

# The FAP Gene Support Group

Familial Adenomatous Polyposis

[www.fapgene.com](http://www.fapgene.com)

## Newsletter October 2016

It is hard to believe that our last Newsletter was almost two years ago in December 2014. We had talked about a quarterly one but I suppose reports on our Annual Events took over. So with this year's Chat Day cancelled there is a hole to be filled and hopefully some good news for the future.

In 2015 we realised the need to become part of Facebook. On the website we had links to various groups but not one run by FAP Gene. This changed earlier this year when Karen and John opened The FAP Gene Support Groups Facebook Page. In next to no time approved registrations have reached over 130 from across the world. Our thanks to John and Karen for monitoring and running this new venture.

Perhaps one reason for the low numbers for The Chat Day was the increased use of Social Media. Why travel and have all the extra costs involved when you can sit in chair and chat to the whole world. One reason is can you actually beat meeting people face to face, chat to others either individually or as a group? Also listen to various talks by Health Professionals.

In the past we have tried dates in March/April (avoiding where possible Easter Holidays) and September. We have had formal presentations, members own experiences and just good old chin wags. Recently it has been seen more of a Coffee Morning type event although we have had informal talks to give it some structure. Your ideas are important and John Nickels would be delighted to hear them and over the winter look at next year's event.

We would like to thank all those who have been fundraising which without we would not be talking of next year's event. It was likely that our website would revert back to just a valuable source of information. Added to those funds is 1,000 Euro for our involvement with the Swiss pharmaceutical company Tillotts Pharma AG. I have just realized that two years ago we were invited by another company Cancer Prevention Pharmaceuticals Inc. (CPP) based in Arizona to help promote details of a worldwide trial for patients with FAP. The two companies now have received a formal license to further the treatment in Europe and Japan. The following link is for several press releases from CPP. <http://canprevent.com/media/>

So this winter is looking like a significant time for FAP Gene. John Nickels after a chat with Wendy is looking at a Dentist, Optician and a dietician to give talks. Also a new venue which may attract a wider age group. Once again we need ideas.

I will be looking at a major overhaul of the website as even I find it hard to see the things I am looking for. The Google Search within the website helps but a simpler menu is needed. It has already been suggested that the search facility is moved to the top of the menu which will happen today.

We have also been asked for help with a survey from a PhD Student. The purpose of the survey is to guide the development of a website, which will then be set up to provide generic information about different genetic conditions which give a vulnerability to bowel cancer and also a secure way of sharing more personal information electronically. This is rather like the Kintalk.org website in America but with information that is UK and NHS validated.

If anyone would like copies of our new FAP Gene leaflet please e mail your address and will pop some in the post. Also any places or publications we could approach to mention our group you might think of would be appreciated.

Mick Mason October 3<sup>rd</sup> 2016

Secretary/Chairman Mick Mason 12 Freeby Close Melton Mowbray Leicestershire LE13 1HN

Tel: 01664-566101 E-Mail [mickmason@fapgene.com](mailto:mickmason@fapgene.com)

Fundraiser/Events John Nickels 20 Bretby Lane Bretby Burton upon Trent DE150QN

Tel: 01283-544168 E-Mail [johnnickels@fapgene.com](mailto:johnnickels@fapgene.com)