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Child fighting a losing battle against rare genetic disease

ANANYA PANDA
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Sirajuddin and Anwari Begum, parents of seven-year-old Mohammed Ahmed who happens to be the first patient to be awarded free treatment for Gaucher at AIIMS following a verdict from the High Court in April this year, are worried about the fate of their last surviving child.

As after providing treatment to the child in June, the All India Institute of Medical Sciences (AIIMS) "stopped" it stating that it had not received any funds from the Delhi government. The child was supposed to get the next round of treatment scheduled on July 8 and 22, but the parents are left in gloom after being sent back by the AIIMS.

Standing with distended abdomen, swollen lymph nodes, thin limbs and black-brown skin pigmentation, Mohammed was one among scores of Gaucher disease patients who accompanied by their families silently marched to the Prime Minister's residence today to seek financial support from the government.

The walk, organised by Lysosomal Storage Disorder Support Society (LSDSS) on the occasion of the first International Gaucher Day, saw participation from patients along with their parents holding placards and banners. They called for a national policy to provide lifelong free treatment to people suffering from such rare diseases.

"Again destiny brought him to the same place he started. With each passing day, Ahmed's condition was deteriorating fast. 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 think of losing my fifth child," said Sirajuddin, a rickshaw puller.

Diagnosed with Gaucher as an infant, Ahmed suffered from fever, his abdomen started swelling and his weight came down to mere 13 kg at the age of six, Mohammad's four siblings (three boys and one girl) have already lost their battle to the rare genetic disease.