



The ileostomy & internal pouch

Support Group

Registered Charity

Report for EOA Meeting, Lviv, May 2011

BACKGROUND

IA was founded in 1956 when groups which had been started in Birmingham, London and Leeds met together to form a national association. As time passed, further local groups came into being and there are now fifty-four member organisations spread throughout the United Kingdom and Ireland. We also have a postal branch.

IA's objects are:

1. To help anyone whose colon has been, or is about to be, removed by surgical procedure or who has an ileostomy.
2. To promote and co-ordinate research into bowel disease and other conditions leading to the removal of the colon, surgical procedures pertaining thereto, and related matters, and further to promote the dissemination of knowledge gained by such research.
3. To keep ileostomists and others informed of all matters of interest to IA by the periodic dissemination of information by way of the publication of a Journal, by arranging conferences, seminars and courses on topics of interest, and in any other manner which is charitable and which the trustees consider appropriate.

ACHIEVEMENT OF OBJECTIVES

Enquiries received at national office remain consistent year on year. 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 leaflets have been specially written by IA's honorary consultant advisers and by members with particular experiences and expertise upon which they can draw.

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.

We have been reviewing and developing our communication strategy. The review includes the effectiveness of the current publications which are very often the first contact people have with the organisation.

www.iasupport.org

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A new logo and the development of the IA brand in softer colours was introduced to provide a fresh, softer look and underpin the core values of listening, informing and supporting. A major part of this initiative has been to achieve a positive and consistent approach to all communications, the website and promotional materials and the way the organisation presents itself to healthcare professionals and the general public. This review is continuing with a revision of literature.

The three-year fellowship with the Royal College of Surgeons continues into a third year and is progressing well. This research project is to try to identify whether specific bacterial flora are involved in the pathogenesis of the inflammation of the bowel in people with inflammatory bowel disease and pouchitis and which particular interleukins and cytokines are involved in the process. It is hoped that this will then lead to more specific anti inflammatory therapies for treatment of the conditions. It is hoped that the information gained will help develop new treatment strategies to reduce the risk of developing pouchitis.

The three-year fellowship with CORE (previously The Digestive Disorders Foundation) continued into the second year and is progressing well. The aim of this research project, which is being undertaken at The Imperial College, London, is to look at the role of microbiological, immunological and genetic factors in fistulating perianal Crohn's disease and to look in detail at the different bacteria and immune cells within idiopathic and Crohn's fistula tracts in order to help understand more about the causes of these fistulae, to suggest new avenues of treatment for patients with and without stomas and identify possible therapies,

SERVICES FOR MEMBERS

The IA Journal is an important resource to members, providing relevant and topical information. Given the cross-section of IA membership, the Journal must appeal 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 12,000 copies per issue, the Journal reaches a large number of people on a worldwide basis.

Advice and practical/financial assistance was given to members on welfare matters and general enquiries covered subjects such as benefits, disabled badge parking, disability discrimination, travel, and water metering.

A new and active Young IA sub-committee continued with the work of providing support for member organisations to encourage younger members to have some involvement in the running of the local member organisations. Young IA nights out in cities as far apart as Birmingham, London and the Highlands of Scotland gave younger members the chance to meet others and talk informally. Efforts were also made to forge a closer working relationship with paediatric stoma care nurses in an endeavour to meet the needs of the younger ostomate. IA also provided sponsorship for families to attend activity weekends for young people aged 6-18 with bladder and bowel diversions.

Support for members with ileo-anal pouches was enhanced with the introduction of informal events to provide a space for members to talk in a relaxed atmosphere and provide an opportunity to discuss issues and experiences to give an extra level of support. Pouch Information days are also being organised to inform and support this section of our membership. A travel certificate describing the internal pouch was produced in ten different languages and this has proved 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, IA decided to produce a travel certificate for ileostomies. As with the certificate for the internal pouch this has proved to be very popular and useful.



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LIAISON WITH OTHER GROUPS

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, enabling us to make joint representation to Government bodies and other agencies. The international relations co-ordinator represented IA on a task force within the International Ostomy Association (IOA) to help shape the future of international support to ostomates.

Our continued liaison with the Royal College of Nursing, the World Council of Enterostomal Therapists (WCET) UK, the Royal College of Surgeons of England, CORE (formerly the Digestive Disorders Foundation), the Kingston Trust, the Association of Coloproctology of Great Britain & Ireland (ACPGB&I) and the British Healthcare Trades Association (BHTA), Patients, Industry and Professionals (PIPs) Forum proved mutually beneficial.

The national secretary and IA's liaison with stoma care nursing continued to represent members' interests at Government level, 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.

SUMMARY

IA continues to develop programmes and strategies to support members and anyone who meets the objects of the charity. The level of members remains fairly constant at just under 10,000 year on year. The number of new members joining increases but those moving on keeps pace. The results of our recent membership survey demonstrate that members are very happy with IA therefore there is some evidence that people join for support then move on when their confidence returns.

The executive committee continues to discuss, review and develop strategic plans for the organisation at an annual review meeting in May each year to ensure that IA continues to listen, inform and support those who live with these long term conditions.

ANNE DEMICK
National Secretary
March 2011

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