

**J**ordan Harris turned five last Saturday - he had the usual party treats, friends, cakes, balloons and a clown. But this was no ordinary birthday - it was just another milestone in Jordan's tragic story, writes Dan Foster.

As all the other children sat and ate jelly, sweets, and ice cream, Jordan could only stare wantonly, whilst being fed through a tube containing tasteless liquidised food, offering just a calorie per millilitre.

As all the other children sang and laughed at the clown, Jordan could only sit, strapped in his adapted chair and smile - whilst his younger sister Jasmine looked on, oblivious to the torment and suffering that has plagued her family for the past two years.

Jordan Harris, from Rotherhithe, is no ordinary child. He is slowly dying from 'late Infantile Batten's', a rare and degenerative neurological-muscular disease, which has savagely attacked his nervous system, rendering him immobile, and speechless within a matter of months. Sadly, he may never see his sixth birthday - as this time next year, he will possibly be blind.

As another day ends, mum Tina carefully lays him on the floor and methodically begins his daily exercises - opening his clenched fists, bending his lifeless legs, and moving his fingers to stop his joints from seizing.

"I wanted to make a nice day for him. It breaks my heart, seeing him sat there whilst his friends are all playing, I wanted him to enjoy his party - every minute for Jordan is so precious," said Tina.

For the past two years Tina Harris has been on an emotional roller-coaster of fear and despair as she has watched her perfect little boy draw away from a 'cheeky, charming' normal two-year-old, into a quiet and tormented five-year-old shell.

"He's still my Jordan", Tina explained, looking into his deep blue eyes. "His personality is still there, he smiles when others are happy and laughs if people are cheering at the football.

"It's when he is in pain that it's the worst, he gets really distressed and cries out. He can't tell me where it hurts and you can't console him - I just don't know what to do sometimes, it is so painful for a mother when you can't help your own child.

"I watch him sleeping soundly, and



# See the film - and help give Jordan hope

he looks like any normal little boy, but knowing that this disease is killing him drives me crazy with worry. I just want to be able to relax and stop all the bad thoughts for a minute, but it doesn't stop, it's there all the time, and it's so hard to put on a brave face, when all you want to do is cry."

"He seems to deteriorate a little bit more every day and the loss of his vision scares me the most - that world of darkness - it frightens me to think that one day he might not be able to see his family."

**I**n August, Jordan had a feeding tube fitted in his stomach, held in place by an internal metal plate, after weeks of struggling to swallow simple and small amounts of food.

A large syringe now provides him liquidised nourishment, which can never be held too high as the effect of gravity helping it pass through the plastic tubing can cause him great discomfort.

"It was really difficult for us getting our heads around feeding Jordan this way, but he seems happier and more contented. The hospital are pleased as he is filling out a bit

now, but it's not easy to get enthusiastic when he shouldn't have to be in this situation in the first place."

Jasmine, just 18 months old, is very attentive to Jordan, and delicately wipes away the saliva from around his mouth and chin with a tissue. She frequently smiles and kisses her sick older brother, and it is moments like these, which have helped to brighten Tina's day:

"My husband Mark and I, have spent a lot of time in hospital with Jordan and I always miss Jasmine's little grin, it brings a bit of happiness to our lives, but I feel guilty. Sometimes as I would like to spend more time with her and enjoy her, like any other mother."

**"I just want to shout to everybody 'help me, help me get my little boy better'"**  
Mum Tina

Worryingly, Jasmine has a one in four chance of having late infantile batten's, as it is a faulty recessive gene, passed by both parents to their offspring. The family have an agonising wait until she is a few months older to see if she has been dealt the same cruel fate as her brother.

"It's something we always think about, 'if and when, we get Jasmine tested', but it is hoped that the younger the child, the better chance they have to make a full recovery if a cure is found - and I wouldn't want to miss out on that chance. We have to deal with these thoughts on a daily basis and I'm not sure how we'd cope if Jasmine was also diagnosed."

People from all across the Southwark community have been helping to raise money for Jordan, and the family have been recently granted charity status for the 'Jordan Jay Trust'.

"The kindness and support we have received from many people helps us so much and we hope and pray that with enough money, the treatment will be soon and successful - but we still need to keep going," said Tina.

Pioneering gene transfer therapy in America is Jordan's only chance of survival and the first human trials to find a cure for late infantile batten's are expected early next year. As the disease is so rare, funding is limited; therefore, the onus is on the 500 families affected worldwide to raise money for the research, which will cost hundreds of thousands of pounds.

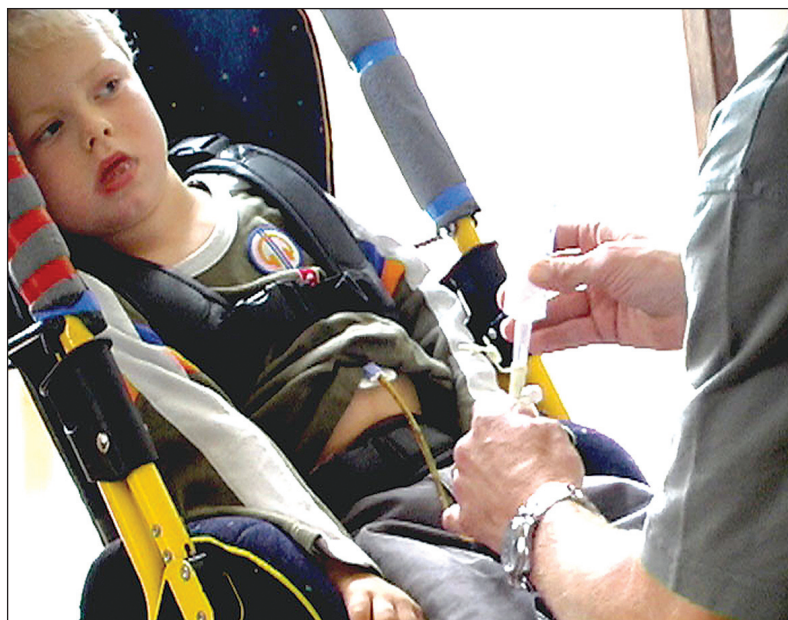
"I just want to shout to everybody 'help me, help me get my little boy better' - Jordan is the love of my life and thinking he may not be here some day tears me apart," Tina said.

"I sometimes think 'how are we going to get through this, have we enough energy to keep fighting?', but I know with enough support we can, and we have that.

"I want to keep fighting, so we can make sure that Jordan's sixth birthday party will be his best one ever."

**The documentary 'Fighting for Jordan: The Tina Harris Story' features as part of Southwark: The Movie, to be shown at UCI cinemas Surrey Quays on the 13th October. The performance starts at 7pm.**

**Tickets are priced £6.50 and all money raised will be donated to the Jordan Jay Trust. They are available to buy on 020 72315258 or by logging onto www.tmax.co.uk.**



**Call now  
020 7231  
5258  
for tickets**

**Above and below: Jasmine gives her sick brother some loving attention. Below right: Jordan now has to be fed by a tube into his stomach.**