

The Robert's Family Story

By John Roberts

It wasn't until his son developed a rare form of liver cancer that John discovered he had FAP

Like most things in my life, finding out that I had FAP was not straightforward. There were several hints, via my mother and brother, but it was not until my son became ill with a statistically linked illness and I had a second bowel check that it was confirmed. One of the interesting things about FAP is that the children of FAP parents can have Hepatoblastoma (children's liver cancer) more frequently than it happens to the general population, it is very rare. But, that was the round about way I found I had FAP.

My family history is as follows. My mother died of bowel cancer at the age of 58 in 1970. I developed a phobia of cancer and read a lot about it and found that it was mainly lifestyle and environmental, so I altered my diet, plenty of bran and got on with life.

I got married in 1979 and in the summer of 1985 my wife Fran was expecting George. Also in the summer of 1985 my brother Edwin then aged 40 was found to have polyps in his large bowel. It was thought that it was FAP so I was checked the day after his operation and given the all clear with the suggestion that if I was clear so would our child be. So again we got on with our life.

Later, two of Edwin's three children were diagnosed as having FAP and have been monitored since. Edwin was also diagnosed as having secondary cancer. He finished work and was given 6 months to live.

Near the Christmas of 1989 Edwin was admitted to hospital with a bowel blockage. The staff wanted to know what was wrong with him and why he didn't work. Unfortunately his notes had been lost so he told them about the secondary tumour and they replied they could not find any evidence of a tumour. Just after Christmas he was put on the scanner and there was no trace of a tumour! But his health was not good.

In the Spring of 1992 we realised that George was poorly the symptoms were similar to a virus, at the third visit by the GP he was admitted to Derby Children's Hospital (DCH). It was diagnosed as a tumour of some type within two hours. He went on to have chemotherapy over three months at Nottingham Queen's Medical Centre and the DCH. This treatment shrunk the tumour but they were unable to do the required operation to remove the tumour from the liver because the tumour had grown around the portal vein and had created lots of small veins to supply the liver with blood - George would have haemorrhaged to death.

The next port of call was Birmingham Children's Hospital (BCH) where he had a liver transplant in October 1993. This was considered a success and George had several good full years but in September 1997 he became tired and suffered from back pain. This was put down to carrying his school bag; in reality it was referred pain.

In January 1998 it was realised he had secondary tumours in his chest. So we were sent to BCH again, George said, " why? You go there for cancer I have only got back pain" He was his usual positive self and said "and if it is cancer I will beat it"

After a failed attempt in chemotherapy, when he was at death's door with liver failure he rallied but it was too late for the next session of chemotherapy and the same thing could have happened again. He now worked towards coming home and eventually he became able to exist without the overnight feed

We brought him home at the beginning of May. The weather was nice and we were able to take George out for visits and especially shopping. I called this stage 'retail therapy' it gave him a lift.

We had a week's holiday at Burnham-on-Sea courtesy of The James McDonald Cancer Trust. George was still keeping us busy collecting Dr. Who books and we visited Legoland.

At the beginning of July we had a week at Aberystwyth with The Christian Lewis Trust. By now he was slowing down but enjoyed reading four new Star Wars books. He died on Friday 24th July 1998 the last day of school term.

When George was at Birmingham Children's Hospital for assessment, the doctors, being aware of my family history, said I should be investigated, as I should have FAP too. My age at this time was 51. They took blood tests and looked at the pigment at the back of my eye, then suggested a flexible sigmoidoscopy, an inspection of my large bowel.

I behaved like an Ostrich with its head in the sand and put this off for as long as possible, but two months after George's liver transplant I had to undergo the bowel inspection.

"Yes" the surgeon said "I had better have a look at you" In February 1993 I had an operation to remove my large bowel and had an ileo-anal pouch installed. It has not been perfect, possibly because the operation was done in one stage. Another reason could have been my age, 51. One problem as I see it, is that you go into hospital a healthy person. No matter how positive you are about it, your body is different and you will never be quite the same again.

Initially with the bowel on strike after the operation, I was well. On the fifth day the bowel did start and an hour later I was hoping it would stop, but it was 48 hours before there was any respite. I was still very positive and after 12 days got back home. I was still going to the loo 25 times a day (it seemed to be mostly at night!). After three months I reached a plateau of ten times a day, where I seem to have stuck.

There are moments when this can get you down. The stress of all that happened about George could have contributed to this higher rate of loo visits. As I was a three-shift worker, I was taken off the night shift, but working two afternoon shifts and one morning shift every three weeks has not contributed to giving one's life a regular rhythm. I get very tired. I still cannot work out cause and effect where food is concerned. And, just to make things more interesting I had a mental aberration at work and broke my left femur in October 1997.

More stress! Just as I was thinking about going back to work, we found George had got his second cancer. My occupational therapy was completed pushing his wheelchair up the long corridors of Derby City Hospital. It was like a wheeled Zimmer frame and George held my walking stick.

Since the above was written, I have retired and also discovered psyllium husks fibre powder which has improved my life considerably as long as I remember to take it but it is generally not too long before the penny drops! It has increased the time between loo visits and reduced soreness (from the enzymes trying to dissolve your skin) so I don't need creams anymore.

I have also found that through helping at my sailing club on disabled days (RYA Sailability) that my problems are not as bad as I thought. One can only be encouraged by their enthusiasm.

Edwin's children have both had total colectomies and ileo rectal anastomosis. They have both recover well, I guess it helps having youth on your side.