

A DAD'S STORY by Howard Davies

"I made an effort to avoid contact with support groups. They were for people that needed support and I certainly didn't. I was facing up to things and planning for the future. I was being sensible and logical... and miserable. I didn't feel sorry for myself and nor did I once think "why me?" so therefore I was coping. I flew a banner that stated that 'Ben's attitude to his disease would be a reflection of mine' so I made sure that my attitude was positive. On the inside I was contorted with grief.

Ben grew. He didn't grow quickly but he grew. He carried on walking. He didn't walk very quickly but he walked. He played football, swam, canoed and rode his bike. He talked, and my word he talked. I never expected so many questions. His wit and intelligence amazed me. His reaction to his now obvious set of disabilities made me burn with pride. I had never figured that Ben would appear to be facing his 'problem' so positively. I was also acutely aware that my grief was based on how I imagined Ben would feel about this disease, and in reality there was no way that I could foresee how he would feel. With Ben feeling positive we could all feel positive.

I plucked up the courage and decided to attend a conference. Yes we had heard of the conference and even seen the photographs but have never wanted to go. I really didn't want Ben to see how things might turn out. I didn't want to see how things might turn out. I did however, want to see how research into the control of the disease might be progressing.

We met other people with Morquio's disease; we met people with all manner of MPS diseases. We met parents and carers. We met specialists. In speaking to people we found support. I found support and only then realised we had always needed it. Not in any cathartic way, just to know we weren't alone. And we weren't. We found hope. We found inspiration.

Ben has Morquio's disease. That's the way it is. He has a disease. A disease that at the moment is incurable. We are a family. We are not your usual family. One of our three boys has Morquio's disease. There is nothing that we can do about it so we mustn't let it eat us up. We can however, learn to live with it. It is not always negative.

We have all come to know Morquio's disease, but none more closely than Ben. He amazes me and I love him deeply. I will always look up to him."