# ASSOCIATION Incorporating all types of urinary diversion

UROSTOMY

Life as a young urostomate

Lucy's road to recovery

## From cancer to crossing three countries

John and Wendy's story of hope and gratitude

## Look after your skin

Top tips from a stoma care nurse

#### **Money matters**

Are you getting the benefits you're entitled to?

#### Ask the experts

UA webinars coming soon



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Ross, CeraPlus™ Product User

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CE



Ostomy Care Healthy skin. Positive outcomes.

## Welcome to our spring Journal



ith spring being associated with V newness, it couldn't be a more appropriate time to introduce UA's new-look Journal. We hope you like it!

We welcome your feedback as well as your contributions for the Journal. Please get in touch via editor@ urostomyassociation.org.uk or at Urostomy Association, Office 205, No 9 Journey Campus, Castle Park, Cambridge CB3 0AX.

Articles, emails and letters for consideration for the summer edition should arrive no later than 15 June.

Thank you.

It's FREE to join the UA as well as really straightforward find out more on page 38.

The fresh design isn't just a revamp, it's the result of making changes you've been telling us you want to see, such as photographs of younger people as well as those more mature and better use of space on the pages, making articles easier to read. Thank you to everyone who has contributed to this edition, from Lucy, Petrina, John and Mike sharing their experiences of overcoming huge health challenges, to magazine designer Chris Allen, who has skilfully translated your Journal feedback into our

new design.

The Journal isn't UA's only resource to receive a 'spruce up' we've been making some changes to our website too: a smarter, more modern look and improved navigation to make it easier for you to find the information you need. There's still work to do, but be sure to visit our blog section with real-life stories as well as articles kindly contributed by stoma care professionals. The website is also where you'll find the UA's strategic plan, setting out our charity's direction of travel for the next three years. If you're not online, please get in touch on 01223 910854 and we'll

post a copy to you.

Wishing you healthy, happy spring.



Paola Simoneschi Editor

PS This is your Journal and we'd love to hear from you! Please see the lefthand column for our contact details.



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### **UROSTOMY ASSOCIATION**

#### On the cover

Lucy Curran and Barney. Turn to page 8 to read Lucy's story.



**UA Transformation Director:** Samantha Sherratt

**Editor:** Paola Simoneschi

**Designer:** Chris Allen, The Upper Room

**Printer:** One Digital, Brighton

#### **Journal advertising**

Published three times a year (spring, summer and winter), the Journal is the UA's flagship magazine. We welcome advertising – please get in touch via editor@urostomyassociation.org.uk to discuss your requirements.

#### **Photo credits**

Thank you to UA supporters who have provided photos for this edition. All other photos are courtesy of Canva unless otherwise stated.

#### **Disclaimer**

The views expressed by contributors are not necessarily those of the Urostomy Association. Great care has been taken to ensure accuracy, but we cannot accept responsibility for errors or omissions. The display or description of products or services, or the inclusion of advertisements or inserts within this magazine, does not constitute an endorsement or recommendation by the Association.

#### Listen to the Journal FREE of charge

A recorded version of this magazine is available free of charge for people who are partially sighted or blind. Please email *info@ urostomyassociation.org.uk* or call **01223 910854** to find out more.

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## **UROSTOMY** About the UA and our support for you



**Registered charity England** and Wales: 1131072

Scotland: SCO47740

#### About us

Life with a urinary diversion can feel daunting, so it's vital that people have somewhere reliable to turn for the reassurance and support they need, from diagnosis to living life to the full again. The Urostomy Association is the national charity for them and for their families and carers, too.

We never want anyone who may be feeling anxious to miss out on our support. That's why we provide our services **free** of charge, regardless of their financial circumstances, so they can access what they need, when they need it, helping them stay well so they can enjoy life.

We offer information and support through our helpline, website, regular magazine and e-newsletters, group meetings, social media and fact sheets.

Office address: Urostomy Association Office 205 No 9 Journey Campus **Castle Park** Cambridge CB3 0AX

We also campaign on behalf of everyone living with a urinary diversion, making sure their voices are heard wherever they need to be.

#### **One-to-one support**

There is nothing quite like speaking to someone who understands what you may be going through because they have been there too. We can link you up with one of our trained volunteers in your area who knows from their own experience what it is like going through surgery for a urinary diversion and adapting to life afterwards.

Our volunteers provide support in person, over the telephone and online. Wherever possible, we aim to link you to someone who has the same type of urinary diversion as you.

#### National Executive Committee (Directors and Trustees)

#### National President

#### **Professor Derek Rosario**

**Consultant Urological Surgeon** Royal Hallamshire Hospital Contact: via info@

#### urostomyassociation.org.uk

Chair

#### **Brian Fretwell** Contact: chairman@ urostomyassociation.org.uk

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- Contact: william.burden@ urostomyassociation.org.uk
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- Contact: chairman@ urostomyassociation.org.uk
- Julie Varley (Cambridge, Sheffield & District and Yorkshire & Humberside branches)
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Email: info@urostomyassociation.org.uk

Web: www.urostomyassociation.org.uk

#### Join our friendly community

Joining the UA is really straightforward - and we'd love to welcome you! Simply complete the form on page 39 of this magazine, or the one on our website: www.urostomyassociation.org. *uk/join-now*, and we'll send you our news and information the way you want to receive it.

#### Show your support for UA

As a charity, we can only do what we do thanks to the generosity of our supporters. Making a donation of whatever you can afford helps us continue our vital work for evervone who needs us.

You can donate online at www.urostomyassociation.org.uk/ *shop/donate*, fill in the donation form at the back of the Journal or call our office on 01223 910854.



We are looking for people living with a stoma, as well as healthy individuals without a stoma, to take part in non-invasive skin research at our Birmingham skin clinic.

The Central Skin Sciences Institute (CSSI) combines skin health research with reliable, innovative testing methods and expert clinical knowledge to provide you with the best support during our clinical investigations.

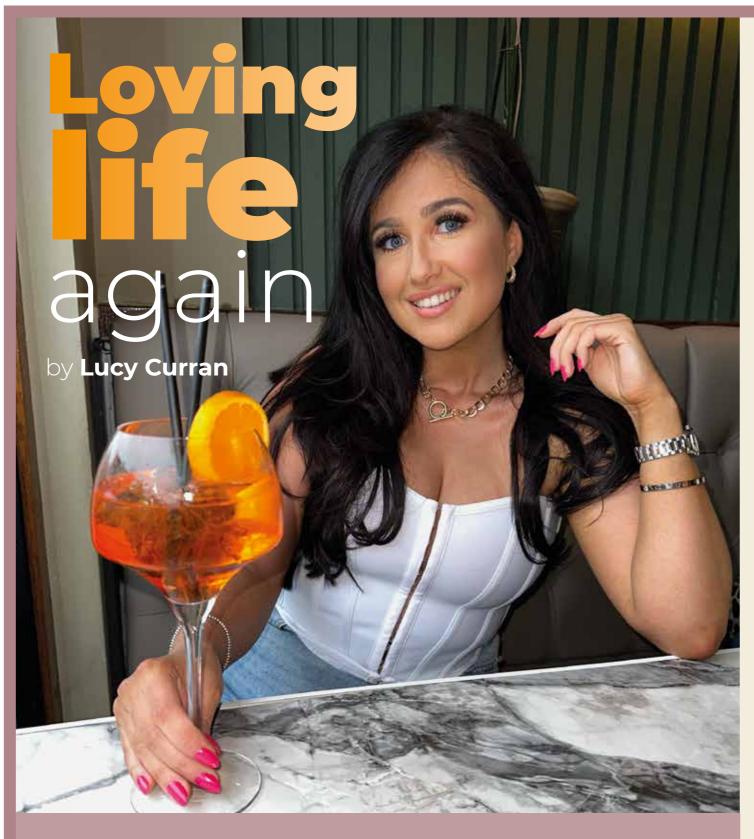
We want to improve the quality of life for people living with skin conditions, or medical devices worn on the body, by conducting research that will help us develop new adhesive technologies.

If you would like more information or to discuss any questions you may have, please contact our Clinical Research Coordinator on 0121 333 1592.

By joining our database and taking part in our studies, you will be helping us to learn more about the skin and develop medical device adhesives that could improve the quality of life of people who wear a medical device.

Will I get paid? You will be reimbursed for any reasonable travel expenses to the CSSI, and we will compensate you for your time attending the CSSI during the study. Details of payments for the study are calculated based on the level of required commitment and time.

How do I sign-up? To find out more about CSSI, where we are and to complete our signup form, please visit www.cssinstitute.co.uk



My journey to where I am today, living with a urostomy at just 30 years old, began three years back, when I was diagnosed with cervical cancer. Little did I know this wouldn't be the first time I'd hear the words "You've got cancer", or that I'd need life-changing surgery at such a young age.

Neither would I have guessed my journey would lead me to some of the most inspiring people I've ever met and that by coming together, we could be a powerful voice for others living with a stoma.

#### **Diagnosis during** lockdown

It was 2021 when I first noticed I was bleeding between periods, but I put it down to not taking my contraceptive pill properly – until it happened again. I knew it was important to see a GP, but the country being in lockdown made that easier said than done. Another month went by before I booked the smear test that would ultimately turn my world upside down.

Even if, like me, you suspect it, nothing can quite prepare you for hearing you have cancer, let alone that it's already spread to surrounding tissue. I still remember the ripples of fear that went through me, as well as how hard it was telling my family and friends.

Treatment was seven weeks of chemo and radiotherapy, but I was unable to have the internal radiation I needed - the risk of perforating my womb being too high. So, even after getting the 'all clear' 12 weeks later, I couldn't shake the sinking feeling that the cancer would return.

#### **Devastating blow**

I did try to follow the hospital's advice to get on with life as normal, but if only! Treatment had thrown me straight into early menopause, and it felt

in vain for advice while grappling with the crushing reality that I wouldn't be able to have the family I'd always planned. On top of this, I was struggling to get HRT for my menopausal symptoms. It shocked me just how hard it was to be heard.

after being declared cancerfree, I noticed symptoms

<sup>44</sup> Hearing the cancer had returned was so much harder second time around not just for me but my family too."

like a whirlwind as I searched

returning. My fears were confirmed, and hearing the cancer had come back felt so much harder on me and my family second time around.

Chemo wouldn't cure me, only prolong my life, so when I was offered surgery to remove my bladder and create a urostomy, it was Even worse, just 11 months the hope we all desperately needed.

#### Life with 'Pam'

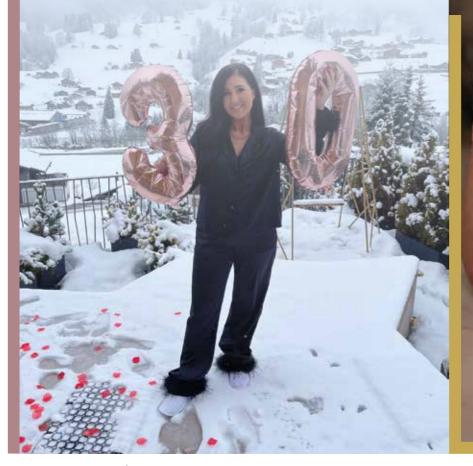
There were good and bad days as I recovered from such a major operation, but adapting to my stoma bag got easier once I was home. Life with my pee pouch 'Pam' is second nature now.

I'm embracing life again, working as a Finance Manager and enjoying walks with my dog Barney, as well as holidays and nights out with friends.

I still like getting dressed up. Sometimes there's a slight bulge

where my bag is if I'm wearing close-fitting clothes. I'm relaxed about it though. I worry about leaks, but I don't let that hold me back either. And on the plus side, there's no more queuing for the loo at festivals!

By sharing my story here and via my Instagram account @ kickingcancerinthecrotch, I want to spread awareness and hope. If I can help even one person, that would mean the world to me.



We are showing that in our own unique way, we are all beautiful and strong.

CalvinKlein

Going for gold

Lucy Curran and

Petrina Barber photographed by Jody Wright.

It was while adapting to life with a urostomy that Lucy Curran heard about fitness model and campaigner Petrina Barber (left). Excitingly, she went on to feature in a powerful photo campaign for Beyond the Stoma, the platform founded by Petrina for people with any type of stoma.

Petrina, 42, has not only overcome the cervical cancer she was diagnosed with at age 31, five months after giving birth to her son, she has also endured heavy chemotherapy, radiation, kidney failure, sepsis and multiple major surgeries, most recently bowel

surgery, resulting in a permanent colostomy. She said: "There are many ways in which someone can end up needing an ostomy, and I wanted Beyond the Stoma to represent all perspectives. It's about positivity, diversity and inclusivity, and encouraging people to dream big and never settle for less than they deserve.

"Our photography campaign came about after a lightbulb moment about how to reposition the narrative of life with a stoma using the Japanese art of Kintsugi, which roughly translates as 'joining with gold' and describes the technique of restoring broken vases using gold leaf.

"Kintsugi has always been a metaphor for my own life – taking something considered 'broken' that would be traditionally deemed less valuable by society and turning it into something more beautiful. As the visual concept for our campaign, it highlights the individuality of each person with a stoma.

"Typically, there's even less awareness of urostomies than On the day of the photoshoot, Lucy found any nerves about For more information, visit *www.beyondthestoma.com*. You can

colostomies and ileostomies, so it was crucial to include urostomates in the campaign as well as people who have two types of stoma. In our own unique way, we are all beautiful and strong." being in front of the camera with her bag on show were soon quelled. She said: "Jody the photographer was so good at putting us all at ease, and the atmosphere was really positive. It's exciting being part of such a groundbreaking project that's all about empowering people, whatever type of stoma they have." follow Petrina on her Instagram account, @petrinabarberstoma.

## Money matters

ealth and disability benefits are a lifeline for many people, but trying to find reliable information to help you claim any benefits to which you may be entitled can sometimes feel like navigating your way through a maze.

While we can't provide advice on your personal eligibility for claiming benefits, we hope our summary with signposting to trusted sources of further information will help you find what you need to see if you qualify, saving you time and frustration.

For specific advice for your personal circumstances, we recommend contacting your local branch of Citizen's Advice. As well as helping you check your eligibility for benefits, they can advise you on how to complete any relevant application forms. There's a list of other helpful sources at the end of this article.



#### **Disability Living** Allowance (DLA)

DLA is gradually being replaced by PIP (Personal Independence Payment) for people aged 16 or older. However, if you were born before 9 April 1948, you should keep getting and renewing your DLA instead of moving to PIP.

If you've reached state pension age and your DLA ended more than a year ago, you can't claim DLA or PIP. You will need to claim Attendance Allowance instead – please see below.

#### **Attendance Allowance**

Attendance Allowance is a non-means tested benefit for people over state pension age. You may be eligible if you have a long-term physical or mental health condition or disability that means you need help with your personal care, such as washing and dressing, or supervision to keep you safe.

If you're awarded Attendance Allowance, you can spend it on whatever you want that makes life easier. You don't have to spend it on paying for care. However, your local council or trust can take Attendance Allowance into account when working out how much you need to pay for the care services you receive.

For more information, visit www.gov.uk/attendanceallowance.

#### Personal Independence Payment (PIP) -**England and Wales**

If you struggle with everyday tasks or your mobility, you could be entitled to claim the Personal Independence Payment (PIP). It is not a means-tested benefit so you may be able to claim even if you are working, or have other income or savings. There are two parts to PIP:

- a daily living part, if you need help with everyday tasks
- a mobility part, if you need help with getting around

Whether you get one or both parts, and how much you get, depends on how difficult you find everyday tasks and getting around. It's worth knowing that if you put in a claim for PIP, you usually have an assessment by a healthcare professional as part of your claim. If your claim is turned down or you don't get the level of benefit you think you should get, you'll be told how to appeal.

If you qualify for PIP, you may also be entitled to extra money on top of your existing benefits, such as a reduction in your council tax and discounts on travel.

Check your eligibility and find further details at www.gov.uk/pip.

#### Adult Disability Payment – Scotland

In Scotland, PIP has been replaced by the Adult Disability Payment (ADP). You may be eligible if you're aged between 16 and pension age and need help taking part in everyday life or find it difficult to get around.

If you're state pension age or over, you can apply for Attendance Allowance instead of PIP or Adult Disability Payment.

Visit www.mygov.scot/ adult-disability-payment for more information.



#### **Carer's Allowance**

If you're caring for someone who has a urinary diversion and receives a disability benefit, you may be able to claim Carer's Allowance, as long as you are providing care for a minimum of 35 hours a week. You do not have to be related to, or live with, the person you care for. Find out more at **www.gov.** uk/carers-allowance.

<sup>44</sup> If you qualify for PIP, you may also be entitled to extra money on top of your existing benefits."

#### **HELPFUL SOURCES**

**Citizens Advice:** www.citizensadvice.org.uk

Scope (England and Wales): www.scope.org.uk

Turn2Us (benefits calculator): benefits-calculator.turn2us. org.uk

## Money matters

iving with a disability or health condition often comes with additional expenses, from the cost of medication and equipment to paying for the extra water you use.

#### **Prescription charges**

Everyone living in Scotland, Wales and Northern Ireland is entitled to free prescriptions.

If you live in England, are under the age of 60 and have a permanent stoma, you can apply for a medical exemption certificate. To do this, you'll need to complete form FP92A (available from your GP surgery) and return it to your doctor. Once you have the certificate, your prescriptions will be free of charge. However, you will need to renew your certificate every five years.

#### **Reducing your** water bill

If you live in England or Wales, have a water meter and receive means-tested benefits, you may be entitled to a reduction in your water bill if your health condition

means you need to use large quantities of water.

To find out more about the WaterSure scheme, contact your water supplier.

#### **Disabled Facilities** Grant

To help people with disabilities stay in their own homes, local authorities can award a grant towards the cost of essential housing adaptations.

For more information, contact your local authority or visit **www.gov.uk/apply**disabled-facilities-grant.

## **Rocialle Direct Prescription** Home Delivery Service



A dedicated Prescription Home Delivery Service supporting the needs of people living with a stoma and most importantly, providing a total commitment to serving customers with what they need, when they need it!

- $\bullet$ can also receive prescriptions electronically
- Friendly customer service team dedicated to delivering a personalised service •
- Nominate a preferred delivery address and delivery date •
- Orders will always be delivered in discreet and unbranded packaging

## How to place your presciption order:

www.rocialledirect.com/home-delivery

Freephone 0800 008 6646



We can request your products from your GP or prescribing unit on your behalf and



service

# Walk of hope and gratitude

BY JOHN CUNNINGHAM

or many who take on the epic challenge of walking from Land's End to John O'Groats, it's a bucket list 'must do', a test of endurance and a celebration of the human spirit.

For my wife Wendy and me, it is all of this and more - an act of gratitude for my recovery from advanced bowel cancer following surgery for a colostomy and a urostomy too. It's also an opportunity to show that living with a stoma (or even two!) does not need to hold you back from doing what you enjoy. Along the way, we'll be raising funds for charities close to our hearts.

Life sometimes throws you a huge curveball. Back in March 2020 - shortly before the first UK lockdown and just as I was looking forward to retirement, I was diagnosed with stage 3-4 bowel cancer. To say that getting this news was a wake-up call would be a massive understatement. As Wendy and I took it in, we realised that to help us both and give me the very best chance of beating the cancer, we'd need to make some lifestyle changes, including replacing processed food with healthier organic choices - a change that led to us each losing three stone in weight.

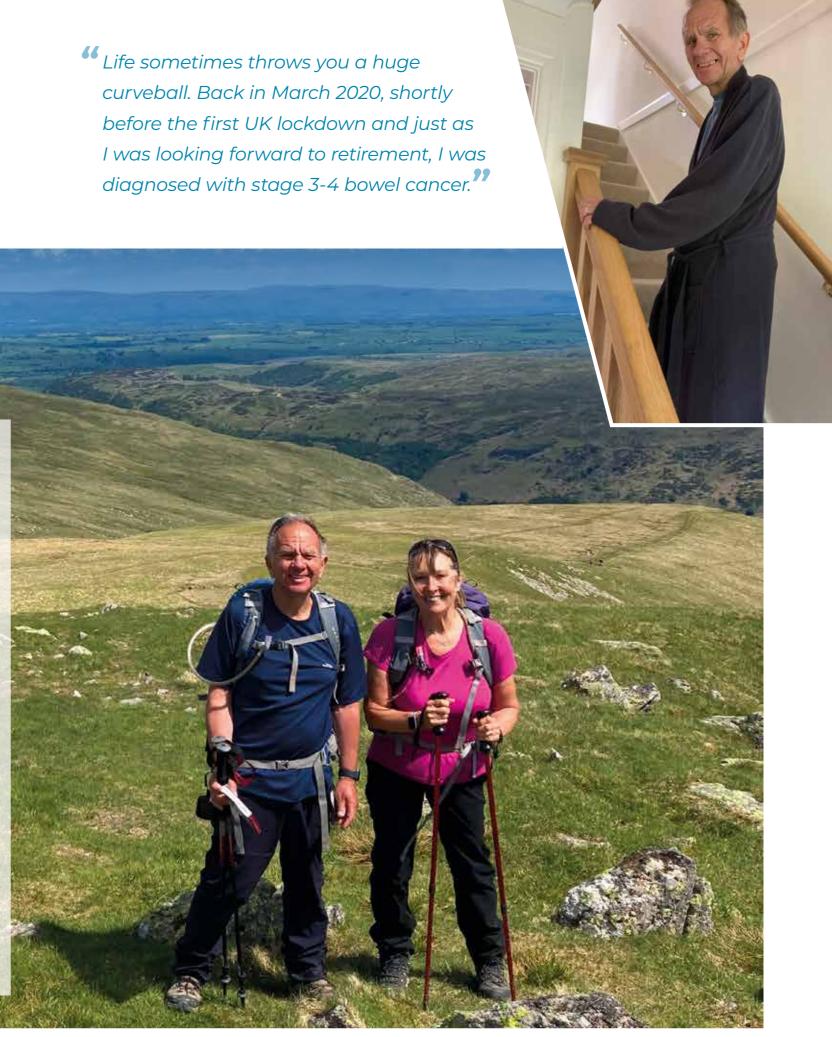
While five weeks of intense chemotherapy, plus radiotherapy, shrank the tumour to such an extent that the staff looking after me at Milton Keynes Hospital were completely amazed, my bowel cancer journey did not end there. By January 2021, I was getting symptoms I couldn't ignore and, with a scan showing a shadow on my prostate, I was referred to specialists at St Mark's

Hospital in London for further investigation.

#### Life-changing surgery

It was my consultant at St Mark's who explained that the cancer was growing again. I'd need radical, lifechanging surgery to remove it and create a colostomy and urostomy, meaning that for the rest of my life I'd be wearing two bags to collect my poo and wee. The surgeon would also need to remove my bladder, prostate and surrounding tissues, which was a lot to process but would give me the best possible chance of surviving the cancer.

All through my treatment and 15-hour surgery, the month in intensive care that followed and the tough



# Walk of hope and gratitude

#### CONTINUED

process of rehabilitation at home, Wendy and I held fast to our faith. We knew many friends and family were praying for us, which was really uplifting.

We also held tight to our retirement plan of walking from Land's End to John O'Groats. As keen walkers whose adventures have included climbing Mount Kilimanjaro, following the Inca Trail and trekking to Everest Base Camp in Nepal - plus completing many UK routes - we never gave up hope it would happen, despite the uncertainty facing us after I was diagnosed.

#### **Embracing the** challenge

I'm finally well enough to take on our epic walk and feeling more confident of completing it while managing both stomas. Meanwhile, the past few months have been a whirlwind of planning for us both, mapping out our route and making all the necessary huge logistical arrangements.

We start from Lands' End on 1 April, aiming to reach our destination of John O' Groats in three months. We've hired a campervan, so we'll be spending each day walking and then getting lifts to or from the van. It's only thanks to friends and family, as well as the kindness of strangers who've got in touch via our Instagram page (@bonkerswithbags), that we can do it this way.

I'm so incredibly grateful to have reached this point. It hasn't been easy, and I could never have made it without Wendy. She has been with me every step of the way. Covering the length of three countries, our chosen route will see us cover around 1,000 miles - which feels both daunting and exciting! We want to show people there can be life after cancer, even with two stomas. There is hope, so never give up on your dreams.

<sup>44</sup> I'm so incredibly grateful to have reached this point. It hasn't been easy, and I could never have made it without Wendy. She has been with me every step of the way."

#### It worked for us

Wendy Cunningham, a retired Advanced Nurse Practitioner, supported husband John throughout his cancer treatment and recovery from surgery. With the aim of helping those in similar circumstances, she shares the couple's 'top tips'.

- Aim to get yourself as fit as possible before your operation, and if you are overweight, try to lose some. It's important not to overdo this though, bearing in mind that you will lose weight after your surgery.
- If you can afford to, buy organic food to avoid pesticides. We also reduced the amount of processed food and sugar in our diet, and

we feel so much better for it.

- Hold onto a goal to work towards post-surgery.
- If you can, try to avoid being discharged from hospital on a Friday. In many areas, GP surgeries and stoma nurse clinics are not open during weekends.
- Practise selfcompassion. It's natural to have down days, so be kind to yourself – and keep going.
- Don't expect to be up and running straight away. It takes time to recover after such major surgery.
- Your stoma nurse is there to answer your gueries and address any concerns.
- Being part of a local stoma group has been



"Never give up hope"

helpful to us and we've found we can be helpful to others, too. The UA has several branches and groups or can link you up with a trained 'buddy' in your area who can provide you with support.

- Accept counselling if you need it. Going through stoma surgery can feel akin to a bereavement and affect your body image, but it does get better and you will learn to live again.
- Never give up hope.

"Wedi'r ddringfa anodda, y daw'r olygfa orau" "The best view comes after your toughest climb"

# ASSOCIATION Campaigns



aking sure the voices of our community are heard wherever they need to be is a vital part of the Association's work. Here's all the latest news on our charity's campaigns.

#### **Boys need Bins**

Our Boys need Bins campaign continues to go from strength to strength, supporting men who are incontinent to get access to sanitary bins in both work and public toilets.

We joined forces with Prostate Cancer UK (PCUK), other national bodies and the All Party Parliamentary Group for Bladder and Bowel Continence Care to urge the government to make it law to have bins in all male toilets nationally. It's simply not good enough that men have to use a disabled toilet to access a sanitary bin.

Men have told the campaign that they feel



embarrassed about this and don't consider themselves to be disabled.

Our goal is to make sanitary bins available in men's toilets across the UK. This way, men can dispose of their sanitary waste easily, safely and with the dignity

they deserve.

Special thanks to Donna Watson, a UA volunteer based in Belfast, for getting agreement from two airports there to install bins in their men's toilets.

Other campaign 'wins' to date include...

- More than 20 councils across England, Scotland and Wales making changes so that men can access bins in public toilets.
- Pub chain Wetherspoons installing bins in all its pubs nationwide.
- 1,300 views of a TENA video featuring men talking openly about their experience of incontinence.

You can show your support for the campaign by sending PCUK's 'Lifting the Lid on Male Incontinence' report to your MP or local councillor and asking them to join

the movement - visit www. *prostatecanceruk.org* and search 'Boys need bins' to find out more. We'd be happy to support your efforts, so do keep us posted!

#### Supporting equitable healthcare

In what is likely to be an election year, we are proud to join National Voices – the leading coalition of health and social care charities in England - in its Manifesto for Equitable Healthcare, putting forward three general election priorities:

- Pioneer a cross-government strategy to reduce the gap in healthy life expectancy.
- Introduce a package of measures to reduce the health impact of the rising cost of living.
- Focus on getting the basics right.

National Voices has been working on, and refining, its asks since the party conferences in September, and we're pleased, as

members of this important alliance, to join others in making contributions throughout this process. The manifesto is supported by a common theme ensuring that the NHS works for all, not just those who know how to navigate the system or who come from more privileged backgrounds. In the manifesto we seek to remind politicians that adopting these three priorities will not just improve things for patients but will also help drive NHS stability and wider economic benefits. Find out more at www.

nationalvoices.org.uk/ publications.

#### **Response to Part IX of** the 'Drug Tariff'

Thanks to feedback received from stoma care nurses, senior clinicians and patients, the Urostomy Association has responded to the Department of Health and Social Care (DHSC) consultation focusing on Part IX of the 'Drug Tariff'



- the list of medical devices approved by NHS Prescription Services to be prescribed by authorised healthcare practitioners, such as GPs and stoma nurses. Urostomy bags and associated equipment are contained within this list.

In recent years, the world of medical devices has evolved dramatically, and in February 2023 the government set out its Medical Technology Strategy modernising Part IX of the Drug Tariff. The aim of the review is to ensure that patients are offered the right product, in the right place, at the right price.

The DHSC engaged with patient, industry, and clinical stakeholders to seek feedback on each of the proposed changes. To read the UA's paper responding to the consultation, please visit www. urostomyassociation.org.uk/ news/ua-response-to-part-ixdrug-tariff-consultation.

## Frequently asked questions

f you've been told you need surgery to remove your bladder and create a urinary diversion, it's only natural to have lots of questions. Whether you are in this situation yourself or you know someone who is, the 'Frequently asked questions' page on our website is where you'll find answers to the most common questions we receive via our telephone helpline and private Facebook group.



We cover everything from "What is a urostomy?" and "How is the surgery performed?" to how to care for your stoma and what to expect on the road to recovery and embracing life again.

Even better, our information is jargon free! Visit *urostomyassociation.org.uk/* support-for-you/frequently-asked-questions to find out what you need to know.

> If you have any further questions or just need a listening ear, please don't hesitate to get in touch. You can call us on 01223 910854, send an email to *info@urostomyassociation*. org.uk or write to us at: Urostomy Association, Office 205, No 9 Journey Campus, Castle Park, Cambridge CB3 0AX.



#### **UROSTOMY** ASSOCIATION

## Treasurer opportunity

#### Are you as good with figures as you are with people and keen to make a difference as a volunteer?

If you're experienced in financial management, analysis and reporting, and care about people adapting to life with a urinary diversion, you could be the Treasurer we're seeking to join our friendly, dedicated Board of Trustees.

As well as contributing to the overall strategy for our organisation, our Treasurer will provide the robust financial management we need to thrive for everyone who needs us now and in the future.

This is a remote position, and is likely to involve a commitment of three or four hours a month.

For further information, please visit: www.urostomyassociation.org.uk/news/ new-treasurer-recruitment/

t's better to give than receive, the saying goes, and did you know you can celebrate good times while supporting the vital work of the Urostomy Association?

# CELEBRATE GOOD TIMES!

Whether it's a birthday, anniversary or other milestone moment, giving in celebration is an uplifting way to raise funds that make a real difference to the lives of people facing, or living with, a urinary diversion across the UK.

Whatever the occasion, by asking your friends and family to make a charitable donation instead of giving presents, you can support our ongoing work, which does so much to help people stay well and enjoy an active life after surgery.

We've made it as straightforward as possible for you to give in celebration - simply choose the way that suits you best.

#### Set up an online collection page

Setting up a JustGiving page you can share with friends, family and colleagues is quick



and easy. Your page will automatically keep track of all the donations you receive, and those who give can leave you a message at the same time. Plus, JustGiving sends the donations straight through to the Association, so you can focus on your celebrations!

Simply visit *www.justgiving*. *com/urostomy* and follow the steps to get your page set up, ready to share via email or your social media.

#### **Request donation** envelopes

Each envelope has a

Planning a party? We can supply you with personalised envelopes to send out with your invitations or leave on tables for your guests to fill at your event – the ideal way to ask friends to give a little something at their discretion. donation form inside, and you simply return everything to the Association. All you need to do is call the office on 01223 910854 and tell us what you'd like to appear on the front of your envelope.



#### **Donate online**

If you'd like to make a single or regular gift online, you can do this via our website at: www. urostomyassociation.org.uk/ shop/donate.

#### By post

If you want to send a donation by cheque/CAF cheque, please make it payable to the Urostomy Association and send it to: Office 205, No 9 Journey Campus, Castle Park, Castle Hill, Cambridge, CB3 0AX. For the donation form to send with your cheque, please turn to the back of this magazine.

#### By phone

You can call us to make your donation over the phone. Our telephone number is 01223 910854 and lines are open between 9:30am and 5:30pm, Monday to Friday.

Thank you for giving in celebration to make a difference for others.

# Family-inspired fashion

nspired by her grandfather, who lives with a urostomy, young entrepreneur Hanan Tantush is harnessing her design talent to create stylish, comfortable and functional clothing people with a stoma can feel good about.

Hanan, 21, founded her brand Intotum (Latin for 'all together') after noticing her grandad, Mike Myers, had lost his spark and become rather reclusive following his operation. Having previously bounced back after lung cancer and multiple surgeries, including a quadruple bypass operation, adjusting to life with a stoma had left Mike avoiding social situations.

"Grandad had always been proud to show off his scars, but this time was different," said Hanan, who lives in London. "Wearing a stoma bag was a big adjustment and I could see it was impacting the way he dressed. Trouser waistbands were too tight, so he went from being smartly dressed to living in baggy jogging bottoms, feeling uncomfortable within himself."

Searching for a solution, Hanan was shocked by the lack of clothing choice for people with health conditions and disabilities, which spurred her into tackling the issue herself. Already part way through her studies at the London College of Fashion, she decided to design functional pieces without compromising on comfort or style, and Intotum was born!

Since then, she has won several prestigious graduate business competitions, securing support to help take her company forward. She has even shown her collection - with designs for people in wheelchairs, as well as for those with ostomies and sensory needs – at this year's London Fashion Week, a rare achievement for such a young brand.

"Whether your disability is visible or hidden, your clothes should make you feel good and fit comfortably," said Hanan. "Intotum's adaptive pieces cover a variety of disabilities so people can pick garments according to their specific needs.

"Grandad isn't just the inspiration behind the company, he's my biggest supporter. We want Intotum to grow so people with disabilities feel seen within fashion. It's about being

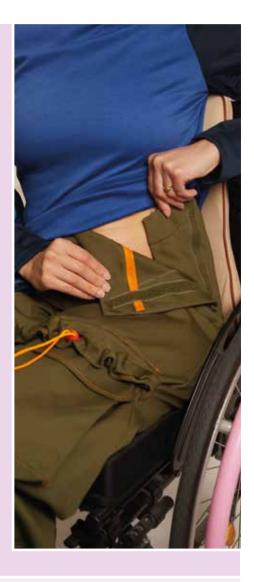
inclusive so that everyone feels empowered." www.intotumfashion.com

#### Survey and casting

Do you struggle to find clothes you like that also suit your needs? Sharing your thoughts via enquiries@ intotumfashion.com could inspire future designs and increase choice for the stoma community. Interested in being part of Intotum's promotional campaign? Sign up for the photo shoot casting via the email above or the Facebook/Instagram account *@intotum\_fashion*.

> "My surgery went smoothly, but adjusting to the new lifestyle I inherited was a different matter. Due to blood vessel issues my stoma is on my waistline, which made finding a suitable bag really difficult. I lived in jogging bottoms and just didn't feel like me.

"Hanan has always had a flair for design and when I said I'd love trousers that would allow me to use public toilets without 'dropping everything' to the floor, she took up



the challenge to design a side-opening pair that have given me back my dignity. Life feels good again and I rarely miss going to see the football.

"I couldn't be prouder of my granddaughter and everything she's achieved. Intotum is giving the disabled community access to fashionable clothing they can wear with full confidence. I can't express my excitement about its future – and Hanan's – enough!"

Mike Myers, 82

#### My name is Jackie McPhail. I have specialised in stoma care nursing since 1985 and am currently working as an Honorary Stoma Care Nurse at the Royal Marsden Hospital.

I hold a postgraduate certificate in advanced nursing practice and have previously served as Honorary Secretary for the Association of Stoma Care Nurses. I helped update the standards document, published in 2021.

As a nurse I have ensured that my practice is evidence based, to help provide products that assist with maintaining peristomal skin (ie skin around the stoma) and preventing leakage.

Getting right to the point, healthy skin can mean a happier you. The condition of the skin around your stoma can make a big difference to your comfort and confidence with an ostomy. Skin irritation around the stoma may affect your quality of life.

## **Essential Hygiene and Peristomal Skin Care**

Good daily hygiene and skin care routines help to promote healthy peristomal skin. Take care of yourself with this essential knowledge.

### Get peristomal skin care and hygiene tips

After your urostomy surgery, it is really important that you know how to look after yourself at home. This includes physical hygiene and caring for the skin around your stoma.

#### Peristomal skin care

The skin around the stoma is called the peristomal skin. Here are some practical tips for keeping it healthy:

- Get into the habit of cleaning the peristomal skin each time you change your barrier.
- For most people, water is sufficient for cleaning the skin. Less is better when caring for the skin around the stoma. If you prefer to use soap, it is usually best to use one without moisturisers, fragrance and perfumes, since these may interfere with the skin barrier adhesion.
- If you discover discoloured, broken or moist skin around the stoma, contact your ostomy care nurse or healthcare professional.
- Examine your peristomal skin regularly to check for any changes and ensure it looks healthy.

The peristomal skin should remain intact without irritation, rash or discolouration. It should look like the skin anywhere else on your body.

#### **Bathing and showering**

With a urostomy it is recommended that if you have a shower, you can take the pouch off. You should not do this in a bath or for swimming.

Here are some helpful tips:

- You can shower with your pouch on or off the choice is yours. However, removing the pouch from a two-piece system before showering may weaken the skin barrier adhesion.
- If you find the skin barrier adhesion weakening, it is best to leave the pouch on or remove both the pouch and skin barrier.
- Soap residue can sometimes interfere with how well the skin barrier sticks to your skin, so choose a cleansing product that's free of residues, moisturisers and oils.
- If you use a two-piece pouching system, you may want to switch to a new pouch after the shower.

Skin starts out healthy



Frequent skin barrier changes can lead to a type of peristomal skin complication called skin stripping

Leads to damaged skin

Reduced skin barriei adherence

Follow these tips to help keep your pouching system secure and your skin barrier adhesion strong so you can bathe and shower with confidence.

This article is kindly sponsored by Hollister.

For all articles, visit www.hollister.co.uk/en-gb/ostomycare/ostomylearningcenter For any information on Hollister products, please get in touch on 0800 521 377.

We serve people living with an ostomy and those who care for them. We are committed to helping empower those who use our products with the independence to maintain a rewarding, dignified life. View our comprehensive portfolio of ostomy care products, and access helpful educational resources here. (http://www.hollister.co.uk/ostomycare)

The testimonials, statements and opinions presented are applicable to the person depicted. These testimonials are representative of that person's experiences, but the exact results and experience will be unique and individual to each person.

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## Ask the experts

hether you're considering or already have a urinary diversion, you may have all sorts of questions about how this might affect your life day to day, from how to prevent leakage to what you need to pack when going on holiday.



At the Urostomy Association (UA) we've been listening to your helpline and Facebook queries and designing a series of webinars (live, interactive events you can join from your desktop or mobile device over the internet) exploring some of the most common topics.

The webinars, which we're running once a month to start with, will each last an hour and comprise a 20-minute introduction from a subject-matter expert, 20

With spring approaching and thoughts turning to holidays, our first topic will be travel. Join us on **Thursday 11** April, at 6pm.

minutes 'real life experience' from two UA volunteers, and 20 minutes for questions and answers.

With spring approaching and thoughts turning to holidays, our first topic will be travel. Join us on Thursday 11 April, at 6pm.

The webinars are free to attend, and bookable via the events list on our website: https://urostomyassociation. org.uk/events. We look forward to seeing you!

www.urostomyassociation.org.uk/events

et's face it, the start of spring has been pretty soggy for most of us! Here's to sunnier weather soon - hopefully - but in the meantime, help beat any blues with these simple ways to bring joy to your day.

#### Walkies!

Whether it's your own dog or you borrow a neighbour's, getting outside with a four-legged friend is a great mood booster. Dogs do all weathers enthusiastically and all that energy can be so infectious!

#### Get creative

According to Age UK's Index of Wellbeing, creativity is the top factor in whether people are happy in later life. From baking cakes to restoring furniture and from writing a journal to taking up photography, being creative can reduce feelings of anxiety and help us express or manage our emotions in a positive and productive way.

#### Use your voice

Belt out your favourite tunes in the shower or join a local choir – either way, you'll reap the benefits of singing, which naturally releases the happiness chemicals dopamine, serotonin and oxytocin, giving your mood a boost.

#### Spend time in nature

Breathing in fresh air and noticing nature, spending time in green spaces is good for us, whether it's a stroll in the park, a moorland hike or being in the garden. Getting outdoors, even for a short time, can set us up for the day or help us wind down.



#### Video call a friend

From Zoom to WhatsApp, there are so many ways to keep connected to the people we care about, even if they're on the other side of the world. Making time for a leisurely catch-up on screen can be almost as good as having them in the same room.



# NEWS FROM OUR BRANCHES

A round-up of news from our regional branches and groups, plus dates of forthcoming meetings.



Cambridge members Edwina, Pete, Marian and Ernie

#### Cambridge

Venue: Cambridge Cancer Help Centre, Scotsdales Garden Centre, 120 Cambridge Rd, Shelford CB22 5JT

**Branch Secretary:** Jane Phillips

#### Email: secretary@ urostomyassociation.org.uk

Our meetings continue to be popular with existing and new members, and we are lucky enough to have UA's new Transformation Director, Samantha Sherratt, living on our doorstep. She has come to see us and has kept us updated on the Association's plans following recent changes - we hope to maintain close interaction with her.

Our Community Stoma Nurse, Jose Caeiro, has also attended a couple of our meetings, which is always helpful. Samantha and Jose

joined us for our Christmas lunch, where a great time was had and lots of raffle prizes won!

We have a number of talks and visits in the pipeline, including a guided tour of one of the many museums in Cambridge, a talk from a member of the Antarctic Research Team and another afternoon tea.

If anyone is interested in coming along to our meetings, please get in touch – we are here to offer support, tips, friendship or just a 'safe' space where you can chat to others living with a urinary diversion. Everyone is made welcome and meetings are always very sociable.

#### DIARY DATES

We meet the morning of every first Tuesday of the month, from 10.30am to 12.30pm.

#### Jane Phillips

"We are here to offer support, tips, friendship or just a 'safe' space where you can chat to others living with a urinary diversion"

#### Lothian **Branch Secretary:**

Rhona McLoughlin

Email: secretary.lothian@ urostomyassociation.org.uk

Our branch has not met for a while now. We had a meeting planned last November, but due to poor uptake we had to cancel it. As mentioned previously, finding a venue that matches everyone's needs is becoming more difficult.

We will shortly be putting out, to the branch members, a guestionnaire which will allow us to determine how we move forward. Several members have suggested venues, but having checked them all out none are particularly suitable for one reason or another.

We see reports in the press of issues with NHS services generally in Scotland. If any member has a particular issue, we can try to help so please let Rhona know via the email address above.

#### Rhona McLoughlin

#### Newcastle

Venue: Maggie's Cancer Care Centre, Melville Grove, Newcastle-upon-Tyne NE7 7AW

Branch Secretary: Eileen Spraggon

Email: secretary.newcastle@ urostomyassociation.org.uk

Our Christmas party was a lovely event, with a tasty buffet and a quiz, plus Michelle keeping us entertained with a good selection of songs. We also had a mini bingo game. Members kindly provided generous prizes for our raffle, including two Christmas hampers put together by Elizabeth. The following week we had our Christmas lunch at the Golf Club, where we had a good catch-up.

We are continuing with our informal monthly meetings at Maggie's Cancer Centre, where we get together for a cuppa and chat. Everyone is welcome - just pop along. We are looking forward to our spring meeting with speaker Gill Castle, the first



person with a stoma to swim the English Channel. She is an inspiration to us all and has a very interesting story to tell. Our best wishes to Branch Secretary Eileen, who is

currently in hospital.

#### DIARY DATES

We meet at 1pm on the first Friday of the month.

#### Ivy Blakey

#### **Sheffield & District**

Venue: Tapton Hall, Shore Lane, Sheffield S10 3BU

**Branch Secretary:** Mary Milner

**Email:** *secretary.sheffield@* urostomyassociation.org.uk

We are looking forward to extending a warm Yorkshire welcome to Samantha Sherratt, UA's new Transformation Director, at our meetings in 2024.

In November, we held our Annual General Meeting at Tapton Hall, preceded by the John Topham Memorial Lunch, named after our founding Chairman. Forty-seven members and guests attended. Company representatives were there with their products and on hand to answer

Newcastle Christmas lunch



questions. We are always very grateful for their generous support. We also had our usual craft table selling cards and other goodies, including a colourful array of pouch covers made by one of our members. The stall raised £76 and the raffle £144, all in aid of branch funds.

We enjoyed a lovely lunch, including meat and potato pie (always a Yorkshire favourite, especially when served with a good dollop of Henderson's Relish!). The lunch always gives us plenty of time to chat, catching up with old friends and getting to know newer members.

Lunch was followed by our branch AGM, where Martyn Oxley was formally elected as Branch Chair, having been coopted to the position last year. Mary Milner was re-elected as Secretary, as well as taking on the job of Acting Treasurer, though the branch is still actively seeking someone for this role. All other committee members were happy to remain in post.

#### DIARY DATES

Saturday 6 April and Saturday 29 June. Meetings start at 2pm, with product displays from 1.30pm.

**Mary Milner** 



# NEWS FROM OUR BRANCHES

#### Shropshire, Wales & the Marches

Venue: Bicton Village Hall, Bicton, Shrewsbury

#### **Branch Secretary:**

Toni Haines

#### **Email:** *secretary.shropshire@* urostomyassociation.org.uk

We held our last meeting of 2023 on 26 October. We had a decent turnout of members, including those who joined us from across the branch via Zoom.

Due to other stoma-related meetings happening the same day, we had just one company representative, Alex Browning from Hollister/Dansac. Alex was also our speaker, and she was a great success. We have made sure that this October's meeting doesn't clash with anything stoma-related going on in Stoke!

In November and December, we held three subsidised Christmas lunches, one each in South and North Wales and one in Shrewsbury. All were well attended, with the venues going out of their way to make sure everything went seamlessly.

At our North Wales Christmas lunch, previous branch and UA President Alan de Bolla and his wife Maggie

#### joined us and we enjoyed a catch-up. In Shrewsbury, we were joined by Urinary Specialist Nurses Susie Sutton and Becky Smith. At the South Wales Christmas lunch, four company representatives kindly paid for the room hire, and after displaying their wares, they joined us for lunch.

Having won £50 in a 200+ Club draw, our Treasurer Geoff Harris kindly used the money to buy the five remaining framed panoramic photos from the large collection generously donated to the UA by branch member Graham Catherall. In all, sales and raffles of Graham's work have raised hundreds for the UA, and Don and I now have an uncluttered spare room - win, win!

We are looking forward to our first in-person branch meeting of the year, in March, and those unable to travel to Bicton Village Hall are welcome to join us via Zoom. Our speaker will be Natalie Smith from Pelican, who will tell us about the history of the company as well as the products they offer.

#### DIARY DATES

Saturday 23 March, 1–4.30pm, Saturday 6 July, 1–5pm

**Toni Haines** 

#### **Yorkshire &** Humberside

Venue: Salvation Army Church, Hunslet Hall Road, Hunslet, Leeds LS11 6QB

Secretary: David Legood

#### Email: secretary.yorkshire@ urostomyassociation.org.uk

We held our last meeting of 2023 in November, attended by 22 members and guests. The majority of the meeting was spent discussing the future of the Association, and it was agreed that flowers should be sent from the branch to former CEO Hazel Pixley as a gesture of thanks for all her help and support over the years.

On 29 November, we represented the UA at the Pinderfields Hospital Wakefield Patient Wellbeing Day, where plenty of urostomy patients showed interest in what the Association has to offer regarding help and support.

Our first meeting of 2024 was on 24 February. We had the pleasure of welcoming Samantha Sherratt, the UA's new Transformation Director, who had travelled from Cambridge. Samantha gave a detailed account as to the future of the UA, putting emphasis on the

importance of its members. Her presentation was much appreciated by all who attended, with all our concerns answered.

#### DIARY DATES

Our meeting starts at 2pm, with company representatives on hand to answer questions from 1.15pm.

#### David Legood

#### **London & Surrey news**

In November, we held a joint meeting with the bladder cancer support group at Charing Cross Hospital - an opportunity to exchange experiences and tips for mutual benefit. One attendee brought an example with him of how he had doubled the length of the drainage tube on a night bag so that it could hang from the bottom of a bed rather than over the side. This reduces disturbance from the bag during the night. Other helpful tips were

provided by the hospital stoma nurses who attended. In January, members Mark and Mary Hopkins kindly invited us to lunch at their house in Kew. Eighteen people attended for a very enjoyable event, and the UA's Samantha Sherratt set out her aspirations for the Association. Mark's stoma nurse Jo Sica also attended and shared useful stoma care tips. Despite the time of year, we were able to get into the garden for a group photo. We also held a raffle in aid of the UA, raising £93.

At 2pm on 27 March, we'll be joining the Charing Cross Hospital bladder cancer support group for a presentation by stoma product supplier Coloplast. This will be in the Maggie's Centre in front of the hospital. Information will be sent out to London and Surrey members, but in the meantime, anyone who'd like more details can get in touch with me at brianglicksman@gmail.com or on 020 8642 1899.

**Brian Glicksman** 

London and Surrey group members



#### Northern Ireland **Support Group news**

It's been a busy winter for our members, with several gatherings for coffee and chat. Our thanks to Tesco for offering their free community room at Knocknagoney as often as we want it, with tea and cake thrown in. We're also grateful to Respond for hosting a lovely Christmas lunch in Larne, bringing members together at the festive season.

Two new urostomy volunteers have been trained and are now able to provide support in Northern Ireland. A warm welcome to Michelle and to David (who is hoping to start a men's breakfast club). Meanwhile, we are maintaining our contact with security staff at our two Belfast airports to ensure they deal correctly with urostomates who travel by air. If you are interested in finding out more about our group, please contact me at *donna*. watson@urostomyassociation. org.uk.

Donna Watson

# MAILBOX SPRING 2024

I would like to thank all those who sent gifts and messages during my last few weeks working for the Association. I received several bouquets and plants, as well as chocolates, wine and other items.

I'm taking a breather from work while I decide what to do next, and the 'office' is in process of becoming my hobbies room, although at the moment it seems to be full of 'stuff' waiting to be put on eBay! I'm also looking forward to

being able to get out in the garden, as soon as it warms up a bit.

It was a real pleasure working with you all, and I know that many of you will keep in contact. I remain a full member of the Association, so will continue to follow progress with interest.

With very best wishes *Hazel Pixley, Former CEO of the UA* 

The Journal continues to be very informative and I am very appreciative of the effort everyone puts into compiling the content. *Carol, via email* 

*Editor:* Thank you, Carol. We really appreciate your lovely feedback and hope you'll continue to enjoy the Journal for many years to come.

We look forward to hearing from you, our readers. Please get in touch via *editor@ urostomyassociation.org.uk* or post your letter to *the Urostomy Association, Office 205, No 9 Journey Campus, Castle Park, Cambridge CB3 0AX.* 

#### Conquer Adhesion Challenges with Fusion: Your Skin Friendly Solution to Pouch Security



FUSIC

The unique 2-in-1 medical grade adhesive a barrier film applicator that is revolutionising stoma care.

Secure your pouch Fusion increases adhesion reducing the risk of leaks and extending pouch wear time.

**Protect your skin** Providing a protective layer when applied, Fusion is hypoallergenic and can be used on broken or damaged skin.

Stay active

Fusion is ideal for fluctuating ambient temperatures, humidity and increased physical activity.

on Fo

**98%** of users saw an improvement in adhesion when using Independence Fusion

\*Based on completed Evalu

**200+ Club** PRIZE DRAW Be in it to win it and support the UA too!

Did you know that together, 200+ Club prize draw subscribers raise more than £3,000 a year to help the Urostomy Association continue its trusted support for people living with a urinary diversion? **It costs just £2 to enter each monthly draw and you could scoop a cash prize of up to £250!** 

To enter the draw, please contact UA volunteer Toni Haines, on **01952 400971** or email her via **toni.haines@ urostomyassociation.org.uk**. Please make your payment of £2 per month/£24 per year to the Urostomy Association. You can pay by debit/ credit card, standing order or cheque –contact details are on page 6.

#### 200+ Club winners

Draw date: 29 November 2023 1st prize £250 No 185 Kate lones\*

ist prize	223U	COLON	Kate junes"
2nd prize	£150	No 115	Dave Simmonds
3rd prize	£100	No 149	Dennis Smith
4th prize	£75	No 289	Charlie Thorn
5th prize	£50	No 202	David Taylor*

\*Our thanks to Kate and David for supporting the UA with gifts of £50 and £10 respectively.

#### Draw date: 29 October 2023

<b>1s</b> t prize	£250	No 66	Leslie Badley
2nd prize	£150	No 35	Rosemary Forson
3rd prize	£100	No 167	Rosemary Reed
4th prize	£75	No 147	Keith Ashley*
5th prize	£50	No 125	Geoff Harris**

\*Thank you to Keith for kindly donating his prize to the UA. \*\*Geoff used his prize to buy the remaining stock of Graham Catherall's framed panoramic photos, which were then raffled, raising £238 for the UA. Thank you to both Graham and Geoff for such generous gestures.



# Let's get social

Did you know you can keep up to date with all the latest UA news, campaigns and fundraising through our social media channels?

There's our public Facebook page - *www.* facebook.com/UrostomyAssn - and also our private Facebook group https://www. facebook.com/groups/158052257866449, where urostomates from all over the world post questions, share tips and provide lots of mutual support.

You'll also find us on X (Twitter): www. twitter.com/UrostomyAssn, and LinkedIn: www.linkedin.com/company/urostomyassociation.

Give us a follow and please do share our content with anyone you know who could benefit from the services and resources our charity provides. Thank you!







#### The proud home of Independence Fusion

Add Independence Fusion to your stoma care regime and stay active in 2024. Available on NHS prescription from your GP or usual supplier.

To request a sample please call 0115 975 7254 email enquiries@ipl.uk.com visit our website www.ipl.uk.com/ta-sample or scan the qr code below.





UA Journal | Spring 2024 – Issue 130 3



# Book your FREE design appointment

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## Join our friendly community - there's no fee!



aving a urinary diversion doesn't need to hold you back from doing what you want to do, whether that's enjoying days out, getting back into exercise or travelling overseas. Sign up to join our friendly, inclusive community for tips, resources and support to help you keep well, stay active and get the most out of life.

It's straightforward and free of charge to join the Urostomy Association and we're here for you whether you're facing surgery, recovering afterwards or have been living with a urinary diversion for many years. We're here for your family and carers too.

- Telephone helpline
- One-to-one support\*
- Regular magazine and e-newsletter
- Downloadable resources
- Expert-led webinars
- Local get-togethers
- Private Facebook group

\*Our trained volunteers know from their own experience what it is like facing surgery for a urinary diversion, as well as how it feels adapting to life beyond it. If you're in need of support, we'll link you up with someone in your local area. Wherever possible, this will be someone who has the same type of urinary diversion as you.

www. urostomyassociation. org.uk/join-now.

Join today

To join the Urostomy

opposite and post it to

Association, simply

complete the form

us or go online:

#### We look forward to welcoming you!

## Join the **UROSTOMY ASSOCIATION**

The Urostomy Association (UA) is the nation people with a urinary diversion or preparing their family and carers too. It's free and easy can choose to be as involved as much or as lit



Please complete your details below and w touch. Alternatively, you can scan the QR of or visit urostomyassociation.org.uk/join-n We look forward to welcoming you!

#### **Your details**

Title:	First name:	Last name:					
Date of b	Date of birth: Main telephone number:						
Email add	Email address:						
Address l	ine 1:						
Address l	ine 2:						
Town / Ci	Town / City: Postcode:						
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Cor	ntinent diversion (eg	: Mitrofanoff)	Ot	her	Not applicable		
Reason fo	or operation:		Hosp	oital:			
Please turn over to complete the second part of this form							

SIDE	OF 2
nal charity for to have one, and <b>y to join</b> and you ttle as you wish. re'll be in code <b>now</b> .	

## Join the UROSTOMY ASSOCIATION

How did you hear about us?								
	Nurse/GP/Other healthc	are professional	A	dvert		Open day		Facebook
	Google/Bing, etc	Other (please	specify)					

#### How to receive our news

As part of our community, you'll receive our popular magazine, The Journal, three times a year and, if you leave us your email address, we'll email you our monthly e-updates. Choosing to receive our communications by email saves our small charity money, as well as being kinder to the planet. Please tick the relevant boxes below to indicate how you want to be contacted.

Journal by p	ost	Journal by email		e-newsletter
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We'll also post you updates every now and again on our news, events, fundraising and campaigns.

If you'd like to receive occasional communications from stoma product suppliers, please tick the box below (please note, these will be sent to you by post from the Urostomy Association's mailing house, as we do not share your details with third parties).

#### I give my consent for the UA to send me details from stoma product suppliers:



By submitting this form, you are consenting to the UA holding and processing your data in accordance with our privacy policy, which is available on our website or upon request.

Signature:

Date:



Kind donations help us to run our helpline and keep supporters up to date through our regular magazine, e-newsletters, group meetings, social media and fact sheets. Thanks to donors, we can also increase awareness across healthcare and the general public, and influence urostomy policy and practice. Will you make a donation today? Simply visit *www.urostomyassociation.org.uk/shop/donate.* 

Thank you.

**SIDE 2** OF 2

Scan to donate online or call **01223 910854** 

Please post your completed form to: Urostomy Association, Office 205, No 9 Journey Campus, Castle Park, Cambridge, CB3 0AX.

Registered charity nos: 1131072 (England and Wales) SCO47740 (Scotland)

# Your support

# makes such a difference

Regular, monthly donations are crucial to the Urostomy Association because life with a urinary diversion can feel daunting. It's vital that people have somewhere to turn for reassurance at every stage, from diagnosis to living life to the full again. We provide that support at the UA. But we can only do so thanks to your donations.

With your kindness, we can continue running our helpline and keep people informed and supported through the Journal, e-newsletters, plus group meetings, social media, fact sheets and more. We can also keep on campaigning, making sure the voices of the community we represent are heard wherever they need to be.

#### By giving regularly, you'll help people with a urinary diversion grow in confidence so life can feel more like normal again – or even better than before.

- **£5 a month** could help ensure our helpline is there for anxious callers.
- **£10 a month** could fund a 'meet the expert' webinar so urostomates can directly speak to those in the know.
- **£50 a month** could help ensure there's a local buddy available to provide one-to-one support, drawing on their own experiences of living with a urinary diversion.

It's straightforward to set up a regular donation via our website at *www.urostomyassociation.org.uk*.

If you prefer, please complete the form at the back of this magazine and post it to us at the address given there.

Thank you so much for your support.



## UROSTOMY ASSOCIATION Merchandise

### UA-branded sunflower badges and lanyards

*Our Urostomy Association-branded badges and lanyards are* officially sanctioned by the Hidden Disabilities Sunflower Scheme Limited: www.hdsunflower.com

Lanyard **£2.50** Badge **£1.75** 



### The official Radar KEY

*Our Radar keys are the genuine article – other* keys purchased online **may not be** genuine and may not work. **Official** Radar key £3.50

HIDDENG

#### All prices include p&p within the UK

To place your order by credit/debit card, please call **01223 910854** or visit *www.urostomyassociation.org.uk/shop*. Alternatively, please complete the form below and send it, together with a cheque made payable to the Urostomy Association, to: The Urostomy Association, Office 205, No 9 Journey Campus, Castle Park, Cambridge CB3 0AX

Please send me:	Sunflower <b>lanyard</b>	Quantity	
	Sunflower <b>badge</b>	Quantity	
	Radar <b>key</b>	Quantity	
Title: First name:		Last name:	
Address:			
		Postcode:	
Email:		Tel:	

#### Complete this side to support the Urostomy Association with a single gift

Thank you for making a real difference to the lives of people facing, or living with, a urinary diversion across the UK. To make a donation, you can either use this form or scan the QR code below to donate online.

Alternatively, by donating monthly you can provide a consistent source of funding that enables us to plan and deliver our support programmes. Please use the form overleaf to give a regular gift.

Thank you for your kindness.

Scan to donate online or call 01223 910854

**Please return** 

this form to:

Urostomy

Association, Office 205,

No 9 Journey

Castle Park,

Cambridge,

**CB3 0AX.** 

Thank you!

Campus,

<b>1 Your donation</b> I would like to give		£20	£50	£150			
<b>OR</b> other amount	£						
I am enclosing a cheque payable to The Urostomy Association   I would like to donate by debit/credit card							
Card no:	CVV numl	)		(  Maestro issue	Maestro only)		
Signature:			Date	2:			
*If you're uncomforta number so we can cal 2 Your details	ble completing your C I you and complete yo						
Title: First n	ame:		Last nam	e:			
Address:							
			Post	tcode:			
Email:				Te	el:		

<b>1 Your do</b> I would like to	<b>nation</b> o give a single gift of:	£20	£50	£150	
<b>OR</b> other am	ount <b>£</b>				
📃 l am enc	losing a cheque payab	ole to <b>The l</b>	Jrostomy	Associati	ion
I would I	ike to donate by debit	/credit caro	d		
Card no:					(Maestro only)
Expiry date		ımber*		Maestro issi	ue no:
Signature:			Date	2:	
	mfortable completing you can call you and complete tails				
Title:	First name:		Last name	2:	
Address:					
			Post	code:	
Email:				7	Гel:
We may post	you occasional update	es about ou	ir events a	nd fundra	ising and

how support like yours transforms lives. Please indicate if you're happy to stay in touch by:

Phone	SMS

**3** Increase your gift with Gift Aid

Signature:

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I am a UK tax payer

I am a UK taxpayer, and wish you to treat all gifts I have given in the past four years, and all future gifts I make, as Gift Aid donations. By ticking this box I am confirming that I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year, it is my responsibility to pay any difference.

You can see our donor privacy policy on our website at *urostomyassociation. org.uk*. If you want to change the way we communicate with you or wish cancel your Gift Aid declaration, please let us know. Registered charity nos: 1131072 (England and Wales) SCO47740 (Scotland)

### UROSTOMY ASSOCIATION

#### SIDE 1 OF 2

Make your gift worth 25% more at no extra cost to you! Date:



#### Complete this side to support the Urostomy Association with a regular monthly gift

## UROSTOMY ASSOCIATION

#### **SIDE 2** OF 2

Thank you for making a real difference to the lives of people facing, or living with, a urinary diversion; we appreciate your generosity and commitment. By making a monthly gift, you can help ensure a consistent source of funding that enables us to more effectively plan and deliver our support programmes. If you prefer to give as single donation today, please complete the other side of this form.

#### Thank you so much for your kindness.



#### 1 Your donation

I would like to give	£5	£10		£20		
<b>OR</b> other amount	£	via my debit/credit card.				
Please take my monthly gift on the 1st of the month or the 15th of the month. Please circle which you prefer. If no date is selected, we will process your gift ont						

Scan to donate online or call 01223 910854



Please return this form to:

> Urostomy Association, Office 205, No 9 Journey Campus, Castle Park, Cambridge, **CB3 0AX.**

Thank you!

rease circle which you prefer. If no date is selected, we will process your gift online		
1st of the month.		
Card no:	(Maestro only	
Expiry date C	V number* Maestro issue no:	
Signature:	Date:	

\*If you're uncomfortable completing your CW number here, please leave us your phone number so we can call you and complete your donation by phone. Thank you.

#### 2 Your details

Title: First name:	Last name:	
Address:		
	Postcode:	
Email:	Tel:	
We may post you occasional updates about our events and fundraising and how support like yours transforms lives. Please indicate if you're happy to stay in touch by:		
Email Phone SMS	Make your gift worth	
<b>3</b> Increase your gift with Gift Aid	25% more at no extra cost to you!	

Signature:

Date:

#### I am a UK tax payer

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