



# IA UPDATE

JANUARY 2022

## Welcome to 2022

Boom! Before we know it here we are at the end of January and heading into the second month of 2022! How did that happen so quickly? It feels good starting a fresh new year and let's hope all our groups will start to feel more comfortable meeting up as the year progresses. At National Office there's been plenty going on. This month's IA Update gives you a bit of an insight.

## Sharing is Caring

Just a reminder that IA Update is a communication tool to keep you and your members up to date with what's going on within IA during those interim months between IA Journals. It's been designed to let you know about things that have short deadlines that may miss out on being in the Journal, or little updates on some of the bigger subjects. It's little nuggets of info that you can share with your members through your own emails or add into your own newsletters.

In particular, our members get lots of opportunities to influence change for ostomates and people living with an internal pouch by taking part in research projects. There's another research project in this month's issue that they may wish to participate in.

Don't hide all this juicy info just within your committee, please share it with your members so they are fully included. We are here to serve our members.

## MO web pages are LIVE

I am delighted to tell you that a number of groups, who provided me with their local information, now have either their web pages created and/or user profiles created. These groups will shortly be receiving the User Guides to add more content themselves.

Take a look at the Devon webpage to see how their local information – hospitals and stoma care services, newsletters and committee information is visible.

<https://devon.iasupport.org/hospitals/>

NW Lancs also have their events listed.

<https://nwlancs.iasupport.org/events/>

As things open up and more events are organised locally, you will be able to update your own pages, which will feed into the website's main Events page.

## Pouch Fistula Research

This month we have been approached by a research fellow at St Marks Hospital who are publicising the Delphi Study for Pouch anal and vaginal fistula core outcomes. If any Internal Pouch members would like to take part in this study, please see how to get involved or receive more information here >>

PAVFCOS  
Developing a core outcome set for pouch fistula

**Do you have a pouch anal or vaginal fistula?**  
If you are over 18 years of age AND have ever had a pouch fistula-  
We would like to hear from you!

- We want to know what patients think **define successful treatment**
- What **outcomes** are important following treatment

The study involves 2 surveys over 8 weeks  
Each online survey will take 10 minutes to complete

For more information go to:  
<https://delphimanager.liv.ac.uk/pavfcos/> or email us at [lnwh-tr.pavfcos@nhs.net](mailto:lnwh-tr.pavfcos@nhs.net)

PAVFCOS study management team

# Back to Better Living

**Things are really ramping up now to the AGM and Information Day on 25th/ 26th March at the Park Inn by Radisson, Northampton. It really will be a very special 'Come Back' event.**

The Information Day is a mix of conference and exhibition with all the top names in the stoma appliance sector having their exhibition stands there for you to chat and try samples.

The conference is entitled '*Back to Better Living*' and has an amazing line up of speakers. These include Professor Gordon Carlson CBE; Sophie Medlin, IA's Dietitian and Chair for the Dietetic Association for London; Sarah Russell, IA's Clinical Exercise Specialist and founder of The Ostomy Studio; Rali Marinova, stoma nurse at St Mark's Hospital; and Zarah Perry-Woodford, Nurse Consultant at St Mark's Academic Institute.

The Bryan Brooke Lecture will be delivered by Dr Calum Lyon, entitled '*Abdominal stomas and the skin; a special relationship*'.

Alongside this eminent line-up there are additional workshops run by Internal Pouch, Young IA, and Sarah Russell. Each will host a morning and afternoon workshop so there is plenty for delegates to attend throughout the day.

Internal Pouch will be running Q&A sessions around better living with an internal pouch, and Sarah Russell will be running interactive core and pelvic floor exercises for hernias.

..... more>>



Dr Calum Lyon



Sarah Russell



Rali Marinova



Zarah Perry-Woodford



Sophie Medlin



Prof Gordon Carlson, CBE

## Programme

Prof Gordon Carlson - '*Consent for medical treatment in the 21st century. What might Bryan Brooke have made of the modern doctor-patient relationship?*'

Sophie Medlin - '*Nutrition and hydration to regain health and maintain well-being*'

Sarah Russell - '*Living with a parastomal hernia*'

Rali Marinova - '*Is that a new pouch you've got (or do you always walk like that . . . )?*'

Dr Calum Lyon - '*Abdominal stomas and the skin; a special relationship*'

Zarah Perry-Woodford - '*Evolving stoma nursing services*'

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Young IA are running two different workshops. The morning will be a presentation by Sam Wilkinson of *Chronically Working*, entitled '*Back to Better Working*' and will cover issues around getting back into the workplace after surgery and understanding what to expect.

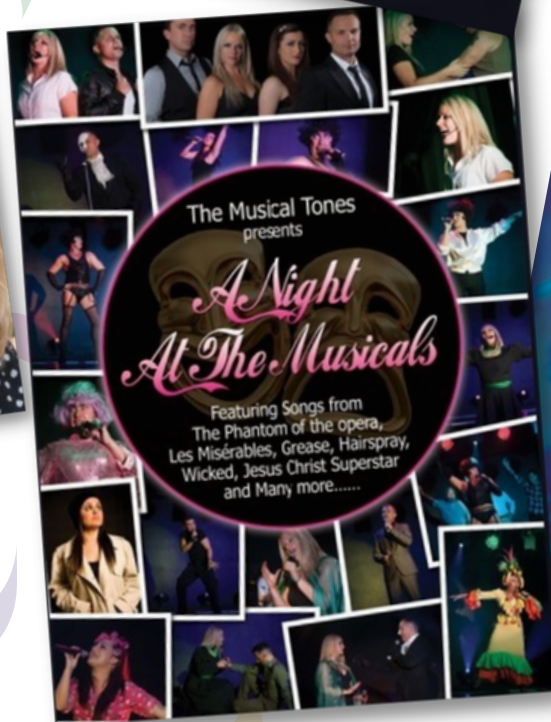
The afternoon session sees World Champion Bodybuilder, Zoey Wright, talking about her journey from IBD to becoming a world champion both with her ileostomy, and now also with her internal pouch. This is a phenomenal talk on what is possible. This is supported by a panel of guests who've also gone on to do amazing things in the world of sport.

And if you didn't think that was a jam-packed day already, then you've still got a fantastic dinner to attend and live entertainment. Embracing the world of Musicals, our live band – *The Musical Tones* – is headed up by performers from some on London's top shows including *Miss Saigon* and Cole Porter's *Anything Goes*, and have performed with Sir Cliff Richard.

We are also laying on a Fun Photo Booth for you to take away all the memories of a fantastic night!



**Sam Wilkinson**



**If you've not yet booked your place for the best event in town, then you can simply download the booking form from the IA website and send it in to National Office  
<https://iasupport.org/event/ia-information-day-march-26-2022/>**



## Social Media & Other Policies

***Did you know we have a Policies section on our website?***

It's so important that IA provide transparent and quality service for its members and work in an open and accountable way that builds the trust and respect of our stakeholders. To this end, you will find the following policies are all publicly available:

- Whistblowing Policy
- Safeguarding Policy
- Complaints Policy
- Social Media Policy

The Social Media policy has been created to set out expectations around the use of social media by Member Organisations, including posting guidelines and moderation policy for online user-generated content. As the popularity of social media as a form of communication grows, it is important that such communication channels are properly managed to ensure they are used effectively to support members and other stakeholders, enhance IA's reputation and contribute to the pursuit of its charitable aims.

If you've not yet read the policy, you will find a link to the Policies in the footer on every page of the IA website.

## Events

**Tell us what you are up to this year with any events you have planned as things open up. Our events page on the website is looking a little sparse at the moment. We do include any online events you are hosting, so keep us posted.**

**Email your events to  
[caroline.bramwell@iasupport.org](mailto:caroline.bramwell@iasupport.org)**

## Urgent Shout out for Annual Reports



As we head towards our Information Day in March we are now at the point of compiling the reports from all the MOs that will be included in IA's Annual Brochure 2022. Thank you to those who've sent their reports through.

However, we are still missing reports from a number of groups. If things rings a bell in your head and you've not yet submitted your report, please could you send this through to Leann at the office urgently on [info@iasupport.org](mailto:info@iasupport.org)

Reports should include:

- ➡ Membership (affiliate groups only)
  - ➡ One2One Support (previously Visiting)
  - ➡ Data Collection
  - ➡ Your group's annual written report where you have the opportunity to provide an update of your group's achievements and initiatives over the past year.
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