



President: Prof. Raj Persad

Vice President Mr Paul Sylvester

Bristol Ostomates Self Support Group

Supported by Macmillan

Macmillan Cancer Support



NEWSLETTER – AUTUMN 2023



Welcome to our Autumn Newsletter. You will find below details of our Summer Meeting and other news.

JUNE MEETING: We were pleased to welcome Aileen Fraser back to a BOSS meeting. Aileen is the Irritable Bowel Disease Advanced Clinical Practitioner, Lead Inflammatory Bowel Disease Nurse at Bristol Royal Infirmary. She gave a very interesting talk on the similarities and differences between IBD and IBS, self-help and present and future treatment. Aileen also mentioned Rehydration Solution Recipes. This has now been emailed and hard copies will be available at the September Open Day and the December Meeting.

The trade table was hosted by Melanie and Maria from Suportx/Ami who enjoyed meeting both new and long-standing BOSS members. Suportx/AMI will also be exhibiting at our September Open Day.

Macmillan Support Grant : We are grateful to Macmillan for their financial support of BOSS for the next 12 months. Their grant includes support of our refreshments both at the regular meetings and also the upcoming Open Day. Thank you to members who wrote comments in our new book. Your comments will be used to assist Macmillan in evaluating the impact of BOSS membership.

New Members Welcome! We always welcome new members – come and give us a try! Hopefully you will enjoy your first meeting and become a member! We guarantee a warm welcome!



Stoma Supplies to Refugees including Ukraine: Janet continues to collect surplus supplies and £5k of supplies have been sent to Ukraine via the Lions. Refugee Aid has also arranged to send another £5k worth of supplies to other refugees.

Your Stoma Prescriptions As you aware, your Stoma Supplies will soon be signed off by the Stoma Nurses rather than your GP. As a consequence, you may find some items have been changed. If you find the new item does not suit you for any reason, please contact your Stoma Nurse and explain any problems you are having. They will do their best to resolve any issues.

BOSS OPEN DAY

SATURDAY 2ND SEPTEMBER 2023

1000 – 1330

FUTURE INN, BOND STREET, BRISTOL BS1 3EN

Everyone is welcome to come along to our Open Day on Saturday 2nd September. Drop in at your convenience between 1000 and 1330 hours. You can meet and chat to a range of exhibitors including The Avon Company, BBraun, Bristol & Weston Hospitals Charity, Coloplast, Colostomy UK, CUI Wear, Dansac, Hollister, Irwin Mitchell Solicitors, Ileostomy Association, Opus/Alliance Pharma, Peak Medical, Pelican, Penlan Medical, Rhodes Pharma, Salts and Suportx/AMI. The Hospital Stoma Nurses will also be present.

The Future Inn is located opposite Cabot Circus. The Hotel is within walking distance from the Bus Station and well served by local public transport.

Directions by car: Exit the M4 at junction 19, and then take the M32 into Bristol 'City Centre'. At the end of M32 merge left after the traffic lights on Bond Street. Parking is available.

Parking: Half price car parking is available at the 'Cabot Circus' multi-storey – the entrance to the car park is located 50 meters past the 'Office Outlet' unit on your left. Upon arrival, drive straight in and take a ticket. Parking for the hotel is available on all levels, however we advise guests to park nearer the ground floor for easier access. Make your way to the hotel via the exit on the ground floor. On departure please present your ticket to the Hotel's reception team who shall validate your ticket to receive the 50% discount. The balance should then be paid at the car park pay station.

Please come along and say hello – you can also enjoy a cup of tea or coffee!

How to find The Future Inn



Bristol Clean Air Zone is now in operation for Central Bristol. For more information and to check your vehicle and/or pay the charge, please use the website www.gov.uk/clean-air-zones.

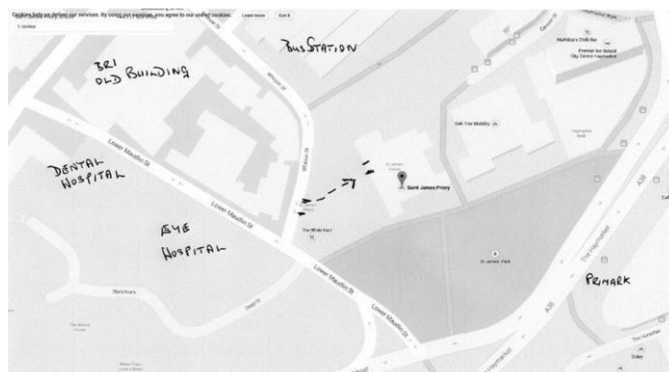
Future Meetings at St James Priory, Whitson Street, Bristol BS1 3NZ – just behind the Bus station - all at 2pm

2nd December/Christmas 2023 – Speaker will be Geoff Vian from the RNLI and trade table will be hosted by Kim from Rapidcare/White Rose

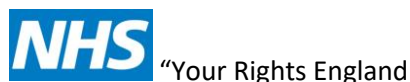
2024 Dates – Saturdays 2nd March, 1st June, 7th September and 7th December 2024

A Stoma Nurse is normally in attendance at our meetings. There is a raffle and the talk by the speaker is followed by tea, coffee and delicious cakes. There is also an opportunity to chat with fellow ostomates and Committee members. Details of the venue follow. All meetings start at 2pm and normally finish before 4pm.

How to get to St James Priory



The below article taken from Tidings Magazine produced by Colostomy UK may be of interest



'The NHS Constitution establishes the principles and values of the NHS in England. It sets out the rights for patients which the NHS is committed to achieve by ensuring the fair and effective management of resources and care'

1. You have the right to be given information about the treatment options available to you, what they involve and their risks and benefits. (*NHS Constitution*)
2. You have the right to be involved in making decisions about your care and should be offered the opportunity to participate. The Health and Social Care Act requires your local NHS to promote patient involvement in decisions about their treatment. (*Handbook to the NHS Constitution*)
3. Suppliers should fulfil orders for any appliance approved for use on the NHS. If they are unable to fulfil an order they must either forward the order on to another supplier (if they have your permission to do so) OR provide you with the details of two other suppliers who can fulfil it.

Suppliers should also be able to provide appropriate advice about the products they sell, for example how to use, clean and care for them. They may also be able to offer you online support to help you manage your condition, for example by preparing you a personalised web-based care plan. (*The National Health Service (Pharmaceutical and Local Pharmaceutical Services) Regulations 2013*)

4. Your local NHS has the right to make decisions over which treatments to fund, you have the right to expect those decisions to be made following a proper consideration of the evidence. If your local Clinical Commissioning Group decides not to fund a medical device which you and your doctor or healthcare professional feels is right for you, they should explain that decision to you. (*NHS Constitution*)
5. You may be entitled to free prescriptions if you regularly use ostomy or urology appliances, particularly if
 - You have a permanent stoma;
 - You need an appliance or continuous surgical dressing because of a permanent fistula (an abnormal passageway between two organs, or an organ and the exterior of the body);

- Are being treated for cancer, the effects of cancer or the effects of cancer treatment; or
- You cannot go out without the help of another person because of a continuous physical disability.

Alternatively, if you are over sixty or are on benefits because of low income you may also be entitled to help with prescription costs.

6. You can decide how to get your prescription supplies dispensed. You can obtain prescription supplies in five different ways
 - You can let the supply company (sometimes called DACs) handle everything – you place an order with them and they will contact your GP to get the prescription;
 - You can place an order with a supply company and then send them your prescription yourself;
 - Your GP can handle everything – you can ask your GP to send the prescription to your supply company of choice. Some GP practices also have a dispensing arm that may be able to provide your appliance;
 - You can order on the NHS Electronic Prescription Service (EPS) via your GP or nurse. You will need to nominate your supply company and prescriptions will be sent there electronically, reducing delivery time;
 - You can take your prescription to a local pharmacy.
7. You have the right to expect pharmacies and suppliers to provide supplementary items (such as disposable wipes and disposal bags) when fulfilling a prescription for incontinence, stoma, catheter, erectile dysfunction, wound drainage and irrigation appliances. (*The National Health Service (Pharmaceutical and Local Pharmaceutical Services) Regulations 2013*).
8. You have the right to have supplies delivered discreetly to your home. The packaging and method of delivering continence, stoma, catheter, erectile dysfunction, wound drainage and anal irrigation appliances must not indicate the nature of what is being delivered. (*The National Health Service (Pharmaceutical and Local Pharmaceutical Services) Regulations 2013*)
9. You have the right to an urgent supply of appliances from a pharmacy or supplier without a prescription, if your doctor (or another health professional who can make prescriptions) asks them to do so. This will require your doctor (or the other prescriber) to agree to provide a prescription within 72 hours. (*The National Health Service (Pharmaceutical and Local Pharmaceutical Services) Regulations 2013*)”

***** End of Article *****

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.avon@iasupport.org
Avon IA Tel: 01454 883309. Or 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 Tel: 01386 430140. Or e-mail info@urostomyassociation.org.uk

Bladder and Bowel Community email help@bladderandbowel.org or www.bladderandbowel.org .

Stoma Nurses – Bristol Royal Infirmary and Weston Hospitals – 0117 342 7638 - stomacarenurses@uhbw.nhs.uk
Southmead Stoma Team – 0117 414 0270 - stoma@nbt.nhs.uk

Radar Keys, for use in disabled toilets are available from: The Disabled Living Centre, Vassell Drive, Gill Avenue, Fishponds, Bristol. Tel 0117 9653651. Cost of key £5.

Our group listeners are: Jan Clark 01934 248114, Christina Hammond 07773 869503 or Dave Morgan 01934 511020 or you can e-mail Janet.Clark@ostomy.org.uk