

FAP Gene Newsletter December 2005

It is time to start thinking about the **Regional FAP Family Day** that has been loosely planned since July. We have waited until after the first St. Mark's Information Day on the 12th of November 2005 to see how that worked. It was so successful and because it was over subscribed Kay Neale has arranged a repeat on May 6th 2006 which will be basically be of the same format. It will also give Mick a chance to go as he missed the first due to his sons wedding in America.

On a regional level the main aim is to see if people with FAP want to meet other people with FAP. Over the past years Mick and I have both been in contact with others by letter and phone and know it has helped us realise our families are not the only ones affected by FAP. We know we cannot compete with St. Mark's which is a national leader, but, we can complement it. We plan to have couple of speakers, even hoping to twist the arm of somebody at St. Mark's. Mick is also contacting the local genetic centres for any help they might be able provide.

St. Mark's format was an introduction to FAP (Familial Adenomatous Polyposis) and how it affects us and our families, also how different families have different experiences. One finds out why some people have one operation and others a different one. For example I have had the total colectomy with internal pouch operation while my brother and two of his children have had total colectomy with ileorectal anastomosis. Another alternative is the total colectomy with ileostomy. It depends on age and preference. The 15 to 25 year olds will be offered ileorectal anastomosis, from 25 years the internal ileoanal pouch with the option of the ileostomy.

It was strange at the St. Mark's day to see 80 people whose lives had been affected by FAP. That must have been a world record! It would be nice to bring people together in a regional meeting.

I offered the SSC as a venue because I have access to it as member. It is easy to get to as long as you have car (sorry to say I have only just realised not everybody has cars) and can find junction 3 on the A50. We will be able to offer a buffet lunch and the total cost per person should be £5. The facilities consist of one large room for 50 or so people. But, we will continue even with a lesser number.

We are both very aware of confidentiality and under no circumstances will any details be revealed to other parties. Also we have used the name FAPGENE purely for convenience to open a bank account. Although the website might imply a company this is not the case as we are two people who with the support of others would like to see if there is a need for days like the one proposed. It is hoped that eventually similar days might be held in other areas of the UK.

John Roberts December 2005

Contacts

Mick Mason 01664-566101 E Mail mickmason@fapgene.com