Further Travels December 2004 by Mick Mason

It is over a year since I wrote the first part of my Genetic Journey and I have started this conclusion several times but never managed more than a few lines. Must be old age as my interest in reading books also vanished and is still only there for the most interesting ones. My concentration varies considerably as does my energy so it's making use of the good days and having an afternoon nap on the others. Luckily they don't appear on a Saturday when Leicester City are at home. Could be I'm not willing to waste my season ticket money. Time seems to have flown by and it is hard at times to get the dates right as so much has happened, some good and some not so good.

In July 2003 my close relative had a successful operation to prevent colon cancer, which was a certainty within a couple of years. Again the feelings of guilt were around but at this time with the help of Ann my wife and our children I was better prepared.

Also by this time I was involved with designing two websites, well three actually counting one for the Leicestershire Primary Schools Chess Association. The other two were for The Rutland and Melton Cancer Support Group and Coping with Cancer (www.c-w-c.org.uk) in Leicester. Besides running the sites I benefited from the support both gave to Ann and me. Not one for fundraising I was able to indirectly help both as the work was done as a volunteer.

At the end of 2003 I had about 10 appointments to go on our calendar for the next year even before it started. Mind you I had some hope as it might mean the last visits to my surgeon and oncologist. I knew by now the genetic checks would continue in some form for the rest of my life but saw these two as the main hurdles for the year.

In October 2003 a short clip of an article from CancerBAcup appeared in one of Ann's magazines about cancer genetics. I was surprised that it mentioned the good news, which was that these genes in breast, bowel, ovarian and prostate cancer didn't mean you would get cancer. Not quite true for FAP, so I telephoned CancerBAcup and found with the room available for the article it had been impossible to contain everything about the genes concerned. I was also asked if I would be interested in reading a draft copy of their new Genetic Cancer Booklet with about 50 others.

At the time I never dreamt of what this might lead too. I found the booklet very enlightening and wished something similar had been available a few years earlier. Then I was asked if I would be interested in my name being put forward to being part of a group of patients involved with some new genetic cancer projects, which the DoH and Macmillan were proposing. With so much going on with appointments and the usual family hiccups I wasn't sure and was left to think about it.

By November 2003 things had quietened down a bit and Ann knowing of my growing interest in trying to understand the FAP gene and its implications on our lives persuaded me to say yes and see what happened. The outcome was that I was one of about a dozen asked to form The National User Advisor Group for the projects. Quite a grand title but would involve only about four meetings a year and some reading of reports etc.

This has given me an interest and at the same time help to promote the feelings of patients and relatives in regards to the genetic cancer disorders. I felt like many that at times we were talked about but not to, as if our own thoughts were unimportant.

Through the group I have made new friends and enjoyed the journeys to London, and York even if rather tiring. This also led to my own website www.fapgene.co.uk to add to the others. It actually was still my third at the time as I had handed over the Rutland one. That wasn't for long though as The Lakeland's Day Care Hospice in Corby heard about me and asked for advice. Again I looked on it as fundraising so added www.lakelandsdaycarehospice.org.uk to my list. Lucky I am retired! I now spend a day a week at the hospice tweaking old computers and getting something back in return, new friends who help to lift the gloomy days and brighten up even the brighter ones as well.

Throughout the year I have been asked to help with publicity about bowel cancer as mentioned with CancerBacup and Macmillan. Word must get around as Beating Bowel Cancer contacted the Leicester Mercury for an article and the Melton Times have had their three pennyworths.

Perhaps the most intriguing was to help with the launch of The Prime Health Magazine for men. The editor from Dr. Foster (a website well worth a visit www.doctorfoster.co.uk) contacted me and asked if I would attend a film session to be used at its launch in Birmingham. My friends mentioned about being made up and my youngest son even thought the address in Marylebone sounded a bit dodgy. So imagine my state of mind when on arriving I was directed to the make-up room. I nearly died but was made to feel at home and ready for an interview before the camera. I think they told all of us involved how good we had been and I asked if I could take the ‘new me’ home instead of the older version. Mind you there was a funny look from one chap on the underground.

Although I was under the stoma department at Leicester Glenfield Hospital I was asked by the Leicester Royal Infirmary Stoma Department to do a bit of visiting for them. Again this led to other things and coffee mornings for Loud Tie Day were spent giving a helping hand. It was here I found out about the bowel cancer support group ‘Moving On’ which meets once a month at the L.R.I. During the year and until recently it gave both of us valuable support and knowledge about how to cope with cancer and the days out in Bridgnorth and Stratford on Avon not to mention post Christmas meals will always be remembered. It has a rather apt name for during 2004 I decided it was time to move on. I had been given an OK by both my surgeon and oncologist and the interests of the genetic side of my cancer provided a different kind of support.

The most nerve-wracking days were early in 2004 when I was waiting for the results of a CT scan after a niggling pain in the groin. I had been used to ultrasounds but this was to me serious stuff. Both of us were shaking as our oncologist came into the room with a smile and a look as if to say what are you worried about. The relief that nothing was wrong was almost as bad as waiting. I did notice though that he had no notes with him and assumed for the future that this would be a good sign if it happened again.

It was only a few months later that we were shaking for a different reason when he told us that the next time he saw me he hoped would be in a supermarket. The emotions were so mixed and it literally took days for the news to sink in and the fact that they were happy not to see me. In late 2004 I had my last appointment with my surgeon. There was going to be another one in 2005 but as I had a thank you card, which I said would be a pity to waste; he agreed to take me off his books.

Another side to my story is volunteering as a patient for the student doctor examinations at Glenfield Hospital. There was an ulterior motive as it gave me the chance to mention the genetic side to these would be doctors and a hope for the future that a more general knowledge would be known about the subject. Also I have enjoyed giving a brief tale of my journey several times to health professionals taking the cancer care module course through the L.R.I.

My website www.fapgene.co.uk nearly never happened and I must thank the genetic centre at the L.R.I. for their interest which eventually got me going. It is in its early days and was designed to put links in one place about FAP. I worked closely with John Smail of The Ileostomy and Internal Pouch Support Group (www.the-ia.org.uk) when it was realised that surgery to prevent cancer because of FAP would most likely mean either an internal pouch or ileostomy. The ia already had a discussion forum and while we were thinking about adding an FAP section the matter was raised by one of the ia’s members. Saved me a lot of work and also helps promote the interests of both parties. Thanks to Diane.

So what does the future now hold. An endoscopy in April 2004 revealed polyps in my duodenum, which will need annual checks on. These are not so aggressive as those in the colon and the gastroenterologist put them into perspective by saying I was more at risk of complications with my diabetes and blood pressure than the polyps turning cancerous.

I will also see my dermatologist who is interested in my cysts, which after around 160 still manage to appear in various parts. With a little persuasion I managed to make my visit an annual affair instead of six monthly.

I have forgotten to mention Gardner’s Syndrome which I was diagnosed with which is now seen as part of FAP and not a separate genetic fault (or so I read somewhere).

There are several things that might happen through FAP/Gardner’s Syndrome but the chances vary and the view seems to be not to worry about everything as it might not happen. I can accept that but like a posting on the Discussion Forum mentioned. You have an operation to remove the certainty of colon cancer and are then left to realise that this pest of a gene has several tricks up its sleeve, which might affect you over many years to come.

So with Christmas approaching and my 62nd birthday on Boxing Day we seem to be coping with FAP most of the while however there will always be times when it raises its head as check-ups approach or an ache starts somewhere and you begin to wonder. However because of the gene my cancer was caught early enough to be treated successfully.

I also wonder how many people in the UK have FAP as the only statistics point to the percentage of bowel cancer caused by the gene. How many have the gene and had preventative surgery and are not included in those statistics.

It is hoped to arrange a meeting for Fap'ists in late 2005. The Polyposis Registry at St Mark's Hospital in London are looking at arranging this and more details should be available by the middle of 2005.

Over the five years I could not thank all those concerned with my treatments enough and to those that have given support to Ann and myself in various ways another large thank you.