

Comparing St Mark's Polyposis Registry Information Day and FAP Gene Family Day.

Two Information Days for Patients with FAP and their relatives within a matter of weeks. One in Harrow at St. Mark's Hospital (After the one in November 2005 was over subscribed) organised by The Polyposis Registry which attracted over 60 and the other at Swarkestone Sailing Club in Derbyshire organised by FAP Gene with 21 people enjoying another interesting day.

Both gave those attending a unique experience and a chance to talk, ask questions and meet others in a similar position. Pre teens to senior citizens, girls, boys, ladies and gents, surgeons, genetic counsellors and other members of the medical fraternity all seemed eager to make the days a success.

St. Mark's with a more formal approach and workshops including an intriguing DIY endoscopy simulator. Whatever questions were asked, answers were given, even when at the odd time when there was uncertainty over the answer others were on hand to make sure the question was answered. Amazing how the children were asking questions as well and understanding so well some of the oddities of FAP.

At last I heard from a surgeon the three types of operations and the for's and against each one whether for personal or medical reasons. It made me realise that you cannot always get what you might hope for but at least it should be more of a joint decision based on the facts available.

There were numerous questions about having a second opinion or being referred to another hospital. Sometimes over dissatisfaction with previous treatment but often it would seem about the confidence in their current consultant providing the best possible treatment. This perhaps caused by the inconsistency of information given to them. Not surprising at times as it was explained that even within the same family, with the genetic fault in the same DNA position, symptoms and future problems can vary so greatly.

What is Gardner's Syndrome? Why isn't it called the FAP gene? Why is it the APC gene? Gardner's Syndrome is an old name for FAP. The gene for an eye disease with the initials FAP was found before our FAP gene so it got there first and grabbed the name. Another old name for FAP, Adenomatous Polyposis Coli, APC, was used to name our FAP gene.

Meanwhile at the Sailing Club a leisurely start whilst those baffled by its location (Satellite Navigation Systems send you to a village a few miles away) were awaited a few nervous people got to know each other. What a relief for John and myself who had jumped into the unknown with all four feet wondering if anyone would be interested.

An introduction to Swarkestone and FAP by John was followed by myself pointing out how other branches of the medical community might see a hint of

FAP other than bowel symptoms. Freckles behind the eye (although occurring in the normal population), cysts, dental problems and bony growths.

A hot buffet and then Kay Neale from the Polyposis Registry told us about the history of the Registry and FAP and Chris Jordan from SLA Pharma with almost a basic science lesson on the new Alfa Capsules which have shown promise in trials of affecting polyp growth in the colon. I shall remember now Omega 3 and fatty acids.

So what is the future now the first days are over? It was reassuring to hear that St. Mark's are looking at an annual event around November and FAP Gene with their annual day in March. It will be challenging to find speakers and vary the content and yet perhaps retain some of the old for newer folk.

Since those days several genetic Centres have shown an interest in holding their own Information Days and FAP Gene through needing a bank account are in the process of becoming a self support group. Early days but it promises to be an interesting time.

My final thought is that until last year I had spoken to many with FAP and their relatives but actually only met two other families. Within so short a time this has changed dramatically and at the same time increased my awareness of FAP. Of how others are coping with it, trying to lead normal lives and yet find the time to attend such days and pass on their experiences.

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