

BILE ACID DIARRHOEA SUPPORT

BADUK 

Making **BAD** days better

What's News

Keep on Running 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 are so grateful for people who help us do this, firstly, our very own BAD UK Committee member and treasurer Nicola O'Connell will be running the Coventry Half Marathon on Sunday 24th March at Coventry Cathedral.



Although Nicki has done this run before, it was a few years ago and since then she has struggled with an injury so is going to find this time extra hard.

Please help Nicki along her journey by donation at;

uk.virginmoneygiving.com/NicolaOConnell1



On Sunday 28th April we have the London Marathon where a friend of BAD UK Ella, will be running for us. Ella is a doctor specialising in gastrointestinal disorders. She says 'by running the London marathon in aid of BAD UK, I hope to help this fantastic charity continue to support and educate patients and health professionals'.

Please help Ella raise money for BAD UK and donate to;

uk.virginmoneygiving.com/EllaMozdiak

We then have the London Vitality Run on Bank Holiday Monday 27th May where we have managed to reserve 5 places for BAD UK members to represent our charity. We currently have Karen Slade, Liz Smith, Zoe Tonks and Rhia Butler running for us. We are currently looking for one more runner, so if this is of interest to you please contact Alex Hardwick – socialsecretary@bad-uk.org.

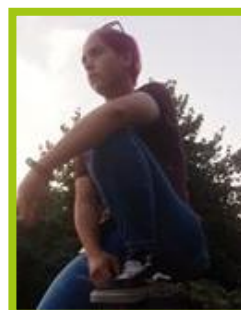
Karen ran the Brighton Marathon last year representing BAD UK and raised over £1100. We hope we can count on your support for these fantastic girls and give them the motivation they need.



Liz and Karen



Zoe



Rhia

Please donate to;

uk.virginmoneygiving.com/Team/BADassrunners



‘BAM at its finest days’ – today being one of them!

A story by Kerry Laker

I had my official diagnosis of Bile Acid Malabsorption in January 2018. I had my gallbladder removed in December 2012, prior to knowing I had gallbladder issues, I had ongoing bouts of diarrhoea but after the gallbladder diagnosis, I put it down to that.

On having my gallbladder removed, life carried on but quickly included issues after eating. When I say issues, I mean issues as in I very quickly needed the toilet after eating, often only just making it to the toilet! I visited my GP many times, was sent for ultrasound scans, had blood tests and everything came back as nothing wrong – I was told I had Irritable Bowel Syndrome.

The GP issued medication which made the pains in my stomach and bowel easier. One visit to a different GP ended up with me in tears, the GP was cold and had no time for me, and told me, “Do you think if I had a cure for your toilet problems, that I would be sat here? No, I would be rich on an island!” I walked out of the surgery and cried all the way home.

The diarrhoea continued, so another GP appointment and I finally had someone who listened to me, I was sent to see a Gastro consultant. I attended the appointment, I felt listened to for once since this whole episode had started. I was sent for a Colonoscopy to check for Chron’s, given a prescription for Questran and discharged. The Questran helped me for about a year, taking 2 sachets a day, finding I could only tolerate Questran Light, not normal Questran. Unfortunately, over time the diarrhoea returned with vengeance.

I built myself up to go back to the GP, had another amazing doctor, whom I later found out also worked in the Gastro department at our local hospital, I was sent back to the consultant again. The consultant I saw this time was brilliant, they listened to me, read my history and sent me for the SeHCAT Scan.

In August 2017, I swallowed the tablet, returned for my scan and a week later was scanned again. In October a letter dropped through the door informing me I had Bile Acid Malabsorption and was given an appointment for January 2018. I felt disappointed to be told in a letter of my diagnosis but kept in mind that I wasn’t going mad, there was ‘something’.

In January 2018, I eagerly went to the appointment, was met again by the lovely consultant, who confirmed the contents of the letter and gave me my percentage of 1.5% retention. I was given a prescription for Colesevelam due to my intolerance of Questran and discharged back to my GP. These tablets have changed my life, I am working 4.5 days a week now and I feel settled in general. I do have days where things aren’t great – I call them my ‘BAM at its finest days’ – today being one of them!

I have done my research on BAM, looked at websites, articles and have found support online. I have found a couple of groups on Facebook created for sufferers of BAM, which I have found really supportive and it’s been great to hear other people’s stories – I now know I’m not alone. I can talk with people on the groups that understand, my family have been amazing, but they don’t truly understand, and they admit that. One of the owners of a group asked for some help approving posts and members to the group, which I volunteered for and became involved in.

One day I got home and while sitting with a cup of tea, found that the owner of the group planned shut the group down due to not having time to run it, this made me feel sad and from looking at posts within the group it made other members feel this way too. Within a few hours the group had shut.

The next day I couldn’t get the group off my mind, so when I got home I contacted the lady who shut it down and asked if I could take it over. She quickly replied and said I could and opened it up for me making me admin for the group. I was so pleased! I nervously posted in the group that I had taken over and the group will still run and awaited to see what happened. I was quickly inundated with responses from members thanking me for what I had done, it made me realise how important that group was to so many people who suffer like I do.

Since running the group, I realised that sometimes people may be seeking answers to their posts quickly, and when I am at work I can’t have my phone on me. So, I have sought help from other members and now have 3 moderators to help approve posts and members. Since having BAM taking over the group is one of the best things that I have done, it makes me feel great knowing that our little group of around 1500 members are there for one another and we understand one another. We help each other through the bad days, answer questions for one another and we also love a bit of toilet humour.

My group on Facebook is:

BAM / BSM Bile Acid Malabsorption Support Group



Research and Surveys Updates

2nd Patient Reported Outcomes Survey:

BAD UK are pleased to announce our 2nd Patient Survey is now live. The 2nd Patient Survey is open to everyone with this condition and is not restricted to the UK. This is a very comprehensive survey which can take about 30-45 minutes to complete and looks at all aspects of this condition. It is quite long but can be saved at every point and returned to when you have time.

The survey will remain open until the **28th February** when we will then start to analyse the results.

A complete report will then be made available online for everyone to access and share.

The results and article publication of our 1st Patient Survey are available on the BAD UK website and available as a leaflet, see the Information Pack in our online store.

To take the survey enter the below path into your browser:

<https://www.smartsurvey.co.uk/s/2nd-BAD-Patient-Survey/>

Patient Support Group Survey:

We had a fantastic response with 33 people saying they would be willing to lead a group. We are now identifying locations in the top areas and contacting people whom showed an interest in running a group. In addition to our Coventry and London groups we are aiming to have another 6 up and running this year.

The top areas were:

- * South East
- * West Midlands
- * North West
- * East Midlands
- * South West
- * North East



We are pleased to announce that BAD UK are now working with **Talk Health**.

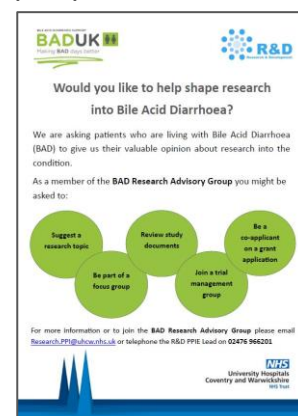
Talk Health are a team who are keen to provide the latest health information and support to communities and GP practices.

By working with them, we can raise awareness of the condition across their communities and social media networks. They provide platforms for us to hold online clinics and sessions, on their blog and health condition forums as well as patient education tools.

Research

We are now working with two organisations Nottingham Trent University and University Hospital Coventry and Warwickshire to undertake research into BAD from the patient's perspective.

NOTTINGHAM
TRENT UNIVERSITY



BAD UK are also launching our own research register where people with BAD can register their interest in types of research they would be interesting in supporting. BAD UK will then only email people if a vetted research study meets the preferences you have registered on our database. We will never share your information with any researches, we will just use the information we hold to notify you of any studies that meet your criteria, and provide you with information about the study and the contact details of who to contact if you do wish to participate

Welcome our new Volunteers

Welcome to Kerry Laker and Chelsea Jerome whom have recently joined our team of volunteers.

Kerry is supporting us to grow our social media profile and connect with other groups and charities to raise awareness of our condition.

Chelsea will be supporting us to undertake a freedom of information request about what diagnostic services are currently available to people with BAD within the NHS.

Massive thanks to Kerry for 12 days of BAD-mas!

A BAD Story Campaign

Did you know?

455,000 Facebook users have seen the campaign videos

55,000 people have visited the www.abadstory.com website

2,500 people have shared the campaign videos or awareness content on social media

Amazing results, thank you to all of you who help reach these figures!



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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COVENTRY MEETING

Monday 8th April 2019
5.30pm - 7.30pm
CSB (Clinical Science Building)
University Hospital
Clifford Bridge Rd, Coventry, CV2 2DX

5.30pm - 6.00pm
Meet and greet other members and the Committee for a chat

6.00pm - 6.30pm
Guest Speaker - Judy Burrell
Judy is a Dietician and will be talking about best foods to help with BAD symptoms

6.30pm - 7.30pm
BAD UK Meeting – General talk, Questions and Raffle

EVERYONE WELCOME
Sufferers, family and friends, medical professionals.
If you are able to attend please email coventrymeetings@bad-uk.org so we can make sure we've booked the best size room, but please feel free to just come along.

Bring some money!
As well as our BAD UK shop where you can purchase items at a reduced cost, we also have a raffle with some lovely prizes and treats. Any donations of £20 or over can also receive a Thank You Donation pack at this meeting! All profits and donations are invested back into the BAD UK Charity, to help develop future awareness and research

BAD UK was at the Big Bowel Event in London

On the 16th November we had Clare Pitchford and Laura Gentles representing BAD UK at London's Big Bowel Conference. A big thank you to you both for doing such a great job.

They spoke to many people about living with this condition and had lots of enquiries from other charities supporting people with bowel conditions as well as patients, consultants, medical researchers and nurses.



It's important for our charity to have representation at events like these, as it helps us with current and future connections who can keep us up to date with what's new.

**BIG BOWEL
EVENT**
16 NOV 2018



Bowel &
Cancer
Research

CCT Venues-Barbican, 135-137 Aldersgate St, London EC1A 4JA

It's not obvious something is wrong with me, it's a hidden disability

by Steve Woolley

I have been really suffering with my stomach for the last 14 months but suffered in silence for years before.

I have been virtually a recluse for 14 months and I felt that people that I saw didn't understand what I was going through and then people I hadn't seen thought I had become a hermit or died! so I posted the following on Facebook;

"I feel I need to explain about my medical condition, that some people are aware of and some not at all. A lot won't know that have seen me in the last year or so, as I've tried to hide it.

For over 20 years I have suffered with stomach issues and have avoided wheat. This was following various tests and trips to see consultants.

Although I am not allergic to wheat I am intolerant to it. This has been hard at times I feel a fraud as I wasn't diagnosed. It's been hard at work during working lunches as its not practical to whip out a salad whilst others ate sandwiches.

When I became ill, I had played in a charity 5 a side football match and 4 other friends were also ill the proceeding days following the match, so was it related to some bug I had picked up, or was it due to the Chinese takeaway I had after the football match, or was it linked to the severe food poisoning I had a few years before in Portugal, or maybe it's none of these!

In that time of 20 years, I've had good and bad days, sometimes the bad masked by taking around 3 or 4 loperamide tablets a day. Sometimes I could grin and bear it, other times I couldn't hide the pain and anguish, this made me reclusive, unsociable, irritable or grumpy. Sometimes you just want to be alone and hide away but the reality is this help's no one in my opinion and honesty is the best solution so people can appreciate and be appreciative of what you are going through. To those affected, please accept my apologies if you bore the brunt of this - it's been hard to control!

This has got a lot worse over the last 3 years (possibly my body reacting to the trauma we went through, I almost lost my daughter Jess - she was in hospital for almost 3 months when she was turning 3. She was rushed into the high dependency unit approximately a dozen times and at one stage had to be resuscitated in my arms). She now appears a healthy young girl to an observer but is under consultant care still and is being treated for what is thought to be asthma. Another example of looks can be deceiving.

At times I've quadrupled the medicines I should take (more than 12 loperamides) so I could do normal things like go to see the football with my mates.

Regularly, I would take tablets daily to get me through a day at work. I just wanted to do normal things. I used to love my away days with the lads or an evening out with the wife.

I did visit my local GP over the years and was brushed off with 'it's only IBS'.

A year or so ago my body gave in and luckily, I was referred quite quickly to a consultant by my GP. I think a lot of the medical care we receive is based on the GP you see. My consultant has been very supportive.

For the last year it's been like a prison sentence, not going out on special occasions such as my step daughter's 18th birthday, weddings, socialising with beers and meals, missing lots of Derby County matches and leaving very early when I have gone to home matches to avoid traffic. My worst fears are being trapped in a public place or being trapped in a traffic jam.

Although not life threatening, I was diagnosed with Bile Acid Malabsorption or Bile Acid Diarrhoea. It's an embarrassing and degrading illness. At it's worse I was going to the loo 80 times a day!

The problem is it can hit you at any time with little warning. If you see me dashing somewhere, it's usually to a toilet. I'm not being rude it's just, well needs must! I'm not as bad now but still out of control and completely rules my life. The medicines "control" my movements to a degree and I still have very bad days. I'm currently on 4 types of tablets totalling 16 per day in total for life. It's taken control of my life and at times sanity. I can no longer be spontaneous as I methodically plan where and what I do, but more importantly where toilets are. The find a toilet app is a godsend. I'm still trying to get better control and continuing various treatments.

In fact, it's not obvious something is wrong with me, so it's really a hidden disability.

I hope these treatments will come good and part of me getting better is to acknowledge my life won't or is unlikely to be the same again. It's obviously stressful, creates anxiety and depressing at times. I try to put a brave face on and hide behind the banter I give out. Only my wife sees the distress I'm in at times.

I've had holidays for the sake of the kids and wife. Without these I feel my marriage would have ended. However, to do this I effectively overdose the medication to mask the issue but severely suffer afterwards, sometimes I think it worth the suffering. There is no win situation with this condition. I must do this to give them a normal life. Even they notice my toilet dashes.

I also feel the combination of this condition and the medication has made me put on weight, despite exercise and healthy eating nothing shifts those excess pounds! It's affected me greatly, I haven't been at work for over a year and time becomes tedious.

I don't want sympathy, it's more to raise awareness of the condition and to say sorry to you, if you feel I'm being over cheeky, distant, stropky, grumpy or unsociable!

Also, to make people aware that not all disabilities are visual. There is a non-profit making charity from Derby who promote awareness of hidden disabilities. It's amazing the amount of illnesses that are hidden. This charity is there to promote awareness of such issues. We can and need to use disability toilets sometimes despite the fact we are not in a wheelchair.

Lastly I want to say a big thank you to my wife Kate for all her support and sorry to Kate and the kids for the impact it has on their lives."

After posting this I was overwhelmed by the number of likes, comments, texts and phone calls I received. All were positive and spoke about how brave I was to open up and talk about my condition and how I was feeling.

My message to you all is never think you are alone, and that people won't support you. We are all different and the person next to you may also have some form of hidden illness also.

For me I take each day in turn and hope the output from the medicines, CBT and dietician will allow me to control the illness and return to work and get back to living my life.

Thank You Steve for a great story, if you would like to know more about the Hidden Disabilities charity, visit;

www.hiddendisabilities.org.uk



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.

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Visit www.terracycle.co.uk to find out more and select BAD UK as your chosen charity



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



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