

“ZOE TRULY HAD THE HOLIDAY OF A LIFETIME”

Jacqui Jones, 50, from Hampshire explains why Dreamflight's holidays are so important to seriously ill children

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Zoe with Alisha, one of the friends she made in Florida

Jacqui Jones will never forget dropping off her daughter, Zoe, now 15, at a Heathrow Airport hotel last October to begin her Dreamflight adventure. “We had been by each other's side almost constantly for years so I was dreading it,” says Jacqui. “However, from the second she arrived, the emphasis was on fun and joy and laughter. Zoe deserved the holiday of a lifetime after everything she had been through so I was incredibly happy for her.”

Zoe was born eight weeks early and spent six weeks in intensive care. “She was fine when we took her home. However, over the next few months, her head began to grow rapidly. Our health visitor put us in touch with a specialist at the John Radcliffe Hospital

in Oxford, who diagnosed her with hydrocephalus (a build-up of fluid on the brain) when she was 18 months old.”

Jacqui was told that Zoe would need a shunt in her

brain, a specialist device that drains cerebral fluid down into her tummy via tubing, as one ventricle in her brain was not doing this properly. “We were terrified as it was a major brain

“EVERYONE WAS IN THE SAME BOAT, HAVING HAD SERIOUS STUFF THROWN AT THEM THROUGHOUT THEIR LIFE, BUT THE TRIP GAVE THEM INDEPENDENCE AND SHOWED THEM THEY COULD STILL ENJOY LIFE”

operation, but the surgery seemed to go well.”

However, when Zoe was three and a half, she started vomiting daily. “I took her to the GP, who said it was probably just a virus, but we were worried. She was delayed with her speech so couldn't really tell us about her pain, but her neurosurgeon had warned us that if she developed headaches and sickness, it could be down to a shunt malfunction.”

After a week of vomiting, Zoe suddenly collapsed.

“We rushed her to Southampton General Hospital, which had the nearest neurological unit. It felt like she was dying in our arms. We were told her shunt had stopped working and she needed an urgent operation to replace it. Thankfully it made her feel instantly better.”

Over the next ten years, Zoe experienced several problems with the shunt and valves (which control the flow of cerebrospinal fluid) in her brain. “I've lost

count of the number of brain operations Zoe has had. Two years ago, she became seriously unwell for five weeks and was shaking in intense pain.

We were sent to Great Ormond Street Hospital,

where her valve was replaced. A few months later, she had to have a second valve put in, then a third one last April to stop the pumps from over-draining the cerebral fluid. They'd never put a third valve in for a child before, but it seems to have helped.”

In the midst of this, Zoe also fell ill with anti-NMDA receptor encephalitis, a rare autoimmune disease and type of brain inflammation that causes psychosis. “Zoe had memory loss and hallucinations, where she'd scream at night thinking there was a man dangling from her curtains. For the next year, we were in and out of hospital while she had steroids pumped through her veins and she was

given mycophenolate mofetil, a drug which helped manage the encephalitis.”

At around the same time, Zoe was also diagnosed with an ovarian tumour, which is often the cause of anti-NMDA receptor encephalitis. “Her tumour was the size of an orange by the time they found it, so ➤

Dreamflight has taken more than 6,000 deserving children on holiday to Florida

The total cost of the Dreamflight trip each year is in the region of £750,000, which equals approximately £3,500 per child. This is funded solely by voluntary contributions

The trip builds confidence and independence. Many children have never been away from their parents before

“ZOE HAS MADE GREAT LASTING FRIENDSHIPS AND MEMORIES TO TREASURE FOR EVER”

she lost her left ovary and was left with a scar about four inches long. Thankfully the results showed the tumour was benign, but it was a real worry.”

In March last year, Zoe's school nurse, Tina, told Jacqui she had put Zoe forward for a Dreamflight holiday – where 192 children with a serious disability or illness are taken on a ten-day trip to Florida each year. “A few months later, we were told Zoe had been accepted and would be in the Jedi group on the *Star Wars*-themed trip, alongside 15 other children. Zoe was so excited. They went to theme parks, swam with dolphins, and had themed parties every

because they didn't want to leave all their new friends.”

Since her return, Jacqui has noticed the difference in Zoe. “Although she is an incredibly positive and smiley girl, I could see she'd lost a lot of confidence before the trip. Being so unwell and away from school meant she has lost friendships, and the steroids had caused her to gain weight, which in turn made her self-conscious. However, on the holiday, she felt for almost the first time that nobody was judging her. Everyone on the trip was in the same boat, having had

night, and a graduation party on the last night, where they all cried

serious stuff thrown at them throughout their life. The holidays also gave the children an independence and showed them that even though they've got these conditions, they can still enjoy life.”

For Jacqui and Zoe, it is an experience that they will never forget. “We were given a DVD with footage of the ten days, and Zoe has made some fantastic memories and lasting friendships. Although she will always have hydrocephalus – and she may need more operations in the future – she is doing fantastically and has come back a confident, happy, well child who has had a holiday of a lifetime she will never forget. I'm so grateful to Dreamflight for that.” *

Dreamflight: Changing Children's Lives

TOTAL RAISED: £69,819

➔ The money raised in The Candis Big Give will help the charity to send 20 children on holiday in 2019. It will cover all costs, including travel and food, accommodation, medical expenses, entertainment, entry to theme parks and a dolphin swim. It will also go towards a reunion party after the holiday and the production of a DVD with footage of their trip as a keepsake for the children and to share with their loved ones back home. Visit dreamflight.org to find out more.



Zoe made lots of friends on her ten-day trip to Florida