

Beating Bowel Cancer
My Genetic Journey
More Thoughts – April/December 2009

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The Booklet

The reason for the booklet in 2006 was initially to raise funds for FAPGene and The Beating Bowel Cancer Charity. This changed with 500 copies being printed thanks to SLA Pharma Ltd who are involved in trials with Omega 3 Alfa Tablets at St George's and St. Mark's Hospitals in London and Harrow.

Some booklets were sold and a few donations received from around 100 complimentary copies were sent out. We were then left with 400 copies sitting in a cupboard. Even after more were given out at various events we went to it still seemed a waste. So with John Roberts it was decided to use them for awareness and any donations would be treated as a bonus. 100 copies were given to Beating Bowel Cancer for their own use and eventually we are now left with around 40. These we will continue to make available at events around the country.

Three years ago when I first started writing the booklet I found that FAP was rarely known even in some medical circles. This was one of the main reasons for our awareness campaign. My involvement with The Macmillan/Dept of Health Genetic Cancer Pilot Schemes not only increased my own awareness of Genetics in Cancers but also gave me an opportunity to mention FAP whenever appropriate. Perhaps at times I over did this but gradually I realised there is so much common ground for those affected by any of the cancer genes.

It would be rash to say I became an expert on FAP which I was once called even by one of my own consultants. A better view is that I became very aware of many of the aspects of the gene in non-medical terms and had the chance to make this knowledge available through our website, talks and events.

Respectability

We have always tried to avoid conflict with Health Professionals over the work of FAPGene. A better way we found was to work with them and this has worked far beyond our wildest dreams.

We knew from the website statistics that many medical institutions and individuals around the world were making use of the information we were making available. In the early days there were many e mails congratulating us and seeking more information and advice. The e mails have tailed off but still around 1000 visitors a year look at more than 3 pages. One person searched for 'Man on Lawnmower' which took them to our Annual Family/Information Day at Swarkestone Sailing Club near Derby and a picture of John on the lawnmower.

The end result is that I have been invited to events run by Guy's Hospital and The National Genetics Education Centre in Birmingham for Health Professionals Only. I felt quite honoured by this.

November 2006 involved giving a talk at three workshops at The National Cancer Network Development Programme Conference near Heathrow.

Another was a visit to Liverpool where a talk was given to the Merseyside and Cheshire Cancer Network. For both of these I concentrated on things apart from the threat of colon cancer that the gene can cause. Also how rare some of these are and that even within the same family the genes effects can be so different.

In May 2007 I was asked with another member of the Macmillan Projects to help with an hour's discussion on Genetic Cancer's to students on a MSc course for Genetic Councilors at The Royal Marsden Hospital in London. Both of us went down extremely well and next year we have an hour each to enable more questions.

Perhaps the highlight of my new career was being called 'A Key Speaker' at the launch of The National Genetics Education Centre website 'Telling Stories' at The Millennium Stadium in Cardiff. This also opened a new door with a talk to 3rd Year Dietician Students at Coventry University in November 2007.

John has also been busy with talks at The Derby Hospitals Cancer Group and our own FAP Family/Information Days at Swarkestone.

Cancerbackup who updated their Understanding Genetic Cancers' booklet in 2007 now include our website as a useful source of information. Also they are producing a fact sheet on FAP which is due out in early 2008.

The National Genetics Education Centre also includes a link to us on their new training website 'Telling Stories'.

In May 2008 The Huntsman Cancer Institute Familial Colon Cancer Registry in Utah accepted us to provide a link to their newsletters.

Our Annual Family/Information Days have included talks by Kay Neale and Sue Clarke from The Polyposis Registry St. Mark's Hospital in Harrow - Wendy Chorley, Derby Hospitals - Sharon Lomas, Macmillan Cancer Support - Chris Jordan, SLA Pharma Ltd - Melanie Ripley and Carol Fahey, Oldham PCT - Alison Metcalf, The Family Talk Project at Birmingham University - Emma Tonkin, Glamorgan University and The Telling Stories website - Wolfram Nolte, FAP Support Group Germany. All of whom not only helped to make them successful days but hopefully took away a wealth of knowledge as well.

My Own Thoughts

Most of the events I have been to are about genetic cancers in general and not specific to FAP. The differences for a patient are perhaps thought to be much the same initially whichever gene is involved. This was my view but now feel it is not quite true.

With FAP it is virtually certain that without surgery you will get Colon Cancer. Perhaps this helps in deciding surgery is the best and perhaps only option for the patient to take.

However with Breast Cancer the risk is around 85% of having the cancer. So, an extra problem, do I take that 15% risk of being OK or opt for surgery that might not be needed.

Then back to FAP for surgery. There are three operations available in most cases yet it is impossible for the consultant or stoma nurses to tell you which will be the best option for having reasonable bowel functions afterwards. Sometimes these options are reduced due to medical conditions but it is something else you have to make a decision about.

There is so much to think about and take in, as in my case I was recovering from major surgery, had been told I had cancer, needed chemotherapy and also that our children and other relatives might be affected. Also the worry of how Ann my wife would manage to cope with all of this as well. This is something that is often forgotten as the focus of attention tends to be on the patient.

Designer Babies

This is a term I detest and wonder how someone who uses the term would feel if they were affected by one of the genetic conditions which now allows embryo testing.

It is not about having a child with blond hair and blue eyes with large feet which would make for a great rugby player. It is about having the chance to have children unaffected by devastating conditions. I know there are many different points of view but in the end it is up to the parents to decide. They should then not be put in a position of almost committing a crime to have their family.

Should we be told about the other effects of the gene?

A few years after being diagnosed I did ask why I wasn't told about the possibility of facing other medical conditions because of FAP. At least I got an honest answer and one which 5 years later is still the same in many cases. "We didn't want to scare you".

In some ways this is perhaps a fair comment but how devastating when like me, who thought that the removal of my colon and chemotherapy was the end of the matter. Then only to find out other dangers not only might, but did lurk around the corner. It made me think of the Boy Scouts Motto 'Be Prepared'

I do try not to over worry about what the future might hold for me. In April 2006 just before my annual endoscopy to check on my polyps in the stomach and duodenum I was possibly at my lowest point for years. For some reason I found myself wondering if I would be around to collect my old age pension in December 2007.

The endoscopy gave me another year without any treatment needed and the worry disappeared but still before this years check-up I had become a bit on edge. However I am far more positive thanks to last years chat with my consultant. Now in August 2008 I have been told there are far too many polyps to remove and if they did change I would be facing major surgery. It is a blow but again hopefully there will be no change to report from my continuing annual checks.

Insurance

This I have found to be the hardest subject to try and understand even at a basic level. Should I reveal a genetic test or rather do I have to reveal that I have had such a test?

Despite attending several events where talks were given about this I feel it is almost impossible for the patient to be sure they are getting what they are entitled to, a fair policy at a fair price.

At Swarkestone 2007 there was a lady who was refused Critical Life Insurance due to having a genetic test even though it was negative. Later this decision was reversed.

Sometimes though it is not the genetic condition that prevents or loads a policy but other medical conditions you might have.

Once more we have been contacted about someone who has FAP but never had cancer. They had part of their colon removed and have annual checks top and bottom but has been refused life insurance. Hopefully we will be able to have somewhere definite to refer them to instead of a general insurance website.

Family/Information Days

In 2005 when Kay Neale invited me to meet the staff of The Polyposis Registry at St. Mark's Hospital in Harrow we spoke about Information Days. My own view was that perhaps in 3 or 4 years I might through the website be able to arrange something on a small scale. Kay with previous thoughts of such a day thought the autumn of 2005 would be possibility for the Registry to hold one.

Since that meeting Kay put me in touch with John Roberts (now the other half of FAPGene) another patient with FAP. I wonder if she realised what she had done! Within two years we had both held two information Days though we prefer to call ours Family/Information Days

This was mainly down to John who had helped with the early 'Polyposis Newsletters'. Within a few months he had found a venue at Swarkestone Sailing Club south of Derby. Then proudly announced a rather high profile list of speakers and yet allowing ample time for everyone to have time for informal chats. I called him A STAR which he truly is.

Numbers do not really matter but around 240 in Harrow and around 80 at Swarkestone have benefited from six Information Days in total. Swarkestone 2008 was the highlight of our work so far with 40 attending and plans are afoot for an informal social type event on October 25th 2008. This was suggested by several of those at the last Family Day and already it is proving a popular idea.

So Swarkestone 3.5 as John calls it will have sailing and the chance to chat informally.

Although only nine came on the day they covered three families and gave everyone the time to chat without keeping to a timetable. There will be a repeat next year.

Other FAP Support

The Beating Bowel Cancer Charity like many others has a Patient Forum with help now available for those with a genetic condition. An annual get together of all those involved gives an ideal opportunity to compare notes and just chat to others in a similar position.

John and I are both members of The Ileostomy and Internal Pouch Support Group. John belongs to the Derbyshire/Nottinghamshire branch and Leicestershire is where I belong. The 'IA' has a very well used FAP forum on their website www.the-ia.org.uk and produces National and Regional Journals throughout the year.

In February 2008 we noticed a few visitors to the website from Germany. Not that strange at first as we are now a global website in a way. What was intriguing was they belonged to a National FAP Support Group. Family Assistance Polyposis Coli Ev which was founded in 1990. Their website was quite amazing and included details of an emergency medical passport, something which could be very useful.

The Future

John and I have become great friends and have a similar outlook which is to promote awareness of FAP and the problems it might cause apart from colon cancer. Both of our family's have suffered with some of these effects. We did look at expanding FAPGene and had a long chat with Paul Kerr the Macmillan Cancer Support Co-Coordinator for the area. What an area though from The Borders to Cambridge and across though Merseyside to the Lake District.

The process of obtaining grants seemed rather daunting to two senior citizens and we have decided to stay as we are. This is to promote awareness of FAP through the website, Family/Information Days, talks and articles. This is something we feel comfortable about and looking back on results seem to be doing in a trusted and needed manner.

My own work with Macmillan and The Genetic Cancer Projects has now come to an end and rather disappointing in my own personal view that Oldham PCT was the only one really to carry on with something new that was developed. I like many feel the upheavals in the Health Service came at the wrong time for The Projects and had an adverse effect on most of them. The Genetic Interest Group and The Beating Bowel Cancer Charity however still hold quite an interest for me and this is where my own efforts will continue for a while at least.

Verona Article and Presentation

The summer of 2008 saw John receive an invitation to write an article on Support for FAP Patients. This is to be included in a Springer Publication Polyps and Polyposis for The Rosa Gallo Foundation in Verona, Italy. It took both of us around three months to complete the article of 4,000 words and the help of several of our health professional contacts. Now the hard work seems well worth while as it was accepted and published in January 2009. We were also invited to give a presentation on The Role of Patient Support Groups for FAP in Verona at their Annual Conference. This was a great honour for us and follows another invitation where we gave a talk to Nurses in their 3rd year of a Masters Course at the Nottingham Medical School in June 2008.

Unfortunately John was unable to travel to Verona so with my wife Ann it was decided to make it into a four day break. The hospitality of our hosts was second to none and despite my rather limited range of acceptable food managed to survive and actually enjoy the meals.

My presentation lasted 15 minutes and as I went along it was translated into Italian. This was rather daunting with reading two or three sentences and remembering where I was for the next piece. Still it was very well received and it was with a huge sigh of relief that I sat down.

April 2009

March saw our 4th Annual FAP Gene Family/Information Day. Again three weeks before we are still unsure of how many would be there. It seems us genetic folk are strange in other ways beside the rare condition we have. Perhaps due to our uncertain health it is not always possible to make definite plans. I know that I have a comfort zone and often feel agitated about something which is outside of that zone. Even on our website we see from the statistics many come, look, find what they what and continue on. Then there are the times we have a phone call about how useful the website and its information are and also of course the family days. Both of us get a real lift from those.

Recently with another John who is a regular attendee we travelled to Branston Golf and Country Club near Burton on Trent to see their facilities for future Family Days. It was very impressive and the offer they made would have been taken straight the way by many support groups. However the uncertainty of numbers and reluctance as mentioned previously of not wanting to get into having to raise funds might prove a stumbling block. We are making FAP Gene into a better structured group with membership forms including a year's membership from the Family Day registration fee.

A new project is also being started by Tim Banks at The University of Wales in Newport. The project will make portraits hopefully using micrographic (made using photomicrography, the photographing of cells and DNA through a microscope) images of cells and DNA, with these portraits. This will be mentioned to everyone shortly.

On a health note I have just had more cysts removed this time at Oakham Hospital. This followed seeing a consultant who understood my need not to be constantly reminded of FAP with the cysts. A previous visit to a doctor in Melton Mowbray who was less understanding still riles me. However it is common amongst us with FAP as often different views are given and the need for any regular check-ups vary considerably.

John and I hope eventually a National Data Base of patients with FAP is established. Then we might start to get more understanding of just how many have FAP. At the moment no one knows but the figures must be available but perhaps scattered through surgeries and Genetic Centres. As May approaches we have planned a Informal Chat and Sail Day at Swarkestone for August 1st 2009 and on September 12th 2009 a Chat Day at Branston Golf and Country Club Burton upon Trent Staffordshire.

It is hoped these give everyone a chance to enjoy the company of others in an informal atmosphere and realise that there is a life with FAP. This does vary tremendously from person to person and perhaps another reason to pop along.

In May we are giving a repeat of our talk at Nottingham University to nurses in their 3rd year of a Masters Course. This time John will give an updated version of his overview of FAP talk and I will concentrate on the support side and how FAP can present so many problems but fortunately not to everyone.

Also in May there is my annual check of my duodenum and stomach polyps. These most often present no problems but it is recommended that you have some form of surveillance. Last year I was told there are too many to remove and that a possibility of major surgery might be needed at some time if they change. Even this is unclear and hopefully they never will approach that stage. My consultant is also hopeful on this point but until that annual result nothing is clear like so much in FAP.

Mick Mason

Latest News December 2009

In the summer of 2009 The Swadlincote and District Round Table raised £1,800 for FAP Gene through their Cheap Car Challenge.

The Nottingham talk went very well again and we were invited to two sessions to cover everyone.

An extra talk was to The East Midlands Cancer network genetics Day at Branston in December 2009. With a strict time limit this was the most formal one we had undertaken together. After a lot of practice we managed it and received excellent reports afterwards.

Also this month I was invited to join the Genetic Interest Group at Nottingham School of Nursing. The new leaflets proved there worth as a new colleague asked about talks to Dietetic Students at Nottingham University.

Our two Informal Chat Days went extremely well and are to be a regular item in our calendar. Two new families with three children under 13 who will need their colons removing eventually added a new dimension to our days.

Ann wished we had saved all the old appointment cards and kept a note of who we saw. This came to a head with the need to extract my dodgy wisdom tooth. I was told about seven years ago after a Jaw Bone X Ray that the roots may enter my sinus cavity. This would mean a hospital procedure but it has taken seven months to finally have a second opinion and a new examination after the first consultant dismissed the original findings without having the x rays or report.

So now John and I have quite a full year and whilst our own health is relatively good we can continue. We still have concerns for the future though and keep looking for others to take over the reigns eventually.

Mick Mason
December 2009