



The FAP Gene Support Group

Familial Adenomatous Polyposis and Gardner's Syndrome

www.fapgene.com



Report on our Informal Chat Day 12th September 2009

The Branston Golf and Country Club
Burton upon Trent Staffordshire

First of all we would like to thank everyone involved in making such an excellent venue available to us. It is often a worry when anywhere new is tried and we are pleased to say that we propose to hold a similar event at the same venue next September.

There were 30 of us present at the start to see Andy and Steve from The Swadlincote and District Round Table present FAP Gene with a cheque for £1,800. This had been raised by their Cheap Car Challenge involving four cars bought for less than £200 each and travelling to Edinburgh, London and Cardiff over a weekend. As stunning as this was they also mentioned this was not yet the final total. Needless to say they were given a very warm reception by everyone.

In 2008 at our annual Family/Information Day at Swarkestone Sailing Club Dr Alison Metcalfe from Birmingham University talked about The Family Talk Study. This involved seeing how parents and their children talked to each other about a genetic condition in the family. Today Alison returned to give us the final results. Some members had helped with the study and there were many little nods of the head during her talk.

With being informal and no strict programme there was time for many questions and discussion about the report. It was a nice surprise that Wendy Chorley the Familial Cancer Nurse Specialist from The Derbyshire Hospitals popped in and helped with some answers. Wendy has virtually been our resident health care professional from day one and it is very much appreciated.

This was all noted by Krystle Konteh from The Genetic Interest Group who was later to talk about FAP Genes involvement in The Facilitating Networks Project which will aim to improve communication, information and access for rarer genetic conditions.

The ages ranged from a nine year old to the late sixties with plenty of private discussions going on throughout the day apart from more general ones from the two talks.

Now more about Krystle, who has just finished the first year of the three year project. FAP Gene is one of eight members of The Genetic Interest Group taking part. GIG believes there is a real need for a project such as this as their previous research has highlighted the difficulties that children, adults and families with rare genetic disorders experience in receiving high-quality up-to-date information and optimal healthcare. They are confident that not only will the results of this project benefit the patients they will be working with; it will serve as a template for other Patient Support Groups to utilise in developing their own Networks of Expertise.

The end of the day soon came and all were still chatting away and commenting on how valuable such a day had been. Most had learned of us through our website and hopefully in the future health professionals might be encouraged to find groups similar to ours in the same way for the benefit of their patients.

Mick Mason
September 13th 2009