



The FAP Gene Support Group
Familial Adenomatous Polyposis
www.fapgene.com



FAP Gene Newsletter September 2013
News after Newsletter published – Chat Days will continue

The fact that it is 10 months since our last newsletter perhaps shows that both John and myself have been preoccupied with things apart from FAP Gene. Also our cancellation of the 2012 Chat Day and 2013 Family Day. It was however rather fortunate cancelling the Family Day for as it turned out the access to The Swarkestone Sailing Club was under a few feet of snow. We must have known in advance.

We then decided to hold a free Chat Day on September 14th 2013 (still time to register) as a way to say thank you to our members for understanding that FAP can sometimes cause problems almost out of the blue. It was always understood the future was uncertain from 2004 when the website first went on-line and in late 2005 became a support group. I feel both of us have been fortunate over those years to be in a position to build, with the help of our members and contacts a Support Group that is respected throughout the world. Sounds rather a grand statement but our 'Verona' experience in writing an article for a medical journal made us realize what we had all achieved.

So the past year. We have been able to help several patients with FAP to better understand the condition and pass them on to contacts better equipped to answer some of their questions. The website statistics showed over 7,000 visitors and recently the main search criteria has been Curcumin and ALFA Capsules. The use of both in initial trials has shown promise in having an effect on polyps in the colon and rectum. For myself I hope they also eventually prove effective on polyps in the duodenum as well.

We also keep a close eye on the forums of The IA (The Ileostomy and Internal Pouch Support Group) and ACOR (Association of Cancer Online Resources). However these are very varied in views and replies to topics. For our Chat Day 300 people have viewed the IA topic on it and not one posted a reply. John posts on the ACOR forum occasionally and has got used to a very limited response. It is the same with e mail contacts as we receive very few but at least we are able to help with those we do receive.

With both of us now in our 70's perhaps old age and FAP are catching up with us and we feel it is time to revert back to an Information Website. We will retain any contacts who wish to be available but will not be holding future events. This will also enable us to find fresh up to date information on a more regular basis without the worries of more formal things to organize. We have thought of passing the whole group over to someone else but feel it better to offer our help and support for any new support group. I am sure otherwise we would be looking over our shoulders at what might or might not be going on and also new people might feel the same.

John and I have already had an invite to talk again to Dietetic Students at The University of Nottingham next March and will continue to be available for other talks if needed. It seems we do not bore too many people as over 1,500 have listened to us over the years.

The first family day we had no funds, no idea of how to contact people, no idea if anyone would come and it was only with John's vision that over the years we held 12 events. I initially thought it would take 5 years to hold the first one and must admit to being very sceptical with John's plans. A reason I tricked him into becoming Chairman in those early days.

We will be sending out a report on The Chat Day and also asking if you want us to retain your e mail details.

Finally we want to thank again all those who have helped in whatever way and hopefully will in the future.

Regards
Mick and John