertaken.
        - The Ministry has also initiated an **'Action Research' project** under which Yoga dependent lifestyle is promoted to reduce the complications in the patient suffering from this disease.
    - **Expanded Screening:** Certain states, such as Chhattisgarh and Gujarat, have expanded their screening programmes from hospital to school-based screenings. Extrapolating such screening efforts and implementation strategies to other states will help map the prevalence of the disease.

Way Forward

- SCD is a health burden which not only impacts the individual's life cycle but also impacts the economy as well.
- There is a need to take efforts so that the next generation is free from the disease.
- The industry like FICCI and other stakeholders have to come forward to improve the overall system of managing the Sickle Cell program of the government.

Source: DTE