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## Silent march to mark 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 let-

ter 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

### SEEKING FINANCIAL SUPPORT

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. 17-year-old Sadaf Naaz from Jharkhand, who has been suffering from Gaucher disease since 2008, was one of the participants at the rally.

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