

Ewan's Story

One of the youngest competitors in a recent, aptly entitled "Run for the Children" Fun Run in Bexley was our son, Ewan. As he was only five months old at the time he enlisted my help as "pram pusher" to get around the course. We decided to use the opportunity to raise some funds for ECHO and The Evelina Hospital Appeal. We managed to raise £400 which we divided between the two.

Ewan was born in April this year and weighed in at a well rounded 8lb 6.5oz. Everything appeared normal with him, although he was a very reluctant feeder, until his check at three days old when he and I were due to be discharged. The Paediatrician noticed a possible heart murmur and asked for an ECG to be done. The ECG confirmed a hole in the heart. One of the midwives then decided to check his weight. He had lost 11 ounces in just three days - it's normal for babies to lose some birth weight but it's usually about 10% over five days so alarm bells began to ring.

We stayed in hospital for a few more days until Ewan appeared to be taking his feeds better. However, it was still a real struggle to get milk down him and the midwives put that down to him being a "lazy feeder". The hospital said they would get in touch with the Evelina Children's Hospital to arrange for a check up on his hole in the heart. We'd never heard of the Evelina up to that point. Little did we know that we would be having a lot more to do with them than we anticipated at the time...

The weekend after we were discharged Ewan began vomiting. It was very intermittent and, being new parents, we put it down to over feeding or a dodgy tummy. It was a bank holiday and having rung NHS direct and being reassured by them we decided against going to A&E. However, on Tuesday morning instinct told us something wasn't really right so we took Ewan to the GP just for a check up.

Whether the SATs machine was inaccurate or Ewan's level dropped we shall never know but his reading came up as 84% at our GP's surgery and she told us to take him directly to A&E with a letter from her explaining her findings.



Ewan in Evelina

Ewan's SATs had improved when we got to A&E but they were concerned about the GP's findings. One of the paediatricians, who had a background in cardiology, said she could hear something underneath the heart murmur and arranged for him to be admitted to the children's ward overnight. She called the Evelina and they said they wanted to see him the next day. They gave the local hospital instructions for preparing him for that appointment and for the overnight stay.

He was examined further in the ward and it was discovered that his liver was enlarged. They decided that, to save him working any harder, he should be fed hourly by feeding tube. After ten attempts and eight feeding tubes, they finally got it inserted when a neo-natal nurse was called. Ewan was given just 15mls of milk hourly - enough to keep him stable but not enough to make his digestive system work too hard and cause his heart to suffer. He also had a saline drip inserted in his hand to keep him hydrated.

Next day, Wednesday, he and I were taken by ambulance to the Evelina. By the time we arrived Ewan was deathly pale, sweating and clammy. Neither his dad - Ken, nor I knew what to expect but we weren't prepared for what happened next. Ewan had an echo done and it showed severe aortic stenosis as well as the hole in the heart. The aortic valve was malformed with two leaflets instead of three and this was causing intense pressure build up which made the walls of the aorta itself thicken up. The consultant, Dr Krasemann, said the valve needed to be opened further to relieve the pressure and our choices were open heart surgery or to have balloon inserted to pop open the valve. This would leave the valve floppy but would relieve the pressure without a full operation and he would recommend that with open heart surgery as a back up if needed.



Ewan with mum and dad

We were in shock. We'd gone in with a little boy who was very ill but who had, as far as we knew, a hole

in the heart. We had been told by a senior paediatrician at our local hospital that the majority of holes heal themselves. Now we were being told that, without some sort of procedure or surgery, Ewan would not make it beyond the next few weeks as he was critical. The one thing it did explain was his being a “lazy feeder” as the midwives at the local hospital had put it. He couldn’t breathe and feed at the same time as the oxygenated blood wasn’t going around his body properly to fuel his digestive system so his body had decided to breathe at the expense of feeding. Nobody had put two and two together about that. I’ve since given the midwives full information about his condition so, if someone’s baby shows similar signs in the future we hope they will get alarm bells ringing quicker.

The balloon dilatation procedure was scheduled to take place the following day and Ewan was prepared for the procedure and his overnight stay. We carried him down to the operating room the following day where he was prepared and we said our goodbyes. It broke our hearts watching our brave little boy laying on an operating table at just two weeks old, ready for theatre and not being able to go any further with him. I think both of us, like any parent, would have gladly gone through the procedure without anaesthetic rather than see him there.

The procedure would take about 30 minutes we were told so we were sent off to get some breakfast. One hour later we still hadn’t heard anything so went back to the ward. The nurse checked and found out that Ewan had only just gone into theatre as they had had problems getting tubes etc., into his veins because they had begun to collapse. They had had to put two tubes into his neck as they couldn’t use the veins in his arms. So we went off for a walk around the hospital again to try to take our minds off the next, vital, thirty minutes.

As we headed back to the lift a little later my mobile phone rang. It was our nurse, Nigel. Dr Krasemann wanted to see us on the ward. Our hearts were in our mouths – what did that mean?

Only one of the lifts was working and we had to wait for another, it seemed ages before we managed to get up to the ward and Dr Krasemann wasn’t there. Suddenly we saw him coming towards us with a huge grin on his face. “You do remember that I said I would come and find you on the ward after surgery don’t you?” he said. Er, no, that piece of information hadn’t actually registered earlier in the day! “Well, the procedure went well, the aortic valve is 70% open so I am very pleased. You can go to him in the recovery room” said the doctor. We went through every emotion in those few sentences.

We headed down to the recovery room where Ewan decided he didn’t want the drama to end. Whilst he was happy to wriggle around he would not open his eyes and, half an hour later, we were taken back to the ward to carry on trying to rouse him. One of the doctors, who had been trying to get blood from Ewan the previous day and had had to use umpteen needles in the process, came by to see how he was. He’d been so upset at having to put Ewan through the blood gathering process and wanted to make sure he was OK. As soon as Ewan heard his voice his eyes pinged open as if to say “Keep him away from me, I don’t have that much blood left!”. Overnight Ewan was monitored and given Heparin to thin his blood as his feet were still not showing a good pulse.

On Saturday we were sent back to the local hospital for overnight observation and the next day Ewan was discharged.

From that day he turned from a “lazy feeder” into the milk monster. He would still need a break during a feed and we eventually settled into a routine of stop start feeding sometimes over an hour if he didn’t

take a good size feed at one go. He soon moved from 9th percentile on the baby weight growth chart to 50th percentile (he was 75th when he was born but had lost so much weight) and he's maintained that for a couple of months now. He's just started weaning and loves his food. He giggles all the time when he's being fed and is such a happy little chap, always greeting us with a huge grin every morning.

Ewan went back for his first check up at the Evelina in June. There was a lot of regurgitation across the valve as it was floppy as we expected. The prognosis was that he would probably need a valve replacement sooner rather than later but Dr Krasemann wanted to keep him under observation so we made an appointment to return in September.

The next appointment found us prepared to be told he needed open heart surgery. We were amazed when the echo began. The valve appeared to be working almost properly with no regurgitation and just the usual turbulence caused by the hole in the heart. The aorta has begun to lose its muscular look and was doing its job well. The doctor said that, if Ewan had been an ordinary child he would say his heart wasn't great but, for a child with aortic stenosis it was looking very good. The Evelina now believe, if things carry on as they have done, that valve replacement surgery may be delayed until Ewan is an adult with balloon procedures carried out if he needs them in between.

We were so grateful to the Evelina for the help they had given Ewan that I registered us for a Fun Run in early September to raise some money. The one thing that kept us going during our time in the hospital was having the chance to escape Camel ward by using the family room which we knew ECHO had paid for. Just having a chat with other parents over a cup of coffee the night before all our children were due for their operations made us feel more confident and that we were not alone.

The Fun Run was organised under the banner of "Run For The Children" a charity that tries to encourage children to lead a healthy life. As I said to the organiser I can't think of a better way of celebrating Ewan's change in health than taking part in this run. The run was only 3km. However, I am almost 2 stone overweight, which I keep blaming on my pregnancy but as Ewan is now 6 months old I think I shall have to find another excuse! That coupled with pushing Ewan in his pram, uphill, over bark and gravel meant my calves felt like I'd run a marathon! Ewan enjoyed himself though and flirted shamelessly with all the ladies as usual.

We can't thank the Evelina hospital enough for giving us our son back and for giving Ewan the chance to lead a life we were only dreaming about a few short months ago.

And the best bit of advice we were given? Well that came from Dr Krasemann who stopped me as we were leaving on the Saturday following his procedure and said "Remember, Ewan is a child first and a patient second. Let us do the worrying about managing his condition. You concentrate on giving him the kind of childhood a little boy should have". It's hard to remember that sometimes. I'm sure both Ken and I will be having kittens at those milestones such as the first time he goes out alone, goes to school, leaves home etc., but the point is that we've now been given a chance to see those milestones and that's down to the wonderful staff at the Evelina Children's Hospital.

Jackie Grant

