



A brother's love

James wants to find a cure
for his little sister's cancer...

WHEN CHLOE BALLOQUI grows up, she would like to be a vet, possibly one specialising in hippos. In the meantime she'd dearly love a rabbit, but family pets are, for now, off the cards. Chloe, four, suffers from high-risk neuroblastoma, one of the rarest childhood cancers, and her compromised system is vulnerable to infection.

Chloe is one of three young cancer patients featured in *Raining in My Heart*, a deeply moving documentary about the gamble of joining a last-throw-of-the-dice hospital treatment trial. Immunotherapy uses the body's own natural defences to fight the cancer, which in neuroblastoma is diagnosed in fewer than 100 children a year.

"We know, in principle, that patients who are treated on clinical trials do better than those who are not," says Daniel Morgenstern, consultant and lecturer in oncology at Great Ormond Street Hospital. "And of course, every child who participates in a clinical trial is contributing information to improve things for the future."

Because of the rarity of Chloe's cancer the data gathered from her treatment is all the more valuable. "When we were considering the immunotherapy trial, it was effectively 'this chance or no chance,'" says dad Richard, a business analyst. "What are you going to do?"

Mum Karen adds, "Once you're told your child might die, life can't be the same. The diagnosis

changed us completely. We've always tried to be very straight with Chloe's brother, James, explaining everything that Chloe's going through. And I think James would be quite angry with us if we didn't tell him everything."

James, nine, is firm on this point: "Of course I need to know everything. She's my sister." And he has an ambitious game plan: "I want to be an oncologist. I've already given a presentation about neuroblastoma at my school, but what I really want is to find a cure for children like Chloe."

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There is so much love, so much determined positivity, wrapped around the little girl in the Princess Elsa hat (with long, woollen hair-plait attached). It breaks your heart to learn that, for Chloe, the immunotherapy trial has not delivered the longed-for result.

"We were told quite clearly that there was a 50/50 chance the cancer would come back. And it has," says Richard. "But we want other parents in our position to have hope. Because immunotherapy *does* work for some children. And Chloe's data will help the diagnostics of the

tumours; the way she has responded will help push forward the science. It helps to know that."

The family now faces the possibility of joining a new clinical trial in the US and is raising funds for the treatment with Neuroblastoma Children's Cancer Alliance (donations already top £155,000). "People ask us, 'Aren't you angry you've got to find money to go abroad?'" says Richard. "But we're not angry. I'm a huge defender of the NHS. We've got two of the greatest doctors in the world for neuroblastoma at Great Ormond Street, and they've been amazing. It's just that the time has come to try something new."

If Chloe goes to America, it will be with every good wish from Great Ormond Street. "In terms of Chloe's future treatment, there is nothing that I think she needs, that is a proven benefit, she can't access here," says Daniel Morgenstern. "But there are always going to be yet more options available somewhere else in the world, and it's just not possible for all of those ideas to be trialled in the UK."

Raining in my Heart is one of those programmes that makes parents pull their children close and count their blessings. It's a reflex that, remarkably, Richard and Karen have never lost: "Over the last year and a half we've seen a lot of sick children. So many people we've become close to have lost their child over that time," says Karen. "Well, Chloe's still with us. We couldn't ask for anything more." **E JANE DICKSON**