

The FAP Gene Support Groups 3rd Annual Informal Chat Day

The Branston Golf and Country Club Burton upon Trent Staffordshire Saturday 4th September 2010

Once again we held the event at this rather luxurious setting and attracted twenty people including four visiting for the first time. The latter always gives a boost to both organizers and those attending. We have always stressed it is not the number that counts but what is gained from such a day. Meeting others with FAP for the first time 20 years since being diagnosed sounds amazing. However it is not a one off for us and hopefully something FAP Gene is helping to put right.

In true FAP Gene fashion a rather casual start to the day with tea, coffee and shortbread helping to break the ice. This time our members came from Plymouth, Bridgnorth, Stockton on Tees, Walsall, Wakefield, Derby, Melton Mowbray, Bretby, Sheffield and London. Apologies if I have missed someone.

Mick started by welcoming everyone and mentioned some of the subjects that might prove interesting to chat about during the day. These included the effect on absorption of medication due to the lack of a large bowel, Vitamin B12 deficiency, Videoing of future events, members own experiences, trials and a quick look at the early days of The FAP Gene Website.

There were also details of the talks given to around 900 health professionals and those interested in FAP over the past 3 years by John and Mick. These are now adapted to the audience which have included Dieticians, Student Nurses, Cancer Networks and our own events.

With everyone settled down John gave his updated Introduction to FAP Presentation and his decision to include Curcumin (The Indian Spice) in his diet. In a private trial by Peter, one of John's contacts, sanctioned by his GP and consultants, this has shown significant benefits in the control of polyps in the colon. John has often been forced, in a nice way, to start our Family Days with versions of this talk. For those who have often heard it Mick is sure they appreciate how much it has changed and been updated over the past 5 years.

Progress on FAP Gene's involvement in The Genetic Alliance UK Networking Project was given by project leader Krystle Konteh. Krystle is always a popular visitor and was asked about what happens after the project finishes and the chance of any findings being implemented. With 7 other groups involved she had high hopes that some would but everyone was aware this depends on the future changes in the NHS especially with the Primary Care Trusts and Cancer Networks.

Kay from Shropshire was asked to give some advice for those looking at fundraising after her own mammoth effort raised funds for equipment in The Shrewsbury and Telford Hospital Trust. This was well received and showed what is possible but with a lot of time, effort and concentration.

There were varied opinions on videoing of future events. Most seemed quite happy in principle but several wonder if it would inhibit the main object of the day, the informal chat. We encourage free speech for want of a better phrase and it was agreed we would look further into it all. An audio only version was suggested with editing but with the same concerns. The initial thought had been raised by a member who is unable to travel to our events and for others in a similar position. Afterwards Mick realised he actually had an audio version of his booklet 'My Genetic Journey' on CD. Anyone wanting a copy only has to contact him.

Then it was over to general chat and with no formal programme this continued with most needing to be almost kicked out at 4pm as we finished. We felt this just proved how much this sort of day is needed and even without formal speakers it was successful.

Once again our thanks to the staff at The Branston Golf and Country Club for looking after our needs and hopefully we shall be returning next Autumn.

John and Mick

September 2010