



How do you raise half a million pounds for charity? First of all, something extraordinary must happen to you. Something which forces you to re-assess your life and ask yourself questions that you never wanted to ask.

That moment came to me in Great Ormond Street Hospital sixteen years ago. My son Fraser had gone to the hospital to undergo some tests. We knew something was wrong with Fraser's balance, but in all other aspects he was a beautiful, healthy little boy.

He was ten years old and I worshipped him. OK he couldn't kick a ball, but I was sure that we would fix it whatever was wrong, and I dreamed of all the amazing things we would do together.

I was at my business in York when I received a call from my wife.

"Graham, I would like you to come down to London now."
"Why?" I asked, "It's really inconvenient. What's wrong?"
"Graham, just come down."

She wouldn't tell me why, she simply said it was about Fraser.

I arrived at the hospital and was led into a room with my wife and a doctor.
"I am sorry to inform you Mr Kennedy, but I believe your son has Friedreich's ataxia."

My wife held my hand.

"What's Friedreich's ataxia?" I asked.

"It's a genetic disorder and I'm afraid currently there is no cure or any treatment". She explained the symptoms and told me that my son would be in a wheelchair in his early teens.

There was worse to come. The next day another doctor told us that our precious seven year old daughter, who we thought was fit and healthy, had Friedreich's ataxia too.

It was too much. Too much to cope with.

We left the hospital with the children in the back of the car. Both of us were in shock. We couldn't speak and I was thinking that life wasn't worth living.

From the back of the car came a little voice, "I'm hungry. Can we have a MacDonald's please?" I laughed, looked at my wife, saw her beautiful face and knew we would carry on.

My wife got involved with Ataxia UK and encouraged me to raise funds towards research into Friedreich's ataxia. I came up with the idea of a 50 mile bike ride. I hadn't been on a bike since I was a teenager, but I had a great bunch of friends and a super PA to help me organise it. We adopted the pyramid approach; ten friends who in turn asked their friends, who asked their friends.

That was in 1991. I took 111 superheroes on a 50 mile route from York to Filey. We had no costs as I managed to persuade lots of people to volunteer to help. We raised over £20,000. Everybody had a great time and I was amazed by people's generosity.

That year, all our efforts seemed worthwhile as there was a breakthrough that led to the discovery and identification of the FA gene. Pre-natal genetic testing was now possible.

In 1992 a miracle happened. My wife gave birth to a little girl and we knew she would not have Friedreich's ataxia.

The miracle was repeated in 1995. We had another daughter, and we knew she was free from Friedreich's ataxia too.

Over the next fourteen years I continued to organise bike rides. The events got bigger and the funds we raised kept increasing. I encouraged the team approach and in 1994 and 95 we had over 400 riders. We made it fun by giving cyclists stupid names and called all the helpers Bumstoppers. I managed to get everything we needed either sponsored or donated, so that every penny raised went to the charity.

I didn't want superfit people, so I targeted leaders of businesses and individuals to whom the ride presented a real physical challenge. I wanted to make people believe in themselves and encouraged them to make high sponsorship targets. I applied the business formula by providing everything they needed to raise money down to the letters they should send to prospective sponsors. Everybody got a T shirt and a certificate at the end of each ride. The main thing was to make it fun and worthwhile. Life long friendships were formed and we continued to increase the fundraising.

In September 2006 I organised my tenth ride and I took 110 Combat Troopers to Belgium to do a 110Km ride. We raised over £80,000, breaking the £500,000 barrier in funds raised directly from the bike rides.

I still don't know why God chooses innocents to cope with ataxia, but I do know that you can never give up. I believe that one day there will be a cure and I will do my best to help make that happen.

I hope this gives strength to those parents who face similar nightmares. My advice to you is that life is too short. The future is there to be changed. Get on your bike and get some sponsors!

Graham Kennedy

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