



# IA UPDATE

IA GROUPS NEWSLETTER



DECEMBER 2021

## Another year comes to a close

As the last days of 2021 close in, we can look back and see that whilst it's been a tough year for many, we've still managed to support more and more people. The office kept on running, taking calls, emails and keeping the wheels turning, so no-one was left without support when they needed it.

## Keeping Members Informed

IA Update was created to build a closer communication channel with our Member Organisations to share with you things that are happening within the Charity and at National Office. We are very happy for this to be shared with your members, although not everything will be of relevance to them (such as call outs for reports etc), so you can be selective about which bits are relevant and extract whatever info you would like for your own communications and newsletters.

National Office is not, however, able to post this out to members which is why we are in the process of setting up a digital subscription link, so any member who wishes to receive it can do so (without the bits that are only relevant to committees) and have it drop into their email Inbox.

***More details about how to subscribe to this will be in January's IA Update.***

## IBD UK

As another year of collaboration sitting on the Board of IBD UK comes to an end, we look back with pride at how much has been achieved. IBD UK is a partnership of organisations working together for everyone affected by inflammatory bowel disease. In spite of Covid 19, we were able to collectively launch the IBD UK national report with considerable impact and as a springboard for further focussed activity to promote the needs of people with Crohn's and Colitis in health systems across the UK.

IBD UK is now in a great position to develop a Quality Improvement programme of work and to build towards the next round of benchmarking in 2023, with dedicated working groups and a new steering group, which our PR & Communications Manager, Caroline Bramwell will sit on.

## Christmas Contact

Whilst the office doesn't officially close for Christmas, our team will still have time to put their feet up and enjoy the festive season.

Emails will be monitored and voicemails will be picked up, but will only be responded to if they are urgent.

Our social media will also have some beady eyes being kept on it, as we receive messages via these platforms too.

# One2One Support Update

One2One Support is gradually becoming part of our everyday conversation, although old habits die hard, and the word “visiting” does occasionally slip into our vocabulary! We hope you are all spreading the news of this re-launch and encouraging those members who would wish to be Support Volunteers to get in touch with national office ([info@iasupport.org](mailto:info@iasupport.org)). The more we use One2One Support, the quicker we will all get used to it.

The first online “Effective Communication Skills” course has gone well, thanks to the very enthusiastic participants who were brave enough to take part. It has been a great learning experience for us all and we are confident that we will add new Support Volunteers to IA both locally and nationally. Sincere thanks to the trainers who have worked very hard to deliver this quality course.

We are looking forward to having another Zoom session with the One2One Support co-ordinators on 19 January 2022 at 7 p.m. It would be marvellous to have all member organisations represented, so can I please encourage you to have a conversation with your co-ordinator, or a member of your



committee, to make sure someone can attend. Please note this date in your diary and wait for the email invitation from national office.

And for the Support Volunteers, we are planning some refresher training (by popular request!), again via Zoom, and will let you have further details about that in the next IA Update.

And finally ..... a wee reminder that Leann is looking forward to receiving details of your local support volunteers for the national database. Thank you all for your support during 2021 and best wishes for 2022.

**Anne Demick**  
**Chair, One2One Support sub-**  
**committee**

*Don't Forget*

## IA Annual Reports 2020-2021

We would like to remind you that the annual reports for Member Organisations are due by 10th January, to be included in IA's Annual Brochure 2022. 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 over the past year

Thank you to all MOs who have already submitted these, and for those that remain outstanding please may we request every effort be made for these to be returned to national office by the due date.

If any assistance or guidance is required, please contact the office who will be happy to help

# Member Organisation Web Pages

*A while back an email was sent to all MO Secretaries advising that we are finalising group page administration and would be grateful if you could help with the completion of some documentation, to help us identify login details for the groups and if a 'local information' page is required. We are still missing a lot of forms, so would kindly ask that if you haven't filled out the documents yet, that you do so asap, so we can get you up and running.*

## **Login Details**

Previously a single login was made available to groups, however in line with recommended IT security practice, we will issue login details per user so login details are assigned to individuals only. For this reason we strongly discourage sharing login details please. Each user login will only allow that individual access to administer their own group page.

## **Local Information page**

Where required by the group, we will add a 'local information' link to your group page menu. This will enable details such as 'local hospitals', 'local clinics', 'local SCNs' or similar to be added to the page in a structured format, in keeping with the style of the website.

The template we sent out allows for completion of the details in the simplest form so we can create the page with content on your behalf before handing over for your continued administration. If the page requires the upload of files, e.g. previous presentations from local events, please indicate this on the template and email them to [caroline.bramwell@iasupport.org](mailto:caroline.bramwell@iasupport.org).

The template provides for up to six links on the local information page to different local information; if you require additional links please add as required to the word or PDF document.

Once we receive your completed form we will issue login details and a guide to updating group pages to the named individuals and create your local information page, where indicated.

*If you require the documents and templates to be sent over again, please email [caroline.bramwell@iasupport.org](mailto:caroline.bramwell@iasupport.org)*



## **What are you hearing?**

We are receiving enquiries from individuals and through our member organisations about concerns around members not being able to receive their usual preferred products via prescription, or from their usual delivery company. We'd like to know if you are receiving queries about this in your area?

We are aware of local CCG product formularies, where CCGs, or groups of CCGs, have agreed a list of 'accepted' products and recommended brands. This particularly applies to additional (accessory) products.

Please email the office with any concerns being raised, as we'd like to identify if this is occurring in any particular areas.

As this is such a current topic of interest we have invited Zarah Perry-Woodford to speak about prescription management services at our Information Day on 26th March.





# Pouchitis Study

In the Autumn issue of *IA Journal*, we featured a study being undertaken by MAC Clinical Research for a potential treatment for chronic pouch inflammation in patients with ulcerative colitis. We have been advised that this study is now complete but there is a strong possibility of a secondary part commencing around Q3 2022.

Thank you to all those who chose to take part in this study. As soon as the sponsor shares the data with us, we will be sharing with all of our members.

## Information Day

With the Information Day now publicly announced as being held on Saturday 26th March, we can now reveal that the theme for the event is:

### 'Back to Better Living'

The day will be packed full of presentations, workshops and the Bryan Brooke lecture with a core focus around wellbeing - from skin care, through to exercise, back to work and back to better living.

Workshops will be delivered with special interest topics from the Internal Pouch sub-committee and the Young IA.

Bookings are now being taken for the event, with documents having been posted out to the MOs.

# Presto



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Development

One of the research programmes that are currently seeking input from IA members is from Professor Lesley Dibley, a researcher at the University of Greenwich who specialises in peoples' experiences of chronic conditions. They are seeking to develop a new questionnaire for assessing psychosocial adjustment to stoma in people with IBD.

They are looking for participants who would be willing to talk about their experiences which they can then draw on to develop the new questionnaire. If you are interested and would like to know more, please go to:

**[https://docs.gre.ac.uk/\\_data/assets/pdf\\_file/0033/259638/presto-pis-phase-1-interviews.pdf](https://docs.gre.ac.uk/_data/assets/pdf_file/0033/259638/presto-pis-phase-1-interviews.pdf)**

This will take you to a page on the university website which will tell you all about the Presto study. You will also find information there on how to get in touch with them if you want to take part.

