

BILE ACID DIARRHOEA SUPPORT

BADUKMaking **BAD** days better

What's News

BAD UK Fundraising Madness

This year we have made a big push raising funds for BAD UK. Fundraising is a massive part of our charity, we need funds to pay for surveys, research meetings and groups. Our charity is all about raising awareness of Bile Acid Diarrhoea and finding out more about it.

We would like to say a **BIG THANK YOU** to all who help raise the fund and everyone who donated.

On Sunday 24th March BAD UK Committee member and treasurer Nicola O'Connell ran the Coventry Half Marathon at Coventry Cathedral.

Even carrying an injury, Nicki did the run in an amazing 2 hours and 8 minutes which she was over the moon about and for BAD UK she raised £322.50 with gift aid. Well done Nicki, amazing job!



On Sunday 28th April friend of BAD UK Ella Mozdiak Ran the London Marathon. Ella is a doctor specialising in gastrointestinal disorders and was very pleased to be supporting BAD UK.

Ella ran the marathon in 5 hrs, 8 minutes and 51 seconds, she raised an amazing £1,225.00 with gift aid for BAD UK. Well done Ella that's an amazing job, your hard work is an inspiration to us.



On Bank Holiday Monday 27th May our very own BAD UK members Karen Slade and Liz Smith ran the London Vitality 10km Run. Sadly Zoe and Rhia had to pull out last minute, but we managed to fill one of the places with Liz's daughter Jasmine.

The BADass runners raised a fantastic £956.25 with gift aid. Well done girls, an amazing job and just proves that even with this condition you can achieve amazing goals. We hope you inspire other sufferers of BAD that nothing can stop you!



Can you help Stuart's fundraising for BAD UK

Stuart Brown is fundraising for BAD UK and next week he will take on his Coast to Coast Rat Race challenge.

Stuarts Story;

Since 1984 I have struggled with chronic Diarrhoea, lots of tests, special diets, an incorrect diagnosis of IBS and 35 years later I have finally been tested for and diagnosed with Bile Acid Malabsorption/ Diarrhoea. (BAM or BAD)

The treatment for this is to eat less than 40g of fat (that's only 4 Kit Kats!!!!) a day and take Bile Acid binders, this will continue for life.

I'm not after sympathy, there are people who suffer much worse than myself with this. Some folks rarely leave their homes for fear of "accidents" whilst out. The reason for myself raising money for BAD UK is to help raise awareness, not just to the general public, but also to GPs and Doctors.

The Rat Race Coast to Coast Event is on 14th September in Nairn, Scotland. It's 105 miles of Running, Cycling and Kayak past the historic Cawdor Castle, the legendary Loch Ness and the mountainous Glen Nevis and Glen Coe on unforgiving Highland terrain.

Please support Stuart's challenge, he has BAD himself and this is a huge challenge for him. He is so close to his target! Let's help get his there.

You can sponsor Stuart's page at;

<https://uk.virginmoneygiving.com/StuartBrown65>



Latest Update on Bile Binder Shortages & Findings

We recently ran a poll on our Facebook due to the amount of concerned member experiencing a medication shortage. Here are the results;

POLL FINDINGS

Thanks to those of you whom participated in our poll about your current experiences of obtaining bile binder (bile acid sequestration) medications.

We thought it would be helpful to summarize the findings. Whilst it's concerning that some people are experiencing significant problems and are without bile binders (3.3%), it is good to see that a higher proportion of you (12.1%) have been able to obtain bile binding medications.

15.4% (161) of our active membership (1046) have participated in the poll

7.1% (74) - are experiencing no problems

0.8% (8) have successfully obtained an alternative bile binder

4.2% (44) - are experiencing delays in obtaining regular prescriptions

3.3% (35) - are unable to obtain bile binders due to being unable to get GP / consultant to change to an alternative or alternative prescription not being available either.

NHS SPECIALIST PHARMACY WEBSITE UPDATE

The SPS have advised that yesterday they have updated their website with the latest information on

the stock availability of bile binders and revised memo for GP's and Pharmacists. The memo advises that the manufacturing of Questran & Questran light is moving over to a new company.

Things you can do to help your pharmacist obtain your bile binding medications:

✓ Plan ahead for ordering your regular prescription by ordering your repeat as soon as your GP practice allows (depending on the area you live in different CCGs there may be variations in number of days before your current prescription runs out (e.g. 7-14 days) and the frequency of ordering repeats (E.g. some area only allow repeats on a monthly basis others allow regular or scripting to be ordered on a 3 monthly basis)

✓ Submit your prescription immediately to your pharmacy and explain the shortage situation to them.

✓ If your pharmacist is not aware of the problem, advise them of the Specialist Pharmacy Services website for all latest updates/actions pharmacists and GP's/Consultants need to consider/undertake

We will continue to liaise with the NHS Specialist Pharmacy Services and update you as soon as we can.

Should the current situation continue we will monitor it through the use of polls as we have found this an effective way to gauge a snap shot view of how it is affecting BAD patients.

BAD UK Petition for more NHS funding

BAD UK have launched an online government petition to request for more NHS funding to be allocated Bile Acid Diarrhoea research and to help improve medication shortages in the UK.

Please help us with more signatures by logging onto;

<https://petition.parliament.uk/petitions/269458>

Our petition is specifically targeting further funding into research for BAD. This would potentially improve any future medication shortages we experience. Funding for research would allow research into different medications and licensing for medications, plus so much more!

So far, we have just over 1000 signatures, and as with all these government petitions you won't get looked at until you have enough people wanting it to happen, so please get online and help.



Petitions

UK Government and Parliament

Petition

Provide better funding for Bile Acid Diarrhoea and improve medication shortages

More than 100,000 people in the UK have BAD. There is an ongoing shortage of medication used to treat the condition. There are only 3 companies who manufacture the medications for the UK, who are unable to meet the demand.

There has been no long term funding invested in how to treat the condition.

[▼ More details](#)

Bile Acid Diarrhoea is a debilitating condition that without a correct diagnosis and medication, can make life very difficult for its sufferers. Due to medication shortages, people are now without treatment, causing their bowel condition to be uncontrolled and are unable to leave their homes or go to work.

This is unacceptable, essential research funding is required to prevent this from happening again and to improve future treatment options for BAD. Please sign to help us make changes

[Sign this petition](#)

1,036 signatures

Fundraising a different kind of way for BAD UK

One of our amazing members Emily Hyatt has chosen BAD UK as her charity for her annual raffle.

Every year Emily does a raffle to raise money for her chosen charity. Last year she raised around £750.

Emily's Story;

Why BAD-UK? You may not have heard of Bile Acid Diarrhoea. When I got diagnosed with it in 2010 the only article I could find on it that wasn't in a medical journal was a jargon heavy Wikipedia entry. I didn't understand all the overly medicalised crap the consultant had told me about my ileum or something so I just kind of took the pills he offered and did as I was told and it helped a lot. Before the pills I pooped between 4 and 10 times a day. Seriously. I thought that was normal. It was only after a chat with a friend about poo that I realised that was REALLY not normal! On pills when I don't have a flair up it's now 3-5 times a day. A VAST improvement! I also have a lot less stomach cramps and well, let's just say I haven't had an "accident" for a while either! Poo isn't cool, or glamorous, it's funny sometimes thankfully so that gives me a platform to talk about it humorously. Bile Acid Diarrhoea varies in severity, mines quite mild, so my main symptoms are too much poo, cramps, bloating and fatigue.

For people with more severe bad or have the condition in tandem with other conditions such as Crohns, colitis and celiac disease it can be very disabling. It's hard to talk about at work too: "Hey so I have this thing where I poo like ten times a day" - some workplaces don't want to know so people will get labelled lazy, BAD UK do some nice flyers you can give your boss/loved one/anyone. Not even GPs know about this condition sometimes. When I started at a new GP after moving house she was all "eh? no you can't have pills they're expensive, what even is this" thankfully my consultant stepped in. That doesn't happen for everyone. At the moment as well our medication supplies have been interrupted, that may well worsen post-Brexit. I'm hoarding and rationing my medication which is well, a bit poo.

To read Emily's full story and how to enter the raffle, please head over to the raffle via Virgin Money Giving:

<https://uk.virginmoneygiving.com/EmilyHyatt>

If you're a fan of the Manic Street Preachers, then this raffle is for you!

Last entries 5pm on 24th October, the raffle will take place live at 7pm on 25th October 2019 on;

<https://www.facebook.com/groups/957716347647200/>

£1.50 a go or four tickets for a fiver

Good Luck Emily!



Raise funds for BAD UK every time you shop online

Find us on easyfundraising to start:

<https://www.easyfundraising.org.uk/causes/bad-uk/>



Shop with over 3,300 online stores



£20 Million raised

1.2 Million users

100,000 causes

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BADUK

Making BAD days better

LONDON MEETING

Wednesday 30th October 2019

6.30pm - 8.30pm

Davy's at Plantation Place

Unit 8, Plantation Place, Mincing Lane, Tower Hill,
London, EC3R 7BD

Special Guest Speaker – Professor Julian Walters

The Professor of Gastroenterology is joining us
to answer your questions about BAD

EVERYONE WELCOME

Sufferers, family and friends, medical professionals.

If you are able to attend please email

londonmeetings@bad-uk.org

so we can make sure we've booked the best size room.

Location: www.davy.co.uk/vine-bardavys-at-plantation-place/



Bring some money!



The BAD UK shop will be here!
You will be able to purchase RADAR Keys,
the new BAD toilet cards and Pill Holders,
all at a reduced cost.

All profits and donations are invested back
into the BAD UK Charity, to help develop
future awareness and research

BAD UK Donations and Support



Donate £20 to BAD UK and you can receive a BAD UK Donation Pack. You will receive a limited-edition BAD UK mug, Keyring, Toilet Card, Pens and Leaflets as a Thank You from us. To donate for this pack, visit our online shop.

www.bad-uk.org/online-store

Here you can also request a leaflet pack where you will receive 6 of all our leaflets to give out to Family, Friends, GPs. We just ask for £1.50 to cover P&P.



BAD UK on Social Media

Help share the awareness of BAD and follow our social media pages. You can follow us on;



BAD UK - Bile Acid Diarrhoea /
Malabsorption / Salts



@baduksupport



bad.uk