

Couple's agony over children's short future

By Sam Greenhill, Daily Mail
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It is a disease so rare that only 500 children in the world have it.

But fate has dealt Tina and Mark Harris the cruellest of hands - because two of those children belong to them.

The result is that six-year-old Jordan and three-year-old Jasmine are destined to die before the age of nine.



Pic: Cavan Pawson
Agony: Harris' fear for children

There is no current cure for Batten's disease - a genetic disorder that gradually destroys brain cells, causing blindness, deafness, loss of muscle control and then death.

Mrs Harris said: "It was bad enough to find out that Jordan had it, but when Jasmine was diagnosed with it too, our world just fell apart.

"We could not believe that both our children would suffer like this. They say lightning doesn't strike twice, but it has in our family."

Defective gene

Jordan was healthy until he suffered his first seizure in March 2001. Within a year, he began falling over with frightening regularity. Then he lost his power of speech, was unable to walk and needed help to eat.

Doctors finally diagnosed him with late infantile Batten's disease, triggered when both parents of a child carry a defective Batten gene.

The couple were warned there was a 25 per cent chance that Jasmine would develop the condition.

Mrs Harris, 42, of South London, said: "We never thought life would be so cruel, but in December 2003, we were told she had it too."

Mr Harris, a 44-year-old maintenance-engineer, added: "It is just unbearable to look at the children and think that Jasmine is going to end up like Jordan."

But despite her tragic fate, the little girl has yet to fully succumb to the disease and is proving a loving helper to her big brother.

Full of life

She wipes his tears away when he cries and makes him laugh.

"She is full of life, which almost makes it worse to know she will not live to the age of ten," said Mrs Harris.

Most sufferers die by the age of seven and are not expected to live beyond nine. The only prospect of a cure is offered by research being done at Cornell University in New York.

But Mrs Harris said: "We both think that Jordan and Jasmine will be dead by the time a cure becomes available."

The Harrises have set up a charity, the Jordan Jay Trust, to raise money for research into Batten's disease, named after the British paediatrician who first described the condition in 1903.

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