

The Greatest Love of All

by
Julie Carr

I grew up with Ectodermal Dysplasia (although we never knew what it was called) not because I have it but I have an elder brother with it and a cousin, my eldest brother also had it but died at 3 months old. So I suppose when we had our first born I should have asked questions when he was overdue and had peeling skin, but he was healthy at birth, the fact that he looked like my brother I kept to myself and put firmly to the back of my mind.

We had it confirmed that Luke had ED when he was 3 months old and in hospital in an incubator.

Luke's first 3 months had been so difficult he couldn't swallow food, was always sick, never put on any weight, ran very high temperatures and had rashes every other day, but my word he could smile a smile that would melt your heart. I guess we knew we were in for a long haul at the hospital when everybody, nurses, doctors and even the consultant called us by our Christian names.

Six weeks later we left hospital with Luke and with warnings ringing in our ears and lessons on 'mouth to mouth' firmly lodged in our memory banks.

Before Luke reached 5 he had had numerous stays in hospital, 3 further occasions in an incubator on top of this he also had Meningitis. At this stage I guess we were as low as humanly possible. Luke was different not just because he had ED, he was just different.

Luke was 14 last Saturday he is small, has asthma, eczema, wears false teeth, has thin white hair, overheats and has horrendous nasal congestion but....He plays football every week, has numerous friends boys and girls, has just completed a scuba diving course, entered a new school and has top marks in many subjects. He lives life to the full, is enthusiastic about everything and does it all with a smile on his face. He is his little sisters' hero and of course ours. He has worried us, scared us, made us cry and laugh and made us very proud. He has made me a better parent and taught me one or two things about life and myself.

Luke has a sense of humour that is years ahead of himself like the time he was playing table football with his friend and they lost the ball so the boys used Luke's false teeth as the ball. His friend's Mum was worried and thought that it wasn't a good idea to which Luke replied "It's OK I've not got germs I've got ED and you can't catch that". He was 6 at the time.

ED is a part of our everyday lives and we all deal with it but it isn't the major issue in our lives, our children and their childhood is the major issue in this

house, but ED has played its part and it is impossible to imagine our lives without it.

"The Greatest Love Of All" has been a great comfort to both myself and Luke, try listening to it, it is inspirational.

I believe that children are our future teach them well and let them lead the way

Show them all the beauty they possess inside

Give them a sense of pride to make it easier

Let the children's laughter remind us how we used to

Learning to love yourself is the Greatest Love Of All.

Some names and locations have been changed in order to preserve confidentiality.

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