

NEWS

So young, so brave: cancer guinea pigs

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Fabian Bates, pictured with sister Cassia, is undergoing immunotherapy treatment (True Vision/Hello!)

LIKE any big brother, James Balloqui is proud and protective of his sister Chloe, a lively four-year-old. "I am proud of her because she is so strong, even stronger than me I think," he said.

James, 9, has good reason to believe that. Chloe is among a group of children who have become guinea pigs for tests of an experimental new treatment that doctors hope will one day beat cancer.

Her parents Karen and Richard Balloqui, from London, have agreed to let Chloe take part in clinical trials along with about 20 other young patients at Great Ormond Street Hospital.

The children are involved in trials of immunotherapy treatment, hailed as the most promising approach to cancer since the development of chemotherapy nearly 80 years ago. It involves harnessing and strengthening the immune system to fight the cancer cells, either by administering drugs or by genetically modifying white cells to do the same job.

"It is mind-blowing what these children go through. They are so young when they come to us. The families are so brave," said Chloe's consultant, Daniel Morgenstern.

He is leading the British arm of a Europe-wide trial into immunotherapy treatments for neuroblastoma, one of the most aggressive cancers and the one Chloe suffers from. The rare condition mainly affects young children and develops from nerve cells called neuroblasts, which run down the back of the chest and stomach. About 100 children a year are diagnosed in the UK.

Chloe was diagnosed in October 2013 when she was two. Only two out of five children diagnosed at this age will survive.

Morgenstern says it is vital to remember that these patient pioneers against cancer are still children. They turn the hospital into a playground when they can and enjoy seeing familiar faces among staff and patients on their regular visits. "The treatment becomes a normal part of their lives," he said.

For two years a film crew has followed three children, including Chloe, as they are treated in the clinical trials. ITV will broadcast *Raining in My Heart* on April 15, revealing the stories of Fabian, Sophie and Chloe and their battle for health. The filmmakers have asked that the children's results are not revealed in advance of the documentary.

Morgenstern acknowledges that not all the children in the trials, covering various cancers, will recover but adds that as the tests advance, outcomes are improving as doctors learn to modify treatments for the best results.

Fabian Bates was diagnosed with acute lymphoblastic leukaemia in 2006 after his parents noticed a small lump on his neck. Three years ago, when he was nine and being treated in hospital, he met the Duchess of Cambridge. She later wrote him a letter telling him how she had been touched by his "strength of character" and "positive energy".

For several years after he had conventional chemotherapy the cancer seemed to be in remission. When it returned his parents Darrell and Lydia Bates, from west London, agreed that he could take part in trials at Great Ormond Street led by Professor Persis Amrolia.

The film shows how, when Fabian's sister Cassia offers to donate T cells from her bone marrow to help him, he offers to buy her a gift. "I have got £15," he says as they lie in a field looking up at the sky, adding: "I'm not spending it all on you, I have to use my money wisely."

Cassia's white cells are genetically modified in a laboratory in France and given to Fabian in a bone marrow transplant. He nicknames them Tank T cells and tells Lydia he is looking forward to growing up and getting a wife and a car.

Fabian tries to carry on as normal, attending a youth club after a day in hospital. When the pain becomes too great, he wanders over to his mother and asks for more morphine so that he can carry on playing.

Taking part in the same trial is Sophie Ryan-Palmer, whose motto, she explains, is "happy happy happy; fun fun fun and always smile".

Diagnosed with cancer when she was two, Sophie has tubes surgically implanted in her body to make it easier for her to take her drugs. She goes to school between treatments, makes cakes for a charity bake sale with her friends and follows the fortunes of One Direction, her favourite pop band. When her cancer returns for a fourth time at the age of 11, her reaction is remarkable. "Of course I was upset but there's something we can do. So we do it," she says. Sophie joins Amrolia's trial and is due to receive cells genetically modified to fight her cancer. Her mother said: "Fingers crossed, my little girl gets what she deserves — a long life."

Chloe's father Richard, a business analyst, says that while they were worried about the trial, they felt they had no choice. "Immunotherapy is the future of treatment for these children. We have always been realistic. It does not work for every child," he said. In the film his daughter says: "I'm a bit better, a little bit better . . . I want to get better."

Last week Richard said the treatment had been partly successful but Chloe was not yet cancer free. "If children did not take part in trials, successful treatments would be even further away," he said. "It takes hundreds of children and years of results. You have to have proof [that] things work."

Morgenstern said: "Neuroblastoma was fatal not so long ago. Gradually we are seeing small rates of improvement. Children who get to the end of the immunotherapy treatment have a 65-70% survival rate."