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# Southwark News



**Your guide to all the Easter fun**  
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**FIND OUT WHO HAS GOT A BLUE PLAQUE**

# HELP ME LIVE!

## US therapy may give Jordan a fighting chance



By Paul Guest

A **DESPERATE** Rotherhithe family is appealing to the local community to come together and help raise money, in a bid to give their four-year-old boy a fighting chance against a life-threatening genetic disorder.

The Harris family has launched the appeal to get their son Jordan to America - the only place where he could receive treatment for a rare disorder called late infantile batten's. Only 500 children in the world have been diagnosed with the condition, which affects children aged between two and four.

After initially being told that the condition was fatal, the family have now discovered that the only possible hope is gene transfer therapy. "We've known for three months that Jordan has it and it's been agony" said his mum Tina. "If we didn't have hope we'd go crazy." They still do not know

whether their one-year-old daughter could also be affected.

The Downtown Club have offered to stage a fundraising night, but the family is appealing to as many people as possible, in order to give Jordan the best chance of getting treatment.

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## DANCER 'SHOT AT BUGSY MALONE CLUB PARTY'

By Court Reporter

**AN OLD KENT Road partygoer was shot while dancing at a Bugsy Malone theme night after the gunman was refused entry to a nightclub, a court heard this week.**

Thirty-one-year-old Christopher Roberts, of Woburn Court, Masters Drive, Bermondsey, flew into a rage when he was told The Scene venue was full and fired a volley of shots at the doormen, it is claimed. The bullets missed their intended target, but one struck accounts clerk Eve Soton in the leg as she danced in the club.

An Old Bailey jury heard how the gun attack caused 'near hysteria' as revellers fled from the packed nightclub. It is not known how many shots were fired, because gunshots featured on music playing at the '30s gangster night.

Roberts turned up at the Old Kent Road after midnight on May 1, 2000, and was told by doorman Douglas Njoku the venue was full to its 250 capacity, the court heard.

"Not being content with that, he started to barge his way through," said Ms Alex Lewis, prosecuting. "Finding his path blocked he became a little more aggressive and directed abuse at Mr Njoku. When it was clear he wasn't going to get his way, he left shouting racial threats." The court heard that Roberts formed his hand into a gun, aimed it at the bouncer and hissed: "I'll be back. I'll shoot you, you spade." Ms Lewis said: "After this incident Mr Njoku thought it was an idle threat - the kind he had become used to from working as a doorman."

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W alworth man in court charged with killing his father

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Kids Company could make a move to Peckham



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# Rotherhithe charity bash to give Jordan gene transfer

By Paul Guest

**WHEN Rotherhithe tot Jordan Harris was diagnosed with late infantile batters disease in January, doctors told his parents that the disease was fatal and that there was no treatment.**

The news was a devastating blow for the four-year-old's family, yet they refused to accept that there was no hope of a cure. After speaking to other parents whose children suffered from the illness and finding out everything they possibly could, they stumbled across a groundbreaking research initiative in America. Up until the age of two, Jordan was a happy, lively and robust little boy, never bothered by as much as a cold. He was slightly behind in his speech and language development but no cause for great concern.

Then in March 2001, Jordan had his first seizure. His GP immediately referred him to Professor Robinson, one of the most experienced paediatric neurologists in the World. Several tests and MRI scans all came back normal, and Jordan was prescribed with anti-convulsion drugs.

Then in the spring of 2002, Jordan started tripping and falling over unexpectedly. Further tests in the summer

gave the first indication that the epilepsy was secondary to some more serious disease. When blood tests came back inconclusive, Jordan went into hospital last August and tests showed significant shrinkage of his brain, but still gave no definitive answer.

Last October, Jordan was again in hospital for a liver, muscle and skin biopsy. By then Jordan had lost all speech, was unable to walk unaided and needed help with feeding. On January 13 this year, he was finally diagnosed as having the rare neurodegenerative disorder called neuronal ceroid lipofuscinosis, also known as late infantile batters.

"We've known for three months and it's been agony" said Jordan's mum Tina. "If we didn't have hope we'd go crazy." Due to the debilitating illness Jordan cannot walk, talk and soon he will have to be fed through a tube. There is also the possibility that Jordan's younger sister Jasmine, 1, could contract the disease, but this will not be known for some time.

Gene transfer therapy, now offers the Harris family hope and the possibility that Jordan could recover and live a healthy, normal life. However, with only just over 500 cases world-wide, the rarity of the disease does not at-

tract much funding and it is because of this that a charity evening will be held on May 18 at the Downtown Club in Rotherhithe.

The evening will run from 4pm-11pm and involve an auction, a raffle and a barbecue. It is hoped that the money raised will contribute to other fundraising ideas around the world attempting to help Jordan and other sufferers like him.

"We don't have that long and nothing is guaranteed, but money talks and the more money we raise the more chance Jordan has of being cured," said Tina.

"Everyone we have come in contact with wants to help, it has been very heart-warming," she added. Tina would especially like to thank the Downtown Club who are providing the venue free of charge and also Alfred Salter Nursery who have cared for Jordan 'fantastically'.

The evening has been organised by Jordan's aunt, Toni, and she has no doubt as to how important it could be for saving Jordan's life: "Anyone who has met Jordan knows he is one of the strongest, most affectionate and inspirational little people they will ever meet.

"He teaches everyone around him about strength and perseverance. He struggles to do what most people



**BRAVE TOT... Jordan and his one-year-old sister Jasmine**

take for granted but still has a smile on his face. Please help us in our fight to keep our little boy alive."

Tickets for the event cost £10 and are available directly from the Downtown Club on 020 7231 8838.

Any contribution to the appeal would be welcome and could help save Jordan's life.

## What is late infantile batters?

**LATE INFANTILE batters is a rare genetic disorder. There are just over 500 known cases worldwide. To be affected, a child must inherit two defective genes, one from each parent. The disease generally starts when the child is between two and four years old.**

The most promising treatment looks to be gene transfer therapy, which would introduce a functioning gene into the central nervous system of a patient.

The gene would produce the necessary enzyme that is required to remove the

harmful storage material. The first trials of this treatment are expected to take place later this year. If the treatment is successful it could be a potential cure for around another 40 genetic disorders and save the lives of thousands of children.

**If you would like to contribute to the Jordan Harris fund call the 'News' on 020 7231 5258**