



# The FAP Gene Support Group

(Familial Adenomatous Polyposis)

[www.fapgene.org.uk](http://www.fapgene.org.uk)



## Report on The 5<sup>th</sup> Annual FAP Gene Support Group Family/Information Day

Swarkestone Sailing Club Derbyshire Saturday March 27<sup>th</sup> 2010

For the first time we reached our capacity with 50 people attending on a bright but blustery day at Swarkestone. A good mixture of old and new faces included patients, relatives, friends, health professionals and a couple of dogs one of whom always joined in the applause with a few well timed barks. Ages ranged from a few weeks to the late 60's with eleven Health Professionals also taking the opportunity to benefit from the days talks. We followed a well proven course, rather apt for a sailing club; a relaxing venue which I must say adds much to the day.

John was spared for the first time in five years the task of giving the first all important talk as David Foreman the Colorectal Clinical Tutor from Derby Hospitals used a 'Who wants to be Millionaire' question style for his 'Introduction and Revision of FAP'. Never has the subject of FAP received such treatment and it really set the mood for the day with everyone involved and also showing their knowledge of quite a complicated gene. Still not that unexpected as most with rare genetic conditions gradually become expert patients but not many have a chance to show off their skills gained often over quite a period of time.

John has been involved with The Derby/Burton Cancer Network Patient Partnership Forum for only a short time. However he felt that one way to raise awareness of FAP was to encourage others to join the Forums in their own area. He also managed to entice its facilitator Mary Rawson to explain the role of these Forums. These are spread around the country and can include several Primary Care Trusts areas and also influence the National Cancer Network. This continued our theme of having information on education in the morning session and Mary gave an interesting and easily understood picture of a way we could all help bring more attention of genetics to the health service.

FAP Gene is one of eight Rare Genetic Conditions that The Genetic Interest Group is gathering together in The Facilitating Networks of Expertise Project. Over the past year Krystle Konteh the Project Lead visited us at our informal Chat Day last September. This time with Krystle unable to come we were delighted to welcome Melissa Hillier the Assistant Director of GIG in her place. I must admit I had a slight doubt about Melissa arranging everyone into three groups to each look at one question and use their experiences for the benefit of the project. So to say I was stunned with the response is an understatement and I think we would still be there except for the time restraints of the day. Krystle will also be very pleased with the information from everyone and Melissa deserved the warm applause she received. For John and me it gave us the chance to disappear to the back and pretend we weren't involved.

Last year Jo Aston gave a talk on her family's affair with FAP and the interest shown by everyone at the time meant we needed someone to give a repeat of a patient's story this time. It was lucky that our Fundraiser John Nickels volunteered. I say volunteered but it is said that John Roberts and I have a way of suggesting things and then just accepting they will be done. What was different was that John doesn't have FAP and has been a carer for his three children since his wife Sally lost her life to ovarian cancer with secondary bowel cancer whilst they were still young. He told what has now become a more common tale of tell tale signs of FAP through non bowel problems which were missed. I say missed but perhaps better to say unknown in many quarters at that time. Through the treatment of cysts and dental problems in two of their children it was eventually found that Sally had FAP and the bowel cancer was in fact the primary cancer.

After a rather lengthy lunch break to enjoy the excellent buffet prepared by Clare Dr Alison Metcalfe of Birmingham University gave the final findings of The Family Talk Study, another project which included some members of FAP Gene. This looked at the way not only parents talk to children and vice versa about a genetic illness but children talking amongst themselves. There are several recommendations being put forward and again Alison's report was well received.

Kay Neale the Manager of The Polyposis Registry at St Mark's Hospital in Harrow usually gives a more detailed view of Genetics and FAP. So after four years it was suggested she might like to do a question and answers session. Entitled 'Liquorice Allsorts without the Liquorice'. Questions were sent to Kay from members and some by the committee on a variety of topics. All proved interesting and ranged from 'What happens if I have Polyposis but the gene fault cannot be found? to the way trials of new treatment are run. Kay also explained the way other variations of Polyposis are being found and the need sometimes for these to be checked for if no FAP fault is found. A most interesting session and a repeat next year is on the cards.



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Our final speaker was Mr. Nicholas Hurst a Consultant Colorectal Surgeon from Derby Hospitals. A talk entitled simply 'Operations and Questions'. What might and might not be possible surgically or what can and cannot be done surgically. This was very much in the same semi humorous but serious way which started the day. How far things have to be pulled and tugged to make a pouch and what might just stop that happening. That you should discuss the surgical options and work with the surgeon for the best options. There was a mention of ongoing surveillance for various extra bits that the gene presents including the thyroid and duodenal polyps. How simple the colon looks in diagrams with two bends and then what it is really like with many twists and turns. So much and yet so easily understood.

With the talks over then the talking started. There was tea, coffee and for the adventurous a ride in the rescue boats. No one seemed in a rush to leave which was mentioned quite often and certainly the speakers were kept busy tidying up many loose ends that the day had raised. For John Roberts, John Nickels and me it had been a rewarding and almost a relaxing time preparing for the day. This was helped by news of a donation from S.L.A. Pharma (UK) Ltd which was given to help us raise awareness, provide support for patients and help educate through our Family/Information and Informal Chat Days. Also a fundraising event by The Swadlincote and District Round Table last summer has ensured a continuation of our annual events.

It has even been suggested that we might think about organising a day on FAP for Health Professionals. We realise that FAP is just one of many genetic conditions but the realisation that the threat of colon cancer is only the start of things is often missed.

Our thanks go to all the speakers who received a book token for giving their time and helping to make it yet another huge success. Clare was given something more refreshing after a day looking after our gastric needs in a different way. Also our thanks to those who travelled from Teesside, Lancashire, Shropshire, The West Midlands, Lincolnshire, Leicestershire, Nottinghamshire, Derbyshire, Yorkshire and Staffordshire.

It was only whilst planning the event that John and I realised we have given talks on FAP to about 800 health professionals, student nurses and student dieticians in the past three years. A group we would like to add is GP's though.

The next event is our 2<sup>nd</sup> Annual Informal Chat Day at The Branston Golf and Country Club, Burton upon Trent, Staffordshire on Saturday September 4<sup>th</sup> 2010.

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## Acknowledgements

Branston Golf and Country Club	<a href="http://www.branstonclub.co.uk">http://www.branstonclub.co.uk</a>
Derby Hospitals	<a href="http://www.derbyhospitals.nhs.uk">http://www.derbyhospitals.nhs.uk</a>
Facilitating Networks of Expertise Project	<a href="http://www.gig.org.uk/projects/facilitatingnetworks.htm">http://www.gig.org.uk/projects/facilitatingnetworks.htm</a>
Family Talk Study	<a href="http://www.fapgene.org.uk/familytalk.html">http://www.fapgene.org.uk/familytalk.html</a>
FAP Gene Informal Chat Day 2010	<a href="http://fapgene.org.uk/chatday2010.html">http://fapgene.org.uk/chatday2010.html</a>
Patient Participation Forum	<a href="http://www.burtonhospitals.nhs.uk/PAS/patLeaf/ppf.asp">http://www.burtonhospitals.nhs.uk/PAS/patLeaf/ppf.asp</a>
Polyposis Registry St Mark's Hospital	<a href="http://polyposisregistry.org.uk">http://polyposisregistry.org.uk</a>
S.L.A. Pharma (UK) Ltd	<a href="http://www.slapharma.com">http://www.slapharma.com</a>
Swadlincote and District Round Table	<a href="http://www.swadlincote308.org.uk">http://www.swadlincote308.org.uk</a>
Swarkestone Sailing Club	<a href="http://www.swarkestonesc.co.uk/mainframeset.htm">http://www.swarkestonesc.co.uk/mainframeset.htm</a>