



## Newsletter December 2011

Welcome to everyone and a pleasant Christmas and New Year. I must apologise for the rarity of newsletters this year but think how valuable that will make them in the future. Talking of which we will be altering our website in The New Year to [www.fapgene.com](http://www.fapgene.com) to reflect our worldwide membership. Eventually E Mail addresses will be altered but visitors will be forwarded to the new address. Over 5,000 visits are made each year and lately The FAP for Kids Book has seen the largest interest and we now have stock of this booklet. We will also be having specialist pages for Australia, The USA and Eire. Rest assured nothing else will alter and will cost FAP gene just £9 a year extra.

The past year has seen FAP Gene continue to grow with our Family/Information Day a sell out and a respectable number at The Informal Chat Day. Dates for next year are Swarkestone on Saturday 31st March 2012 and Branston Golf and Country Club on Saturday September 22nd 2012. Professor Phillips from St Mark's Hospital is already confirmed as a speaker in September and Dr. Julian Barwell of Leicester Genetics for Swarkestone. Also this year we feel that FAP Gene has become a true Support group and many thanks to those who have offered their support to others. We try to pair up age, sex, surgery etc where possible; sometimes this is impossible but does work if needed.

Our talks this year, some for the 4<sup>th</sup> time, have also been well received. Between us we have tested the patience of Student Nurses at Nottingham QMC and Birmingham University. Also Student Dieticians at Nottingham University Sutton Bonnington and Coventry University and then Colorectal Nurses at The Royal Marsden Hospital in London. The content which started purely about FAP, how it had affected John and I, the surgical choices and various extra effects of the gene has changed. Now we include how FAP Gene has progressed and the latest news on research and education plus some humour in appropriate places of course.

Our finances remain in good health with funds to last into 2013 but still look for anything to carry on with the annual events we hold. Talking of which our thanks go to all our speakers over the years who have given their time free of charge to help promote FAP and making sure we are all kept up-to-date with the latest news. It will be sad not to see Krystle Kontoh of The Genetic Alliance UK again as the Facilitating Networks project has finished and Krystle is off to New York. Our best wishes go with her.

The changes in Primary Care Trusts and large deficits have affected many of us and who knows where it will all end. John was involved in the Derby Burton Cancer Network Patient Partnership Forum which unfortunately no longer has funding so it finished in September 2011. It is disappointing as it was a way of feedback from patients getting back into the NHS. Also natural products which have shown to have an effect on polyps in the colon and possibly the duodenum have also been virtually impossible to obtain through prescription. This is perhaps understandable in some ways as Curcumin and ALFA Capsules are not approved by NICE (National Institute for Health and Clinical Excellence). However further research is hoped for which may eventually get the necessary approval. We will keep you informed on anything we hear in regards to this.

Finally we would like to add more stories to our website so in The New Year have a think about it and how it may help others.

Best Wishes

Mick and John The FAP Gene Support Group December 2011