

Family with unusual muscular disorder gives stem cells a shot

5 Brothers, Uncle At Sion Hospital For Injections

Malathy Iyer TNN

Mumbai: Aurangabad farmer Narayan Sonawane and wife Jijabai have been on their toes for the last three days at Sion Hospital's neurosurgery ward: their youngest son and five grandsons are here for 'treatment' of one of the most debilitating diseases called Duchenne Muscular Dystrophy. Weakened by the muscle-wasting disease (which makes the child wheelchair-bound within the first decade of his life), the boys struggle to stand steadily or walk a distance.

But the family is hopeful. On Thursday morning, the six boys who are in the 6-17 age group, received stem cell injections at the civic-run hospital in a bid to arrest the progress of the disease. The family didn't bring along the seventh child—who is barely three. "When we heard about stem cell injections helping children with muscular dystrophy, we hired a van for Rs 10,000 and brought all our children here," said the aged couple.

Their youngest son was detected with the condition five years ago, and screening in the family revealed that three of his daughters were carriers of the genetic mutation that causes the disorder. "These three daughters have two sons each and they all suffer from the disorder," said Sonawane. All the children fall after walking a distance and walk on their toes.

Sion Hospital started offering stem cell therapy for neurological disorders in April 2007; since then, about 200 patients have received the treatment, including 72 patients suffering from muscular dystrophy. "We have noted that if children come to us earlier than when the disorder has rendered them bed-ridden, the results are more encouraging," said Dr Alok Sharma, head of neurosurgery in Sion Hospital. "It's not a cure yet, but certainly they experience a better quality of life. Patients have better control over their movement. They have better balance and can even hold things."

"We have treated 72 patients of different types of muscular dystrophy with a 93 % success rate. In all the patients, the disease progression has halted and in a significant majority there have been definitive neurological improvements in their ability to stand and walk," said Sharma.

About Sonawane's children, Sharma said, "They got admitted on November 8. After some investigations like EMG, Musculoskeletal MRI etc., they were operated for stem cell transplant on Thursday. They all tolerated the procedure well without any problems. They will be discharged on Saturday and will be asked to follow up after one month for evaluation."

Bhagwan Nikam, son-in-law of Sonawane, said, "It has been difficult for the family to manage financially because of the children's plight. There are tests and medicines to pay for. But we came to Sion Hospital as we want our children to have a better life and continue attending school."

One of the first patients of Duchenne Muscular Dystrophy to receive the injection at Sion Hospital, Ankur Chandu Kant, is, meanwhile, doing better than he did in the last decade. Said his father Chandu: "My son's life is possibly just 5% of what a normal life should be. But this 5% has been assisted by the two stem cell injections he received last year."

STEMMING OUT A DISORDER

Duchenne Muscular Dystrophy is a congenital neuromuscular disorder caused by a defective gene

Males are more prone to the disorder than women who are mainly carriers of the gene. It occurs in approximately 1 out of every 3,600 male infants

Patients usually live till the age of 25

Stem cell therapy has emerged as a possible treatment. In Mumbai, Sion Hospital offers stem cell injections to these patients; so far, 72 patients have been given these injections

Under the therapy, a small amount of bone marrow fluid is taken from the patient's marrow, processed in a laboratory, and then injected into the patient's muscles and spinal cord



LINED UP FOR A CURE: Narayan Sonawane has brought his son and five grandsons to Sion Hospital in the hope that they will be cured of Duchenne Muscular Dystrophy