



The ileostomy & internal pouch

**Support Group**

Registered Charity

## **How it all began**

IA is proud to reflect on almost six decades of providing help and support to people who, for whatever reason, find themselves faced with the prospect of bowel surgery. It is impossible to overstate the contribution that Professor Bryan Brooke made in devising a procedure that has enhanced the lives of thousands, perhaps hundreds of thousands, of people around the world. When Professor Lionel Hardy, who was a senior physician in Birmingham with a special interest in ulcerative colitis, brought samples of a thin rubber bag and adhesive back from America in 1955, he invited Bryan Brooke, who was then Reader in Surgery at the University of Birmingham, to undertake ileostomy on some of his patients in a manner that would enable the use of the new appliance. The Brooke eversion technique produced outstandingly successful results and surgery became a treatment of choice of inflammatory bowel disease. One of those patients was a lady called Doreen Harris who had surgery in 1947 and the introduction of the rubber bag revolutionised her life. Professor Hardy and Bryan Brooke were great believers in patients helping one another and Doreen was called upon frequently to speak to other people in a similar situation to herself, to the extent that she began discussions with Bryan Brooke about starting up a patient group..... and the rest is history!

From small beginnings in 1956, IA has grown to an organisation of around 10,000 members from over 50 member organisations covering all parts of the UK and Ireland. Each member organisation has a medical president and a working committee who have freedom in operation to meet the needs of the local community. All officers of the national executive committee, divisional and branch committees have an ileostomy or ileo anal pouch. The governing body of IA is its National Council which consists of the honorary president, the trustees, and one representative from each member organisation. This National Council elects the president and the executive committee which is responsible, through the national secretary, for the overall and day-to-day administration of the association. As an organisation, IA has been very fortunate to have the support of medical presidents. Professor Bryan Brooke MD FRCS remained national president until 1982 when he was succeeded by Professor Sir Miles Irving DSc (Hon) MD ChM FRCS FMedSci. In 1992 Professor Norman Williams MS FRCS FMedSci took on the position and remained national president until 2008 when current national president, Professor Neil Mortensen, MBChB MD MA FRCS Eng FRCS Glas FRCS Edin took over. IA relies heavily on their expertise in many of the areas it covers.

## **Specialist Nursing**

Since its formation, IA has sought to work closely with all aspects of care for patients and as the organisation grew, the need for other specialist areas of patient support was set up. To have specialist nursing care for stoma patients was identified as an essential service in the late 1960s when Sir Ian Todd, FRCS and Bryan Brooke approached the Department of Health to lobby for specialist stoma care nursing to be set up. Having this dedicated service in hospital and in the community has been, and continues to be, invaluable to those who are about to have bowel surgery.

## **Personal Contact and Experience**

One of the most important services IA can offer is personal contact. That is why the organisation was formed and it remains one of the key objectives. Working in partnership with the stoma care nursing organisations, IA developed a qualified visiting course and in the years since its introduction, there are over 120 qualified visitors throughout the UK who support the other visitors who have been providing this valuable service since IA was founded in 1956. There is no doubt that carefully selected visitors who have been given the right training should make a positive difference to the rehabilitation of a patient and provide the right support for the stoma care nurse.

Inflammatory bowel diseases are no respecter of persons and IA has a varied membership so a wide experience base is required to cover all aspects of lifestyle, gender and age. Addressing the needs of younger members continues to be a challenge and a dedicated committee of younger members is in place to offer help and guidance to their peers. A separate section has been set up on the website ([www.iasupport.org](http://www.iasupport.org)) and events are organised to allow young people to meet together in informal situations.

The days of the thin rubber bag were numbered with the introduction of plastic disposable appliances which have revolutionised the lives of stoma patients. IA has always maintained a close working relationship with the manufacturers to assist in the design of reliable and high quality appliances, which provide ostomists with the confidence to live relatively normal active lives and be valuable members of the community.

## **Spreading the Word**

As a continuing and important part of IA's role, a quarterly Journal is produced and sent to all members, to stoma care nurses and others with an interest in the work of the organisation. The Journal contains articles of interest, letters from readers, information on products and practical information that is valuable to new and existing members. Promoting the work and support that can be obtained from IA is vital and a presence at selected surgical and nursing exhibitions and conferences encourages this most worthwhile link. Introduction of a website has proved extremely popular and it is possible now to join on-line, to make donations, to download information including medical articles and participate in moderated forums on a variety of subjects.

## **Coping with Life in the 21<sup>st</sup> Century**

As things change, the need for an organisation to maintain high standards becomes even greater. Many innovative new procedures have been developed during this period and there is no doubt that IA needs to keep pace with the trends to meet the challenges that these present. To demonstrate the support available to those patients opting for an ileo-anal pouch as an alternative to ileostomy, IA took a bold step in 1993 to change the name and the constitution of the organisation. A pouch section on the website and specialised literature is available for this section of IA's membership.

None of this could have been achieved without the support of surgeons, doctors, nurses, Government bodies, but most of all our volunteers who, together with the healthcare professionals, provide a vital link in patients' recovery, their lifestyle and in expanding the knowledge base of two uncompromising and debilitating illnesses. The aims and causes IA seeks to promote are explicit. The need for help, whether directed to the subject or to the individual, is urgent and continuous.

Reflecting on the past 58 years, IA has made a difference – the organisation was founded by patients to help other patients with the assistance of professionals. Returning to Bryan Brooke who once said “Anyone faced with the prospect of an ileostomy must react with dismay, even horror... however, as so often in life, reality proves better than the prospect and much better than the imagination”, IA can say with assurance “*Because we know, we care.*”

For full details on the activities of IA, contact can be made via the website ([www.iasupport.org](http://www.iasupport.org)) or with the national office at:

Peverill House, 1-5 Mill Road, Ballyclare, BT39 9DR

e-mail : [info@iasupport.org](mailto:info@iasupport.org)

Freephone 0800 0184 724

Anne Demick

National Secretary

February 2014