

## Report on FAP Family/Information Day

### Swarkestone March 2007

They say better late than never and hopefully it is with this report. I have tried to finish it several times and now in January 2008 feel more up to it for some reason. Perhaps it is John preparing Swarkestone 2008 that has done the trick.

We had 31 people attend and both of us were pleased with the number as until the last few weeks we are always unsure how many will come. The main problem is we do not have direct contact with patients who have FAP and rely on the website, flyers left at various health related events, talks we give and word of mouth. In 2008 we hope to be nearer the 45 mark and would like everyone's help in promoting it in anyway they think fit or even unfit!

So back to March 2007, a nice sunny day and the usual change of programme at the last minute this time due to illness. People came from Taunton, Cardiff, Newcastle, West Midlands, Leicestershire, Derbyshire, Lancashire and South Yorkshire.

John gave an overview of FAP and only the fact he might have to repeat it again prevents the whole talk being made available on the website. Also we learned a fair bit about Swarkestone Bridge and Bonny Prince Charlie who came as far south as the bridge before returning back home to Scotland.

Our Clinical Psychologist calling off at the last minute through illness was covered by Wendy Chorley from Derbyshire Hospitals who is like our resident awkward question answerer. Wendy talked about the psychological problems for children and adults on hearing the news they have FAP. This led to a fair number of questions and proved an interesting topic of conversation.

Derek who also came last year with his wife then talked about how he found out he had FAP and the frustrations and almost anger that his parents had not told him. An article written by Derek is on the website.

We then chatted about how FAP had affected others and the lack of a national programme for monitoring patients. A family with four generations from The West Midlands was pleased with their initial diagnosis and treatment but had heard nothing since. They were surprised others were having checks for various other problems with the gene.

Lunch was the usual leisurely affair and again an ideal time for everyone to chat and swap notes etc. After Lunch Mick who was involved with the NHS/Macmillan Cancer Genetic Cancer Projects introduced Sharon Lomas from Macmillan Cancer Support who explained how seven projects were started around the country ( Oldham PCT, Poole PCT, West Coast PCT, Guys, The Royal Marsden/St Georges in London, Leeds and Teesside.). These were looking at improving standards for patients of all genetic cancers.

Melanie Ripley and Carol from Oldham PCT then talked about how Oldham had approached the problem of providing genetic cancer services and making them more accessible and raising people's awareness.

A rather quick summing up of the day did give time for those willing to have a trip on The Sailing Clubs Rescue Boat which was a real bonus on a bright summery day.

Mick Mason January 2008