	Publication: The Times of India
	Edition: New Delhi
	Date: 27th July 2014
	Page: 05

On Gaucher's Day, SOS to PM

TIMES NEWS NETWORK

New Delhi: Hundreds of patients suffering from Gaucher's disease silently marched to the prime minister's residence on Saturday to demand a national policy to provide free treatment to people suffering from such rare diseases.

The walk, organized by Lysosomal Storage Disorder Support Society (LSDSS) on the first International Gaucher's Day, saw participation from patients along with their parents holding placards and banners.

Present among them was seven-year-old Mohammed Ahmed along with his parents Sirajuddin and Anwari Begum, the first patient to be awarded free treatment at AIIMS following a verdict from the high court in April this year.

With symptoms ranging from a distended abdomen and swollen lymph nodes to thin limbs and a blackish brown skin pigmentation, 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 disorder.

TOI

7-year-old Ahmed is the first Gaucher patient to get free treatment

On the first International Gaucher's Day, patients, along with their parents, marched to the PM's house, demanding a national policy for free treatment to people with such rare diseases

"Ahmed's condition is deteriorating with every passing day. He needs ERT (Enzyme Replacement Therapy), which is the only available treatment, for the rest of his life. It costs Rs 6 lakh every month. I cannot think of losing my fifth child," said Sirajuddin, a rickshaw-puller.

Activist advocate Ashok Aggarwal, who is representing Ahmed in Delhi high court, said, "A one-time aid and occasional private funding is not the solution. The government has to take a stand and be accountable for the lives of these patients."

Gaucher's disease is an inherited genetic condition that causes fat deposits to build up in organs and bones. Of the 45 rare genetic disorders known as Lysosomal Storage Disorders (LSD), it is the most common one. People with Gaucher's disease do not have enough of an important enzyme (glucocerebrosidase) required to break down a certain type of fat molecule (glucocerebroside).

As a result, cells filled with the undigested fat—called Gaucher cells—build up in different parts of the body, primarily the liver, spleen and bone marrow.

"Over 5,000 babies are born in India every year with rare life-threatening disorders called lysosomal storage disorders . Effective government intervention is a must. The rarity of the disease or high cost should not act as a deterrent for treatment of orphaned diseased patients," Dr I C Verma, director of Centre for Medical Genetics, Sir Ganga Ram Hospital, said.