

Ethan's Story



Ethan

No one said being a parent was going to be easy, but I didn't expect, and wasn't prepared to hear that the child I had so long wanted would have a heart defect, Pulmonary Valve Stenosis (PVS).

Even now after 3 years I can still remember sitting in a little side room, converted into a 'comfortable' seating area with my wife Jo, waiting for Dr Simpson to come in and talk to us.

Ethan, never enjoyed the scans and would do anything to avoid a clear scan being taken, after 4 return trips to our local hospital the decision was made to go to Guys as their equipment was more advanced.

The scan took about 30/40 minutes and it was conducted in total silence, looking at the monitor with the changing red and blue colours was very un-nerving for both Jo and I.

After the scan we both just sat in this room not knowing why we were being kept, worry running through our minds. Dr Simpson finally arrived after about 10 minutes and dropped the biggest bombshell on us, leaving us utterly bamboozled. The news of the heart problem was bad enough but then to be informed our son could also suffer from Noonan syndrome and other side effects was hard to accept.

We travelled home in disbelief. I was trying to be supportive but I was scared out of mind with worry. When we got home we spent a great deal of time on the internet investigating Noonan's and other possible problems associated with PVS, preparing ourselves for what might shortly become a reality.

Every parent wants their child to be born perfect in every way and I was no different. I kept a great deal of what I was feeling to myself in the ensuing months not wanting to show how much I was hurting inside. More important to me was being supportive to Jo and making sure she knew I was there for her and our unborn son.

I wasn't too concerned with the heart condition as I was pretty sure we all would get through it, for me the hardest thing for me to accept was my son could suffer from Noonan syndrome. I was scared I wouldn't be able to handle a child with special needs. It took a great deal of soul searching and reading up on the condition to realise that no matter how severe, Ethan's condition, he was going to be my son and it was my responsibility to be there for him. Once I had overcome my own issues I couldn't wait for Ethan to be born and to start enjoying parenthood.

Looking back, I know we were very lucky to have found out about Ethan's condition while he was still in the womb, although the next 16 weeks were full of worry.

Ethan was born two weeks early on December 15th 2003, in St Thomas's Hospital. We were able to have a little cuddle before he was transferred by ambulance to Guys. The first couple of days Jo and I commuted to Guys and only returned to St Thomas's to sleep.

The nurses and doctors in SCBU were fantastic and provided us with the support we needed. Ethan looked so tiny with various tubes sticking out of him but the bond between me and my son was made. Jo and I were so happy and although we knew Ethan was still going to have an operation my fears no longer mattered. Ethan was examined for visible signs of Noonan's and thankfully nothing was forthcoming. Unfortunately Noonan's can develop as the child grows up. Although it isn't something Jo and I knowingly look out for, we do keep an eye out for any symptoms.

We moved from St Thomas's into The Ronald McDonald House close to Guys for the remaining time we spent in London. It was so convenient to be 5 minutes from the hospital and we are eternally grateful for the support of the staff.

Ethan was soon well enough to be moved to a ward. He was still attached to the heart monitor, which we kept a close eye on and a mild panic swept over us every time it beeped!

It was in the ward that we became parents, feeding, bathing and clothing Ethan and at the same time the realisation that although we wanted to be at home, how would we cope without the assistance of the nurses.

I was humbled by the time I spent on the ward. Not only the time spent with Ethan but the courage of the other children on the ward, some so much more ill than Ethan. These children gave me the strength and hope for Ethan.

Seeing Ethan have test after test every day was heartbreaking, hearing him cry uncontrollably as yet another blood withdrawal was taken was one of the most upsetting moments for me. One lasting memory was seeing a doctor bending my son's foot back in order to take more blood and being totally powerless to prevent his hurt was awful.

Jo and I were given the news that perhaps we may be able to take Ethan home for Christmas and then

bring him back in the New Year for his operation. Although I would have loved to take Ethan home I just wanted the operation to be over with so we could all go home together without the worry of having to come back.

I got my wish and at 7 days old, on December 22nd Ethan was operated on. My mind was a total haze on the walk down to the operating theatre. Seeing my little boy being prepared for his operation and with tears in our eyes we said our goodbyes.

We had three hours to waste so we went to a restaurant and over a pretty bland meal we talked about our future. I tried to keep my composure but was pretty unsuccessful as several times during the meal my eyes glazed over. Never has three hours taken so long!

We sheepishly entered the hospital and taken down to the recovery area. As soon as I saw him lying in his cot, tears swelled in my eyes once more at the news that the operation was successful. He was taken back to the ward to recover. I had pretty much consigned myself to staying in hospital over Christmas, but I really didn't care. What was important was that Ethan was recovering well and any immediate dangers were now over.

Ethan made an amazing recovery and on Christmas Eve we were allowed to take Ethan home for the first time. A manic Christmas ensued with all of our family around us.

Ethan will always have his heart condition, however he is doing very well and only requires yearly check-ups at St Thomas's.

As a family we have been lucky to attend some of the events organised by ECHO and our appreciation goes out to everyone in ECHO for their hard work.

I had for a long time wanted to run the London Marathon, so when the opportunity to combine both running the marathon and to some fundraising for Echo came, I jumped at the chance.

My journey started on January 1st 2007 and with a new pair of trainers and a schedule in hand, I started my three and a half months training in earnest. Having not run a great deal in the past 15 years, I was surprised how easy it was for me to get back into the swing of things.

Jo became a running widow as I pounded the streets day or night, rain or shine. I loved every minute and with the sensible eating and cutting out alcohol, I felt the fittest I have in years.

April 22nd 2007, the big day! Waking early I was feeling a little jaded but ready for the days events. I started on my epic journey by train and then followed the masses and masses of people coming from all directions making their way to their start areas. The atmosphere was electric and friendly with everyone I met looking forward to the day.

By 9.30 I was in my starting pen waiting patiently with my fellow 'athletes'. It was during this time with the sun shining brightly and the temperature creeping into the 20's, I started to get a little nervous. The start had been bothering me as I didn't want to spend 10/15 minutes trying to get over the start line and tripping over other people, so I was relieved when I managed to find a clear route to the start line and after only two and half minutes.

Despite drinking at every drinks station, the heat was becoming a real problem. It was at 6 miles when I realised I wouldn't be able to achieve my target time so slowed down to preserved energy.

The next 7 miles were pretty uneventful, the crowd that lined the street were great and I was enjoying the run now that I was running for myself rather than to a time.

It was just on Tower Bridge I started to struggle, my legs still felt fine but the problem I had was my shoulders tensing up and causing me great discomfort but I carried on trying my best to relax them as much as possible.

Running through Canary Wharf, I was greeted by the cheers from my family, I had been cheered on throughout the race by total strangers but now this was my family and it spurred me on a little more.

I got to 18 miles, how, I'm not sure as I had hit 'the wall' and was now really struggling. I adopted the run/walk method and this was working well for me. My legs and shoulders were hurting and I was seriously questioning my sanity at starting the run in the first place.

The worst part of the run for me was all the time I had to think during the run, the doubts, the pain, not wanting to give up for both me and more importantly for everyone that had supported ECHO through me. I struggled on and was walking now more than running but I was determined to finish what I had started back in January at all costs.

Running up Embankment I knew I was close to the end and with the crowds, 6 and 7 deep cheering along the road, the noise was deafening, I decided to give the last couple of miles my all and just run. The pain I experienced over the last miles was excruciating, my legs, my shoulders and just for good measure my chest was also hurting! Passing Big Ben on my left, I just kept on going and after finally turning in the Mall I knew I had done it and it would soon be over.

Crossing the line a wave of relief spread over me, all I wanted to do now was lie down and give my body the rest it deserved. I collected my medal and goody bag and sat down leaning against a tree, proud I had finally achieved my goal. The only thing left for me to do was to locate my bag which was in the very last lorry and find my family.

At the time I vowed never to do another marathon again EVER, I soon changed my mind on the way home as the pain subsided. I'm doing my next one in October, for fun!

Thank you ECHO for giving me the chance to give a little back.

Adam Tackley



Adam and Ethan