

Lily's Story So Far...

By Rich and Sue

Lily... As in the flower, stands for Purity Innocence and Beauty. These words could easily be used to describe our lovely Lily, along with other not so flattering words such as cheeky, messy, stubborn and naughty. As with all "special" babies she has been through so much already in her short life but still always manages to find a smile and our family life simply wouldn't be "normal" without her.



Like all children Lily has her moments, normally when we are out shopping or in places she doesn't feel happy. We just wish that when we are out and about and Lily does not hear me, or people think she is being naughty that they would understand all that she has been through and what an amazing girl she is.

Well where to start.... After losing our baby boy Joseph (23 weeks into pregnancy) in November 2004 we were filled with joy in finding out that we were expecting again. At the doctor's advice we decided to proceed with a nuchal translucency scan to make sure that the baby was developing properly. This scan was not available on the N.H.S so we had to pay for it ourselves as private patients. However, at around £200 we felt it was a price worth paying for our own piece of mind. We were told after the scan that due to my age and previous history there was an increased risk that the baby could have either T13 or T18 but things looked

ok. Despite this warning we carried on with the pregnancy without having any further tests in the belief that everything would be fine. Our consultant gave us lots of support and encouragement that things were progressing well and I was scanned every month.

Around Easter 2006 I developed severe itching and upon seeing my consultant was admitted straight into hospital. Once admitted I was told that I had a condition called cholestasis and that although not linked to the baby, he/she was very small and there could be a genetic problem.

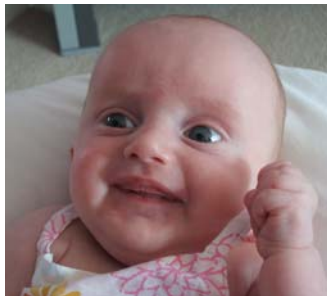
After a difficult birth, Lily Ann Orme was born on 10 May 2006 at 1.01 weighing 3lb 9oz. She was very small but perfect. She needed a little help with breathing, had to be kept warm and also struggled to feed from the breast but we kept persevering. Lily was eventually transferred to neo natal on the insistence of the midwife (neo natal did not want to take her) as she was struggling to maintain her temperature and could still not feed properly.



Lily was on the unit to teach her how to suck and feed but she became jaundiced and was put into an incubator. She also had tightly clenched hands and a droopy eye. With the results of the nuchal scan still on my mind I asked them to do a chromosome test but they refused saying that "there is no point, she has no dysmorphic features". With some good

care on the unit Lily improved and finally came home two weeks later on the 24th May 2006, our wedding anniversary. What a wonderful present!

We had a wonderful summer. My other children loved their baby sister and she soon established herself as part of the family. It would be fair to say Lily was a pretty miserable baby and cried and slept a lot. We noticed that when she was sleeping she made awful noises (like snoring) so I mentioned this to my health visitor but she thought it was because she was small, and she was now taking her feeds and gaining weight.



In September she was sent to hospital as her breathing was not very good. However, I was sent home after being told "we have all had small babies", and basically that I was being paranoid. She was taken into hospital 5-6 times after that but always sent home after being told it was nothing serious. Eventually we were informed that Lily would be referred to a dietician and a pediatrician but we were warned there was a waiting list.

At six months old I started to wean Lily which turned out to be a nightmare. She was struggling to keep any food down by now and was sleeping for most of the time. By the March of 2007 Lily looked awful and during the weekend of the 10th March she became very unwell. Worried sick I took her to see a friend (who happens to be a G.P) who on seeing her rang the hospital to tell them that she needed a very ill baby admitting. Chest x-rays and further tests showed she had pneumonia and a collapsed lung. Lily was put into a cot with a clear plastic box that

covered her head (head box) to give her oxygen and a sedative to help calm her down. After a few days the course of antibiotics had started to take affect and Lily started to improve but in general our little girl was still poorly.

There is a well known saying that, "*It is not what you know but who you know*" and this could not be truer in Lily's healthcare from this point on in her life. During Lily's stay in hospital for the pneumonia she was being visited by another family friend (who was also a G.P) when she recognised one of the consultants on the ward from her medical school days. Having exchanged pleasantries with him she asked him if he would look at Lily as she was worried that she was not getting the care she needed or that we as her parents were not told what was happening. Although Lily was not one of his patients he had a look at her, listened to her breathing and had a look at her notes. We will never forget the look on his face as he read through her notes, asked us to excuse him and then promptly disappeared with them.

He returned a short while later with a collection of other doctors to inform us what treatment Lily was getting, what additional treatment she needed and what additional tests would need to be carried out to find out why Lily was having the problems she had. Hallelujah! We had found a doctor who really could make things happen. We were quickly put under the care of a fantastic lady consultant who was very thorough, wonderfully caring and always had time to talk to us about what was happening and why.

Once Lily's breathing improved she was subjected to a host of tests to try and find out what the underlying problem was for her poor health. A heart and lung scan apparently showed nothing wrong with Lily's heart but the consultant stated that she had chronic lung disease and queried a vascular ring (an irregular structure of

the heart and arteries). We were also told that she could have cystic fibrosis and a sweat test would be carried out. This involved wrapping up one of her arms in a plastic sheet and collecting the sweat for analysis. Much to our relief this again came back negative. A bronchoscopy was carried out so that the doctors could see inside Lily's lungs to check for any damage or obvious signs of a problem. This again showed nothing significant but did highlight a slight compression of her left bronchus. We were told this could be nothing or could support the idea of a vascular ring.

Despite the endless tests Lily continued to improve and was getting back to her normal self. We still did not have any answers but our little girl was once again on the mend. We were then visited by a speech and language therapist and dietician to help us with her feeding difficulties. Finally with Lily now 10 months old a geneticist came to see us and informed us they would be checking Lily for genetic related conditions. The results would take 6-8 weeks and we were again reassured that they did not expect to find anything as Lily did not present any obvious signs of genetic abnormalities or dysmorphic features.

After two weeks on the ward Lily was finally allowed home, only to return the very next day with pneumonia again. This was thought to be have brought on by the bronchoscopy. A further two week stay included an oxygen mask and nose prongs (not good for a grumpy, snotty 10 month old baby) which got Lily well enough to come home. This time she came home with a nasogastric tube (N.G) so that we could continue to feed her special formula milk, Infatrini, which was to help make her stronger and accelerate her weight gain. Feeding Lily with an N.G tube took some getting used to and was quite upsetting for the whole family. However, as always Lily took it in stride and found the tube a good toy to play with. She soon became an expert at picking off the

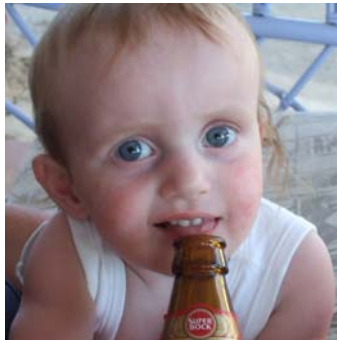
sticking plaster and pulling out the tube. At first this meant calling out the nurse to re-insert it but after a while we became confident enough to re-insert the tube ourselves. This was a simple enough task but one that was always upsetting for Lily and us as it made her cry uncontrollably. She also developed a fear of plasters and to this day does not like anybody messing around with her nose.



Life returned to normal for a while (as normal as it can be with a poorly baby and 3 other young children in the house) until the 16th April when we received a phone call from the hospital asking us to go straight in to talk with the consultant and geneticist. Within an hour we had been given the shattering news that our darling little girl had a genetic abnormality called Trisomy 18 mosaic. Once the shock had sunk in the doctors tried to explain what this could mean for Lily including the things she would probably be unable to do or achieve. Although they gave us some information (including a very good leaflet introducing us to SOFT) the geneticist could not tell us much about her condition as she had never seen a patient with it. She also explained that due to the nature of the condition the effects are completely unpredictable and Lily would need to be closely monitored by a host of health professionals.

We left the hospital with the news that our beautiful daughter might not walk, talk, feed, go to mainstream school, have children of her own or do any of the things that our other children do. As we write this it seems funny how at the time

we focused so much on what she wouldn't be able to do but now take great joy in all of the things that she is able to do.



We came home in a state of shock and could not believe that they had got it so wrong. We had been asking them since she was born to do tests but they had refused. After scouring the internet for information and doing as much research as we could we endured the task of telling our families the news. Coming from large close families this was particularly difficult as people became very emotional and seemed compelled to argue that they must have it wrong and that she is "normal". Despite being incredibly upset by the news our families were incredibly supportive and continue to give us and Lily all the love and support we could ask for. We would go as far to say she has now become more than a little spoiled by her grandparents, uncles, aunts and cousins.

On May 10th 2007 Lily had her first birthday. We had a fantastic day with a big family garden party at home – Lily loved it. The next day we had to go to a specialist heart hospital (Glenfield Hospital, Leicester) where they gave Lily a thorough going over including an E.C.G and detailed heart scan. The hospital staff were brilliant with Lily and us and we were quickly seen by a consultant and given the news that Lily had numerous holes in her heart (V.S.D's). They had detected at least four main holes and a number of smaller holes. Although they were not causing any major concern at the time, further operations would be

required to see if they were affecting her lungs. He also explained that the holes could close up by themselves as Lily started to grow and become stronger, and that her poor start to life could have something to do with them being there. We went back to the hospital on July 6th and were told that she would be in for at least five days. Lily had a cardiac catheter inserted to check the pressures inside her heart and for any other abnormalities. Much to our relief we were told that the blood flow through her heart was good and that the holes were not causing a problem. They were also confident that they were not affecting her lungs and that no further surgery would be needed, although she would still need to be checked every six months. After the operation she amazed everybody with how quickly she recovered and was home after just one night's stay on the ward.



With everybody in need of a well deserved break we decided to go on a family holiday to Portugal in September. We were pretty nervous about taking her abroad but once we had sorted out appropriate health and travel insurance (which was pretty expensive) we found everybody, including the airline and airports very helpful. We were provided with a special box (rumble trunk) for taking Lily's medical supplies in and given extra free baggage allowance by the airline. The holiday was a real success and we had a truly relaxing two weeks in the sun and Lily seemed to come on in leaps and bounds. She loved the beach and pool but was a little scared of the sea.

Despite Lily's improvement it was decided that it would be appropriate for her to have a gastrostomy fitted as she was not eating enough to keep her energy levels up and was still sleeping a lot. This would allow us to feed her through the night to increase her calorie intake and improve her nutrition. We had noticed for some time that Lily was not always hearing us very well. Tests had been carried out and it was confirmed that she had got glue ear so would need grommets. In view of the amount of anesthetic Lily had already received it was agreed that both operations would be carried out at the same time. This took some arranging by the hospital as it involved two different teams from different departments. Arrangements were made and on the 18th December she had both operations done. Lily again recovered quickly and came out after two nights in hospital.



Due to the large number of people involved with Lily, a care plan was put into place. Once the plan was in place we had multidisciplinary meetings where all the medical staff that were involved with Lily would meet together to discuss how she was getting on and what additional help or support was needed. Lily loves them because it means she can show off to everybody – always the entertainer.

After the operation to have the gastrostomy and grommets fitted Lily

really improved and her health remained pretty good. She had the odd illness but no more than your average toddler. The only difference is that the average cold could develop into a lot more with Lily so we continue to watch her closely. We had monthly appointments with dieticians and speech and language therapists to teach her to eat (breathe and swallow at the same time) and she had physiotherapy to help her to crawl, stand and eventually to walk. Although none of this seemed to come naturally she got lots of help from her big brother Daniel and sisters Rebecca and Ellen, and started walking unaided two weeks before her 2nd birthday – What a day.

With things going well in the autumn 2008 we decided it was time to try Lily at the local preschool. Our other children had all been there and they were happy to take Lily on a Thursday afternoon but she screamed the place down and would not settle. We were advised that Lily needed to be seen by an educational psychologist who could assess and advise on Lily's educational needs. An initial assessment confirmed that Lily was a little delayed in her development and would need one to one support. Funding was provided by the local authority and she was tried again after Easter this year with the one to one support and she seemed to enjoy herself much more. After the summer holidays she will be going to pre-school two mornings a week which we hope she will enjoy and will be good for her. Her speech is progressing well and she is singing rhymes (in her own little way) – she loves Mr Tumble.



Unfortunately just before Christmas 2008,

Lily developed pneumonia and a collapsed lung again. She was in hospital for a week but received good care and seemed to pick up better this time. We had another scary time in May of this year a few days after her third birthday. I took her to the doctors as she was not very well but he said he did not think she had a chest infection. However, with her history and as I knew her best he would send her straight to the hospital for a chest x-ray. Mum was right - it was found that she had pneumonia again but we were able to take her home on oral antibiotics! However, these did not seem to work and she got worse so we took her back the next day and she was admitted for I.V antibiotics.

Further tests found that she had developed Kawasaki disease which is a virus that attacks the coronary arteries of the heart. Luckily we had caught it early and she was given immunoglobulin treatment. Once she had recovered from the virus she was sent to the heart hospital to check that there was no damage. Thankfully all was ok and we have had no other scares since.

Along with her main problems Lily has various other conditions that have to be monitored. We had always noticed that Lily squinted a lot and disliked bright lights. It was later confirmed by the hospital that she has photophobia and needs to wear sunglasses. Despite some initial problems she doesn't seem to mind wearing them now and she looks a real cutie in them. We have also found that Lily has scoliosis (curvature of the spine) which is being monitored yearly for any dramatic changes. A recent appointment at the Glenfield hospital confirmed that two of the VSD's have closed and the two that are left are very small and appear to be closing which is obviously fantastic news and one less thing to worry about.

Now three Lily really is doing well, is no longer on any medication and continues

to amaze us and the medical people. Along the way her development has been helped by a whole host of brilliant dedicated people. She also now eats most things and has a particular liking for crisps and cheese strings. She is still fed with the pump at night through her gastrostomy to increase her calorie intake but this is now being reduced with the goal of having the feeding tube removed (fingers crossed).

We went to the SOFT Family Day where we met some truly wonderful people. Lily loved it and was a very playful cheeky girl making herself known to most people - sorry. We met some inspirational people and I am pleased to have made friends with many of the mums that I now keep in regular contact through facebook!



Lily showing off a chocolatey face at the SOFT Family Day!

When we were first told that our daughter was not "genetically perfect" we thought our world had fallen in. We have to watch on as she continues to fight hard against illness, puts up with test after test and recovers from operation after operation. But despite this she continues to grow, continues to thrive and continues to be a shining light in all of our lives.

Lily as in the flower- beautiful.

