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Silent march in Delhi marks Gaucher Disease Awareness month

NEW DELHI: A silent march was held in the national capital on Saturday to mark the Gaucher Disease Awareness month.

The walk was organised by Lysosomal Storage Disorder Support Society (LSDSS) with the aim to sensitise people and seek financial support from the government for the treatment of the rare, debilitating genetic disorder.

About 50 children, some even having difficulty to walk, and their parents holding placards and banners participated in the walk from Tolstoy Marg to Jantar Mantar.

They also submitted a letter of appeal addressed to the Prime Minister, Union Health minister and Delhi Chief Minister for creating a corpus fund and national health programme for the management of the rare genetic disorders having 500 identified, affected and registered children in India.

"Gaucher is a curable disease. The life saving enzyme treatment is available but Enzyme Replacement Therapy is too expensive and prohibitive, and is administered lifelong. Due to high treatment cost which ranges between Rs 40 lakh to Rs 1.50 crore per year per child," Manjit Singh, President and NCR coordinator,

LSDSS said.

"World over state governments are providing the medicine free to their citizens at the state's expense. We too are looking up to the government for support in terms of arranging diagnostics facilities across India and treatment of this debilitating disease," he added.

Neerja Gupta, Assistant Professor and Senior Research Officer from Genetics Unit, Dept of Pediatrics, AIIMS, said, "Gaucher disease is a rare condition passed down through families. It belongs to a category of 45 rare, genetic disorders known as Lysosomal Storage Disorders (LSD) and is the most common LSD. LSDs result from absence or malfunctioning of a specific enzyme in the human body." 17-year-old Sadaf Naaz from Jharkhand, who has been suffering from Gaucher disease since 2008, was one of the participants at the rally. "I had to remove my spleen after it got enlarged. Now I cannot concentrate and my body pains most of the time with frequent vomiting. I am tired of my illness. God does not listen to us. We are hoping against hope. I appeal to the Government to arrange for my medicine and that of others," she said. *Agencies*