



## Newsletter November 2012

This past year has seen several changes to our plans but we did enjoy with everyone The 7<sup>th</sup> Family/Information Day at Swarkestone in March. 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. 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 and then 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. Also a link to the clinical genetics FAP podcast.

<http://www.youtube.com/user/ClinicalGenetics?feature=watch>

John and I have often talked about how fortunate we had been with our own health and the ability to organize and run the group. However John's surgery to remove his gall bladder and my own family's hiccups eventually changed this. We were forced to cancel The Chat Day at Branston a week before and now after careful consideration have decided to cancel both events for 2013. This is more to give us a chance to charge our batteries up whilst still giving new information through our website and e mails. Perhaps in 2014 a move away from Swarkestone which always has to be the last Saturday in March and often clashes with Easter and school holidays to Branston in May. Nothing certain, nothing planned but an idea.

Our website although attracting very few e mails this year has seen a rise in visitor numbers of 6,500 from around 5,000 which has taken us past the 40,000 mark since 2005. We have known for a few years that many look, see and continue on their way. Perhaps we have too much information but this is a good thing. The main difference as well has been the surge in numbers looking at information for children from all over the world. We have added separate pages for New Zealand/Australia and North America which again seems to have improved visitors along with our changing the site to a dot com domain.

We have managed to continue our talks to student nurses and dieticians at The Universities of Nottingham, Coventry and Birmingham and being involved with Julian and his Lifestyle and Cancer Awareness Evening Workshop in Leicester.

After three years I eventually managed to get a video of my upper G/I scan with many thanks going to my consultant. It is interesting to see the use of dye to enhance any polyps and seeing biopsies being taken. The final two minutes are with a side view scope for looking round the corner into the bile duct or so I am told. There is a link to You Tube [http://www.youtube.com/watch?v=Pgd5\\_j6L-vo&feature=youtu.be](http://www.youtube.com/watch?v=Pgd5_j6L-vo&feature=youtu.be) on the website. It also gave me a chance to practice my skills by adding classical music. Not for the faint hearted but I do have free copies available.

Finally we are financially very sound with few overheads and therefore still no need for any membership fees. Over the winter we will look at the content on the website and perhaps try and encourage a few more articles from members or an update to existing articles.

Also pleasant festivities for Thanksgiving, Christmas and The New Year.

Best Wishes

Mick and John The FAP Gene Support Group November 2012