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'Corporates must help Gaucher patients'

NEW DELHI, DHNS: Doctors suggested that private companies should pay for treatment of Gaucher's disease as part of corporate social responsibility.

The cost of treating these disorders, annually, ranges from Rs 40 lakh to Rs 1.5 crore per child.

The doctors were speaking on the occasion of Gaucher's Disease Awareness Day on Saturday, which was marked by a silent march from Janpath to Jantar Mantar by some 100 children, accompanied by their parents.

Organised by Lysosomal Storage Disorder Support Society (LSDSS), the march was

held to draw attention to this disease and seek financial support from the government for treatment of the disease.

LSDSS is a national support group comprising patients, their families and caregivers. There are 500 identified, affected and registered children suffering from lysosomal storage disorder in India.

"Gaucher is a curable disease. The life-saving enzyme treatment is available but enzyme replacement therapy is too expensive and is administered lifelong," said Manjit Singh, president of LSDSS.

"World over, state governments are providing the medi-

cine 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.

Dr Ratna Dua Puri of Ganga Ram Hospital said that even many doctors don't know about this disease. She asked the society to include every new case to the group. "Given the rarity of this disease, they get extremely depressed thinking they are an isolated case. They will feel more comfortable knowing that they have more people to share and discuss their pain," she said.