

News Update

Issue 4 Spring 2017



The Big Bowel Event

Get involved in bowel disease research on Thursday 8th June 2017.

This event is all about involvement and engagement with research and will provide members of the public with a unique opportunity to actively contribute to the latest developments in bowel disease research, from colorectal cancer to Inflammatory Bowel Disease and IBS.

During the moming sessions, you will learn about latest developments and thinking in diagnostics and care, from self-management to lifestyle considerations and harnessing new technologies, from apps to microchips.

In the afternoon, you will join the research innovators in round table sessions with the aim of using your own knowledge and experience to improve the direction and outcomes of the research.

Professor Matt Brookes will also be talking about his new diagnostic work for bile acid malabsorption and will run an afternoon workshop on the topic, so if you or others with a real interest in BAM would come along it would be great for everyone.

What's on at the Big Bowel Event?

You will have the chance to connect with some of the UK's leading researchers, co topics from bowel cancer to IBD and IBS.

Session one - Lifestyle and your bowel disease

- Pro-inflammatory and carcinogenic foods and their antidotes, or what to eat more of and what to eat less of.
- Designing a physical activity programme for people with bowel cancer and a stoma that is enjoyable and improves quality of life.

 Developing an education and support app for Inflammatory Bowel Disease (IBD) patients.

Session two - Clinical trials, what's new?

- CapaCiTY the world's largest programs research into the treatment of chronic constipation in adults, performed in the UKNHS.
- IBS School a pilot study comparing an educational group with an online approach to support people to self-manage.
- SUBSONIC a study to find out if the most popular surgical treatment for faecal incontinence called sacral neuromodulation works and why

Session three - Devices, data & developing services

- Directing treatment the expanding role of MRI.
- · Ostom-I Alert smart stoma bag technology.
- Bile Acid Malabsorption developing a more effective and cheaper test for this common cause of diarrhoea.
- Improving services for people with anal cancer.
- How effective is Consent for Contact in increasing opportunities to participate, and patient recruitment to IBS clinical trials?

Where is the Big Bowel Event?

Please register for free tickets online at www.bowelcancerresearch.org. The event is happening at Maple House in the centre of Birmingham. The venue is very accessible via rail, bus and driving.

Come along for refreshments at 10.00am, the event will end at 4.00pm.



*Information taken from www.bowelcancerresearch.org

Living with a BAD Girl

My lovely wife Ann and I have been together over 50 years. She has always had a volatile, erratic and sometimes aggressive bowel problems!

As well as BAD being dreadful for my wife, it has had a huge impact upon me and my family. Every trip, visit, journey and holiday is overshadowed with a fission of anxiety and trepidation, due to the inevitable and inconvenient toilet stops.

I have often wondered how much time of our life together has been spent doing detours, searching and waiting outside of toilets. Is it minutes, hours, days or even weeks in total?

Ann's problem was always a mystery until the amazing Gastroenterology doctors at the University Hospital Coventry and Warwickshire diagnosed Bile Acid Diarrhoea about 5 years ago. Sadly, due to Ann's complex medical problems the drug that works well for BAD (Cholestyramine), could not be taken. She had to use conventional "bunging up" medication (Loperamide) instead, which helps somewhat.

Many of life's pleasures: holidays, walks in the countryside are problematic due to lack of toilets. This has resulted in many 'Alfresco Events', of which some are too unseemly to mention here! However, this has caused several highly amusing episodes which we can share with some of our closest friends, causing much hilarity. A good sense of humour and laughter are powerful tools in coping with this problem, and as Ann's husband I hope I have helped her in this way.

I have often thought that I would like to have small round blue plaques made saying "Ann has c#@ped here!" I could fix these in many places, woods, beaches, etc!



Another job for me is to have a rucksack on my back with spare pants, pads and various cleaning tissues/materials. This too, gives Ann some peace of mind.

Driving for me can be eventful as well. There have been many occasions when Ann is desperately gripping the passenger seat with white knuckles. I have frequently wished our car had blue flashing lights and horns to speed our way through the traffic.



I also think that BAD sufferers must have some sort of transmitter in their bowels that always turn traffic lights to red when approaching them!

One of the most important roles is to help keep **up Ann's morale and self**-esteem. This horrible problem makes her feel very low and unattractive and this is simply not true,

I do hope these few words bring home the fact that this unpleasant condition affects others as well, but with input from me, the tremendous help form the BAM support UK group, Dr Ramesh Arasaradnam and his incredible team, we carry on smiling.

Peter Crowley

Thank you!

Big thank you to Peter and Ann for sharing their story with BAM Support UK and letting us share it with all our members.

If you have a story about BAM you would like to share, please e-mail admin@bamsupportuk.org we can keep you anonymous if you wish!



We almost made it.....

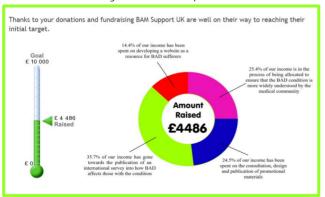
Firstly, we would like to say a BIG THANK YOU to all of you, for your support, sales and donations we have received so far throughout 2016 and 2017.

All our profits from RADAR Keys and Just Can't Wait Card sales, Support Meeting shop sales, raffles and donations.

Fundraising and public donations have helped us the most this year, as well as donation websites like Easyfundraising and Givey have all given us a big boost this year.

Your support towards our charity has been overwhelming and makes our work worthwhile.

To our BAM Support UK Facebook members, we would also like to thank you all for supporting one another with your own experiences, tips and advice. All of you are a vital part of BAM Support, people rely on you being there for them every day to answer their urgent questions. Social media is such a big part of our everyday lives now, which makes this the best way for us to spread awareness.



Now for the almost good news, at the beginning of April 2017, the end of 2016/2017 tax year, the total for money raised for this year was £3879.59. Which is amazing for a small charity that has only been running for less than 2 years.

By the end of the tax year we were aiming to make the milestone figure of £5000, which is the minimum a charity needs to make to be able to apply for a registered charity number. We came so close, but had been waiting for a grant to be paid to us, which would have taken us well over the target. Unfortunately, this had not arrived before April deadline. However, on the plus side it now means we have a good start off to this year's total.

Looking forward to reaching this **year's** total, we urge you all to help us! Please think of BAM Support UK as your chosen charity if you are having an event, fun run, charity day or bake sale. Every little will help. You can also donate on our website through Givey or Paypal.

We have a running total of what we have all raised on our website, so please go online and visit www.bamsupportuk.org to see how well we are doing.

If we reach our £5,000 target this tax year then we can apply for our full charity status number, which will mean we can apply for many government grants, research and sign up to bigger fundraising events like the London Marathon.

Have you visited our shop?

Online at www.bamsupportuk.org/shop.html
you can purchase RADAR Keys and Just Can.html
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You can purchase RADAR Keys and Just Wall toilet cards.

There are two types of keys available. The economy key with a smaller head, which is easy to put on your keys or the standard head which has a bigger head and easier to turn, also easier to find in a busy handbag!

BAM Support UK Toilet cards are for you to be able to discretely request the use of a non-public toilet.



Standard Key - £6.50 Economy Key - £6.00



Toilet Card - £3.00

Next Meeting - BAM Support UK Coventry Support Group

The next meeting will be held on,

Friday 9th June 2017

5.30pm - 7.30pm CSB, University Hospital, Coventry.

Please feel free to just turn up but it would be appreciated if you could email us to and let us know you will be attending, so we to have an idea of numbers and a big enough room for everyone.

Please e-mail;

chairman@bamsupportuk.org



Please bring your own drinks as refreshments are not supplied currently.

There is also charge for using the car park.

Top Tips & Tricks

Yoqitea Organic Stomach Ease

1 Cup.

Joanne said – 'I drink it before a meal and it's eased my stomach considerably'

Carol made her own version — 'For one cup I put a big pinch of fennel seeds, a big pinch of ground ginger and one cardamom pod in my mortar and ground it a bit with the pestle. I put all this in a small jug and poured onto it a cupful of just off the boil water, and left it covered to infuse for about 5 minutes. Then I strained it into a cup through the tea strainer and added a bit of sugar'.

Slimfast Milk Shakes

Two scoops with 250ml of milk or soya.

Carol said – 'Recently I tried this. I was very careful to read the ingredients of all the flavors as one or two of them have a sweetener in but others don't. I have used the strawberry one, twice a day, not for slimming but just because it tastes nice and it has really helped to bind me. Honestly I wouldn't have believed it but it's really helping. I don't know what is in it but it's nice and I'm going to carry on with it. I'm not saying it's for everyone but I'm liking the results'





Do you shop online?

Step 1: Head over to https://new.easyfundraising.org.

uk/causes/bamsupportuk and join for free. Don't forget to download the App. Step 2: Every time you shop online

Go to easyfundraising <u>first</u> or log on the app, find the site you want and start shopping.



easyfundraising.org.uk feel good shopping

Step 3: After you've checked

The retailer will make a donation to **BAM Support UK** for no extra cost whatsoever!

Produced by Jonathan Briscoe and Nealee Hardwick