

## **COPING WITH FAP: THE ROLE OF PATIENTS' ASSOCIATIONS 2008**

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### **Abstract**

This is our personal story of how two senior citizens found out about Familial Adenomatous Polyposis (FAP) late in life. Circumstances gave us the time to investigate and understand FAP from a layman's point of view and also to help others come to terms with the challenge of FAP.

We recognised the need for uncomplicated information for those affected by FAP and a centralised point for this information without the need to scour The Internet. So FAPGene (<http://www.fapgene.org.uk>) was born. Those searching on the Internet for information about the APC Gene which contains FAP are most likely to have found a mass of technical articles often requiring a subscription. We found that a search for FAP is far more productive to a patients needs Very early on we found that patients/individuals often made initial contact via E: Mail with no further enquiry after the information they needed was passed on. This is reflected in our following article where FAP is described as a lonely disease.

One of the success points shown is our ability to work with Health Professionals and not cross that border into providing medical information. Again many patients [or] individuals were given contact numbers for these medical questions.

The question of whether FAPGene will progress to a true Support Group or Patient Association depends on several things including the age of John and Mick and their own state of health. At the moment they are fortunately able to continue improving the scope of FAPGene but the future is uncertain

## Introduction

We have been asked to write about FAP Patient Associations. Patient Associations or Support Groups, which we will use interchangeably and can take several forms, such as a web site, an internet forum or a physical group where people can meet. As Laura Szabo-Cohen wrote “There is no community in more need of support groups than the FAP population....but neither is there a population more scattered, so we must make our own arrangements.”[1]



Fig 1 Swarkestone Sailing Club Derbyshire United Kingdom

Our own attempt started as a web site and after three years seems to be turning into a patient led support group. This is a result of organising, through the website, an FAP Family and Information day at Swarkestone Sailing Club (Fig 1) in the East Midlands of the UK. We are pleased to report that we have just held the third and each one has attracted an increasing number of attendees.

To demonstrate the need for patient associations we would like to highlight the need that FAP patients have for information and the lengths they usually have to go to, to find it. More especially, how initially they may prefer to be anonymous; the need to meet other people with the same condition develops once they have made contact and come to understand that there are other people with the same worries and problems as themselves.

## **John's story**

John's mother died of bowel cancer in 1970, but it was not until 1985 when his brother developed polyps in his large bowel, had a total colectomy and Ileo Rectal Anastomosis (IRA) that FAP was mentioned. John then had an initial examination with a sigmoidoscope and was declared clear of polyps. In 1992 his son developed hepatoblastoma, (a liver cancer) at age 6 years. As there is a statistical link to FAP, it was suggested that John be checked again and this time Polyposis was found and later confirmed as FAP. Aged 52 years he had a total colectomy and (internal) ileoanal pouch installed. Later two of his brother's three children had total colectomies with IRA.

John first started looking for information in 1993 by using a letter to the Journal of the Ileostomy and Internal Pouch Support Association Group (The IA) [2], a small number of whose members were people with FAP looking for support for pouch or ileostomy problems. This provided two contacts in the UK so they were able to support each other over the telephone for several years. Also, a third lady, in Vancouver, British Columbia, sent a long letter of her experience and copies of the Hereditary Colon Cancer Newsletter. This enabled John to get on the mailing list for a time and alerted him to the wide range of problems from which people with FAP can suffer.

Later in the quest there was contact with Kay Neale at the St. Mark's Hospital FAP Registry at Harrow, London. This led to his involvement in the production of a newsletter "Polypost" for a year or so. A little later at a Red Lion Group meeting (another pouch group), at St. Mark's, Kay told him about Mick who had a web site about FAP and his experiences. Fortunately Mick lived within 40 miles of John and was the first person with FAP that John had met face to face locally. Others were family and the four or five people at the Red Lion Group meeting in London 120 miles away..

## **Mick's story**

In February 2002 at the age of 59 Mick was diagnosed with Familial Adenomatous Polyposis following colon cancer and a genetic test June 1999. With his wife they came away from the Genetic Centre worried and confused. If only they had something to take home and read it would have helped so much.

Early in 2003 the thought of an information website on FAP crossed their minds as very little was available on The Internet. They had still met no one else with FAP but felt sure there must be others in the same position, almost crying out for information.

APC is the name of the actual gene, but searching in Google with this only seemed to find rather technical information. Mick was told he had FAP and it was genetic so FAPGene sounded about right as the name for his new website. Also, he felt patients were more likely to search for FAP rather than APC.

Mick decided only non-medical information would be included and to work with the health professionals rather than against them. Links to other suitable websites, personal stories and latest news on FAP research would also be included.

In late 2004 the website was ready and FAPGene was launched to the world (<http://www.fapgene.org.uk>). Not a lot of pages but Mick had managed to add two personal stories – of his own. These were articles he had written for the IA Journal. ‘The Fashion Show’, his account of his debut as a male model at an event organised by Stoma Care Nurses at The Leicester Royal Infirmary. This was followed by the booklet ‘My Genetic Journey’ (<http://www.fapgene.com/booklet.html>), which speaks for itself.

There were four critical moments which really helped to boost the profile of FAPGene. A small snippet in a magazine by CancerBackup stated that having a genetic cancer gene did not mean you would get cancer. With FAP cancer was almost certain to develop without major preventative surgery. A phone call to CancerBackup was well received and resulted in his name being forwarded for involvement in a joint Department of Health and Macmillan Cancer Support Genetics Partnership Programme. [3]

This was the second critical point which eventually led to a very receptive audience for promoting awareness of FAP and the FAPGene website.

In 2005 the website was having visitors in a steady if not spectacular stream. Details had been forwarded to all and sundry with little in return. This was until the third critical moment came when Mick received a call from Kay Neale at the Polyposis Registry at St Marks Hospital in Harrow.

Kay had seen the website and invited Mick to meet her staff. His idea of eventual Family Information Days was something the Registry had thought about in the past. However a lack of time and resources had been a major stumbling block. Mick left with high hopes that the Polyposis Registry would soon have their first event whilst he felt FAPGene's was still a few years away.

The final critical moment for Mick was when Kay put him in touch with John Roberts who lived in Derby. They had exactly the same views about the need to raise awareness of FAP and organise Family/Information Days.

Sounds so simple but Mick was a little sceptical at first when John mentioned holding the first event the following March of 2006. Not only that, but with quite high profile speakers.

The rest is history as they say and is well documented in other parts of the article and perhaps best left to John. Mick added that a combination of things had helped to make FAPGene successful rather than anything major. To hold their first Family/Information Day in 2006 just months after the first one at St Marks was a great achievement. They felt that they had finally arrived.

### **-Forums**

The following explains why FAPGene does not have its own Internet Forum. Initially security concerns and also if there is a forum in a country with a small FAP population it is best to share one rather than compete.

### **FAPGene and the IA**

With many more people now on The Internet it is not surprising that Discussion Forums are so popular. A Forum at FAPGene seemed an obvious move.

Mick decided to use a ready made product from the website host. Within days literally hundreds of postings appeared with almost every one giving direct links to questionable websites. This was totally unacceptable and the venture had a premature ending. Mick enquired of The IA if a section on their Forum could be made for FAP Patients.

Several members of The IA had FAP but at first the administrator thought FAPGene were better providing their own. He said he would help in any way possible in setting up a more secure Forum. In September 2004, however, a young lady in Scotland also expressed an interest which triggered a change of heart and saw an FAP section provided. Within weeks it blossomed and to avoid any duplication it was decided to provide a direct link from FAPGene. This also helped to promote the FAPGene website itself.

There were many topics raised but a small number of replies in comparison to the number of views. This seems to prove Mick and John's own theory that many patients with FAP are content to find information anonymously and without committing themselves to any form of membership.

There are also other forums available, generally American based but with an international user list. Several of our members have also used Facebook on The Internet. (Table 1)

### **Organisation of FAPGene**

How is <http://www.fapgene.org.uk> organised?

Basically Mick and John find information about FAP which they think other FAP sufferers may find interesting and add it to the website. Sometimes this is a link to a particular website or a reproduced article if permission is obtained.

The knowledge they gained from doing this and their experience on medical support group information days (IA and Red Lion Group) gave them the confidence to form a support group. In this, they were supported by Kay Neale, of the St. Mark's Hospital Polyposis Registry, and other professionals, without whom they perhaps would have not been successful.

Prior to the first 2006 Information Day a small committee with Mick as treasurer/secretary, John as chairman and Mick's wife as a committee member was formed in order to open a bank account; this allowed them greater flexibility.

However after listening to Wolfram Nolte, Vice President of Familienhilfe Polyposis coli e.V. at Swarkestone in 2008, who spoke of their 250 members throughout Germany, they realised that with FAPGene there is no formal review of what they were doing as there are no actual members. (One could say they must be doing something right as people do return to their yearly meetings.)

So they aim to formalise an idea that Mick had in that payment for attendance at the Information Day also includes a year's membership to the Group. An AGM could be held at the start of the Information Day, which would allow the members to increase participation in the running of FAPGene. They also feel that they have to consider what will happen to FAPGene in its present form if they find that they cannot continue to run it themselves. They are both retired and although committed to continue for the foreseeable future, when the inevitable happens, they would both wish that FAPGene carries on and also develops.

FAPGene has been fortunate to receive several donations from people over the past two years. These donations with the registration fees (7.50 Euros/£6.00) from the Swarkestone Family/Information Days have given them an annual budget of around 375 Euros (£300). The funds now provide for a buffet lunch and a donation to Swarkestone Sailing Club in lieu of a hire charge.

Whereas The Family/Information Days are mainly John's domain, Mick provides the website expertise on a voluntary basis and Internet Costs are 35 Euros (£28.00) per annum.

The extra income this year already ensures they have the funds in place to support all their costs for 2008/9

### **Education/Research**

Mick's contacts with CancerBackup and Macmillan led to invitations to speak to groups of professionals and people in training. Recently Mick and John gave a presentation to a group of nurse students on a Masters Course, which was well received. Tony Farine, who organised the occasion at Nottingham Medical School, sent the following comments, "Thank you so much for your time and also the presentation. I think that the talk went very well". FAPGene have also been active in promoting the 'Family Talk' project' at the School of Health Sciences at Birmingham University [3].

'Family Talk' is a research project that hopes to find out more about families' experiences of living and coping with certain types of illness or disability, and how it is discussed amongst family members. Dr Alison Metcalfe, the project lead, gave an overview of its progress at Swarkestone 2008. Also at the same Information Day Dr Emma Tonkin gave a talk on the NHS National Genetics Education and Development Centre's resource, 'Telling Stories: Understanding Real Life Genetics' [4]. This has been developed to illustrate the impact and utility of genetics on real life health care. Later, she e-mailed to say, "My thanks go to Mick and John for allowing me the opportunity to talk. I found the day really interesting and learnt a lot"

FAPGene find it interesting that patient stories can be used in different ways, one, to explain the dynamics of communication within the family and the other to record patient experience and use it in a teaching experience for professionals using a web site.

Research is a subject that most people affected by FAP are interested in. Any hope of providing a family without risk of FAP is in the hands of researchers and the companies they are involved with.

In 2006 SLA Pharma a pharmaceutical company gave a talk at Swarkestone on Alfa Capsules containing Omega 3 The company also then printed 500 copies of Mick's 'Genetic Journey' booklet for FAPGene which has been used to raise awareness of FAP around the UK.

### **Family/Information Days**

These days are arranged around four main speakers. Local speakers in the morning with the first giving a general outline of FAP and its history; this is followed by a speciality speaker.

In the afternoon they have speakers from St. Mark's Hospital, Harrow and London. This is generally Kay Neale, Nurse Specialist in Polyposis and manager of the Polyposis Registry talking about genetics or various complications of FAP. This year Miss Sue Clark, a Consultant Surgeon, spoke about which operation to carry out for FAP patients. She also, answered questions about desmoid tumours as several of those present had this problem. (Fig 2)





Fig. 2 Family Day Swarkestone 2008

The simple design of the building, which accommodates 50 people, allows people to mingle and exchange information and also encourage each other. This is enhanced by a structured programme, which also includes free time for extra discussions.

(Fig. 3) (Fig. 4)



Fig. 3 John Roberts Chairman



Fig. 4 Mick Mason Founder

## Conclusions

There is a need for another channel for FAP information other than the usual medical one. The size of the problem is more than can be comfortably dealt with in the consulting room; one could say it is almost a degree level course in its own right. While the website is a good first move, information days have provided an environment where clinicians and patients join together to gain knowledge, whilst allowing patients the chance for face to face meetings with their peers.

The strengths of FAPGene include the respectability it has gained from many professionals and professional bodies. Also, despite having no formal membership as yet, an increasing number of people are interested in adding their own personal stories.

Another strength of FAPGene is that it is mainly promoted through its website and as such is available to almost everyone worldwide. It is an ideal place to advertise both the FAPGene and St Mark's Hospital annual Information Days for those people who wish to meet face to face. Before John and Mick helped to generate enough confidence that an Information Day would be well attended, there were none; now there are two a year in the UK, one in London and one in the Midlands. Prior to 2005 contacting FAP patients directly in the UK had to be through the medical profession. Now there are two patient groups, who work together to inform, educate and support people with FAP.

### **Personal Note Mick**

I feel that perhaps FAPgene has progressed as far as is possible with John and myself. Our website and Family Information Days are a success and undoubtedly helped many people over the past three years. I have no doubts that this will continue for a number of years but with the uncertainty over other effects of FAP I feel it is wise that we do not try and expand into something which will detract from what we do successfully.

My own future health is governed by any changes in the many duodenum polyps I have. There are too many to remove and any surgery which might be needed would certainly restrict my involvement with FAPgene. I do feel fortunate that I have escaped lightly in the past compared to some. This is one reason I have been able to cope with FAP and start FAPGene. To actually search for information whilst suffering from the same major problems would have been an impossible task for many people myself included.

It is therefore my hope that others will read this article and build on what John and I have started. The number of people that attend a Family/Information Day is not important. What is important is the

number that goes away with new information and a realisation that others are in a similar position and how they manage to cope.

### **A Professionals Comment.**

This wonderfully informative and friendly website started as a result of a real need for information and support specifically for people whose lives have been touched by FAP. The great success of FAPGene speaks for itself; it has brought together an ever-expanding group of people and enabled them to share experiences and information both through the Internet and the Family Days. Members come from all over the UK and beyond to give and receive support and perhaps most importantly, take some comfort from the realisation that they are not alone in coping with all that FAP throws at them. I thoroughly recommend this excellent site and all it has to offer and congratulate Mick and John for developing such a valuable resource  
Dr Andrea Pithers

### **Comment from Jo Aston (Patient)**

Jo visited the Swarkestone Family/Information Day for the second time in March 2008

Once again thank you for a very informative day! I really enjoyed it and know my family did too. I particularly enjoyed chatting to other people and especially people I recognised from last year. I particularly enjoy finding out about other families' circumstances, tips for coping etc

The idea of paying a yearly membership is a good one – it was a thought I had too when listening to the gentleman from Germany. Newsletters would be good too, it would certainly keep us informed of developments throughout the year. Good ideas!

The amount of work you two put into the day is obvious. I hope you got as much out of it as we did. Since Saturday we have contacted Gill Plumridge with regard to the Family Research and hope to help out with that. We have also contacted West Midlands Genetics Service with regard to repeat testing for the members of our family who had received a negative result (this was after advice given on Saturday by Kay Neale). We are also looking at information for the children in our family (in response to the information from yourselves with regard to the booklet).

So in all it was a very productive day for our family!

If there is anything at all we can do to help – please email one of us.

Thanks again – take care!

Jo Aston

### **Further Resources**

**Familienhilfe Polyposis Coli e.V.** Am Rain 3a, 36277, Schenklengsfeld,

Germany. Tel.: +49 (0) 6629 1821, Fax: +49 (0) 6629 915193.

Email: [info@familienhilfe-polyposis.de](mailto:info@familienhilfe-polyposis.de)

Website: <http://www.familienhilfe-polyposis.de>

### **Hereditary Colon Cancer Letter.**

**Ileostomy and Internal Pouch Support Group.** Peverill House, 1-5 Mill Road,

Ballyclare, County Antrim, Northern Ireland, UK. Tel: +44 (0) 28 9334

4043, Fax: +44 (0) 28 9332 4606. Website: <http://www.the-ia.org.uk>

**Macmillan Cancer Support** (cancer support and campaign charity). 89 Albert

Embankment, London, SE1 7UQ, United Kingdom. Tel: +44 (0) 20 7840

7840, Fax: +44 (0) 20 7840 7841.

Website: [http:// www.macmillan.org.uk](http://www.macmillan.org.uk)

**NHS National Genetics Education and Development Centre.** Morris House,

Birmingham Women's Hospital, Edgbaston, Birmingham,

B15 2TG, United Kingdom. Tel: +44 (0) 121 623 6987. Website:

<http://www.geneticseducation.nhs.uk>

**Polyposis Registry,** St Mark's Hospital, Northwick Park, Watford Road, Harrow,

Middx, HA1 3UJ , United Kingdom. Tel: +44 (0) 20 8235 4270,

Fax: +44 (0) 20 8235 4278. Website: <http://www.polyposisregistry.org.uk>

**Red Lion Group** (ileo-anal pouch charity), St Mark's Hospital, Watford Road,

Harrow HA1 3UJ, United Kingdom. Website:

<http://www.redliongroup.org/j/index.php>

### **Acknowledgements**

**Swarkestone Sailing Club** Swarkestone Lake Swarkestone Derbyshire website

<http://www.swarkestonesc.co.uk>

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Leavesden Watford WD25 7SA Tel: +44 (0)1923 681 001

Fax: +44 (0)1923 681 221 website <http://www.slapharma.com>

Table 1 Forum Statistics

Topic Name	Replies	Views
Desmoid Tumours	221	5,577
Duodenum Polyps	80	2,784
General Chat	33	1,204
Information Days/Support	67	1,717
Cancer after Surgery	23	623
26/06/08 Total Topics	103 854	21,000

#### References

1. Szabo-Cohen L. Finding a Support Group for Polyposis. *Familial Colon Cancer Registry* Spring 2001: 6. Huntsman Cancer Institute, University of Utah.

[http://www.huntsmancancer.org/pdf/fccr/FCCR\\_Spring\\_2001.pdf](http://www.huntsmancancer.org/pdf/fccr/FCCR_Spring_2001.pdf) (accessed 18 July 2008).

2. The Ileostomy and Internal Pouch Support Group Peverill House 1 – 5 Mill Road

Ballyclare Co. Antrim BT39 9DR United Kingdom Tel: +44 (0) 28 9334 4043

Fax: +44 (0) 28 9332 4606 website <http://www.the-ia.org.uk>

3.

[http://www.macmillan.org.uk/About\\_Us/Specialist\\_healthcare/Primary\\_care\\_cancer\\_leads/Genetics\\_Partnership\\_Programme.aspx](http://www.macmillan.org.uk/About_Us/Specialist_healthcare/Primary_care_cancer_leads/Genetics_Partnership_Programme.aspx)

4. Gill Plumridge Family Talk Project School of Health Sciences

52 Pritchatts Rd University of Birmingham B15 2TT United Kingdom

Tel: +44 (0) 121 415 8740 website <http://healthscinet.bham.ac.uk/FamilyTalk>

5. Emma Tonkin Telling Stories Understanding Real Life Genetics

Faculty of Health Sport and Science University of Glamorgan Pontypridd

CF37 1DL United Kingdom Tel: +44 (0) 1443 483156 website

<http://www.geneticseducation.nhs.uk/tellingstories/index.asp>