FAP Gene Newsletter March 2009

In 2008 we were pleased to be invited by Nottingham University to give a talk to around 30 nursing students in their 3rd year of studies. This was our first formal joint presentation. Another talk was a repeat of my own to Dietetic Students at Coventry University. Both are to be repeated in 2009.

Our website has always attracted visitors from around the world many from the U.S.A. including Major Cancer Centres. Several E mails thanked us for providing information levelled at families and easily understood. Others just looked and we feel found what they wanted and passed on.

The most momentous E Mail was a request to write an article on The Role of an FAP Support Group for a medical book to be published by Springer in Italy. John couldn't believe his eyes and at first we were convinced it was a scam and looked hard to see how much they suggested we paid. After verifying the source of the request there started about four months of hard work. This resulted in a 4,000 word document and also an invitation to give a presentation in Verona at the Rosa Gallo Foundations Annual Conference in December 2008.

2009 has seen us help promote a similar day to ours at The MD Anderson Cancer Centre in Texas and the newly formed FAP Support Group 'PolyPeople' linked to The Polyposis Registry at St Marks.

We are a member of 'The Genetic Interest Group' which has around 130 genetic groups as members. Through them we have accepted an invitation to be one of 7 groups that are taking part in a project on networking. Today Krystle Konteh was due to talk about the project but a family bereavement has postponed those plans. I will be giving an idea of her project though. She will however be at our Informal Chat Day in September. Not only is she talking to patients/relatives but also involving health professionals. Already she has talked to Kay Neale and Sue Clarke at St Mark's and Wendy Chorley who is here today.

Krystle is interested in hearing from you about the good and the not so good experiences you have had with the genetic and medical teams. Also were there any barriers you found or gaps in the information or treatment. Support is another item for her and any questions about the questionnaire some of you have filled in.

Contact details are Krystal Konteh E Mail Krystle@gig.org.uk Tel 020 77043141 she would love to hear from you.

website www.gig.org.uk

You are welcome to fill in the FAP Gene Membership Form. This is the start of a more formal base for us. During the year we receive many different notes of genetic information which we will be able to share with you. Also if you wish your details can be circulated among other members so you can keep in touch throughout the year.

We propose to hold an Informal Chat Day in September and would like your views on whether you would be interested. The venue will be Branston Golf and Country Club just outside Burton on Trent off the A38 and include a buffet lunch. Cost £5. The day is also part sponsored by our new sponsors who will be revealed later in the day.

As mentioned Krystle will be there and also Dr Alison Metcalfe giving an update on The Family Talk Project.

Menu
Arrival: Tea and Coffee
Lunch: Jacket Potatoes Fillings- Chilli Con Carne, Cheddar Cheese,
Baked Beans, Coleslaw Mixed Leaf Salad Sausage Rolls

Afternoon Tea, Coffee and Home Made Shortbread

We remain in a very good financial position whilst we still use Swarkestone for our Family Days. We expect to hold Swarkestone 5 in March 2010 as usual.

After that date it is possible we will use Branston Golf and Country Club. However this will require some fundraising as costs are higher but we would keep the registration fee at a maximum of £6 and hopefully lower.

Although we are looking at several changes to the way we run FAP Gene both John and I feel it is right to concentrate on what we do well and that is The Family Day and a website based support group. We would however like to involve others in helping us to keep this going.