

Meet OTW Camper Ben



At four-years old, Ben was diagnosed with relapsing nephrotic syndrome, a renal condition that causes high levels of protein in the urine, low blood albumin levels and high blood lipids. As well as causing Ben pain, the syndrome can also cause swelling in his face, legs and stomach, impacting him physically, psychologically and socially. Ben also suffers from serious asthma and has other conditions caused by premature birth. Steroids are the first form of treatment for nephrotic syndrome and necessary for each relapse. However the drugs cause Ben to feel poorly, aggressive and affect sleep, so periods of treatment are a huge challenge for him and his family. If a child keeps relapsing, powerful second line treatments are needed, but these can have serious side effects such as increased cancer risk or infertility. Ben is on his second session of these drugs now and therefore requires regular blood tests, which he hates.

It was after speaking to another parent on an online support group for nephrotic syndrome that Ben's mum, Hannah, first learnt about Over The Wall's camps.

"Ben was on fluid restriction, and as it was hot he couldn't go to the park with his friends, as he would get too thirsty." explains Hannah. "I felt very sad and powerless to help him. Also, he had been unable to go on his school's residential trip due to confidence issues and all his medicines. So, I decided it was time to call Over The Wall to find out more about their camps."

"After our application in 2017, we were offered a Family Camp place when Ben was eight, and then we returned again in 2018. Both times we had such a wonderful time. Ben often talks about his experiences and still sings Over The Wall camp songs!"

"It was so valuable for him to see and meet other children facing their own individual challenges and for him to see that they too are dealing with a range of different medicines. He was immediately comforted by the fact that he wasn't 'the only one'."

facing challenges

“One of the greatest moments for us was when Ben went off and did a zip wire challenge. This was something he really wouldn’t ordinarily do. Ben would often refuse to go places on his own, and as a younger child he was always very attached to us at all times - so for us to see him go off in a group, whilst being very well cared for, and then completing such a big challenge was an absolutely wonderful moment! He went straight up and came down feeling so empowered by his achievement.”

A massive benefit of Family Camp was finally having some time to reconnect as a family. Ben’s relationship with his brother had pretty much broken down, due to the emotional side effects of steroids.

Hannah says, “At camp, both boys were given attention, we were all made to feel so special. But most importantly, we had fun again. We had almost forgotten how to have fun.”

“Ben really connected with the volunteers. He met one doctor in particular whilst playing pool at camp, and found out he worked at Ben’s hospital! This doctor later introduced him to the ‘Beads of Courage’ scheme* and has helped hugely in combatting Ben’s needle phobia. He has since administered vaccinations which no-one else could achieve. It was great for Ben to meet medical staff in an informal environment. Getting to know everyone in a different capacity really empowered him. The volunteers at camp are truly amazing and are so great at relating to all of the campers.”

After Ben’s time at camp, Hannah explains how she also notices a change in his behaviour, she continues:

“After camp, we noticed that Ben became much more confident. A good example of this is that he will be attending the Health Challenge camp in the summer of 2018, on his own. There is no way he would have contemplated leaving us for five days on his own before his time at Family Camp. What’s great is, we know he’ll be in good hands, we’re confident he’ll be well cared for, and we know that he will have an enormous amount of fun!

*At camp, Brilliance Beads are awarded based on a specific achievement - maybe the camper tried something new for the first time, or conquered a certain fear. The beads act as positive reinforcement, visually reminding the camper of what they have achieved.

