

# Gaucher disease patients march to PM's residence

## Denied free treatment, 7-year-old seeks intervention

**NEW DELHI, DHNS:** Demanding lifelong funding, Gaucher patients gathered outside Prime Minister Narendra Modi's residence after patient Mohammed Ahmed was denied free treatment at AIIMS despite High Court ruling.

The seven-year-old was awarded free treatment at All India Institute of Medical Sciences following a verdict from the High Court in April.

Standing with distended abdomen, swollen lymph nodes, thin limbs and black-brown skin pigmentation, Ahmed is the last surviving child of Sirajuddin and Anwari Begum.

His four siblings have already lost their battle to the rare and highly fatal genetic disease.

Doctors say this is an inherited genetic condition that causes fatty deposits to build up in organs and bones. Of the 45 rare, genetic disorders known as Lysosomal Storage Disorders (LSDS), Gaucher is the most common one.

People with Gaucher disease do not have enough of an important enzyme (glucocerebrosidase) required to break



**Gaucher disease patients march to the Prime Minister's house in support of Mohammed Ahmed, who was awarded free treatment by the High Court, in New Delhi.** DH/ CHAMAN GAUTAM

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.

"More than 5,000 babies are born in India every year with a group of rare life-threatening diseases called LSDS," director of Centre for Medical Genetics at Sir Ganga Ram Hospital, Dr I C Verma, said.

Sirajuddin, who is a rickshaw puller, said, "With each passing

day, Ahmed's condition is rapidly deteriorating. He needed Enzyme Replacement Therapy which is 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."

Nearly, 30 patients along with their parents joined the rally at Jantar Mantar, organised by Lysosomal Storage Disorder Support Society (LSDSS) in solidarity with Ahmed.

After their brief rally,

demonstrators went in a bus to the Prime Minister's residence.

The society in their memorandum to Modi asked for a corpus fund for the treatment of patients suffering from the rare genetic disease.

Activist advocate Ashok Aggarwal who is fighting the case on behalf of Ahmed in the Delhi High Court said, "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."