



President: Prof. Raj Persad

Vice President Mr Paul Sylvester

## Bristol Ostomates Self Support Group



### NEWSLETTER –Autumn 2020



Here are a few things your committee have been up to while we've been away!

Ruth joined a local ladies choir after lockdown and they've just released a socially distanced video recording of "That Man. Check out their website [www.blacksheepharmony.com](http://www.blacksheepharmony.com) to have a listen – they're also looking for new members! She has also been busy writing a blog on "My couch to 5K journey" for the Discover Your Bounce programme – listen on [www.discoveryourbounce.com/my-couch-to-5k-journey/](http://www.discoveryourbounce.com/my-couch-to-5k-journey/). As you can see "lockdown" isn't an excuse not to exercise both mind and body!!

Janet, your secretary, has been raising money with her Lions Club for Children's Hospice South West by walking a marathon around her field. This was in place of the Duck Race they normally hold in May in aid of C.H.S.W. – so far, they've raised £850. You can learn more on [www.cheddarvalelions.org.uk](http://www.cheddarvalelions.org.uk) . Below is the Finish!!



Josh has been cycling from west to east across the country. Here is his story.

"At the end of May, a couple of friends announced plans to bicycle 'Coast 2 Coast' from Whitehaven to Whitby and invited others along. With no real cycling experience, no suitable bike, and having had my ileostomy less than a year, I of course jumped at the chance! With under 7 weeks to get myself prepared, I bought a new bike and started an intensive training programme to give me some chance of completing a challenge met with trepidation by much more experienced cyclists.

The total ride length is over 300km (180 miles) and we had a target of 3 days to complete the ride. The journey starts with dipping your back wheel in the Irish Sea and ends sipping your front wheel in the North Sea. The biggest part of the challenge is the hills - over 4500 meters of climbing, or cycling up three and a half Ben Nevis's if you prefer!

All of this was made easier for the fact we chose to support Friends of Mutake School. The charity works directly with Mutake School near Harare, Zimbabwe. The school has over 1200 primary aged pupils and has only within the last month gained access to running water. There is currently no school kitchen, no library, and children feel genuine excitement in receiving a pencil and a writing book - these are luxury items to them. Knowing that collectively we're to improve the lives of children who want nothing more than to live, learn and be happy made the tough hills easier.

Prior to my operation, I would've wished the guys good luck or at a push may have driven a support vehicle for them, but there would've been no way I'd have joined in on the ride. With IBD life can be a constant battle from one toilet stop to the next when travelling and with aching joints and fatigue I'd have struggled to cycle for a day let alone three. I'm very thankful to the NHS, the surgical team at Southmead and my wonderful Stoma nurses.

There are a lot of misconceptions about life with a stoma and prior to surgery I wondered if I'd ever get back to full strength. I think it's fair to say anything's possible, you just have to have the self-belief and determination to achieve it. "



We've all been inspired by "Colonel" Tom's achievements – let me know what you've been up to and we can feature it in the next Newsletter, on Facebook and our website!

Welcome to our new members, I hope you find the group useful! We hold a raffle at every meeting and the talks are followed by delicious cakes and tea or coffee! There is always time to chat and see what the company reps have to offer. If you have a problem talk to our stoma nurse, Helen – and don't forget to make yourself known to those of us on the committee!

A word of caution – if you wear a hearing aid do be careful putting a mask on and off – I have found 2 hearing aids on the high street in Wells recently, they'd obviously been caught up in a mask and lost!

As you may be aware, we had to cancel our June meeting because of the Covid 19 virus. **We had hoped to be back up and running in September but, unfortunately, this too has had to be cancelled.** The hall isn't open and social distancing would mean a limit on numbers who could attend. In the meantime if you need help/information/support then do get in touch 01934 248114. We are starting to plan next year's calendar – is there any topic you would like to see covered in our talks? Just contact Janet or any of the Committee and we will see what we can do. We will (hopefully) be holding our Open Day again next year. We have put a provisional booking with the Future Inn again as it is so central to Broadmead and the Bus Station and there is a multi-storey car park by the side and it is near the Bus Station and bus routes.

**Subs were due in March and our Treasurer says some of you haven't yet paid or returned the forms sent with the Spring Newsletter. Please keep him happy and let him have your dues! The forms keep your details up to date. The Committee have decided that your membership paid for this year will cover you for next year as well so do keep John happy it'll also keep you on our books as those who haven't paid will be removed after this newsletter.**

Here is Josh's stoma story:- "On Christmas Eve 2007, I had a bad belly. A bad belly that didn't go away. By June 2008 I was diagnosed with Ulcerative Colitis and was at risk of a permanent stoma. Living through pain and medication I made it through to 2013 before being hospitalised, where the stoma conversations began again. I was still adamant that medical treatment was my best option and after many different medications found the perfect combination to finally put me in remission in 2016. I lived a happy and healthy life and was getting on just fine, until the dreaded Colonoscopy letter arrived in Jan 2019. My results came through a couple of months later and I was required to have

a second test. Shortly after this it was confirmed that I still had active inflammation, but more seriously high grade dysplasia. The conversations were now only about when and which surgery I would be having.

At the end of September, I was admitted to Southmead for a subtotal colectomy/ileostomy. This gives me the option of a j-pouch in the future if I wished. My surgical and stoma team were shocked at the speed of my recovery and within a few weeks I was up and about working out what to do with my new life. I (despite terrible social media presence!) found B.O.S.S. and attended the Christmas meeting with warm welcomes.

By the Spring meeting I was elected to the committee on the agreement I would facilitate a Social Media role, which I am pleased to say has been set up across the main platforms - Facebook/Instagram/Twitter.

These can be accessed here:

Facebook: <http://www.facebook.com/groups/bristolostomates>

Instagram: Bristolostomates

Twitter: BOSSostomates “

Can you put a copy of this Newsletter in your local surgery? There may be other stoma patients who don't know about us yet and who could benefit from realising they are not alone with their stoma.

We have an outlet for surplus ostomy supplies so you can bring them along to meetings and we will forward them on. Please ensure that if they are two-piece appliances BOTH parts are there TOGETHER!! Thanks. We can also take unused drugs as long as they are in sealed “wrappers or blisters”. If anyone wonders where they all go the RAFT charity which takes them sends them out to third world countries and refugee camps to be distributed. We also have a second outlet – the charity A to B which sends them out to Albania. So “thank you” in advance. It is a shame there is so much being donated – by that I mean it is a shame that the NHS is paying for so much surplus supplies. A box of bags costs about £100.00p! If you are having problems and are trying out different bags you can get free samples from the supply companies or just order one box at a time and, if you can, cut them yourself until you are sure they are the right bag for you - it helps prevent waste.

At this moment in time we are unable to pass on surplus supplies (charities are mainly shut down) so we are having to store everything until the situation gets back to normal! If you have any to bring to the next meeting give Janet a ring on 01934 248114 to check we have room to take them!

Please bring your used stamps along to the next meeting – Christina has an outlet for these as well!

If anyone feels they can share an experience or information with the rest of the group then please send it to me for inclusion in the next Newsletter – this is your newsletter so feel free to contribute - and it helps me to fill the pages!

Just email [Janet.Clark@ostomy.org.uk](mailto:Janet.Clark@ostomy.org.uk)

Our stoma care nurse is Helen Jarvis and she is usually in attendance at our meetings to give you help, if needed.

Tel:: 07513 120456

If you have an emergency admission to hospital and need some essential nightwear or toiletries, please get in touch as the group has some funding to cover this. Treasurer John on 01934 863679.

Don't forget to check out our website [www.ostomy.org.uk](http://www.ostomy.org.uk) let Janet know if there is anything you would like to see on it! Also our Facebook page - the link is <https://www.facebook.com/bristolostomates/>



### Dates for your Diary

#### **2020**

**5<sup>th</sup> September** . Cancelled

**5<sup>th</sup> December** Christmas Fun! Our talk will be by Consultant Ann Lyons from Southmead Hospital. Our rep will be Sian from Pelican

#### **Useful Contacts:**

**Colostomy UK**, Enterprise House, 95 London Street, Reading RG1 4QA.  
Gen. enquiries Tel: 0118 939 1537. Stoma enquiries Tel: 0800 328 4257.

**Ileostomy and Internal Pouch Support Group**, National Office. IA National Office, Danehurst Court, 35-37 West Street, Rochford, Essex SS4 1BE Tel: 0800 018 4724. E-mail the Local Secretary: Kerr Brown [secretary@ia-avon.org.uk](mailto:secretary@ia-avon.org.uk) Avon IA Tel: 01454 883309. Or [www.avon.iasupport.org](http://www.avon.iasupport.org)

**Urostomy Association**, National Secretary, Hazel Pixley, Central Office, 2. Tyne Place, Mickleton, Chipping Campden, Glos. GL55 6UG. [www.urostomyassociation.org.uk](http://www.urostomyassociation.org.uk) Tel: 01386 430140. Or e-mail [info@urostomyassociation.org.uk](mailto:info@urostomyassociation.org.uk)

**Radar Keys**, for use in disabled toilets are available from: The Disabled Living Centre, Vassell Drive, Gill Avenue, Fishponds, Bristol. Tel 0117 9659353. Cost of key £5.

**Our group listeners are:** Jan Clark 01934 248114 or Christina Hammond 07773 869503 or Dave Morgan 01934 511020 or you can e-mail [Janet.Clark@ostomy.org.uk](mailto:Janet.Clark@ostomy.org.uk) or [chris@ostomy.org.uk](mailto:chris@ostomy.org.uk)

We normally meet in St James's Priory, Whitson Street, Bristol – just behind the Bus station at 2pm.



**Take care and stay safe – hope to see you all in December. If you have any concerns and want to talk – give our listeners a ring.**