



The FAP Gene Support Group

Familial Adenomatous Polyposis
www.fapgene.com



Report on FAP Gene 7th Annual Informal Chat Day Saturday 20th September 2014

Branston Golf and Country Club Burton upon Trent Staffordshire

Photos on line at

<https://plus.google.com/u/0/photos/10237097420397226380/albums/6061221203915808801>

We would like to thank The Swadlincote and District Round Table for sponsoring the day. Also the Branston Golf and Country Club for their continued support.

This was the first event organized by John Nickels. 25 people enjoyed yet another highly successful day including our first visitors from Scotland. Unfortunately the day started with the news that John Roberts had stood down as Chairman after 10 years due to personal reasons. I am sure that everyone sends their best wishes to John and his wife. Our thanks go to John who was responsible for organizing all our events starting with the 2006 Family/Information Day at The Swarkestone Sailing Club in Derbyshire. He will surely be missed.

John Nickels welcomed everyone and then left it to evolve into a very relaxed and enjoyable atmosphere. The blend of Health Professionals, Patients, Relatives and friends has been a tried and trusted over the years but this seemed one of the best yet. Perhaps a reason for John already booking Branston for next year's event on Saturday the 19th of September.

A short AGM reported healthy funds with thanks being given to Vicky and Mark after Mark's Three Peaks Challenge and also Louisa and Russ after the Sky Diving taken on by Russ. These two events have ensured the continuation of FAP Gene for several years to come at least.

For the moment photos are available on the link at the top of the page but will be added soon to the website. The star undoubtedly was Helen who came in at lunchtime only 2 months after a successful bowel transplant.

There was some general talk about whether Genetic Centre's should offer further check-ups for those with FAP after initial surgery. Some do and some don't. It is fortunate that although there are several heightened risks of other complications many patients will never experience any problems. For those deemed at risk the question is also whether they would want any further checks. Added to this came the question of whether checks which could be outside of the patients own NHS Trust would be funded.

After a sumptuous hot buffet, including a rather delicious Millionaires Shortcake, Muditha Samarasinghe from the Polyposis Registry at St Mark's Hospital in Harrow gave a talk on FAP. Muditha has been to several of events and it is hoped this will continue despite her moving on from The Registry.

Then Helen gave us the most fascinating talk any of us will have probably have heard about her recent bowel transplant. It was unbelievable that only two months before she had her surgery. Only the 28th in the UK and the 4th with FAP she now enjoys making up for lost time with home cooking and meals at various venues. Most recent after The Chat Day was driving alone to Oxford to see her consultant where she had the news that another 3 months can pass before another drive down there. I am sure we will hear more from Helen in the future and a fundraising event is being planned in her village in February.

As is usual at the end of the day people are still chatting and seeking help and advice from those present. If you were there and would like to pass on any comments they will be added to this report.

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