Articles

In 2008 we received a request from The Rosa Gallo Foundation in Verona Italy to write a chapter on Support for Patients with FAP for their annual FAP medical book. This was also to include giving a presentation in Verona at their Annual Conference.



It took about three months for John Roberts and Mick Mason to prepare an article which met all the strict guidelines and we became the only nonmedical contributors to the book printed by Springer in December 2008.

Online ISBN 978-88-470-1124-3

We have also been involved with the following

The Family Talk Project Birmingham University Dr. Alison Metcalfe.

Sculpturing a Voice for Genetic Disorders Julia Thomas.

Telling Stories NHS National Genetics Education Centre.

Genetic Networking Project The Genetic Interest Group.

Fundraising

In 2009 John Nickels was instrumental in our first major donation from the Swadlincote and District Round Table. This has so far enabled us to make our Chat Days a free event.

2014/15 saw members raise funds by Sky Diving, The Three Peaks Challenge and a Race Night at a Running Club in Plymouth



Ideas for fundraising are always most welcome. Donations can be made with Pay Pal.

Our thanks go to the following for their support

Swadlincote and District Round Table

Swarkestone Sailing Club

Branston Golf and Country Club Burton upon Trent

SLA Pharma (UK) Ltd.

The Polyposis Registry St. Mark's Hospital

Genetic Alliance UK

Derbyshire Hospitals Familial Cancer Unit

Nottingham Regional Clinical Genetic Service

Leicestershire Clinical Genetics Service

University of Leicester

Contacts

enquiries@fapgene.com fundraiser@fapgene.com

Other contacts via our website.

Familial Adenomatous Polyposis

The FAP Gene Support Group

www.fapgene.com

Founded 2004

We offer Non-Medical Support and Information to those affected or interested in the Bowel Cancer Gene FAP.



2014 Informal Chat Day The Branston Golf and Country Club Burton upon Trent Staffordshire

FAP is a serious condition unless detected early when it can be treated

The FAP Gene Support Group

Founded in 2004 by Mick Mason in Melton Mowbray Leicestershire when he realised there was a need for information on FAP which was reliable, non-medical, up to date and easily understood by patients. It is run totally by volunteers.





In 2005 Kay Neale, Registrar of the FAP Registry based at St Mark's Hospital in Harrow, North London, introduced Mick Mason to John Roberts.

The combination proved a success with Mick's knowledge of website design and John's wish to hold an Information/Family Day in March 2006. These were held until 2012 when it was decided to concentrate on the Informal Chat Days.

In 2014 we celebrated our 10th anniversary and had our 10,000 website visitor. We have also accepted many Individuals from and requests Organisations to provide links to their websites.

Now in 2015 we are holding our 8th Annual Informal Chat Day. These have given patients, relatives, friends and those with an interest in FAP the chance to meet in a relaxed atmosphere. With recent donations we have continued to make these free and attracted people from all over the UK.

The website has also been recommended by both Macmillan Cancer Support and The National Genetics Education and Development Centre as a useful source of information.

Membership

This is entirely free with regular news updates via e mail. Members offer support via e mail or telephone.

E Mail addresses are never revealed to other members without their permission or any third parties.

Family/Information Days

Our first Family/Information Day was held at Swarkestone Sailing Club just south of Derby in March 2006. This was the first patient led meeting of those with FAP in the UK and possibly the world. An extended Lunchtime allowed for plenty of 'Chat' for what was for many the first time of meeting others with or with an interest in FAP.

Speakers offered their time free of charge. At the first event Kay Neale gave a talk on the history of FAP whilst a representative from SLA Pharma UK Ltd gave details of their research into Omega 3 Acids with their Alfa Capsules.



Family/Information Day at Swarkestone

Informal Chat Days

2008 saw our first Free Informal Chat Day at The Swarkestone Sailing Club Derbyshire. In April 2009 we held another successful Chat Day at Swarkestone.

With fundraising received from The Swadlincote and District Round Table it was possible to hold a second day in September of that year at The Branston Golf and Country Club near Burton upon Trent in Staffordshire.. This has now become an annual event which includes a hot buffet lunch and refreshments during the day. Combine this with the very relaxing surroundings and everyone agrees that it makes days to remember.

We are always keen to promote any projects or news on FAP whilst retaining the Informal Style of the day.



Chat Day at Branston



In 2014 a young lady who had recently received a bowel transplant gave one of the most emotive talks we have heard.