1,000 letters, 20 yrs: The struggle to find a place for sickle cell anaemia in textbooks

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FOR OVER two decades, a bespectacled doctor working in Maharashtra's tribal-dominated Gadchiroli district wrote more than 1,000 letters and emails to officers across 15 states, urging them to include information on sickle cell anaemia in school and college curriculum to raise awareness on this hereditary disorder.

Dr Ramesh Katre's efforts bore fruits when Union Minister Nitin Gadkari asked the University Grants Commission (UGC) to request all higher educational institutions across India to consider adding a chapter on this debilitating condition.

On March 28, Manish Joshi, Secretary, UGC, wrote to all universities and colleges "to consider including a chapter on inherited sickle cell anaemia, its cause, treatment, inheritance pattern, modes of testing and prevention in the curriculum of the relevant courses".

"I wrote over 1,000 emails and letters to officers across 15 states, requesting them to include information on this disease in the curriculum. I have treated nearly 20,000 patients with this condition in Gadchiroli district over the last two decades. While treating these patients, I realised that many people succumbed to this blood disorder without even being diagnosed," Katre told The Indian Express.

Sickle cell anaemia is a genetic disorder in which red blood cells become oval shaped due to oxygen deficiency.

The World Health Organization (WHO) states that Africa has the highest burden of sickle cell anaemia. According to the Centre, India has the second-highest burden of this condition in the world. An estimated 30,000-40,000 children born every year suffer from this disorder. The condition is especially widespread among India's tribal population, where one in 86 infants suffers from this condition. Of the 15 states that share the highest incidence of this disease, Maharashtra tops the chart.

Dr Ramesh Katre has treated 20,000 cases

"In the absence of early diagnosis, regular follow-ups and appropriate medical care, sickle cell anaemia remains largely incurable and a life-threatening disease — especially for the very poor, rural, remote, and Scheduled Caste and Scheduled Tribes communities, for whom access to medical care in general is difficult," said Katre.

EXPLAINED

Widespread disorder

SICKLE CELL anaemia is a genetic disorder in which red blood cells become oval shaped due to oxygen deficiency, and can also cause death. India has the second-highest incidence of the disorder, with most cases (one in 86 babies) among tribals.

He said that including information on the disorder in the curriculum will ensure that even school-going children in the remotest part of India will be able to identify its symptoms.

"There is no national data on sickle cell anaemia. There is very little research on the quality of life and mortality related to this disease. WHO figures suggest that 60-70 per cent of children in low and middle-income countries die of sickle cell anaemia," he said.

Last December, The Indian Express had reported that India lacks data on the blood disorder, including related fatalities.

Katre said after a meeting with Gadkari in December 2021, he wrote a letter to him outlining the importance of educating the youth, communities and medical practitioners about this disorder. The minister passed on his recommendation to the Indian Council of Medical Research (ICMR).

On March 24, 2022, Professor Balram Bhargava, then Director General of ICMR, wrote to six government bodies, including the UGC, on the issue. The subject line of his letter read, "Letter from Shri Nitin Gadkari, Hon'ble Minister of Road Transport & Highways forwarding a representation from Dr. Ramesh Katre, President of Arogyandham Sasthan (NGO-Kurkheda) requesting for inclusion of chapter on sickle cell disorder in the syllabus of school education…".

The letter asked the Education Department to consider Katre's recommendations.

"The ICMR is also of the same opinion that SCD (sickle cell disease) awareness at different community levels including school and higher educational institutions through a well-drafted educational programme may be helpful," read the ICMR letter.

In its 2023-24 Budget, the Central government announced its plan to make the country free of sickle cell anaemia by 2047. The mission entails focus on awareness creation, universal

CONTINUED ON PAGE 2

• 1,000 letters, 20 yrs

screening of approximately 7 crore people in the 0-40 years age group in affected tribal areas and counselling through collaborative efforts between Central ministries and state governments.

"If we want to eliminate this disease by 2047, we have to focus on early awareness through the younger generation," said Katre.

Talking about the condition, which leads to significant reduction in life expectancy, he said sickle cell anaemia is characterised by chronic anaemia, acute pain, organ infarction and chronic organ damage. A bone marrow transplant is the only known cure for this condition, but it remains out of reach of tribal communities. The disorder can be diagnosed by a simple blood test — even for a child in the womb — and treatments can help improve the quality of a patient's life.

ABOUT SICKLE CELL DISEASE

Sickle cell disease (SCD) is a genetic condition that affects haemoglobin, which is responsible for carrying oxygen in red blood cells. SCD can result in severe anaemia and even death. Patients are at increased risk of stroke, and damage to lung, kidney, spleen and liver damage. SCD symptoms usually appear by the age of six

THE MOST COMMON SYMPTOMS

- Severe anaemia
- Fatigue
- Extreme pain
- Pain due to bone and joint damage
- Ulcers
- Swelling of hands and legs
- Frequent infections

THE TREATMENT

Bone marrow transplant, which is an expensive option, is the only cure for this disease. If diagnosed early, patients can lead a healthy life with pain medication (as needed), drinking 10 glasses of water each day, blood transfusions and prescription medication

PREVALENCE AND INCIDENCE

The Centre had stated in February 2022 that the Ministry of Tribal Affairs had conducted a screening of tribal population in collaboration with ICMR and the Department of Biotechnology

1,13,83,664 persons screened in different states

9,96,368 (8.75%) tested positive during screening