

Hopes are high as Rotherhithe's Jordan and Jasmine fly to States

By Chris Mullany

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ROTHERHITHE youngsters Jordan and Jasmine Harris fly out to America this week, taking the first step towards what their parents desperately hope will lead to a cure for their genetic illness.

Tina and Mark have spearheaded a fundraising appeal since son Jordan was diagnosed with late infantile battens disease in 2003. An extremely rare condition, battens is brought on by a defective gene, which causes a deficiency of an essential enzyme. This leads to a build up of fats and proteins which eventually forces a child's brain cells to shut down.

In December last year, the family received the news they had been dreading, when daughter Jasmine was diagnosed with the condition. Unlike her brother, she is yet to develop any of the debilitating symptoms.

There are only some 500 children around the world who suffer from the condition, and at present there is no known cure. But pioneering work is being conducted at the Cor-

nell University in the USA, involving gene replacement therapy.

After months of waiting, the family have now been told that both children are to undergo preliminary screening, and fly out to New York tomorrow, September 10. The family are hopeful that they will be selected to undergo treatment amongst the first children.

So far three children have been treated. They each underwent six hours of brain surgery, which involves the drilling of six holes into the child's skull and the injection of the gene therapy into specific targets in their brain. This is major surgery and a traumatic procedure for the children, but they have all made a good recovery. However it will be many months before any real data will be available.

The Jordan Jay Trust was set up just over a year ago, and over £120,000 has been raised. "People have walked, run, cycled, sky-dived, shark-dived, danced, partied, made movies, been auctioned, and raffled their way towards this wonderful sum, and we sincerely thank you all," said Tina. "Without your support we would not be in this position today. However the fight to



HAPPY FAMILY... Jasmine and Jordan with mum Tina

raise more funds continues - we need to raise £250,000.00 over the next two years so that the trial can be completed on time, and as many children as possible can be treated before it is too late for them."

*A sponsored 'seven bridges' walk in aid of the Trust is taking place next Sunday, September 19. The walk begins at 10am, and leaves from Tower Bridge. Please

contact the 'News' on 020 7231 5258 if you would like a sponsorship form.

If you would like to make a donation, you can send cheques to: The Jordan Jay Trust, Alliance House, 49-51 East Road, London N1 6AH, Registered Charity Number 1098918. You can also visit the appeal website at: www.jordanjaytrust.com

