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Silent rally held on World Gaucher's Day

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NEW DELHI: With an aim to sensitise the public and seek financial support from the government to help patients suffering from a group of rare life-threatening diseases called Lysosomal Storage Disorders, a silent rally was held here in the city on the occasion of the first International Gaucher Day.

The walk, organised at Race Course Road, by Lysosomal Storage Disorder Support Society (LSDSS) saw participation from patients along with their parents holding placards and banners appealing for funds from the Prime Minister.

Present at the protest on Saturday was 7-year-old Mohammed Ahmed along with his parents Sirajuddin and Anwari Begum. He was the first



Patients suffering from Gaucher's disease participate in a silent protest rally outside the Prime Minister's house in New Delhi on Saturday.

PHOTO: S. SUBRAMANIAM

patient to be awarded free treatment at the All India Institute of Medical Sciences (AIIMS) following a verdict from the High Court in April this year.

Ahmed is the last surviving child of the couple. His four siblings (three boys and one girl) have already lost their battle to the rare genetic disease. Ahmed was receiving

treatment for a month initially, however, when the family approached AIIMS for the next round of treatment scheduled on 8 and 22 July, he was denied treatment as the management stated that they had not received any funds from the State government.

Diagnosed with Gaucher's disease as an infant, Ahmed suffered from fever, his abdomen started swelling and his weight came down to a mere 13 kg at the age of six. A rickshaw puller by profession, a helpless Sirajuddin recalls: "With each passing day, Ahmed's condition was deteriorating. He needed ERT (Enzyme Replacement Therapy), the only available treatment costing around Rs.5-6 lakh every month for the rest of his life. I cannot bear the thought of losing my fifth child to this debilitating disease."