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No free treatment of Gaucher's disease: AIIMS

Fighting genetic disorder costly, says hospital

NEW DELHI: The All India Institute of Medical Sciences (AIIMS) has told the Delhi High Court that it does not have any provision for free treatment of poor patients suffering from life-threatening Gaucher's disease, a genetic disorder, as it is "exorbitantly expensive and lifelong".

In an affidavit filed in the court of Justice Manmohan, AIIMS also said there are at present "16 patients with Gaucher's disease being treated under humanitarian programmes at AIIMS".

"Five patients are getting reimbursement through the employers of their guardians (employed under the government)," it said.

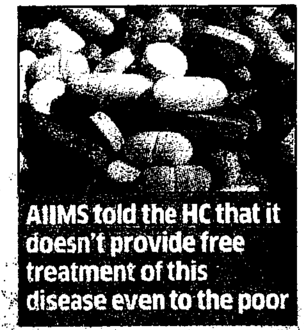
The affidavit was filed in pursuance of the court order on a petition seeking AIIMS to provide free treatment to the seven-year-old son of a rickshaw-puller.

The boy, suffering from Gaucher's disease, is confined at his modest house for want of treatment.

Meanwhile, advocate Ashok Agarwal, who is pursuing the child's case, said Delhi High Court Bar President A S Chandok has collected some money through his personal efforts.

The court had earlier this month asked the Bar to do its bit to help the child.

The father of the ailing child has already lost four children to Gaucher's disease which causes fat to accumulate in cells and certain organs and is characterised by bruising, fatigue, anaemia, low blood platelets and enlargement of the liver and spleen.


AIIMS told the HC that it doesn't provide free treatment of this disease even to the poor

The child had earlier gone to AIIMS and was informed about the Enzyme Replacement Therapy as a lifelong required treatment.

The family was also informed about the possibility of limited access to treatment for the disorder through a compassionate access programme (INCAP) managed by a team of Indian and international medical professionals based on pre-defined guidelines decided on case to case basis, AIIMS said in its affidavit.

The application of the child was not approved under INCAP due to limited availability of the drug under the humanitarian initiative.

He, however, got some financial help from Delhi Arogya Nidhi Kosh which was sufficient for only four vials of Enzyme Replacement Therapy. **PTI**

miscellaneous.