



IA UPDATE



August 2025

Welcome

During peak holiday season, IA was disappointed to hear from many members about poor treatment at some UK airports. See page 2 for our response to this issue.

Our August round-up covers events from around the network, volunteering news and more. Don't forget, we love hearing from you too so please get in touch, whether it's to share your story, give us feedback or let us know about your events: marketing@iasupport.org

Pouch Information Day, 20 September

Novotel Birmingham Centre, 70 Broad Street, Birmingham B1 2HT, 10am-4pm

Everything you ever wanted to know about internal pouches but were afraid to ask

Pouch Information Day, taking place on 20 September in Birmingham, is for those with an internal pouch, those considering one, and those close to them.

Join us for a welcoming and informative event designed to answer your most pressing – and often unspoken – questions about life with an internal pouch.

Speakers include:

- **Mr Richard Lovegrove** – Consultant Colorectal & IBD Surgeon, Worcester
- **Ms Sophie Turigel** – Surgical & Nutritional Support Senior Dietitian, Birmingham
- **Carrie Helman & Aileen MacArthur** – IA's Support Through Therapy Counsellors
- **Anita Sangera or Gabby Szozda**, Advanced Pharmacists, Birmingham
- **Internal Pouch Specialist Nurses**
- **Pouch owners** – Experts by experience from the Internal Pouch Sub-committee



Event format:

- **Morning:** Formal presentations from our speakers.
- **Afternoon:** Interactive 'stations' hosted by experts, allowing small-group discussions and personalised Q&A. This is your chance to speak openly, learn from professionals and peers, and leave feeling more confident and informed.

To find out more and book, please visit: <https://pouch.iasupport.org/pouchday25/>



IA statement: UK airport security

In light of growing concern around the issues people living with a stoma are facing when travelling through UK airport security, **IA has released a statement, available on our website.**



IA is concerned that airports are not held to account in meeting their accessibility obligations through their Airports Accessibility Framework and that much more needs to be done to ensure that the rights of anyone wearing a medical device, such as a stoma bag, are respected.

While IA has been successful in feeding into practices at some regional UK airports, IA calls for the CAA to work with us more holistically to establish detailed, considered guidelines on the training provided to, and by, UK airports, so that ostomates can expect a standardised approach wherever in the UK they are travelling.

How to take action

For those with a complaint about an airport, this should be taken up with the airport in the first instance, but **further action is available through the CAA if you are dissatisfied with the response.**

In order to ascertain the extent of the issues ostomates are encountering at UK airports, **please complete IA's survey.**



Take part in The Patients Association's survey

Did you know that, via The Patients Association, you can use your voice to help improve care for you and other patients, too?

If you've been using prescribed bladder or bowel care products for more than four weeks, the Association is keen to hear from you to help ensure these resources reflect real-world needs and experiences.

So, if you're using stoma care products (such as bags, plates, tape or spray), continence care products (intermittent self-catheters, urine pads, etc.), or trans anal irrigation systems, and would like to provide feedback, please click the link below to take part in the survey. It's straightforward, takes just a few minutes to complete, and is designed to capture a wide range of experiences. <https://www.surveymonkey.com/r/L7XXDMB>



At the end of the survey, you'll have the opportunity to register your interest in two online workshops, where - alongside other patients, plus healthcare professionals - you'll get to explore how bladder and bowel care decisions are made. As a thank you for completing both workshops, The Patients Association is offering an £80 Love2Shop voucher.

Have you seen IA's Information Day 2025 presentation videos?

Don't forget to watch our Information Day presentations covering a host of topics for the ileostomy and internal pouch community. Delivered by experts in their field, the **presentations are available on our website** and on the links shown opposite.

Parastomal Hernia (Dominic Slade):
https://youtu.be/Srz_zK-8EWs

Medication Matters (Uchu Meade):
<https://youtu.be/8n0HJwuByH8>

Advancing SCN Services (Natasha Rolls):
<https://youtu.be/mP7jcovJ8Pc>

Intestinal Failure – Building a National Service (Gordon Carlson): <https://youtu.be/u06dDNvFZT0>

Join us for IA's 70th celebrations, 25 April 2026

Preparations are under way for the charity's 70th anniversary milestone next year, which will be officially celebrated at our Information Day on Saturday 25 April, following the AGM on 24 April (for company law members and board members only).

We're creating yet another packed programme for this special platinum anniversary, so watch this space! You can, of course, expect to be entertained and enlightened by subject matter experts on the topics that matter most.

Once the day's workshops and presentations are complete, we invite you to join us for our celebratory evening entertainment. Don't miss the chance to don your best bib and tucker for our black-tie gala dinner and live music!

Date: AGM (for company law members and board members only): Friday 24 April, time tbc; Information Day: Saturday 25 April, time tbc.

Booking: Please spread the word and save the date(s). We will release more details as soon as we can, and keep you informed through our usual channels, online and in print.



Information Day, 25 April 2026 Chesford Grange Hotel, Kenilworth, Warwickshire CV8 2LD.

The historic manor house hotel is close to a host of attractions to help you make the most of your stay, including castles in Kenilworth and Warwick; Shakespearean theatre, history and heritage in Stratford-upon-Avon; museums, shopping and cathedrals in Coventry, not to mention miles of beautiful countryside to explore.

Share your thoughts for IA's 70th anniversary

Ahead of our 70th anniversary, we invite you to send us a short sentence (up to around 20 words) about what IA means to you – this could perhaps sum up the support, understanding or friendship you have found through the charity, or simply be a bullet point list that describes your emotions. Submissions will be anonymous though we would like to include the name of your group. Your sentence will feature on IA's memory tree, which will be displayed at Information Day next year. We'd love to hear from you! Please send to marketing@iasupport.org

Leak sensor device study: university researchers seek your help

As part of our ongoing commitment to keep you updated on local research in line with your membership with us, we are sharing a research opportunity being undertaken by Ulster University; through validating a new leak sensor device, researchers are looking at the relationship between stoma pouch leakage, quality of life and dietary intake.

If you would like to know more about the research or consider participating, subject to eligibility, please refer to the flyer shown opposite to read the patient information. Additionally, if you wish to apply, please complete the screening questionnaire available via <https://redcap.link/stomasense>. The screening questionnaire will indicate suitability to the research and where suitable, invite a further discussion with the research team who will provide further details.

Stomasense

Researchers at Ulster University are conducting a study which will:

- Validate a new leak detection sensor device
- Investigate the link between diet and stoma pouch leakage

Who can volunteer?

- ✓ Aged 18+ years
- ✓ People with an ileostomy
- ✓ Experiencing frequent leaks from their stoma bag (1+ times per week)



- You will test the sensor at home, continuing your normal routine – we will send you the sensor device equipment and supporting training materials.
- You will be asked to trial two variations of the device (wearing with your usual pouch system), each over a 14-day period.
- You will complete a series of questionnaires and return a food diary at the start and end of each 14-day period.

If you are interested in taking part in the study or would like more information, please complete the screening survey accessed with the QR code below or contact:

Niamh Magee (PhD researcher)
Magee-n20@ulster.ac.uk

Dr Chris Gill (P.I.)
C.Gill@ulster.ac.uk

Biomedical Sciences, Ulster University, Coleraine BT52 1SA





IA Group News from Roy Bustin, Group Relationship Lead

Shared resources

This month we launched our 'IA Group Shared Resources'. As we continue to support the development of our group network, we recognise the importance of providing volunteers with easy access to resources. Things can change quickly in the charity world, so groups need up-to-date resources to help them to continue to make an impact locally. This is an online area, allowing volunteers to access a variety of documents, templates and guides to support your activities. Here, you will find our key policies, volunteer role descriptions, finance matters, social media guidance and much more. If you would like to request access, please email us at volunteering@iasupport.org

Peer leadership development

We've been in discussion with NHS England to find out more about their **Peer Leadership Development Programme**. This is a personal development programme for people with lived experience and is free to access for 28 days.

The programme is delivered online via an accessible and interactive learning platform called FutureLearn. The first two steps are completed in your own time, at your own pace. On the third step, people come together as a small group. Step three is facilitated by the NHS Lived Experience team using FutureLearn and Microsoft Teams. We are now looking for two to three volunteers who might like to trial this programme. If you would like to consider being involved and want further details, please email us at volunteering@iasupport.org

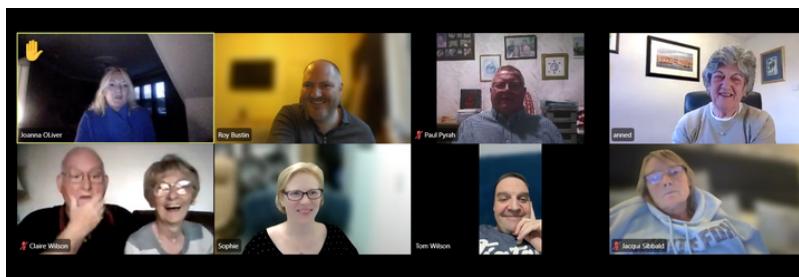
Please note, although this is an NHS England initiative, it is open to anybody in the UK.



Thank you

Thank you to those of you who have been involved in our 'Volunteering in Action' project so far this year. It's great to hear of the actions happening locally and the impact they are making. Look out for details of the next actions that you can get involved in – we would be very grateful for your support.

Thanks also to those who attended our quarterly volunteer network meeting on 1 September (see below). We had some useful discussions and sharing of ideas. If you missed it, we will be running another meeting in December so keep an eye out for the date.



Please do get in touch with me: roy.bustin@iasupport.org if you would like to discuss anything related to your group. I look forward to hearing from you.