

THE LUCKY ESCAPE. Paul's Story

It was early January 2003, when I received the news that I had been diagnosed with FAP and that I would need surgery. After consultations with a surgeon and a genetic consultant, we agreed that a Total Colectomy with Ileorectal Anastomosis (IRA) would be the preferred procedure for me. On 18th March 2003, my life changed for ever. The operation went well, and three weeks later I was allowed to go home to continue the recovery period. Before the operation it was explained that I would require medication to help control my bowel movements and this was indeed the case for eighteen months.

Six months into the recovery I was asked to attend an appointment at a local Cancer Clinic when the full details of the colon biopsy were explained and the FAP condition had been confirmed. The strange thing is I am an inquisitive person, yet the questions just never came out during that appointment. I was left hollow and I suppose in a stage of shock, How can this happen to a relatively healthy forty year old man and require major surgery for such a devastating condition from simply having a “slight” pain in my side, it can't happen can it ?

Well here is the proof. This was only the start, as the doctor explained that I could undergo Blood DNA tests as this condition could be hereditary, and if diagnosed my son, brother and sisters would require screening. As if it was not hard enough to get through to myself but the thought of passing this problem on to my fourteen year old son really took the legs from under me.

A blood sample was sent to Liverpool University for screening, which turned out to be negative. After which a further sample was sent for screening to a clinic in Birmingham. Several months passed and the sample came back as negative, off the hook I thought!! I was then told that the testing was not always conclusive as techniques were still being developed. I was asked if a third sample could be tested for MYH, another gene configuration which is linked to bowel cancer. But after several months that again turned out to be negative.

With only a photo copy of a booklet called “A guide for Families” to read I began to look for answers on the Internet. Most of the information seemed to come from Canada, which proved to be difficult to get hold of. I found Mick Mason's site by chance late one evening. At last I could “talk” to some one who understood, and may have some answers to some of my questions. Mick explained that he was helping to arrange a “family day” when people with FAP could speak to each other along with cancer support staff. So in March 06 I attended the first meeting, it was both very interesting and sad at the same time. You hear of the different stages of this condition and how it had effected family's from all walks of life. How the impact had affected adults, children and teenagers irrespective of their upbringing. Mick introduced me to a lady from St. Mark's hospital in Harrow, who had been working in this area for a number of years. She explained that a Family Day had been scheduled at St. Mark's on the 6th May 2006. This would be a chance to speak to more families and more medical staff.

May the 6th arrived and my brother and I arrived in Harrow at 09:20, ready for the meeting. About sixty or so people turned up which was a bit daunting at first. The medical team held small work shops which consisted of a Bowel Surgeon, Nursing Staff, and Clinic Technicians. The information day lasted until 16:30, and the amount of information gained in one day supersedes any of the books or articles I have read to date.

The staff gave very reassuring presentations, if a question was asked then the facts came to light, they explained that the DNA testing was only 85% effective in locating the faulty gene. This answered one of my questions as to how I could have FAP but the faulty gene would not show up in a test. Again it was interesting to see the different cultural mixtures and age groups touched by FAP.

Both Family days have broken down walls for me and helped let me know that we are not alone and that research is ongoing into this life threatening problem. To date my family have all had at least one negative colonoscopy, and are now under going yearly check ups.

You would think that after three years I should have got use to the changes in my life, because of the bowel operation but can't help missing the football match on a Saturday, or the horse racing at Aintree. I don't go to public events as in my experience football grounds, cinemas' concerts they don't really cater for people with bowel problems. And if it's not bad enough to needing to use the facilities during a night out I find explaining my needs to others who can't understand very draining. I recall in the early days trying to book a seat near the toilet on a plane, and my wife having to explain five times why she was making this request.

The one thing I can't forget is when I was in the recovery room after eleven hours of surgery was the consultant saying " what a lucky escape I had because the polyps had been found". I can assure you on some days when my friends are going out to the races or a football match or when the toilet visits go into double digits I don't feel so lucky. But then again I recall my mother who died of suspected Bowel Cancer six years ago. To watch some one so important so loved waste away in front of you puts things in to prospective.