



FAP Gene Newsletter December 2014

We send our best wishes to everyone for The Festive Season.

At the end of the year we often look back and wonder what the most pleasing time or moment was. In the past FAP Gene has several including our first full house for a Family Information Day in 2011. In 2008 we received an invitation to write an article and give a presentation in Verona Italy. Over the years our members have been acknowledged as a very valuable source of patient information by many organisations.

However perhaps the most startling event in the whole 10 years was the news that one of our members, Helen, had a successful bowel transplant. Not only that but a matter of weeks afterwards she gave a most informal and informative talk at the September Chat Day. We are sure those present will never forget that afternoon and Helen is still recovering well and we hear she was the first person ever to be discharged from the Polyposis Registry at St Mark's Hospital in Harrow.

In 2015 a little later than planned we will be looking at a new leaflet and would like some ideas of what it should include. As well we will be contacting everyone individually to ensure their contact details are up to date and still want to receive e mails from us.

It was with deep regret that John Roberts had to stand down as Chairman three months ago due to personal reasons. I speak to John on a regular basis again and he is making progress on a gradual basis. John Nickels has taken over organizing events and continues to be our fundraiser. Also I will act as Chairman until next September.

The last six months has seen an increase of 20% in website visitors compared to the previous six months. Perhaps two reasons are Peter's continued reporting of his families trial with Curcumin/ALFA Capsules and Daniel's pages on raising awareness of FAP in Hawaii. We would like to include more personal stories if possible next year so please have a think about that and how it does help others.

So what would your FAP wish list include for 2015? We would like to see more reports on research and treatment for Desmoid Tumours. We want to add more information on the other variations of FAP. Your thoughts would be much appreciated.

This past year has seen our 10th Anniversary and the 50,000 visitor to our website and financially, thanks to several welcome fundraising events and sponsorship by The Swarkestone and District Round Table for sponsoring The Chat Day, Louisa and Russ and Mark and Vicky we leave 2014 with a healthy bank balance. Our running costs by the way are around £400 a year including the Free Chat Day.

Below is a You Tube link to an Hawaiian Christmas Song from Bing Crosby supplied by Daniel in Hawaii which is well worth a look at.

<https://www.youtube.com/watch?v=hEvGKUXW0iI> .

Mick Mason
December 2014