

Adam William Freckleton

Adam was born 27 February 1997 after a normal pregnancy, a beautiful boy with a mop of black hair. He was our second child, we had a daughter, Bethany who was two years and six months, a healthy, energetic toddler, when Adam was born.

Ten hours after Adam was born he began making grunting sounds and stopped feeding. He was taken to the neonatal unit and lots of blood tests were performed. One was to test his lactic acid, this result came back raised, and so our journey into hell began as they began to suspect he had a metabolic disorder. I am a registered nurse, so all family and my husband Kevin, were looking to me to provide explanations for why Adam was so ill. This was not my area of expertise, but I was pushed into being the lead for all things 'medical' anyway. A muscle and skin biopsy confirmed our fears and Adam was diagnosed as having Pyruvate Dehydrogenase Deficiency – with a poor prognosis.

Anyone who has experienced a diagnosis of a child with a terminal illness will understand how lost we felt. Adam looked very 'normal', he was weeks old and he was beginning to die. After having a diagnosis, I was frantic to meet other children or people who had experienced such a disease, but as they are rare diseases there was no-one - except for the consultant. I often rang Climb and they provided me with some information on the disorder, but as all children are slightly different the future, for Adam, was very unclear.

Adam was unable to sit up and was very floppy, he also couldn't swallow well so we had a feeding tube inserted to take the effort of choking away from Adam. Throughout Adam's life we had good family support and I was able to go back to work, part time, so I was out of the stressful environment for a little each day. Friends carried out charity fund nights to raise money for Climb and hope someday for a 'cure'. Adam brought the best out of people and my belief that it is through reflection on what's happening that you learn to cope with the endless sleepless nights and hospital admissions.

Adam died aged two years and ten months, suddenly stopped breathing and I tried to get him back – with no hope.

I am opening a Galaxy Tribute Fund in memory of Adam to give back some of the support to Climb, as they do such a fantastic job in the support of parents when faced with a rare metabolic disease. Although Adam's life was short, he brought good out in people. The hours when he was very ill were so hard to bear and I hope one day genetic metabolic diseases will be a thing of the past.

My prayers each day are filled with hope for the parents, children, grandparents and siblings whose life is changed forever by these terrible disorders. So, by raising money and awareness we can begin to light a pathway to our understanding of metabolic disease and so a happier outcome for those affected. "Rest on my darling Adam, our love will keep the flame of hope brightly shining." In loving memory of Adam William Freckleton.

Lynn Freckleton

Total Raised so far: £30.00



Rose Status