

## FAP Gene Newsletter March 2010

What a difference a year makes or perhaps five years to be more precise. The first time we have had a full house for the Annual Family/Information Day and actually closed the registration list. As John once said "We must be doing something right". In fact it seems we are doing most things right.

Over the past year we have both continued with our talks and must be approaching a total audience of 800 These have included Student Nurses, Student Dieticians and a Cancer Network Genetic Day. Venues have been varied with Nottingham University, Nottingham QMC School of Nursing, Coventry University, Birmingham University, Branston Golf and Country Club, The Royal Marsden Hospital London, Millennium Stadium Cardiff and The University of Greenwich.

In September last year we received a donation of £1,800 from The Swadlincote and District Round Table through their Cheap Car Challenge. Instrumental in this was the then appointed fundraiser John Nickels (now John 2). This enabled us to have our first professionally printed leaflet which most of you have seen and has proved a valuable addition to our literature.

This funding has also ensured the future of our Information and Chat Days possibly for the next three years or so. However we will still be looking at any opportunities to top the fund up.

Our main way of gaining publicity is still through our website [www.fapgene.org.uk](http://www.fapgene.org.uk) . In the first five years this has seen 24,000 visitors from across the world including many from academic institutions. However we have also had referrals from The Ileostomy and Internal Pouch Main Office and two Genetic Centres which is encouraging.

Today we have five families and six health professionals visiting for the first time, hence the full house. It is encouraging though that we still attract a few hardened regulars so as John 1 says "We must be doing something right".

FAP Gene is a member of The Genetic Interest Group based in London and recently joined The Long Term Conditions Scotland Association. These both strengthen our position as a National Support Group. Also John and I are both members of the IA whilst John is a member of The Derby/Burton Cancer Network Patient Participation Forum which in turn is part of the East Midlands Cancer Network which covers a population of over 4million people which could have over 500 FAP people using the 1 in 7500 estimate.

Our finances are in fine fettle with a rough estimate of £500 a year to continue with the two events a year as at present. Perhaps now is the time to prepare a more formal budget though.

We hope you find today interesting and any comments are always welcome afterwards whether good or not so good. Also a thank you for coming and making it all possible and another thank you to our speakers

John Roberts, Mick Mason and John Nickels

FAP Gene  
Swarkestone 2010