



Statues can't see: Jeet Narain with his four sons suffering from muscular dystrophy

# In behen's backyard...

**A father in Uttar Pradesh begs the President to let his four boys die**

By Ajay Uprety/LALGANJ

**A**s the four brothers sat on the stony ground to have lunch—a plate of rice and a glass of water—houseflies buzzed around in swarms. Some alighted on the rice, rubbing their hairy legs. But the boys did nothing to shoo them away. They cannot. The siblings—Durgesh, 22, Sarvesh, 20, Brijesh, 16, and Susheel, 13—suffer from muscular dystrophy, a hereditary condition that causes muscles to weaken and waste away. Their father, Jeet Narain, has now written

to the President, seeking permission to euthanise the boys. Pale and weak, Durgesh said: “We have been living like insects. We need our parents’ help to meet all our needs, even for eating and using the toilet. I have given up hope. Every day I wake up wishing I were dead.” The brothers were well at the time of birth, but started falling ill around the age of six. “It began with weakness in the calf muscles,” said Narain. “But as the disease grew severe, they start-

ed falling down while standing and walking. Gradually they became unable to walk.” When doctors in Lalganj failed to diagnose the condition, Narain and wife Prabhavati took the boys to the Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow. “I was told it is a congenital disease with very little hope of cure,” he said. The family stays in Basai Kalan village in Mirzapur district, about 400km from Lucknow. The couple has a young daughter and they are

## Gene hit man

### What is muscular dystrophy?

Genetic, muscular disorder characterised by slow, progressive wasting of muscles. Victims usually get it from one or both parents, but there have been cases of spontaneous mutation, too. The prognosis depends on type and progression.

### Affected group

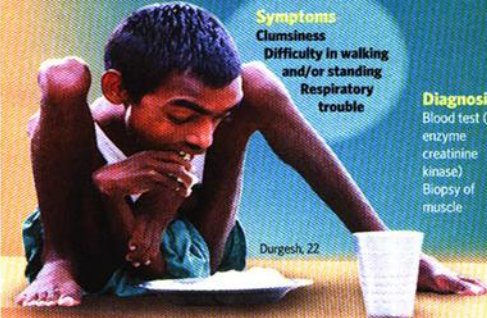
All age groups. Some types noticed in infancy, others in childhood or even in middle-aged adults. Reportedly affects one in 3,500 children in India

### Symptoms

Clumsiness  
Difficulty in walking and/or standing  
Respiratory trouble

### Diagnosis

Blood test (for enzyme creatinine kinase)  
Biopsy of muscle



Durgesh, 22

### Fallout

Progressive disability and deformity  
Decreasing mobility  
Osteoporosis  
Obesity  
Respiratory failure  
Cardiovascular complications



### Treatment

Incurable, but can be managed with exercise, physiotherapy, speech therapy and physical aids such as wheelchair and leg braces. Surgery to correct deformities and cardiovascular aids such as ventilation assistors and pacemakers also help.

afraid that she, too, might develop the condition when she turns six.

A farmer with just two bighas of land, Narain is struggling to feed his family and treat his children. To add to his income, Narain opened a tiny shop, but closed it down, as the boys needed constant assistance. He borrowed Rs 1.20 lakh from a bank and is now in debt. Though he has not kept a record, he has spent Rs 5 lakh for treatment of his sons.

“I cannot go to work. I have to carry them even to the toilet,” he said. But like every mother, Prabhavati is ever hopeful. “I do not understand what

the doctors say,” she said. “They say it is an incurable disease. But I still feel their condition can be improved with proper medication.”

Narain said he got no support from the state even though he had been the ruling Bahujan Samaj Party. He said about a year ago he had sent a letter to Chief Minister Mayawati through the local MLA. The MLA later asked him to submit a fresh letter as he had lost the first one; the second letter, too, was of no use.

Narain is peeved that none of the local leaders or cadre of the BSP helped him despite knowing his