Child with pompe seeks financial aid

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THIRUVANANTHAPURAM: Little Govind was all smiles, hopping between chairs and nodding to the mediapersons gathered around him. Nobody could guess that the six-year-old boy was suffering from Pompe, an extremely rare, disabling and life-threatening genetic disorder. Had not his parents mentioned the rare disease, that has their son under its clutches, at an interaction held here, one would have never known.

The interaction was organised by the Lysosomal Storage Disorder (LSD) Support Society, a national-level patients' group formed by the parents of patients suffering from LSDs.

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Govind is the second child of Manoj and Beena, hailing from Edappally. His sister Sarika, who had also suffered from the same disease, had passed away last year at the age of 10.

Adding to their woes, the doctors had confirmed that Govind shares the same symptoms that had snatched away the life of his sister. Fortunately for him, diagnosis happened a bit earlier.

According to Dr V H Shankar, Genetic Medicine Specialist at SAT Hospital, under whom Govind is being treated, Pompe or Lysosomal Storage Disorder is found only in children. An enzyme called Alpha Gluco Sidase which is necessary for converting food into glucose and glycogen would be absent in such kids, thereby weakening the muscles of heart and lungs, ultimately leading to death - unless promptly diagnosed and treated.

Govind was diagnosed with its juvenile version, which brings a ray of hope that he could be saved, unlike the infant version, when the medical world would not be able to offer assurances. The only way Pompe can be overcome is by administering the same enzyme every fortnight for a lifetime.

This costs around Rs 35,000 per dose of 10 milligrams in India, Dr Shankar said. The dose increases with the increase in the bodyweight of the kid. The enzyme is made in the US and a company called Genzyme in Delhi is the only importer in India.

For Govind, 12 such doses are required per month. The small business run by his father can hardly afford a sum of around ` 4 lakh per month.

From January to July this year, he has already been administered the medicine five times.

Two doses in January were possible with the aid of the State Government, another two in the month of May by the Genzyme company, one in July with the financial aid given by the Punjab National Bank through the Lysosomal Storage Disorder Support Society.

In Kerala, treatment for Pompe is available only in Amrita Institute of Medical Sciences, Kochi and Medical College Hospital, Thiruvananthapuram.

No institution, even life insurance companies, would dare to sponsor a Pompe child as the treatment is costly and that it needs to be provided for a lifetime, Manoj said.

Want to help him, then ring up Manoj on 9846458466.

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