

Parents fight for disease cure

By Patrick Sawyer, Evening Standard
21 April 2005

Tina and Mark Harris have to live with the unbearable knowledge that both their children will die before the age of nine.

Jordan, six, and Jasmine, three, suffer from Batten's disease, an incurable genetic disorder that affects only 500 children across the world.

"We often ask 'why should both our children suffer this?'," says Mrs Harris. "It would have been bad enough for just one, but to have both like this is terrible. They are such lovely children. What have they done to anyone?"

Mrs Harris knows there are no answers to these questions, so most days she and her husband just do, in their words, "what needs to be done". And, as if providing round-the-clock care is not enough, the couple have thrown themselves into fundraising for research into a cure for Batten's disease, holding on to the slim hope that medical science may one day provide an answer.



Pic: Cavan Pawson

The Harris family are not the first to face just this situation. Six years ago siblings Rhys and Charly Daniels died after they were diagnosed with Batten's. Rhys was just short of his eighth birthday when he died after having two bone marrow transplants in an attempt to cure him.

His case came to national attention when his parents went to the High Court over the closure of the hospital where he was being treated. His sister Charly's condition was detected too late for surgery to be attempted. She died aged nine, just a few months after Rhys.

Mrs Harris, of Shooter's Hill, recalls: "In March 2001 Jordan had his first seizure. Until then he'd been a normal child."

In spring 2002 he began falling over with frightening regularity. An MRI scan showed his brain had shrunk significantly.

Over the next few months he lost his power of speech, was unable to walk and needed help feeding. Finally he was diagnosed with late infantile Batten's disease, in which defective genes gradually force brain cells to shut down.

Doctors warned Mr and Mrs Harris - who met on holiday in Greece - that there was a 25 per cent chance Jasmine would inherit the disease. Mrs Harris, 42, said: "We thought life would not be so cruel. But in December 2003 we were told she also had the faulty gene." Mr Harris, 44, a maintenance engineer, said: "It's just unbearable to look at the children and think that Jasmine is going to end up like Jordan."

The only prospect of a cure is offered by pioneering research at Cornell University in New York. The couple, whose case has been highlighted on Five News, have set up a charity named after Jordan. They have raised £160,000 towards the research. "It gives us something to focus on," said Mrs Harris. "It's really heartwarming that so many people out there want to help. It gives us the strength to carry on." In the meantime, they try to follow the advice of one doctor who told them to enjoy their children to the full while they could. "Both kids are full of life and very happy," said Mrs Harris. "You don't cope. You don't have a normal life. You do what you have to do for your children."

- *Jordan and Jasmine's charity can be reached at www.jordanjaytrust.com*