

# From Despair to Hope

by  
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I am sure all you Mums and Dads remember very well the day your little one was diagnosed. Suddenly things that seemed so pressing got completely forgotten and the only thing you could think about was your child and what his/her future now held. For months I had been worried about our first born son David. I related these concerns to my GP but I think he had me down as an over-anxious first mother. But finally, when David was fourteen months old, I found myself sitting opposite a Consultant's desk, and he had a name for all those problems that had been concerning us. A name I might add I could neither pronounce nor even read. The good gentleman wrote it on a piece of paper for me, but true to form, in a complete scribble. He could not tell me much, very little seemed to be available to him. I remember leaving that clinic, my scrap of paper in one hand and my little son bundled under the other arm, partly relieved that at last my suspicions that something was wrong had been confirmed, and terrified for the future of my little son. The Consultant's parting words were, "if you are considering having more children I think you should know you have a 50/50 chance of having another affected child". I was three months pregnant at the time.

Like any parent I wanted everything to be perfect for my children, I was devastated that he should have to carry this burden. I used to kneel beside his cot at night and pray that some miracle would happen and my little son would be cured. I was insulted and cross if anyone said "they always thought he looked different". I read everything I could about ED. Being a nurse I at least knew people to turn to who had access to some information. The most help came from the NFED in USA and a wonderful dentist in Dublin, also a genetic Consultant in Belfast. By then our second son had arrived and we were pleased that he was not affected. We decided to finish our family then and put our energy into raising the two little boys we were given. God had other plans!! One year later Daniel came screaming into our lives. At this stage I only had to hear his first hoarse cry to know that Daniel was also affected. But I was not so sad this time, for watching David I was learning something. David had problems, but God had known about that long before David was ever born. And from very early days I could see that this young man had many talents to compensate. He was very clever. He had a strong personality, and he could take difficulties in his stride. Even at that young age he bravely sat for hours while his dentist crowned his teeth and fitted dentures, asking him loads of questions every time the dentist took his hands out of his mouth!

I watched to see how God had compensated for Daniel. For a start his chap would not tolerate dentures at the age of two and a half like his older brother, and reading and writing was not how he passed his spare time, but Daniel is so laid back and easy going, nothing ever fusses him, and he is always making us laugh. He sees the funny side of life, and if things get to stressful he just 'chills out' and puts his feet up!! I have often collected him from school to find him sitting relaxed with his feet on the desk, and the crazy thing is, he

is the only kid I know who gets away with it. David on the other hand, enjoys being top of his class, and is quite keen to excel on the sports field too. Irish weather suits David as it's seldom hot and he can get on with his sports. Daniel was still stretching his calf muscles, as he observed all the professionals do, but hadn't even noticed the whistle had gone and all his mates were half-way down the pitch!!

I worried about my boys, I cried so many times for them. But these days I just trust God for their future because I believe God has given them all the qualities they need to cope. I guess you could say, I am just a proud Mummy and I will be there for them good days and bad, but I really believe they can be whatever they wish to be and Ectodermal Dysplasia has only served to make them stronger people.

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

This article was first published in our newsletter (Volume 1 Issue 5 - December 1998).