



Lily's Story



Lily was my third daughter and died when she was eight months old of Mitochondrial Disease. Mitochondrial Disease affects the tiny batteries called mitochondria which are in nearly every cell in our bodies. They convert the food we eat into the energy we need to survive. Without healthy mitochondria, Lily did not have enough energy to sustain life.

You many not believe it when I say to you that Dave and I consider ourselves lucky. We did not feel lucky however when we sat at Lily's bedside in intensive care and the consultant came over to us and told us she was going to die. There was nothing anybody could do for her. We were told that Lily had days to live. We were told that she had Mitochondrial Disease for which there is no cure or treatment.

However Lily survived six months from here. We were given the chance to see her smile, play with her toys, bath her, see her big sisters dote on her and cuddle her. We also had time to learn about Lily's condition and understand there was nothing more that we could have done for her. Before Lily's diagnosis we nearly lost her three times to seizures. She was resuscitated after these seizures, but had she died following any one of these, her death would probably have been put down to cot death. We are fortunate that we don't lie in bed night after night thinking that there was something we did wrong.

Those six months gave us memories to treasure forever which will always inspire us. Lily did not catch Mitochondrial Disease, she was born with it. Therefore her life was never meant to be a long life, but I truly believe that her life had a purpose and I think that this is it: The Lily Foundation.

For Lily every day was a physical struggle. With strength and endurance beyond explanation for a person so tiny and so young, she has inspired us all.

