



## 2012 Family/Information Day Report

As usual the sun stayed in and a rather cool wind blew across the lake. However despite the fuel shortage and several apologies for family reasons 30 of us were there to make it another successful day. It was also a relief that a wrong date for our Chat Day in September was spotted by one of the seven visiting us for the first time.

John and I started off the day with a brief introduction to FAP and the history of FAP Gene and how it has evolved over the past eight years. It is still a problem getting in touch with those with FAP and numbers are always a last minute affair. The worry of whether we have enough present to warrant speakers travelling quite a distance in some circumstances prompted a change this time to adding a more informal chat aspect to the day. It seems to have worked well and from next year we will have just one event a year in March at Swarkestone combining the best (we hope) of both days. Wendy Chorley, the Derbyshire Hospitals Familiar Cancer Nurse our almost resident health professional was again available to answer any medical questions.

Cath Moore a member from Yorkshire gave a talk about her 'Cross Stitch' Family Tree and how FAP had affected her family over many years. The mention of a five day hospital stay to have a colonoscopy and all its preparations amazed many of us. Later in the day Cath presented the framed family tree to Kay Neale of the Polyposis Registry at St Mark's Hospital Harrow which was well received by Kay and appreciated by the audience.

A tea break and time for chatting preceded a very interesting talk by Dr Julian Barwell of The Leicester Genetic Clinic based at The Leicester Royal Infirmary. The clinic is one of the smallest if not the smallest in the country but that is now changing. Julian talked about the past, present and future hopes of his and the clinic. This covered Pod casts and community engagement, Supporting Families with Cancer, Tipping points of referrals and inequality of access, Think-Tank, Teaching of under and postgraduate, Chemoprevention, Plasma Markers, Vaccine development in HNPCC and The Future of Genetic Services. There will be more about Julian on our website in the near future.

Lunch is always an event in itself at Swarkestone and our thanks go to the ladies who looked after us throughout the whole day as well. Also a very flexible timetable allows the chat to go on unhindered by shouts to sit down again. It was during lunch we were joined by Jo Rawlings, Muditha Samarasinghe and Kay Neale all from The Polyposis Registry.

Our afternoon session started with Jo Rawlings updating everyone on The Chip Trial or Trial in Pediatric Patients with Familial Adenomatous Polyposis involving the drug Celecoxib. This is for children between the ages of 10 and 17 and covers a period of 5 years for those participating. Jo mentioned how positive some of the young children were and eager to sign up. However there are restrictions on the number of current polyps and also perhaps future problems with taking tablets twice a day and annual check-ups. Everyone saw this as hope for the future in delaying the need for surgery. Muditha Samarasinghe and Kay then ran a Polyposis quiz with the audience split into 3 teams and a basket of fruit for the winners. A really good time for all but there was a different kind of question asked when I was on the same table as John and Wendy. Surprisingly we won. The basket of fruit was then kindly given to the youngest lady in the team.

Then the chat continued for another hour before everyone gradually drifted away. Our thanks go to all those involved as we prepare for the Chat Day on September 22<sup>nd</sup> 2012 at The Branstons Golf and Country Club where our guest speaker will be Professor Robin Phillips Director of The Polyposis Registry.

John and Mick April 2<sup>nd</sup> 2012

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