

Indian-origin boy denied life-saving drug in UK

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London: Six children, including a 6-year-old Indian-origin boy, have been denied life-saving treatment from a rare disease due to high costs by UK's state-funded health service.

Kirath Mann suffers from Duchenne muscular dystrophy (DMD), which affects one in 3,500 boys in Britain and leaves many in a wheelchair before their 10th birthday.Â

His family, from Coventry in the West Midlands region of England, joined forces with other families to campaign to end delays to a breakthrough treatment called Translarna but failed due to high expenses involved.

"We are devastated at having to face yet more disappointment after another hurdle has been put in our way.Â

"All these organisations and National Health Service (NHS) bodies that have been involved in the decision do not seem to be appreciative that this is a rare disease and very progressive one as well," Kirath's mother Jaspal told 'The Coventry Telegraph'.

Kirath and five other boys with the condition even wrote personal letters to British Prime Minister David Cameron in June in a bid to get the drug that could save their lives.

"Hello Prime Minister, my name is Kirath. I am six years old. My legs are poorly. Please help me get the medicine I need," read the letter in his childish scrawl.Â

The National Institute for Health and Care Excellence (NICE), which decides on commissioning new drugs for the NHS, has decided that drug manufacturers PCT Therapeutics need to present more information on the benefits of the drug to coincide with the cost as Translarna can cost up to 4,00,000 pounds per patient a year.

"It was at NICE's discretion to give a positive decision and it was in their remit to do that. But they decided to go for a different approach," she added.

The drug - also known as Ataluren - is the first-ever to tackle the causes of DMD and was approved in Europe in August last year and is available in France, Spain, Germany, Italy and Denmark, but not in the UK.

"We are disappointed not to be able to recommend Ataluren in this draft guidance. After considering the evidence, and the opinions of the clinical and patient experts, the Committee agreed that Ataluren represents an important development in the treatment of DMD.Â

"It could potentially prolong the time before children have to use a wheelchair, compared with best supportive care," said Prof Carole Longson, NICE health technology evaluation centre director.

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