

Our story by Lucy (Heart Mum to Oz)

How can you have one of the best years of your life and also one of the worst at the same time?

This is something I think about a lot because this is what happened to us. 2014 was the year we had our first child Oz, our amazing, funny, caring, clever (now 5yr old) little boy. It was also the year we got told he had a heart condition called Tetralogy of Fallots (a complicated name which means actually there's a few things wrong with it) and our whole world just collapsed.

Pregnancy was going well and we had our 20 week scan and the sonographer said those words "there's a possibility there could be something wrong with the babies heart, you need to come back next week and see the consultant". After an agonising few days wait we saw the consultant who gave us the all clear! Yippee, phew what a relief, he of course said there's no guarantees but he was so confident that he said he wouldn't have even have questioned it if he had done the initial 20 week scan instead of the sonographer. Great now we can just get on with enjoying pregnancy and I pushed it to the back of my mind.

The birth came and was hard work but it went ok.

When we were on the ward some trainee paediatricians did the rounds and checked Oz over. We were told they could hear a heart murmur but it's really common and often murmurs clear up on their own. I remembered my 20 week scan and told them there had been a question mark so they did some more tests and after an echocardiogram confirmed the ToF diagnosis, oh and along with another whammy that often this condition is caused by something else called 22q11 (more on that later) but we'd have to wait for the results of blood tests in a few weeks time to determine that. There was this rush of information and feelings and stuff going on and my head was spinning. Hang on a minute, I can't even pronounce his condition and now here I am phoning our loved ones having to try and explain when I can't comprehend it myself.



Oz got moved onto the special care unit while they liaised with Bristol hospital to determine if he'd need surgery right away or not. I'm not going to lie, that time was hard, I've never felt utter despair like it, utter darkness. If I hadn't have needed to be strong for Oz then I would have completely collapsed but that wasn't an option, this beautiful little boy needed me and I was going to do everything I could do to help him no matter what. This was another feeling I remember so well, an incredible feeling of determination, one like I've

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never ever experienced before, a force so strong that nothing else mattered and nothing was going to stop me from being his voice his advocate, his mummy! I was determined to breastfeed which we both had to learn with the addition of doing it while covered in wires. I was hurt when I got told we had to supplement with formula too otherwise he wouldn't gain weight and his blood sugars were very low.

There were no beds for us in the family rooms on the special care unit so we were allowed to stay on the maternity ward in a separate room and they put a mattress on the floor for my husband so he didn't have to leave us. We then stayed with Oz as long as we could until the doctors would kick us out and we'd either try and get a bit of rest so we were strong enough for when we were allowed back in again or use that time to try and plan our next moves, update family etc. Night time every hour and a half I'd trundle up and down the two floors with my swollen feet to be with him and try and give him comfort and some of my milk. I hated even the shortest amount of time being away from him and I remember trying to watch tv in the communal mum's lounge crying, why can't I have my baby with me like the other mums can. I just wanted him to be healthy and for us to be celebrating like everyone else was.

Amazingly after a few days we were able to take him home and start the battle of getting his weight up and ensuring he stays well so he can be ready for when he needs to have open heart surgery which is usually around 6months old. What a few months they were, getting used to being a new parent is hard enough but then having to navigate everything that comes with having a baby with a heart condition. We also got the diagnosis that his heart condition was caused by a tiny deletion on one of his chromosomes called 22q11.

This was another massive blow, children with 22q11 vary greatly in terms of how it affects them but the list of possible difficulties are as long as your arm and it can affect every major system in the body. So 2014 also meant going through the long list and trying to determine what things the 22q might be affecting other than his heart and some of which we may not know until he's older. Also turns out that the hole in his heart was significant enough that it would have been identifiable at the 20 scan if we had been seen by the correct people.



Just when you think the year hadn't been hard enough, along comes surgery time. You know this day was coming but nothing can prepare you. No child should go through that and no parent should either. The pain of handing him over for surgery and the agonising wait was unbearable. How was this happening to us. I thought, we are one of those parents that you see on TV and think wow that's hard and then try and push it to the back of your mind and carry on doing whatever your doing.



So that was 2014, pretty rubbish really, but, as hard as it was, look at what I'd been given, this incredible little boy who changed my life, brought me so much love and joy and showed me I was capable of things I didn't even know. He was and is, along with his little sister the best thing that's ever happened to me. In 2015, by chance I met my good friend Ruth Hansell. Ruth's little girl has the same heart condition as Oz. At last someone I can talk to who just gets it, someone who I don't have to explain things to cause they already know. Someone who's been in that position and understands in a way some family and friends, despite seeing us go through it, still don't really understand.

Because of this friendship and the way talking to each other helped us, we decided to start a group to support other parents - Heart Children Gloucestershire. This is something I'm really proud of and hope it's helped other parents and given them support at a time when things can sometimes feel very lonely.

Oz is doing amazing, he's had some challenges, like overcoming a speech disorder and having to deal with hyper mobility which makes some physical stuff really hard for him but he's through his first year of school now and we've been told he's even exceeding in some areas of school life too. Not bad considering we didn't know at one point what learning would look like for him given the 22q diagnosis. He has an amazing little sister now too, Ruby. Ruby's heart is fine which was something we were obviously worried about. They love each other so much.

Looking to the future, he'll need more surgery at some point and we have the job of teaching him about his heart more and trying to prepare him for the future as well as talking to Ruby and trying to make sure she's not affected by Oz's heart condition too. As I said her hearts ok as far as we know but heart conditions affect the whole family mentally and it's important siblings get the support they need to deal with things.



When heart heroes came along, I admit, it felt a bit weird accepting help. I'd started my own group to help others and sometimes I felt this responsibility to be strong and give others what they needed instead of being a recipient. Also, I see what other families go through and you think, yeah we've had it hard but some families have had it harder and you question if you deserve it. Taking myself out of the equation though I thought, would Oz benefit and the big answer is YES!

You see, through events and activities organised by them he gets to see other children like him, these are his peers, other children with pirate scars and similar physical abilities. Other children that he doesn't have to compete with like maybe he does with some at school. Ruby gets to see other siblings too and understands that there are lots of families like ours out there. They get to have fun and I get to see them have fun! I also get to spend time with other parents and we can talk about things and help each other.

Kelly from heart heroes has been so lovely, the kids love her and we look forward to going to more activities and events. I'll try harder to accept help. Thank you Heart Heroes.

HEART HEROES FAMILY EVENTS

On July 6th Heart Heroes, Heart families South West and Heart Children Gloucestershire all came together for a Heart Family day out at The Noah's Ark Farm and Zoo in Bristol. The trip was part funded by The Grand Appeal and Heart Heroes.

We had 65 adults/children attend and it was great to see everyone having fun. Heart Heroes set up a base so the families could come and go as they wished especially as it was a very sunny day. Everyone met back up at the same time for lunch and each Heart child received an ice lolly.



Review from two Heart parents ...

'As a parent of a heart hero, days out are sometimes often quite isolating and lonely and its lovely to be part of the group. The volunteers are amazing so approachable, friendly and it was so helpful to be able to pop to the toilet etc and the kids be watched. My kids had the most amazing day making lots of new friends. Having a base was great as my heart warrior tires easily so we were able to sit relax and rest for a bit. Having an opportunity to chat with other heart mums is so important and we were able to catch up with some families we haven't seen for some time and a couple of families we have met through the hospital. Thank you so much for providing us with this amazing opportunity!



"Thank you so much for organising the day out, we had a lovely day. I still feel wobblier than I realise about my daughters' heart, and being able to meet other people yesterday was really wonderful, also just to have a lovely day out and see other families, it still feels like a whole new part of our lives and I really appreciate your support yesterday. I think it was good for my older 2 to come too, because they don't come to appointments and only visit when she's been in hospital, they are removed from it and I want them to feel involved. I'm sure it was a lot of work but I wanted you to know how much I appreciated it"

Newsletter

FUNDRAISING 2019



A huge thank you to all of our supporters

Spaces held with payment

Supporting small local charity Heart Heroes. Children living with heart conditions

PIC-COLLAGE

HEARTHEROES.CO.UK/EVENTS



Heart Heroes Hoodies are available to order via our Facebook/Instagram/twitter pages or email



Numbers still available

100 CLUB

January saw the launch of the Heart Heroes 1st ever 100 Club. For a one-off payment of just £10 - which enters you into 12 draws (one every month for a year) - you can choose any number between 1 - 100 (if still available). At the end of every month 2 numbers will be drawn. The 1st number chosen will win £25.00 with the 2nd number winning a bottle of wine. All money raised from this 100 club goes directly to Heart Heroes.

2019... EVENTS

- RELAX KIDS FAMILY WORKSHOP TBC
- INFLATABLES 5K SEPTEMBER 14TH CHELTENHAM RACECOURSE
- DECEMBER 7TH SKY DIVE
- HEART FAMILIES CHRISTMAS PARTY DECEMBER 15TH