



FAP Gene

Familial Adenomatous Polyposis and Gardner's Syndrome
www.fapgene.org.uk



Family/Information Day Saturday March 18th 2006
Swarkestone Sailing Club Derbyshire
Organisers - John Roberts and Mick Mason

The morning session was organised to give Families and Health Professionals the opportunity to meet each other, talk about FAP and learn from each other how the oddities of this genetic condition has had an effect on their families. It was a very flexible programme and this proved quite successful.

John welcomed everyone to the first meeting of FAP patients outside of London saying how pleased he was that 13 people from 6 families had come and hoped that an interesting day was ahead of them. He also introduced Claire Shaw and Wendy Chorley from the Derbyshire Hospitals who later helped with the medical and technical questions.

John's talk gave a brief history of both The Swarkestone Bridge which overlooks the Sailing Club and an introduction to FAP and Gardner's Syndrome.

The bridge is reputed to be the longest and oldest one built of stone in England and signs of life in the area spread over 4,000 years. An impressive backdrop for the meeting.

He went on to say how surgery was only used for those with colon cancer and not polyps until advances were made after the war and new techniques developed. Also an insight into Eldon J Gardner who spotted families with lots of bony growths and cysts although not yet linked to digestive problems.

The Red Lion Group at St. Mark's and The Ileostomy and Internal Pouch Support Groups were mentioned as sources of valuable information and support after any preventative surgery. FAP Gene could now be seen as providing information that is often sought after this surgery and coping with other problems the gene is capable of throwing up.

This statement finished the talk - **The most important factor is that if you are at risk of FAP to make sure you get all your checks it may not be pleasant but you should stay in this world longer!**

John received a well earned round of applause for his informative talk and then introduced Mick Mason as the founder of the FAP Gene website.

Mick gave an idea of how much interest there is in FAP in the academic world and amongst Health Professionals. He mentioned the CancerBacup Genetic Cancer Booklet, the seven Macmillan Genetic Cancer Projects, Beating Bowel Cancers Newsletter, The Knowledge Parks in Manchester and Newcastle and the Genetics Education Centre in Birmingham. All proved to be of interest all round with families from Liverpool, Sunderland and the Midlands present.



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He then moved on to how he saw on a personal note the difference in FAP to other genetic faults which can lead to cancer. Highlighting the increased risk factor of Breast Cancer Genes (70/80%) compared to FAP (virtually 100%). He acknowledged that this perhaps made it harder initially for someone with one of the Breast Cancer Genes to decide on preventative surgery.

An interesting view was the question of how many different people might spot something in a patient that might point to FAP other than the Family History or change of bowel habits. Mick's talk included Dentists, Opticians, and Dermatologists; most interesting was a comment on the day that their hairdresser had passed a remark on a son's very bumpy head.

This all led to a lively discussion with Wendy Chorley and Claire Shaw from the Derbyshire Hospitals helping with various technical and medical questions.

Joining us for a leisurely lunch, were Kay Neale from The Polyposis Registry at St Mark's with her husband David and from SLA Pharma Chris Jordan. This again provided time for everyone to talk to each other and discuss points from the morning session.

After Lunch Kay gave a talk on the History of the Registry and of FAP. To hear of how it all started in 1924, how it had developed and the reasons for the eventual success of colon operations was most enlightening. The advances in finding another gene was perhaps very relevant to one person where the actual genetic fault has not been found but biopsies prove he has FAP.

Kay then answered a variety of questions about the different aspects of FAP, including Desmoid Tumours, links to other cancers and how complex the genetic process still is.

Chris Jordan of SLA Pharma (www.alfacapsules.com) then took us on a science lesson which led to a better understanding of the new Alfa Capsules. He mentioned their area of special interest and research is the use of ALFA as a preventative treatment for patients who are likely to develop bowel cancer from colon polyps. For those of us with FAP this gives hope for future generations that at least there might be an alternative to such major surgery at an early age.

ALFA at a glance:

- ALFA is a 99% pure omega-3 EPA in a free fatty acid form. It is absorbed in the body up to five times more readily than EPA in other fish oil products.
- 2 capsules of ALFA equate to around 15 capsules of commercially available fish oil.
- The beneficial effect of ALFA may extend beyond colon cancer - it is well documented EPA is vital for maintaining health and preventing other major diseases.

Afterwards we all knew a fair bit about Fatty acids and Omega 3 and 6 and trials which should be held later in the year. Details of this will be on their own website and at www.polyposisregistry.org.uk



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Mick thanked everyone for their contribution during the day especially John who had done most of the donkey work in putting such an interesting and rewarding day together. Also John thanked Clare of Swarkestone Sailing Club for putting on the splendid buffet and drinks throughout the day.

Afterwards John mentioned how strange to give a talk and see people making notes. Perhaps not so unusual for health professionals to do but a sign of how important the information given was seen to be. It has now been agreed to hold another event next year and use the experience we have gained to hopefully provide a repeat of a successful day.

Latest News - Kay has offered to come to the 2007 event and also we are looking at someone providing a talk on 'What happens to your blood sample'. Sharon Lomas of Macmillan has offered to give a talk on the Macmillan Genetic Cancer projects. There will also be time for those with FAP to give their views.

John's thoughts for March 2007 meeting

Numbers - Aim for total of 35 – try to get about 10 professionals
I think 35 is the max we can cope with using a single room
The room divider was good and minimised any disruption
Talk to Wendy and Claire about professionals – At City Hospital Derby there is a new doctor training centre - may be some interest there.

Speakers - Two main speakers again but try to get at least one from a bit closer to allow one in morning

Newcomers A follow up in Local Newspapers with a dedicated reporter. Derby Evening Times, Leicester Mercury. Promotion in the Nottingham and Staffordshire Newspapers and use the Nottinghamshire and Leicestershire IA for awareness.

FAP Website

The website has immense potential but we also need information available for Non-Internet patients. We could produce a free 6 monthly newsletter or quarterly if enough material available. Also we have been approached by Genetic Centres in the North East and North West of England about the possibility of helping organise similar days.

A personal booklet Mick has produced needs to be printed and made available for a donation not a set price. This could now include details of family days and the work of FAP Gene.



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As well we have thoughts of producing a diary for newly diagnosed patients to record appointments, check-ups and results. Especially valuable for those who move into a different area and for remembering dates when treatment might be spread over many years

Over the past 18 months over 50 FAP patients and Health Professionals have sought non-medical advice through the website. We hope to build on that and promote awareness not only of FAP but bowel cancer in general as well.

Our Thanks

We would like to thank all those who came and to say it was a very relieved John and Mick that evening. Not knowing if anyone would be interested was a gamble we were prepared to take and luckily we were not left talking to ourselves.

Also Swarkestone Sailing Club for their hospitality and a hope the sun shines next year.

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