

## Genetic Journey January to June 2005 by Mick Mason

I just wonder how many have found that this year seems to be flying by and wondering where the time has gone. In my own case I suppose now that appointments are very few and a long way apart has made a difference. No more looking at the calendar to check if that particular week is free. No more waiting for the next trip to Leicester other than shopping or to see the City play – even if not back in the Premiership, yet. Already it has seen some special days for Ann and me and hopefully a few more by the end of the year.

So with the help of the calendar – I find my memory gets a bit confused at times – I felt it was time for a bit more about my life without the constant reminder of hospitals.

In October 2004 we decided to have our kitchen and dining room knocked into one large kitchen/diner. Our builder who is a very pleasant chap kept putting the date back and suddenly we realised the kitchen would be installed before the wall was removed.

I always felt it was well within my capabilities as a Wimpey plasterboard wall isn't the sturdiest of constructions and eventually Ann agreed. We have a local tip in Melton Mowbray and over 3 days of about 3 hours each the wall came down and all went to the tip. What a difference it made as the dining room was only used once a year at Christmas and we ended up with a room 5 metres by 4 metres. It wasn't until the middle of March though that we eventually finished due to deciding on a floor covering. Ceramic tiles eventually won and apart from a bit of tarting up we have a room that is far more useful and pleasant to be in.

Last year I had helped The Beating Bowel Cancer Charity with an awareness campaign and also kept in contact with the ladies from CancerBacup. However what a surprise and a pick me up when two invitations arrived within a few days of each other. CancerBacup were having an evening reception for their 25<sup>th</sup> Birthday at St. James's Palace with Princess Alexandra and Beating Bowel Cancer was launching its Patient Voices Forum with a day at The Café Royal. Even better was that Ann was invited as well to the Café Royal which initially put the fear of god in her. How did she think I felt about St. James's Palace?

Both days were something neither of us will forget and it was nice that things I had done to try and help others had been appreciated (with many others) in this way. Another good point was I ended up with a suit that fitted me and was quite surprised how comfortable it felt. To be honest my last suit had been years before for a rather formal dinner with my sister.

The Palace evening was from 6pm to 8pm and quite a chunk of that time I spent with Sandy Geddes ( Patient Information Manager at the Leicester Royal Infirmary Cancer Centre) chatting to Wayne Sleep. He was a fascinating person to listen to and also was very interested in both of us as people. We also met several old friends and made a few new ones before it was time to leave. Later on we had a fish and chip supper in Kensington and the look from the chippy was quite hilarious as we sat with our 'posh clothes' on squirting tomato ketchup on the chips!

We had not had much of a break for a while and decided to have a couple of nights in the centre of London's West End for our visit to the Café Royal. Quite amazing what the Internet can find at reasonable prices. Not a thing we would do very often but being able to step out the hotel virtually straight into Leicester Square was a real bonus.

Our day with Beating Bowel Cancer gave Ann an idea of my other trips to similar events and after a nervous start soon found it interesting and rewarding especially as two of the speakers gave talks on Genetic Cancers and Endoscopies. It wasn't all serious talk as we found whilst listening to a couple of fundraisers with tales of the London Marathon in a diving suit and treks in Peru off the beaten track. Also the lunch was something else to remember.

So our thanks to both of the charities for the invites and making us feel appreciated.

I grumble a lot about Central Trains and the service they provide or rather at times don't provide in our area. However I travelled up to Oldham PCT for the launch of their DoH/Macmillan Genetic Cancer Project. Never again will I grumble for travelling between Manchester and Oldham was like going back in time. Seemed I was on a glorified tram and thanked the stars it was a short journey. Little was I to know that on the return leg I went from Oldham to Liverpool in the same tin shed! What a relief though to then try out one of Virgins latest Pendolino trains down to Nuneaton. A day of contrasts which wasn't spoilt by my old friends Central trains being nearly an hour late on the last leg.

Early in 2005 my website started to show some startling figures in the statistics leaping from 70 to over 150 new visitors a month. Also many e mails from both sides of the fence so to say appreciating what I was trying to do. Now in June that figure is over 300 and I feel quite chuffed about it all considering I nearly abandoned it before it started.

I was invited by Kay Neale the registrar at The Polyposis Registry based at St Mark's Hospital to meet her staff and discuss how our two sites might work together and other ideas. I hadn't realised it all started over 80 years ago and was stunned by the knowledge they had. I do wonder why though that there aren't some standard procedures set for FAP after initial diagnosis. Also the strawberries from the hospital mini market were a real treat for Ann when I got back home. Since that visit a day for FAP families to get together has been set for November 12<sup>th</sup> at St Mark's and also eventually this site will be hosted through the hospital as well.

In April my only check of the year was due with all the usual apprehension. Last year some polyps were found in my small bowel and annual checks were suggested. This seems to be one of those grey areas as there seem different rules or guidelines in different areas of the country and also different ways of checking for them. As this is a non-medical site I will leave that for the FAQ page.

As expected they were still there and will need checking in a year's time. The biopsies were fine and hopefully we can cope with that for now.

I started to enjoy travelling on trains whilst in the RAF and still do. With most of the meetings and events I go to held in London or York this is an added bonus. Ann knows I would always like a trip around Scotland but has booked the next best thing, a trip on a steam train from Melton Mowbray over The Harringworth Viaduct complete with a 3 course dinner later this month.

Now at the beginning of June 2005 we feel for the first time in over 7 years free of urgent or potentially serious appointments. This has however left a huge hole in our calendar and for a while is very strange to get used to.

A lighter side emerged early in the year with my friend Jimby. He had been around the fringes of our lives since coming back from Florida with us. He has had quite a bit of influence as I now have about 20 monkeys of all kinds and colours. So a place on the website was his idea and within minutes had received e mails and photos from a relative. My grandfather once said "Laugh at life and life will laugh at you". How right he was.