



Lara's Story

In May 2011 our lives changed. Our 5-month-old daughter, Lara, was admitted to hospital with pneumonia. 10 days later she was back. The antibiotics hadn't worked and one of her lungs had collapsed. She was intubated, suffered a cardiac arrest and sent to Southampton Intensive Care. Whilst there it was found through various tests that she had a genetic condition, Spinal Muscular atrophy (SMA). We had never heard of it or had any idea that we both had the recessive gene that meant any children we had have a 1 in 4 chance of SMA. It meant that muscle messages didn't get through properly and because of this Lara was prone to chest infections as she couldn't clear her chest properly and her movements were limited.

We spent 8 weeks in Southampton, travelling daily, sleeping there and still trying to be around for our 2-year-old son. They tried 3 times to take the tube out so Lara could breathe for herself, the last time we were told if it didn't work there, were limited options. Luckily it did and she was supported with a face mask. We could hardly see her tiny face as just 2 eyes peered over the mask that covered her mouth and nose. She had twice daily physio to keep her chest clear and nasal and mouth suction that involved passing a tube down her nose into her lungs to keep them free of secretions. She was now being fed by a tube.

In a week we moved from a healthy baby to being told she would probably not make her first birthday. Lara continued to make small improvements, an hour a day without the mask and then 2, the 4, then only at night. We were told we may be able to take her home. We learnt how to feed her, do her physio and suctioning. Finally on Aug 1st we could take her home.

It was amazing but heart breaking as we knew we were taking her home to die. We made the most of each day and just wanted to be a family, to let her know she was much loved and a part of our life. It took some adjusting to. She had machines, a bi-pap machine at night, and community nurses and we had to prepare Ben to the fact that she would die. We had counselling, something we never even thought of before but now necessary.

We made the most of the time and we had 8 fantastic weeks and made wonderful memories.

Lara then got a chest infection, and we all made the decision not to treat it but to manage her pain and make her comfortable. On the morning of Thursday 15th Sept, she died on the sofa with her Mummy, Daddy and big brother all holding her hand.

We will never forget our beautiful smiling daughter, our ray of sunshine.

We are now trying to piece together our lives and try to understand what has happened. At the time we were living it, now we try to process the last year. Weeks away as a family are precious times for us, we still try to make the most of each day. Having the opportunity to meet other families who know where we have been also helps.

Our week in Wales has given us the opportunity to draw our family together, have fun in a safe environment and makes us feel like we are being looked after and cared for. The Trust has extended a big hug to us.

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