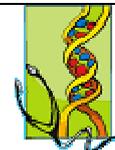


The FAP Gene Support Group  
(Familial Adenomatous Polyposis)  
[www.fapgene.com](http://www.fapgene.com)



Report on 6<sup>th</sup> Annual FAP Gene Family/Information Day  
Saturday March 26<sup>th</sup> 2011 The Swarkestone Sailing Club Derbyshire

Speakers

All about FAP

David Foreman the Colorectal Clinical Tutor from Derby Hospitals.

Genetics

Marie-Anne O'Reilly Genetic Counsellor from Nottingham City Hospital.

Predictive Testing of Children

Ingrid Holme Academic Dept of Clinical Genetics University of Southampton

Update on the Networking Project

Krystle Konteh Genetic Alliance UK

Family Talk Study Update

Professor Alison Metcalfe of Kings College Hospital London

Future Clinical Trials of Alfa Capsules

Chris Jordan SLA Pharma Ltd

Dietary Advice for those without a Colon

Mick and John

That makes it easier as it takes up half a page and less to have to remember. Seriously though John and I would like to thank all our speakers and members who came along to make an interesting and memorable day. Officially we closed registrations with a month to go but still found room for more especially as they were attending for the first time. So finally we had 55 of which 22 were there for the first time.

So where do we start? I suppose with the usual minor hiccups that always try to trip us up. Sue Laundon my Stoma Nurse was unable to make it due to unforeseen circumstances and then the projector wouldn't start up for our first speaker. Not to worry a quick trip to his office and just as he returned John had managed to press almost every button possible and powered it up. With 30 minutes lost there was no panic as John always allows plenty of leeway for such happenings.

This year we are hoping to make all the presentation slides available on line after requests from members unable to travel through various reasons. There was also talk of videoing the whole day which was later dropped as it brought into play the question of confidentiality and whether it might stifle open and frank discussions.

Our usual mix of speakers covered a range of topics including initial genetic testing and diagnosis for both adults and children. The surgical options and how new technology due to training is only available in a few locations. The use of side view scopes in the Duodenum and a dye to enhance polyps. Updates were given on both The Family Talk Study and The Networking Project which FAP Gene have been involved with over a number of years. ALFA Capsules have shown in trials to have an effect on polyps in the colon and rectum and the prospect of further trials gave hope for the future. Finally a short talk on what food may cause changes in your waste system when the colon is removed.

There was also a great amount of interest in Pre-Implantation which ensures a baby is born free of FAP. In the past this has been described as having 'Designer Babies' but for those actually with FAP it is anything but.

Unfortunately the rescue boat trips had to be cancelled but this gave more time to chat and make new acquaintances.

Finally our thanks to The Swarkestone Sailing Club and their Catering Staff for a first class service.

Mick Mason

Secretary

The FAP Gene Support Group

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