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Gaucher disease patients march to PM's house

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NEW DELHI, 26 JULY: In a bid to sensitise the public and seek financial support from the government, a silent rally was held on the occasion of the first International Gaucher Day in the city today.

The walk, organised by Lysosomal Storage Disorder Support Society (LSDSS), saw participation by patients along with their parents holding placards and banners to submit an appeal for funding lifelong treatment to the Prime Minister, Mr Narendra Modi, at his residence.

Present among the patients was 7-year-old Mohammed Ahmed 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. Standing with distended abdomen, swollen lymph nodes, thin limbs and black-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 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 AIIMS management said they had not received any funds from the state government.

Then, destiny again brought him to the same place he started. Dr IC Verma, director, Centre for Medical Genetics, Sir Ganga Ram Hospital, said: "More than 5000 babies are born in India every year with a group of rare life threatening diseases called lysosomal storage disorders (LSDS). Effective government intervention is imperative. The rarity of the disease or high cost should in no way act as deterrent for treatment to such orphaned diseased patients."

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. Government has to take a stand and be accountable for the lives of these patients."

Gaucher disease 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 (LSD), it is the most common one. People with Gaucher 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.

Mr Manjit Singh, president & NCR coordinator, LSDSSp said, "Gaucher is a curable disease. The life saving treatment required lifelong is clearly unaffordable by patients. The world over state governments are providing the medicine free to their citizens at the state's expense. As the number of patients are few, LSDSS appeals to the government to make the treatment available for them and help them lead a normal life."