



Newsletter January 2011

FAP Gene would like to wish everyone a pleasant New Year and that the various ongoing trials with control of Polyps associated with FAP continue to show positive results. At this years Family/Information Day on Saturday March 26th we hope to include information and progress on how some of these trials are progressing with the use of Alfa Capsules, Curcumin, Aspirin and Celecoxib.

As the end of 2010 approached we were told by various people that we have been quite a success. John and I also feel the same but there are things we wish we might have been able to get around to doing. The main one is Regional Family/Information Days and giving those of you unable to get to Swarkestone and Branston the chance to enjoy similar events near to you. Also we now post this Newsletter free to several people without access to The Internet and so if you know of anyone in this position please let us know.

Throughout the year our website has attracted 5,000 visitors from around the world and this month our first from China. We have now passed the 28,000 mark in total and at a cost of around £35 per annum feel it is pretty good value for money. Plus without it there would be no FAP Gene Support Group. We do though receive mail from those not on The Internet but few and far between and this is something we need to improve. Not an easy task when no one knows how many people in the UK have FAP or one of its variations. The Genetic Centres have an idea in their own areas and wouldn't it be nice if someone gathered all this information and produced some realistic figures. How many times have you been asked that same question of "How many have FAP in the UK?"

The Family and Chat Days attracted a total of 80 and again proved there worth. They give for those affected by FAP the chance to listen to and talk to the Academics involved with Research, Education, Surgery, Trials and Genetics. This is also a bonus for the Academic who might not have met let alone chat to someone with FAP and yet was doing such valuable work. We would like to thank all of our speakers who gave their time free of charge in helping to ensure we provide interesting and informative days. Not to forget our members who keep returning so as John says often in his talks "We must be doing something right".

Our talks started a few years ago and now we have given them to over 900 dietetic students, nursing students and academics. We manage to cover many aspects of FAP including surgery and how this can be from a very early age which often amazes our audience. Recently we started to ask the students at the start how many knew of a gene that without major surgery causes colon cancer. The answer was very, very few if any at all. The same question related to breast cancer is almost 100% so our talks are at least unique to them and well received.

Swarkestone 2011 is already being prepared and a full house of 50 is again expected. The registration forms are now available and on our website www.fapgene.org.uk/familyday2011. Once again it includes a hot buffet lunch and the chance of a ride in a rescue boat, weather permitting.

Mick Mason and John Roberts January 2011