



The ileostomy & internal pouch
Support Group

Registered Charity



Report for EOA Meeting, Copenhagen, October 2017

About us

When IA was founded in 1956 by a small group of people in Birmingham, no-one could have foreseen that over 60 years later the organisation would have grown into the leading patient support group for people with ileostomies and ileo-anal pouches in the United Kingdom and Ireland. With 48 member organisations across the country, IA provides personal support to both members and non-members, provided by those with first-hand knowledge of living with an ileostomy or ileo-anal pouch. Our aim is to help people who have had their colon removed return to a full and active life as soon as possible after surgery, deal with the practicalities of everyday living, inspire them to achieve their goals and give them the confidence to live life to the full.

Our work

Our national office continues to receive enquiries from members and non-members needing both support and reassurance, as well as literature giving practical information on a variety of subjects. Our leaflets have been specially written by IA's honorary consultant advisers and by members with particular experiences and expertise upon which they can draw. In the past three years, several new items of literature were produced including information for families and carers, and on staying hydrated.

Information, advice and assistance to existing, new and potential members is provided by member organisations throughout the United Kingdom and Ireland. When requested, specially trained visitors contact patients in hospital or at their homes or provide valuable assistance by telephone and e-mail. The use of the forums on the IA website as a means of communication between those seeking information and those offering helpful recommendations continues to grow rapidly. Our team of qualified visitors fulfil requests from healthcare professionals to provide practical help and support to those facing surgery.

There is a constant flow of enquiries regarding travel and there is high demand for our popular travel certificate, which is written in eleven languages, and explains the conditions of ileostomy and internal pouch. The EOA website has been invaluable in helping us to signpost travellers to help and assistance that is available throughout Europe.

The excellent relationships that our member organisations across the UK and Ireland have with their local hospitals and stoma care nurses help to ensure that as many patients as possible are made aware of the support available across the country. As a result of this partnership and a close working relationship with other stoma patient support organisations, IA national and its member organisations have the opportunity to exhibit and attend many prestigious events across the country, including conferences, exhibitions and hospital open days which allow us to further promote the work of IA.

In celebration of IA's 60th anniversary, and in partnership with the Kingston Trust (KT) and the Bowel Disease Research Foundation (BDRF), IA has arranged a one-off memorial research award dedicated to IA's founder members, which will provide a fitting tribute to mark the considerable contribution of the late Professor Bryan Brooke, Doreen Harris and Nancy & Frank Alexander in starting IA in 1956. The 'IA 60th Anniversary Founding Members' Memorial Research Award' will enable funding for a project or an in-depth national audit of services available to ileostomy and internal pouch patients including the availability of stoma care both before and after surgery, the quality of surgery and the quality of life achieved by these patients 60 years after the founding of IA.

IA was also pleased to contribute to a research project surrounding the Intelligent Anastomotic Pouch. This research project was to create a sensor that can be incorporated into a biodegradable device that can be inserted at the time of creation of a colorectal anastomosis. The sensor would measure a local biomarker of anastomotic leak and provide surgeons with an early warning as to the development of an anastomotic leak.

In addition, IA has provided sponsorship for the production of the an Ileal Pouch Registry by the Association of Coloproctology, Great Britain & Ireland. (ACPGBI).

IA has also funded an observational study on the quality of life and healthcare utilisation in patients with ulcerative colitis undergoing ileal pouch surgery and as well as funded research, IA has assisted in a variety of research projects involving members' participation covering a wide range of subjects.

Our members

Each new member receives an information pack which contains booklets and leaflets on a wide range of relevant subjects covering many aspects of life with an ileostomy or internal pouch.

The IA Journal is also an important resource to members, providing relevant and topical information. Given the cross-section of IA membership, the Journal appeals to all members through the publication of articles covering such diverse subjects as personal stories and fundraising events, which offer encouragement, through to articles about life events and medical issues, which aim to educate. With the production of four issues each year and a print run of 10,000 copies per issue, the Journal reaches a large number of people worldwide.

Advice and practical/financial assistance is given to members on welfare matters and general enquiries covered subjects such as disability discrimination, travel, clothing and benefits, as well as signposting to other appropriate organisations.

Our Young IA sub-committee continues to provide support for member organisations to encourage younger members to have some involvement in the running of the local member organisations and attract new young members using social media such as Facebook, Instagram and Twitter.

The Internal Pouch sub-committee also continues to give support to members with ileo-anal pouches and organise Pouch Information days to inform and support this section of our membership.

Travel certificates for those with ileostomies and internal pouches have been produced and are proving to be a very useful and popular initiative with members and healthcare professionals alike. With the increasing issues and problems associated with travel and in particular body searching at airports, we continue to receive regular enquiries from members and non-members seeking reassurance and information about travelling abroad.

Important relationships

Our excellent working relationship with the two other principal ostomy associations in the UK, the Colostomy Association (CA) and the Urostomy Association (UA) and also with Crohn's & Colitis UK continues and the Royal Colleges of healthcare professionals, enabling us to make joint representation to Government bodies and other agencies to represent members' by taking part in meetings and discussions on new and revised arrangements for the supply of products and services to members in all parts of the United Kingdom and Ireland.

Our future

With the appointment of a new national secretary in January 2016 and the establishment of a new national office, IA continues to develop programmes and strategies to support members and anyone who meets the objects of the charity. As a result of strategic plans to ensure IA continues to listen, inform and support those who live with these long term conditions, IA is now undergoing an organisational restructure which will enable IA to continue to fulfil its aims and objectives in supporting those with an ileostomy or internal pouch, their families, friends and carers whilst, at the same time, adapting to change to meet the challenges of a modern patient led charity.

JACKIE KING

National Secretary
August 2017