After first baby's death, kin of infant with rare blood disorder await miracle

TIMES NEWS NETWORK

Mumbai: When 18-month-old Joel Alstair developed swellings around his right eye and leg, his parents were alarmed. Their elder son too had developed what had then seemed like benign swellings but was later diagnosed as a rare blood disorder called atypical hemolytic uremic syndrome and died two years ago.

"Our suspicions were confirmed at three hospitals we took Joel to since December 19," said his father John . Joel is in Nanavati Hospital in Juhu since December 26, and is improving. "He was given Fresh Frozen Plasma (FFP) infusions every day as his blood counts keep fluctuating," said mother Vanita, who is five months pregnant. The treatment has borne result as his blood parameters are improving and the kidney failure has resolved.

But the disorder is a progressive one. The only treatment available in the US costs thousands of dollars that the family cannot afford, said John.

The family has barely recovered from its elder child's expenses of up to Rs 6 lakh. One genetic test Joel needs costs Rs 40,000. The hospital bill is already Rs 2 lakh, he said.

Social worker Aniruddha Nandi, who is helping organize funds, said, "In atypical hemolytic uremic syndrome, red blood cells are destroyed faster than new ones are created and many of them are abnormal. This leads to breakdown of RBC, low platelets, low hemoglobin, high BP leading to frequent blood transfusion, renal dialysis and perhaps renal/hepatic replacement. The child needs help to survive to an age where such replacements can be done." John said the family has now moved to Dharavi. "I'm the only earning member," he said.

Dr Rajendra Patankar, COO of Nanavati Super Speciality Hospital, said, "Joel was admitted on December 26 with pallor and puffiness of face. Due to a high index of suspicion (family history of previous sibling death), the child was investigated and found to have microangiopathic hemolytic anemia with incipient renal failure," he said.

The child was started on IV fluids and daily Fresh Frozen Plasma (FFP) infusions. "He has shown significant improvement since then and the renal failure has been reversed," said Dr Patankar. "He will, however, require long-term treatment as the disease has a high risk of relapse and high risk of renal morbidity. We have sent samples for a genetic test and that report will guide us about further plan of management."

AFFECTS FUNCTION OF KIDNEYS

- Joel has a very rare condition—atypical hemolytic-uremic syndrome—that primarily affects kidney function
- Abnormal blood clots form in blood vessels in kidneys and restrict or block blood flow
- Red blood cells break down prematurely and get destroyed faster than the body can replace them
- Patients have unusually pale skin, jaundice, shortness of breath, fatigue and a rapid heart rate
- Joel's elder sibling passed away due to this condition two years ago
- The Dharavi family spent ₹5-6 lakh on the elder son and has little to spare for Joel