ISSUE 200 SUMMER 2008

IA Journal

The ileostomy & internal pouch
Support Group

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Quarterly Journal of IA

The Bryan Brooke Lecture 2008

Stoma problems - how common are they, and what can we do to avoid them?

Colitis and Ileostomy - Before and After

This member's experiences did not prevent him taking part in the '3 peaks challenge'

The IA Journal through the Ages

A commemorative article for our 200th issue

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From the editor

John Smail

A warm welcome to this 200th issue of the IA Journal. It is thanks to all those pioneers in the early days of ileostomy surgery back in the 1950s, and the work of countless supporters ever since, that we have reached this significant landmark.

In this edition, I have written a few pages on the history of the **IA** Journal which I hope you will find interesting, including some illustrations of our Journal in its earlier years. In addition, there is a summary of the recent **IA** Bryan Brooke lecture at National Council 2008, and reports from **IA** executive committee members.

I am pleased to say that members continue to send in stories about their personal experiences, which others can share and learn from. On page 48 there is a story from a member who has over ten years experience with his internal pouch and is very happy with it, and on page 54 there is a story from another member whose life with his family improved dramatically following ileostomy surgery. In addition we have several other interesting articles and another excellent selection of readers' letters. I would encourage members to respond to these letters either directly with the author, or via the Journal.

Thank you very much for supporting **IA** - and here's to the next 200 issues!

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IA Journal

The ileostomy & internal pouch
Support Group

In this issue

Front Cover: Photograph by Cepta Burke. Retiring **IA** President Professor Norman Williams MS, FRCS, FMedSci (left), pictured at NC08 with our new President Professor Neil Mortensen MD, FRCS.

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The next edition

IA Journal 201 (Autumn 2008) will be published on 1st September 2008. Final date for editorial contribution to be received is 4th July 2008.

Anne Demick
IA national secretary

Newsdesk

National Council 2008 (NC08) was held in Newcastle upon Tyne on 29th & 30th March where delegates enjoyed a weekend of business meetings, excellent lectures, interactive workshops, socialising with members from all over the country and of course, a very warm welcome from the members of North Eastern **IA**.

Tribute was paid to our National President, Professor Norman Williams MS FRCS FMedSci, as he stood down from office. In his tribute, former President, Professor Sir Miles Irving, DSc (Hon) MD ChM FRCS FMedSci, advised delegates that as a lasting memory of Professor Williams' outstanding contribution to **IA**, the current and any future joint research projects with the Royal College of Surgeons will be named "The Professor Norman Williams **IA** Research Fellowship". Professor Williams was awarded honorary membership of **IA** and presented with a Past President's medal.

We were delighted to welcome our new President, Professor Neil Mortensen MD FRCS and look forward to his leadership in this important time of change for **IA**. A profile of Professor Mortensen will appear in the next edition of the Journal.

We also elected a new chairman of the executive committee. Carolyn Stammers has taken over from David Eades. In thanking David for his leadership of the national executive committee over the past five years, Professor Williams reminded delegates of David's amazing contribution to **IA** - from elected representative to chairman of the finance sub-committee, national secretary, editor of the **IA** Journal, and Trustee of the **IA** of GB Trust, a role that he will continue to fulfil as he acts as mentor to Carolyn as vice-chairman of the national executive committee. David was presented with a small token of appreciation from all his **IA** colleagues. Carolyn Stammers, who was warmly welcomed to her new position, needs no introduction to Journal readers and Carolyn will continue with her other vital role within **IA**, as our liaison with stoma care nursing.

Peter Laflin and Joan Brough were unable to continue in their respective roles on the executive committee because of personal commitments. Richard Shawyer was elected as Young **IA** Co-ordinator and the role of National Visiting Co-ordinator will remain vacant until a suitable candidate can be co-opted.

So, some changes and some new and exciting times for **IA** as we move forward into the future! The theme of the conference was "Image **IA** - 08 and Beyond"; all sessions and workshops focused on the theme and it is hoped that the image of **IA** will be further enhanced in local areas by the ideas and best practices that were shared at this conference.

Department of Health Consultation: "Arrangements under Part IX of the Drug Tariff for the provision of stoma and incontinence appliances - and related services - to Primary Care":

A summary of the responses to the revised proposals to the consultation can be found on the Department of Health's website at the following link: www.dh.gov.uk/Consultations/Responses (DH_083765).

During February and March 2008, the Commercial Directorate held meetings with all stakeholders and advised that a panel of experts had been established to deal with the re-classification of the section of the Drug Tariff (Part IX) that contains details of all stoma and continence products. A report on the meetings and the results of the re-classification has been given to the Health Minister and it is expected that, based on these responses and discussions, a further consultation will be published late in May 2008. This will be accompanied by an impact assessment and there will be a twelve weeks response period. In our meeting with the Commercial Directorate, we were again assured that the Department of Health is still working to the objectives published in the original consultation document that has been ongoing since October 2005.

New officers at member organisations:

There are lots of changes to report to you and I will detail them below. You can find the new contact details for national officers and member organisation secretaries in the Journal Directory on pages 42-45. Contact details for chairmen and treasurers can be obtained from the secretaries.

West of Scotland IA

Richard O'Grady has taken over from John Cleland who has served for six years as treasurer. The committee would like to thank John for his stewardship and welcome Richard to this challenging position in an active member organisation.

IA Northern Ireland

Dr Fiona Wilson is the new treasurer in Northern Ireland, having taken over from Laura McAllister who for the last five years has done a marvellous job of looking after the funds and implementing systems to make the job that little bit easier.

Devon IA

Sylvia Randall has taken over as treasurer from Sue Burgess who has had to step down because of poor health.

North Eastern IA

Sandra Plunton has taken over from Pat Ahern who has served for fourteen years as secretary. Pat's guiding hand on this very active committee has been greatly appreciated and I know she has been, and will continue to be, a great help to Sandra in the hand over period. Pat and Sandra are both former members of the executive committee.

South East London & West Kent IA

I was pleased to be at the meeting when tribute was paid to Pam Thompson, Audrey Walker and Ken Holdaway for their outstanding contribution to this member organisation. Moving from the post of secretary, Rachel Hayward was elected as chairman and Sue Blackwell was welcomed as the new secretary.

Central & North Lancashire IA

Keith Woan has taken over as secretary from Mary Hogarth (see tribute to Mary on page 74).

Peterborough & District IA

Lindsay Mather is the new secretary at Peterborough & District **IA**.

IA Greater London West

Paul Bolt has stepped down as chairman after six years' service and a new chairman is being sought. The committee are pleased to welcome a new secretary, Charulata Patel, who takes over from Sandra Silva.

On behalf of everyone, I would like to record sincere thanks to all of the above people who have served the association so well in their various positions within member organisations for many years now. Welcome to all the new officers; we do hope you enjoy your time in office and wish you all every success. Please don't hesitate to contact national office should you require any help or assistance at any time.

The committee of Humberside **IA** have prepared a tribute to former treasurer, Fred Knapp (page 76) and Kirklees & Calderdale **IA** has lost a dedicated member who for many years was their treasurer. Christine Hamilton lost her brave fight against a terminal illness in December 2007 - she will be greatly missed by all the members of Kirklees & Calderdale **IA**.

Just a little reminder to Journal distributors and secretaries that there was an increase in the postal rates on 7th April 2008.

I do hope you enjoy reading this 200th edition of the **IA** Journal!

We were pleased to welcome the newly elected chairman of the executive committee to national office on 22nd April, pictured here with Karen (secretary to Anne Demick). Also on this visit to Northern Ireland, Carolyn participated in training for a section of the Northern Ireland visitors, and met with our design company to progress the new literature.

The Bryan Brooke Lecture

Stoma Problems: How common are they, and what can we do to avoid them?

The IA Bryan Brooke Lecture at National Council 2008 in Newcastle last March was given by Mr. P.J Lunniss MS, FRCS, a clinical academic colorectal surgeon at Homerton Hospital and St. Bartholomews/Royal London Hospital. He is on the Council of the Association of Coloproctologists, and has written many papers. He has a particular expertise in faecal incontinence and constipation, and complex anal fistulae.

It is not possible to convey the actual presentation of the lecture, however Dr. Elizabeth Rang, **IA** Trustee and an **IA** executive committee member, has kindly prepared the following summary of the main contents of this year's lecture.

Mr P.J. Lunniss MS, FRCS.

Introduction

To put things into context, Mr. Lunniss started his talk by reminding us that Professor Bryan Brooke, when senior lecturer in Birmingham, revolutionised the quality of life of ileostomists by inventing the loop ileostomy where the end of the ileum is brought out and 'everted' to keep it away from the skin. Earlier ileostomies were either kept flush with the skin surface, leading to excoriation and extreme soreness of the skin, or were a simple protruding spout with no eversion, often resulting in inflammation and severe narrowing of the opening. Life then could very miserable for ileostomists. Also, in the 1940s and 1950s, the Fort Dunlop factory in Birmingham started developing stoma appliances, and it could be said that advances in appliances over the past few years have led to even greater improvements in the quality of life of people with stomas, than the advances in surgery.

Current Areas of Concern

Problems connected with stoma formation:

- The formation of a stoma of necessity causes a defect in the muscles of the abdominal wall to enable exteriorisation of the bowel, which may lead to problems over a period of time.
- Complications may occur during the surgical procedure itself.
- Patients and stomatherapists know that problems of leakage and odour are common.
- Only a proportion of complications come to surgeons' attention and it is important that stomatherapists bring these to their notice.

The Department of Health's proposed reform to the funding of services and prescription products for patients with continence and stoma problems may threaten:

- Patients' choice of procedure.
- Consistence in quality of care, including the delivery of specific services and appliances.
- Education and training of stomatherapists.
- Resources for available research and development.
- Primary Care Trusts and NHS Trusts are unlikely to be able to make up the loss of funds currently given by pharmaceutical firms, so there may be a ceiling put on the procedures possible and a more limited choice of appliances available to patients. In addition, about 60% of stomatherapists are at least part-funded by industry and there could also be a problem here.

Stoma Complications Study

This is a large long-term study being carried out by the Homerton Hospital Colorectal Nursing Research Unit and the City University, funded by Hollister, and being carried out in three phases:

Phase I - a retrospective study to determine the frequency and potential risk factors of developing stoma complications.

Phase II - construction of a model of risk and to test it prospectively on patients undergoing an ileostomy operation to see which risk factors are important in the development of complications.

Phase III - determine what measures can be implemented to reduce risk factors and complications.

Phase I - How common are complications in people with stomas, and what are the risk factors?

Initially a random sample of 400 patients was picked from the records of 1408 patients who had undergone the formation of a stoma over a ten year period. From this it was discovered that:

- The average time to first complication was 85 days.
- Two-thirds of complications had arisen by 6 months.
- Less than 4% arose after 2 years.

It was therefore decided to confine the main study to patients who had been followed for at least two years. Of these patients, 647 had colostomies and 569 had ileostomies (total 1216). The vast majority had end-stage stomas. Of these, 681 (56%) had experienced complications (more than one in many cases), and the following details were found, usually from their stoma care records:

Complication	No. of individuals	%
Skin excoriation	379	31.2
Hernias	171	14.1
Bleeding	156	12.8
Prolapse	66	5.4
Retraction	72	5.9
Fistula	74	6.1
Bowel obstruction	116	9.5
Stenosis	52	4.3
Ischaemia	100	8.2
Slough	33	2.7

Risk Factors

29 variables were recorded as possible risk factors including age and gender, co-morbidities, indications for surgery, type of operation, pre-operative siting of stoma, anaesthetic status (reflection of ability of patient to withstand surgery), grade and experience of surgeon, body mass index (BMI) - rarely recorded but important to the incidence of parastomal hernias.

After careful analysis to allow for possible overlap of conditions that might cause problems, the risk factors found to be most significant were:

- Previous heart attacks or cardiac surgery.
- Breathing problems as heavy breathing and coughing may predispose to pressure on the weakened abdominal muscles and thus predispose to hernias.
- Chronic neurological conditions.
- Diabetes - a risk factor for many complications.
- Smoking as cause for breathing and coughing pressures on abdominal muscles.
- Poor anaesthetic status due often to the presence of infections and poor nutrition.
- Surgery for cancer.
- Emergency surgery.

The main protective factors against stoma complications were found to be:

- Surgery for inflammatory bowel disease (as opposed to that for cancer or diverticulitis).
- Planned surgery as opposed to emergency surgery.

- Pre-operative siting of stoma.
- Support pre- and post-operatively of stomatherapists.

This Phase I study which took about 2 years:

- Confirmed that complications of stomas are indeed common.
- Found risk factors can be identified, some of which may potentially be modified before undergoing planned surgery such as treating heart disease, and encouraging patients to stop smoking.
- Found there is a need for a well-designed large scale prospective long term study to look at what could be done to avoid these complications.

Phase II - what can be done now to reduce these complications?

Parastomal Hernias

This was the most serious of the complications arising from stoma formation and occurred in one out of seven of patients in the phase I study. Other studies have shown an incidence of 30-50%. John Golligher, a Leeds surgeon who was involved with **IA** in its early stages, wrote in 1955, “Some degree of herniation around a stoma is so common that this complication can almost be regarded as inevitable”.

Common problems caused by the presence of parastomal hernias are:

- Impact of changes in appearance due to bulging of the abdominal wall leading to worries about body image, particularly in women.
- Discomfort due to a dragging sensation and pulling on the abdominal wall, and also attacks of pain.
- Stomal dysfunction.
- Bulging abdominal wall may lead to leakage of bowel contents due to difficulty in keeping appliances adhered firmly to the abdominal wall.
- Tendency to bowel obstruction due to blockage of adjacent loops of bowel which may sometimes lead to emergency surgery.

Unfortunately surgery for the repair of parastomal hernias is not very successful. Almost 100% of people who have them repaired by opening up the abdominal wall, replacing the bowel within the abdomen, and then sewing up the extra hole around the stoma to allow only the stoma to come out of the wall, will have a recurrence of the hernia. The other possibility of relocating the stoma to the other side of the abdominal wall still has about a 75% chance of recurrence.

In the last 30 years surgery for the prevention of hernias has been explored, particularly through work on the development of reinforcement meshes, which were historically man-made. But putting in a man-made mesh has its own problems:

- The operation is a long and complicated procedure, and can be a big undertaking for the patient.
- Recurrence rates are still quite high.
- The fact that the mesh is a foreign body may result in infection with resultant scarring and deformity of the abdominal wall, leading to difficulty in getting appliances to stick.

- Occasionally the mesh may erode through the abdominal wall and cause a fistula - another passage into the abdomen.
- If any further surgery is required it can be a difficult operation as the mesh may be difficult to remove, as the infection and inflammation tends to make it dissolve into the abdominal wall.

However over the last ten years, a lot of research has been done on the use of animal-derived or probiotic materials in the production of meshes, and these are now available for use. Permacol, a pig-derived collagen sheet, is being explored by Professor Norman Williams. As he said, “instead of trying to use it to repair a parastomal hernia, could we not use it to prevent the hernias?” - this idea is under trial now. Probiotic materials are better than man-made ones because the material is not seen as a foreign body in the way that man-made meshes are, so there is less rejection and little scar tissue and adhesion formation. In addition, the meshes retain their strength for much longer periods.

Certain points need to be clarified before Permacol implants can be used routinely in the formation of stomas:

- Feasibility - is it technically possible to use?
- Safety - is the procedure safe and to the benefit of the patient?
- Potential efficacy - is it going to be a useful procedure?

Ethical approval was obtained for a randomised study on 20 patients to compare the occurrence of parastomal hernias in 10 patients who had had a conventional loop stoma with 10 patients who had the stoma with the addition of Permacol, a collagen implant. The patients were not aware to which arm they were allocated. They were followed up until the stoma was reversed, or at 12 months.

Loop stomas were chosen for the study rather than end stomas because:

- They are reversible in the event of any problems occurring during the study.
- There is the ability to study the host-tissue response because host tissue could be removed if the stoma had to be closed and examined microscopically for any visible reaction.
- Longer term assessment would be possible if reversal were delayed or considered not necessary, to look at the longer term risk of parastomal hernia.

Indicators in terms of age, sex, reason for the operation, and BMI were similar in both arms, and the mean number of previous operations was one in both arms.

The implants are stitched into a pocket underneath where the stoma is brought through the hole in the abdomen, and thus reinforce the strength of the abdominal wall under the stoma.

The results of this small survey showed:

- No patients in the implant arm developed a parastomal hernia over the year’s follow-up, whilst three in the conventional arm did.

- White cell counts remained similar in both arms, suggesting no increase in the risk of infection with an implant, and the C-reactive protein levels, a marker for inflammation, showed no increase over time.
- The implants became enveloped in the host connective tissue, but there was minimal integration and the implants were easily removable.
- The implants did not cause any difficulties in the closing of the stomas.

In summary, the study exploring the effect of using a biological implant for the prevention of parastomal products showed that it:

- Is a safe and feasible technique.
- Shows minimal host implant tissue reaction.
- Is effective in the prevention of parastomal hernias (0/10 versus 3/10).

It was decided that these results justified the setting up of a larger, long-term project under the direction of Professor Norman Williams with funding from **IA**. The 'PROPHECI' study, as it is known, has been set up as a multi-centre trial to confirm whether the use of the collagen mesh, Permacol, in people undergoing an operation for formation of a permanent stoma, will prevent parastomal hernias. It is a randomised controlled trial, comparing the use of the collagen mesh for reinforcement with a control group in which the stoma is constructed without any reinforcement. This study is currently ongoing.

Phase III study - Determine what measures can be introduced to reduce the risk factors and the complications.

In recent years, the ileo-anal pouch procedure is increasingly being offered to individuals with ulcerative colitis as a first choice. This is usually performed by opening up the abdomen or by a laparoscopic procedure. In a minority of patients it is very difficult for the surgeon to be able to reach far enough into the abdominal cavity to remove all the diseased bowel, and there is sometimes a worry that some disease is left behind in the lower rectum or anus which could result in continued symptoms or the potential to develop into a cancer. Sometimes damage can occur to the anal sphincter giving a risk of pouch frequency and leakage. The end result in these cases may be that a permanent ileostomy will have to be performed, even though an ileo-anal pouch had been requested.

In recent years the perineal approach has been used, particularly for reconstruction of the anal sphincter in cases of incontinence, but in these cases the operation is limited to a few centimetres of depth into the abdomen. Professor Norman Williams has been gaining experience in going deeper into the abdomen by the perineal approach, known as the 'APPEAR' operation, and has been developing the ability to treat other conditions of the lower bowel. He is able to go deep enough to see the lower rectum clearly and to be able to decide where it is safe to divide it, remove the diseased part of the rectum, and then bring down the colon and staple it to a suitable part of the remaining bowel above the anal sphincter.

All patients will have a temporary ileostomy to protect the join until it heals.

So far, 15 patient operations have been performed using this procedure, 5 of whom had ulcerative colitis. It was estimated that of these 5 patients, if they had had a standard ileo-anal pouch operation, 4-12 cms of diseased rectum would have been left behind, or the patient would have had to have a permanent ileostomy rather than the ileo-anal pouch they requested. In the early days of the operation there were problems with post-operative infections, but these have now been dealt with. All the patients who had the operation are fully continent, and most have a median daily pouch opening of 3 (1-5) which is very good. All taking part in the trial agreed to undergo tests for the function of the muscles of the back passage, and these showed that there was no damage to the nerves or muscles of the anal sphincter. The 'quality of life' tests also showed scores equivalent to those of the normal population. Although most patients with ulcerative colitis can have the usual ileo-anal pouch operation, for the relatively few who require a deep dissection, this new operation could be the answer.

Mr Lunniss finished his talk by saying that he hoped he had been able to show us that the surgeons are continuing to advance the progress of surgery by providing procedures with even better results for their patients. He emphasised the importance of the continued need for close relations between patients, surgeons, stoma care nurses and industry.

John Smail
Journal Editor

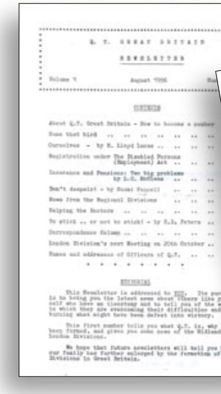
The IA Journal through the Ages

To celebrate the 200th issue of our Journal, I thought I would write a few paragraphs on its history since the association was founded back in 1956, when I was a mere lad of 10 and completely unaware of the major events that would dominate my life in the late 1970s - ulcerative colitis and an ileostomy operation.

Like thousands of others over the years, I have drawn strength from **IA**, from the many friends I have gained since joining, and of course from the **IA** Journal itself which has always been a great source of information, with mutual understanding and support. I am very proud to be editing this 200th edition of a series which has continued without a break since the first ‘Newsletter’ was published in August 1956.

The very first edition was Roneo-duplicated on foolscap paper, however by the following issue it had been reduced to the small booklet format which has been used ever since. The first issue was edited by Dr. Cuthbert Dukes OBE, MD, MSc., FRCS. He was assisted by a committee comprising the Chairman of London Division (Mr. R.D. Peters), the Chairman of the Midlands Division (Mr. T.B. Robinson), and Mr. L.C. McLean.

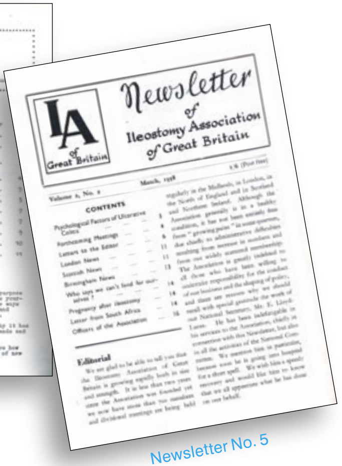
IA was originally known as Q.T. Great Britain, and the first four issues of the association’s publication were known as “Q.T. Great Britain Newsletter”. The first issue with “**IA**” appearing on the front cover was number 5, priced at 1/6d (post free), as shown below.



Q. T. GREAT BRITAIN

NEWSLETTER

Newsletter No. 1



IA of Great Britain

Newsletter of Ileostomy Association of Great Britain

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Editorial

Newsletter No. 5

As we have now reached issue no. 200, I thought members might like to read what the **IA** Journal had to offer on other ‘anniversaries’ in issues 50, 100, and 150.

Journal 50 - Summer 1970

Our president at this time was Professor Bryan Brooke MD, MChir, FRCS, our Chairman Tom Sturgeon, General Secretary Leslie Kingston, and the Journal Editor Mrs. B. Haq. The issue is shown priced at 2/6d for those who remember the pre-decimal days!

ia

quarterly Journal of the Ileostomy Association of Great Britain and Ireland

Journal No. 50

The issue contained an ileostomist’s “ABC” where such things as bathing, belts, bleeding, clinics, and Crohn’s disease were described. Several adverts appeared for such companies as Down Bros (two-piece appliances), Donald Rose Ltd (lightweight rubber bags), Chas Thackeray Ltd (Schacht ileostomy appliance), J G Franklin & Sons (“Translet” easy-change disposable bags), Seton Products Ltd (waterproof strapping), Eschmann England (the “Continental” appliance), Simpla Plastics (“Sassco” system), and finally Charles Bullen Ltd and Salt & Son Ltd both of whom remain involved with the production of stoma products today.

Letters to the Editor featured a variety of subjects, and included the following from a Mrs. Phillips of Gateshead whose letter is as relevant today as it was in 1970:

“I am writing mainly for those ileostomists reading our Journal for the first time and who need strength to go on, and because my heart is full of gratitude to God and all those who work with him. So, all you non-ileostomists who read our Journal and may be bored hearing so much about our ‘new life’, please bear with me.

I became an ileostomist after seven years of ulcerative colitis, during which time every conceivable detail that could go wrong did go wrong. I spent thirteen months in hospital, and lost everything that matters most to a woman - my hair fell out, my figure went from 8½ stone to 5½ stone, and worst of all, I even lost my mind. I only wanted to die. When friends told me of other ileostomists who were leading normal lives, I did not believe them.

But today, two years after my operation, I am not only leading a normal life, but I am actually better in every way than I was before. Before, I was afraid to make new friends for fear of my body or mind letting me down. Today, I am full of confidence and have many new friends. I have so much energy that I am hoping to take up auxiliary nursing. I have regained my hair, my figure, and most important, my peace of mind.

So remember, no matter how much agony of body or mind you may have today, it will pass. And what is a year or two out of a lifetime of happiness? My life used to be hell, now it is sheer heaven on earth. I awake each morning and thank God to be alive, and just cannot wait to get on with another wonderful day.”

Journal 100 - Summer 1983

Our president then was Professor Sir Miles Irving MD, ChM, FRCS, our Chairman Tom Keily, and our National Secretary & Journal Editor Chris Penney. No price is shown as by this time the Journal was being distributed free of charge to members.

Journal No. 100

The main medical article in issue 100 was “Inflammatory Bowel Disease and Arthritis” which remains in print today as one of the articles in the “**IA** Journal Omnibus” (which can be ordered from **IA** National Office). A “Research Round-up” page gave details of a project involving salt and fluid loss from ileostomies, and a project undertaken into possible employment problems following stoma surgery. Another interesting report also contained the names of six members with ileostomies who completed the 1983 London Marathon, and five associate members, all as members of the “**IA** team”. Finally, in the letters section, the following letter appeared anonymously:

“I am 33 years old, married, and shall be returning to work in January 1983 after having surgery at the end of September 1982. It would have been impossible for me to have had more or better help, care and support, either when I had colitis or when I was advised that an operation was the only way to health, or during and after the operation.

*The main reason for my joining **IA** is so that I can read of research results and of new and existing equipment. For me an ileostomy has meant a return of excellent health and spirits after several years of ulcerative colitis. The operation and the inconvenience of managing the stoma are a very small price to pay for that, but I hope that at some time in the future people with u.c. will not need such a drastic solution to their problems. That means research, and research takes money, so in 1983 I shall be able to join in fund-raising activities.....”*

Journal 150 - Winter 1995/1996

Our president then was Professor Norman Williams MS, FRCS, our Executive Committee Chairman Tom Keily, and our National Secretary & Journal Editor David Eades. A ‘commemorative’ article (such as this one) was included, written by David Eades, which described the evolvement of the **IA** Journal up to issue 150.

Journal No. 150

An article containing nutritional advice for internal pouch patients was also included,

together with the results of an ostomates ‘quality of life’ study. **IA**’s “Romanian project” had also just been launched, and an appeal was included for funds. By this time, companies familiar to us all now as regular advertisers were appearing, including Dansac, Hollister, Fittleworth, CliniMed, ConvaTec, Pelican, Bullens and Coloplast.

A sample letter from the ‘dear editor’ section, written by Pauline Lyon-Shaw of Dorchester, read as follows:

“After seventeen miserable years of suffering from ulcerative colitis, I had an ileostomy in May 1987. Life for my family and I just got better from that moment on. I could do everything with the children that I had not been able to do before and we were a ‘normal’ family.

I have now achieved even greater things - I have just returned from a ‘Mum’s Adventure Weekend’ on Dartmoor with the school where I work. During the course of the weekend, I climbed the side of a sheer cliff, abseiled, took part in a river run, trekked across Dartmoor on horseback for two hours, and finally went caving. I was able to participate fully in all those activities with the exception of the ‘maggot run’ in the caves which involved wriggling on your stomach through a very narrow run! This trip has done wonders for my confidence; I feel that I can conquer the world. I will always remember the experience, especially at those times when I feel sorry for myself.”

A member of Richardsons staff preparing for print production.

Checking the proofs before the printing presses run.

Until 1973, the **IA** Journal was published in black & white only, however the Winter edition of 1973 saw ‘spot’ colour used on the front cover for the first time. The use of colour then gradually increased however it was not until 1995 that the ability to have full colour on every page was reached.

Throughout its history, the **IA** Journal has had only eight editors, all of whom have been non-professional editors drawn from within **IA**. Our association has been very fortunate that members have been prepared to volunteer and to develop the necessary expertise to produce what has become a very professional publication. We are of course very grateful to the manufacturers and suppliers, without whose support the **IA** Journal could not have developed as it has. However, it is thanks to you, the readers and members of **IA**, that the Journal has reached its 200th issue after 52 years. It is *your* Journal and it is *your* regular contributions - letters, articles, and photos that fill the pages. Please keep up the good work so we can look forward to our next 200!

Richard Shawyer
Young IA Co-ordinator

Young IA News

Well it really has been a hectic few months in the Young IA area with the build-up to National Council 2008 in Newcastle. What a great conference we had, with the Young IA workshop built around paediatric stoma care, which is pretty much uncharted territory for IA. We also had an evening with the younger members who were attending the conference, as well as local members from Newcastle, on the Friday night - this was received extremely well by all.

At the conference I was elected as your new Young **IA** co-ordinator with Peter Laflin having stood down due to personal reasons. I am sad to report that the Young **IA** sub-committee is losing three previous members, Anna Rennie, Kate Hallett and Jonathan Legge. The committee thank them for all their hard work and wish them every success in their careers which they have gone on to pursue. It is a pleasure to welcome Sue Blackwell to our sub-committee, who is a civil servant. The Young **IA** sub-committee will be formally approved in May by the **IA** executive committee, and we all hope to achieve a lot during the next year.

We intend to continue to have the ‘local’ nights out and these will be supported by Young **IA** to build upon the excellent work completed last year. We also intend to organise another Young **IA** weekend; we are currently discussing and investigating locations and dates and details will be announced shortly so keep an eye on the Journal, **IA** website, and also e-mail me if you want to be added to the Young **IA** mailing list.

Following the workshop at National Council we would also like to investigate how we can cater for the younger members of **IA**. We believe we cater reasonably well for the 18 - 40 age group but at present we don’t cater for the under 18s. As I write, Heather Buck is just about to attend the “Breakaway” weekend which caters for young people with urinary and bowel diversions. We will complete a full report for a future Journal, and we hope that it will be a very successful event.

Please let me know what you think we can do to cater for the younger market. My initial thoughts are perhaps something for teenagers and then move into the paediatric area. I need help in understanding what these people need - my contact details are in the Directory of this Journal (page 42). I can’t really draw upon my own experience as I was only given my ileostomy in my teens. We are also investigating the production of an information sheet that could be handed to teachers and other adults - this should help people understand what the condition is and how this might affect the day to day life of a child in education.

You may remember two Journals ago (J.198) I had an article published on my career as a pilot. I think it would be beneficial to younger people if other young **IA** members wrote in with their stories. The younger people are not alone, and it is always refreshing to read about how other people are coping and what they are up to. Our Journal editor has reserved space for us, so let’s fill that space...start sending your stories and articles to me!

As a sub-committee we are working to help all our Young **IA** members throughout the UK. If you think we can improve something then please let me know and we can build upon your suggestions. I have already taken a copy of the thread “What one thing” from the Young **IA** website forum (www.iasupport.org) and will be reviewing it with the sub-committee. I think this year should be very exciting with the new ideas that are floating around. Let’s all build upon the previous success of Young **IA**, take it forward, and raise our profile.

Rachel Hayward
Pouch Group Co-ordinator

Internal pouch news

It's April as I write this, there is snow outside my window and right now summer seems an awfully long way off. It's hard to imagine what it'll be like to leave my flat without my big winter coat let alone be able to wander around in flip flops! However looking to the months ahead has been very much on my mind, and I guess that looking to future possibilities is something we as IA members do particularly well; I guess most of us have had good training - having IBD means that you're always looking for the possibility of finding a toilet nearby! Experiencing such dramatic surgery forces you into a position to accept your own mortality, and when you emerge from the other side of that place, it feels as though your future possibilities are endless.

So just as it's almost impossible to remember what it feels like to have the warm sun on your skin when you're waiting in the bitter cold rain for a bus that feels as though it's never going to come...it is surely impossible to imagine how your life is going to be if you choose to have an internal pouch. It's such a massive decision to make, and there is a huge pressure to make sure you 'get it right' - decisions are so much more difficult when there is a choice.

This is the overwhelming message that the Pouch Group Committee and I are hearing. Over the last 12 months, since taking over as Pouch Co-ordinator, I have personally been contacted by over 120 people looking for support, and the vast majority of those calls and e-mails have been from those seeking first-hand information to help them make the decision to have internal pouch surgery.

A lot of the information on internal pouches varies greatly; those who are inspired to tell their stories or go on the internet tend to be almost evangelical about their pouch, insisting that it's the best thing ever and everyone should have one, or they are the complete opposite - that their pouch was a dreadful experience and made their life a misery. Most people, however, fall somewhere in the middle, and this disparity is something we clearly need to address.

At National Council we were able to hear Angie Perrin, Specialist Nurse at the John Radcliffe Hospital in Oxford, tell us about her research into quality of life for pouch owners. Angie's findings confirmed what many of us had thought for years - perception of whether a pouch is a ‘success’ or a ‘failure’ is completely subjective and not as simple as surgeons may suggest. The traditional measure of pouch frequency and the magic number of four times a day (any more, then your pouch is a ‘failure’) can be interpreted too literally. I probably go about eight times a day, I go when I need to pee, or if I don’t think I’m going to be near a loo for a while, or if I need to pass wind - I never learned that skill and am always just too scared to risk it. So I would be considered a ‘failure’ - but how can that be so when I have complete control and my pouch doesn’t prevent me from doing anything that I want to do?

Only you can decide what is the best option for you, and I certainly accept that not everyone wants to have a pouch. You may not want to go through more surgery and the risks that involves, and there is certainly a pressure from some surgeons that younger people should have a pouch to have a better body image. I definitely experienced that (although it had the opposite effect and made me want to keep my bag - I thought, why should I change myself to make other people feel comfortable ...?). But don’t be put off by some of the stories you hear, come and find out for yourself and find out first hand. All in all, I think you have to be a bit of a gambler to have an internal pouch - there’s certainly an element of risk - if that’s something you can live with then I reckon the odds are pretty good.

I hope that this year the Pouch Group can continue to build on the success of the very popular ‘Pouch Events’ - the next one, by the way, is on 28th June in Birmingham. Coming out of the feedback from the Pouch Group workshops at NC08, it would make sense to extend an event and organise a weekend for anyone interested in internal pouches to come and find out the various possibilities that lie ahead.

VSL#3 update: Loads of you have been in touch with either me, **IA** National Office or the pouch website forums about obtaining VSL#3 on prescription. As yet VSL#3 is not in the BNF and is classified as a ‘food supplement’ and is therefore not straightforward to prescribe; it will depend on your Primary Care Trust on whether you will be able to get it on the NHS. Ferring, who distribute VSL#3, tell me that this situation is being reviewed, which should make things a lot easier once it is re-classified. I will keep you posted.

Iron deficiency: I had always assumed I was just a bit weird; I knew that some of the colonically challenged are B12 deficient but I hadn’t heard of anyone else who was low in ferritin. I am not able to store iron which makes me anaemic, which shows itself with a low ferritin count (I was down to 2 three weeks ago). I’ve never had an explanation for this and was always told by my various consultants that it wasn’t because of my internal pouch...But ha! - they’re wrong! According to new research at the John Radcliffe Hospital, up to 20% of pouch owners are like me and suffer from low ferritin (although they don’t know why yet), and they now routinely screen their patients. It’s good to know I’m not that weird after all!

Claire Bohr
Paediatric Stoma Nurse
Bristol Royal Hospital for Children

Paediatric Stoma Care - more to it than just small adults

Many UK paediatric stoma nurses work autonomously, many work within a small team that combine specialities. The job can be very isolating, and with very little published literature, it is challenging to accrue best clinical knowledge and practice.

The job has many challenges, one being that the age group of the patients ranges from 0 - 16 years. When caring for a baby or a young child you have the problem of size, you also have to support the parents, and in many cases the baby may only be a few days old. With the middle age group you have to gain the child's confidence, usually through play, and it may take several visits. You then have to communicate with the child in a simple language they understand - and once again there are always anxious parents who need explanations.

Then there is the teenage group, easier to communicate with (sometimes) but who have added pressures - their peers, education, and body image, to name just a few. The job is very challenging, but to give children the confidence to care for their own stomas is hugely rewarding. It is usually the parents who find it the hardest to adjust, and difficult to come to terms with the fact that their child is dependent on stoma care.

In 2005, Helen Woodcock, a paediatric stoma nurse in Sheffield, contacted paediatric stoma nurses throughout the UK and Ireland asking them to attend a day's meeting to establish what interest there would be to form a Paediatric Stoma Nurse Group. Seventeen nurses attended this first meeting, and it was a good opportunity to put faces to the nurses I had been ringing for support and reassurance in my newly appointed job. The day was spent in a lot of discussion - eg. if a group was formally established, who would run it? And how would it benefit paediatric nurses and their patient group?

Over the next few meetings we compiled a mission statement - "The Paediatric Stoma Nurses Group (PSNG) aims to promote excellence in practice for neonates, children and young people with stomas by developing evidence-based health care and influencing national standards and guidelines."

Membership of the group consists of nurses with a special interest in paediatric stoma care. Most of the members work within a dedicated children's hospital and have undertaken a paediatric stoma care course. Like all successful groups, we have terms of reference, aims, and an eye-catching logo. A decision was taken from the beginning not to have a dedicated chairperson. We felt that it needed to be run by the group members themselves, taking it in turns to be host, and delegate to the other members. We meet three times a year, rotating venues around the UK and Ireland.

At present the group has 26 members, with an average of 15 at each meeting. The group is compiling a 'standard of care' document to define good practice in paediatric stoma care. We have standardized some of our individual leaflets, and developed guidelines for paediatric practice. The group acts as a resource for health professionals and industry, updating and developing information and products.

In October 2007, the first dedicated international paediatric stoma conference was held - an opportunity our group could not miss out on. Stoma care conferences are held regularly in the UK, Europe, and internationally, but these mainly focus on adult patients - paediatric updates are very few and far between. Interest was sought within the group, and seven members were granted leave from work and family. As the conference was in Montréal, it would mean more than an overnight stay. Sponsorship was obtained from industry, and **IA** very kindly sponsored a nurse to attend.

127 delegates attended from 17 different countries and it was fantastic that our seven nurses represented such a small island. Over three days we were able to update our knowledge, talk about our concerns, and share our experience of clinical practice. It was reassuring that we may be a small country but our care and knowledge is equal to any. It was a challenging three days as the majority of the presentations were in French - we did have the facility of translation, but some French does not translate directly into English, so some words were missed out!

As the travel time was seven hours, we took some holiday time to discover Montréal - we were very fortunate to arrive just as the trees were turning into their autumn colours - a spectacular sight.

Hopefully this meeting was the first of many. I felt very privileged to have attended the very first paediatric stoma care conference. Without sponsorship, attending this conference would have been impossible, and I am grateful that through sponsorship from **IA**, impossibility became reality.

Some of the delegates attending the international conference.

Press Release
ConvaTec Limited

The Prince's Foundation for Integrated Health

The Prince's Foundation for Integrated Health is a charity dedicated to improving the health of people through a more holistic and natural approach. It recognizes that often a natural all-round approach to lifestyle can help people with health conditions recover, develop and progress through life.

The Foundation has always been a great advocate of the good work of patient groups and has recently given their support to ConvaTec's Great Comebacks® patient programme, which recognises individual achievements following stoma surgery. Great Comebacks® provides information and inspiration to those facing the physical and emotional challenges of inflammatory bowel diseases, colorectal cancer and ostomy surgery whether as a result of a condition developed later in life or at birth.

On 20th March 2008, The Prince of Wales' charity held its own awards ceremony for the Integrated Health Awards, which focus on services in the UK that provide information and empower people to manage their mental, physical and emotional health more effectively.

Prince Charles with Mary Backstrom, Vice President ConvaTec Ltd.

The overall UK winner of the Integrated Health Award, sponsored by Nelsons, went to the Midlothian Sure Start family support scheme that has transformed children's lives through a dedicated, innovative and integrated approach. The staff understand how poverty, poor education, low self-esteem, diet and exercise directly impact the children's development, and work directly with both the children and their parents to improve their daily lifestyles. Amongst the wealth of activities that the schemes offer are; six family support centres, counseling services, personal development courses and children's play groups, which encourage 'learning through play'. The judges felt that the Midlothian scheme stood out for its determination to strengthen parents' ability to maximise their children's potential.

ConvaTec and the Foundation for Integrated Health are working to improve the support networks for ostomates and their families through a series of collaborative activities. Other supporters of the programme are the Colostomy Association, **IA**, UA, the Royal College of Nursing (RCN) and World Council of Enterostomal Therapists (WCET).

If you would like to nominate or share your story please e-mail us on stoma.webcare@bms.com or visit www.greatcomebacks.com or for more information call 0800 282 254.

For further information on the programmes and schemes outlined above please visit www.midlothian.gov.uk/services/ccs/PublicCCSdetails.asp?id=996 or www.greatcomebacks.com/uk/programs/index.shtml.

Donations Report

Legacies	
General Fund	
Ronald Baker	£10,000.00
Frank Burditt	£1,000.00
Minnie Chesmore	£500.00
Donations: External	
General Fund	
Sheila Wood	£1,000.00
Bain Capital Ltd on behalf of Greg Mackin	£1,000.00
In memory of Kenneth Adcook	£240.88
In memory of Lydia Johnson	£210.00
Dan Barter	£153.50
Give As You Earn	£149.10
John Smail	£80.00
Anne Demick	£60.00
George & Jean Duncan	£50.00
Brian Carse	£50.00
Mr D.J. Dottie	£30.00
In memory of Iris Letitia Hutchinson	£20.00
In memory of Jack Cotreave	£10.00
Justgiving fund raisers	
Leo Sharrock - London Marathon sponsorship	£1,007.11
Joanne Raynes - Wilmslow Half Marathon sponsorship	£628.20
Jamie Keegan - Run Around The Driveway 2008	£903.52
Rebecca Wyatt - Wilmslow Half Marathon sponsorship	£292.84
In memory of Peter Butler	£50.00
Stuart Wiseman - Coast to Coast Ride	£47.82
Research Fund	
Mrs Phyl Morris in memory of Bob Morris	£760.00
John Woodhead	£250.00
The Acorn Spiritualist Group	£100.00
Beverley Golbourn	£20.00
Helen Bowen	£15.00
Michael Mason	£10.00
John Lawson	£10.00
Donations: Member Organisations	
Research Fund	
IA Central & North Lancashire	£2,000.00
Leicestershire IA	£2,000.00
IA West of Scotland (The Lynda Sinclair Memorial Research Fund)	£1410.00
Norfolk & Suffolk IA	£1000.00
Lincolnshire IA	£1000.00
Surrey IA	£900.00
Merseyside IA	£250.00
IA Greater London West	£100.00

Nick Moon
IA Treasury Services

2006/2007 Financial Accounts

I am pleased to present the usual annual report on our financial results for the year ending 30th September 2007. These are the figures relating to IA nationally, the accounts of your member organisation are available from your local committee. During the last year IA's assets increased by £202,104 to £4,310,420 and this surplus was entirely due to the increase in value of our investments. Here is a summary of the results by fund:

Fund	Balance 1/10/06 £	Incoming Resources £	Outgoing Resources £	Balance 30/9/07 £
General	364,026	259,538	296,163	327,401
Capital Investment	3,409,253	359,274	0	3,768,527
Elizabeth Clay Memorial	196,384	14,454	8,751	202,087
Total unrestricted funds	**3,969,663**	**633,266**	**304,914**	**4,298,015**
Research	102,710	182,459	310,288	(25,119)
Welfare	18,902	1,371	937	19,336
Bryan Brooke (IA) Overseas Travel	13,592	753	0	14,345
Young IA Bursary	2,557	2,256	970	3,843
Miscellaneous restricted donations	892	47	939	0
Total restricted funds	**138,653**	**186,886**	**313,134**	**12,405**
Grand Total	**4,103,316**	**820,152**	**618,048**	**4,310,420**

The **unrestricted funds** had a routine year. The **General Fund** was reduced as planned but the increase in investment values shown in the Capital Investment Fund more than offset this reduction. The most interesting changes during the year were in the **Research Fund**. The income of £182,459 was mainly due to the accrual of £140,000 in respect of a legacy from Henrietta Harland and the expenditure of £310,288 was due to the fact that we committed to funding two new projects during the year with a combined cost of £300,000. Although none of this money has actually been paid out at this point, it has to be recognised in the accounts. The deficit balance therefore is not a problem, as the funds committed will actually be paid out over the next three years, during which time further income will be generated to rebuild the fund. The **Miscellaneous Restricted Donations Fund** was closed at the end of the year. As all the money left in the fund was restricted for use by Young **IA**, the executive committee decided to transfer it into the **Young IA Bursary Fund**.

These figures show a healthy financial situation for **IA**, but we are continuing to seek ways of using funds constructively and the executive committee have offered a further research fellowship to CORE (formerly the Digestive Disorders Foundation), which will cost in excess of £200,000. In addition, you will be aware that the stock market has been in turmoil since the date of these accounts and it is likely therefore that the year to September 2008 will see a decline in **IA**'s assets, regardless of what we actually spend. However, the executive committee will monitor the situation carefully and take steps to minimise the impact of outside factors on our activities.

Auditor's opinion

In our opinion, these summarised accounts of **IA** for the year ended 30th September 2007 are consistent with the full annual accounts on which we have issued an unqualified opinion.

Jones Avens
Chartered Accountants
& Registered Auditors
Chichester, West Sussex

March 25th 2008

A copy of the full Annual Report and Accounts, approved by the Trustees on 16th February 2008, can be obtained from Nick Moon at the address shown in the Directory on page 42. The full trustees' report and accounts were submitted to the Charity Commission on 8th April 2008.

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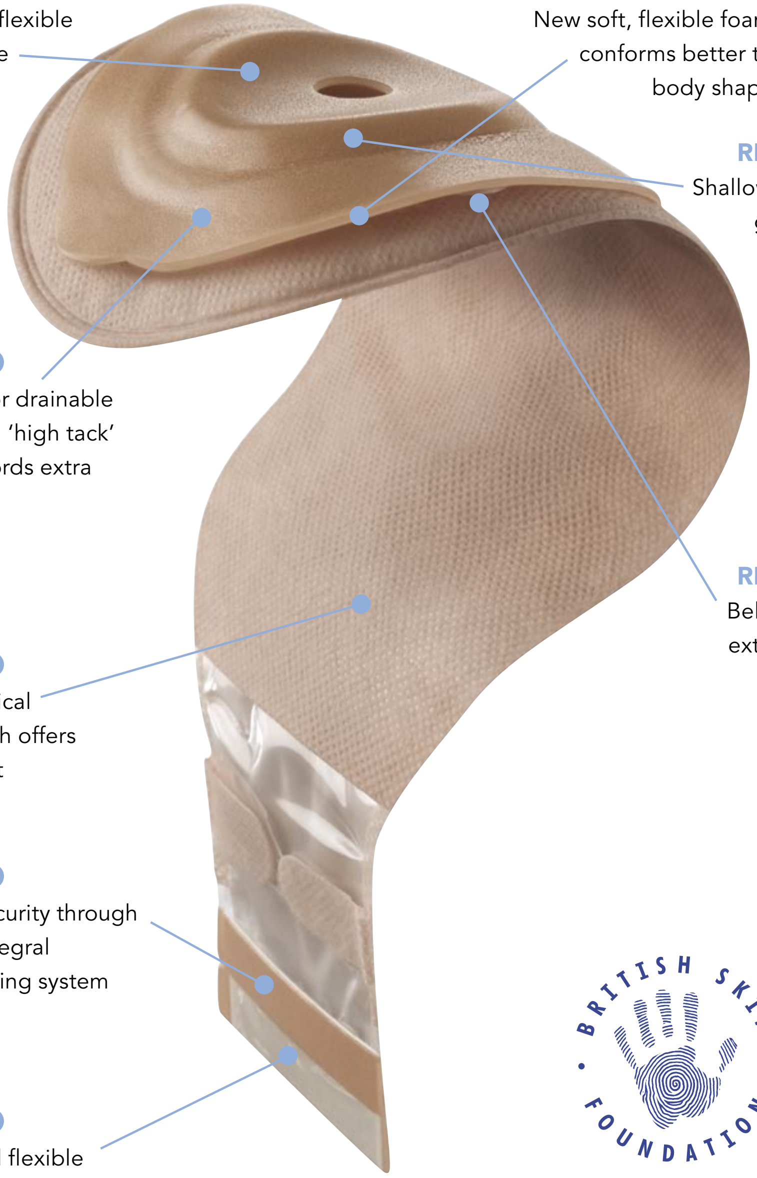

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REASON ②
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REASON ③
New soft, flexible foam conforms better to body shape

REASON ④
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REASON ⑤
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REASON ⑦
Maximum security through a soft and integral opening/closing system

REASON ⑧
New soft and flexible offset strip makes draining and cleaning easier

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Supporting Salts research into healthy stoma skin

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It is the policy of **IA** that all the officers of the national executive committee, divisional and branch committees (apart from medical consultants) shall themselves have had a colectomy and have a full understanding of all that is involved in living with an ileostomy or internal pouch.

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New products and services

the editor

Brunlea

Brunlea Surgical Supplies is a company with long standing credibility, and this year will be **Brunlea's** Silver Jubilee year.

The company registered as appliance contractors in 1983, and specialise in ostomy and incontinence products. Their aim is to ease the trauma and anxiety so often associated with this type of condition by making patients aware that ordering and receiving supplies need not be a problem. **Brunlea** understand and care about patients' situations, and when necessary act as a link with their stoma care nurse.

Brunlea was formed when Mr Wally Thomas, who has many years of service as a medical representative in the stoma care field, saw there was an urgent need to provide a prompt door-to-door delivery service to patients, a service that embodies patient contact and care, is simple to operate, and always available.

Over the last 25 years **Brunlea's** family-run business has grown from strength to strength. The success of the company is testimony to the quality and standard of service they provide, which has been evident by the appreciation expressed by many patients over the years.

The company thanks everyone involved in helping them to provide such a personal touch to their service, and hope the next 25 years will be as successful.

For an immediate response or for any further information, please call **Brunlea's** freephone number on 0800 834712 (see also advert on page 3).

Coloplast

Coloplast have introduced **SenSura Click**, a new product to their SenSura range, and available on prescription from 1st June 2008.

SenSura Click is a 2 piece system which combines the revolutionary SenSura adhesive and the well-known secure Click coupling.

Thanks to a unique double layer adhesive, **SenSura** gives skin friendliness and protection against stomal output, whilst offering security and reassurance with a safety ring coupling that is easy to use. When opening and closing, the coupling will give an audible click indicating the bag is securely fastened to the baseplate and when you remove it again. **SenSura Click** is available in a wide choice of bag sizes and baseplates, giving an extensive choice to ostomists.

SenSura Click is advertised on page 5 of this Journal which gives details on obtaining free samples. Alternatively you can contact Coloplast's award winning Customer Care team on 0800 220 622 for details of the company's full product range, or visit their website at www.coloplast.co.uk

Pelican Healthcare

Pelican Healthcare is pleased to announce the launch of a new range of 2-Piece appliances which are available on prescription now*.

The Pelican Select 2-Piece range of products has been specifically designed to enhance comfort, whilst ensuring maximum security coupled with ease of connection.

Select 2-Piece is available in three pouch sizes: Mini, Standard and Maxi. The unique thumb tab allows easy opening of the outlet for emptying and cleaning, whilst the controlled flow waterproof filter is effective at reducing the risks of pouch pancaking and ballooning. **Select 2-Piece** base plates are available in two sizes: 50mm and 70mm dependent on your stoma size. The Select base plate is unique and extremely flexible offering you maximum comfort.

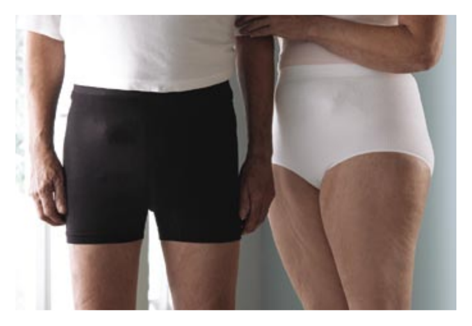
Please see Pelican Healthcare's advertisement in this edition on page 9 to request your complimentary samples, or simply call their Freephone helpline on: 0800 052 7471.

* *Not currently available in Scotland.*

Salts Healthcare

Salts Healthcare have launched the **Simplicity** range of boxers and briefs.

Ostomists who want a little extra security and comfort need look no further than a new and improved range of stoma support wear from Salts Healthcare. Called **Simplicity**, the unisex boxers and ladies briefs are not only made from a lightweight and breathable fabric that keeps the body dry at all times, they also benefit from antibacterial properties.



Simplicity Stoma Support Wear is made in two-way stretch fabric which moves with the body, and features ribbing on the front that gives secure pouch support as well as a flush finish that is virtually invisible under most clothing. The support wear also has a deep and high waistband that offers extra comfort and covers the pouch without preventing the stoma from working. What's more, **Simplicity** briefs have no labels to irritate you when you move, and after washing they can be quickly dried in around 30 minutes.

The **Simplicity** boxers and briefs are available on prescription in the UK in black or white in S/M, M/L and L/XL sizes and form part of Salts' comprehensive range of accessories.

If you would like further information on the new range, need guidance on sizing, or would like to place an order, please call Salts' Freephone number 0800 626388 or visit www.salts.co.uk.

Robert Anderson
Norfolk & Suffolk IA

Coming to Terms with a New Plumbing System

I was diagnosed with ulcerative colitis in 1992 at the age of 23. I had been suffering with diarrhoea and severe bleeding from the rear for nearly a month before I plucked up courage to visit my GP. I thought, like most others I guess, that the problem would clear up, and I was embarrassed about talking to anyone about it.

How I wish now that I had done something sooner. I had lost nearly 3 stone in weight and in photographs from the time I looked like a walking skeleton. It is odd that one seems not to notice these changes in oneself at the time. It is only looking back or meeting someone one hasn't seen for a while that the differences are spotted.

Anyway, my GP arranged for me to visit the proctologist at Ipswich Hospital and prescribed me something for the diarrhoea. I can't remember how effective that was but within a week I was in hospital speaking to a consultant who diagnosed ulcerative colitis (UC) and arranged for a sigmoidoscopy. I can't remember if he prescribed any prednisolone at that stage or not, but I soon found myself back in hospital, this time lying on my side with a 'telescope' up my rear-end! One thing I do remember was the wonderful feeling of euphoria creeping up my arm as the mild anaesthetic was administered into the back of my hand - one bonus to come from the situation!

By this time I had passed my 24th birthday, and for a young man you can probably imagine this was not how one had planned their life to turn out. Of course I'm equally sure that no one, whatever age or gender, would be particularly chuffed with having one of these procedures.

So the consultant confirmed my UC and from then on I started a love-hate relationship with prednisolone. Large doses brought everything under control - I stopped bleeding, my motions began to firm up, and I had much more control over my bowel actions. However, as we know, one cannot stay on large doses of prednisolone forever, and as I gradually reduced the dosage the symptoms would return. I always dreaded getting down to that 10mg stage because I knew that the symptoms of UC would most likely follow.

This yo-yo process of steroid dosage continued for four years before the consultant made an appointment for me to see a surgeon at Ipswich Hospital. The surgeon looked through my records and didn't sugar-coat the pill when he told me that I was facing having to undergo surgery for my condition. I recall crying when that news came. The surgeon and the stoma nurses talked me through the procedure and I was given a video of the surgery to watch. In a way I wish I hadn't seen that - it was like a gory horror movie - but at least I had an idea of what to expect.

That was how I came to find myself in hospital in November 1996 undergoing the first stage of my internal pouch operation. The first operation was carried out and I woke up on a ward in some discomfort but this soon faded as painkillers were administered. I remember crying again when I looked at what the surgeon 'had done' to me. I had a stoma bag attached to my abdomen and a mucus fistula lower down that I do not recall anyone telling me would be there. It must have been a combination of the medication and my feeling sorry for myself that caused me to be quite weepy in hospital, and I suppose if I am honest some of that was vanity and concern for my body image. I had always enjoyed swimming and keeping fit. I had taken up scuba diving and it was difficult to see how this lifestyle was going to work out with a stoma.

> **...you can probably imagine this was not how one had planned their life to turn out.**

I was discharged from hospital and spent the next couple of months at home getting used to the new arrangement for my waste discharge. I was not overly concerned about the situation - it was after all Winter, so there was little scope for baring my stoma to the world. I returned to work at the end of January - I worked then as warehouseman at the Port of Felixstowe - and life continued. I think the worst of it was the mucus fistula that wept quite badly but the stoma bag itself was fine. I had a few leakages at night as I got used to the fitting procedure. As I recall the bag would fill more with wind (a right old Aeolus!) and this would cause it to come loose as I moved around at night.

It wasn't long before I was called back to hospital to have the second stage of the operation. Not a reversal, because I knew that things would not be the same as before I was ill. I had been told to expect my motions to be much like those I had seen from the stoma and that I could expect to be going to the loo up to six times a day and once at night. OK, that sounded reasonable to be rid of the stoma bag and be able to lead something of a more normal life, albeit having to keep one eye on toilet facilities.

> It wasn't long before I was called back to hospital to have the second stage of the operation.

Again I went down to surgery - this was in March of 1997 so hardly any time between operations - but this time I woke up with all sorts of tubes sticking out of me. I had a catheter and a tube in my anus and one in my nose. I had IV drips going into my arm and felt like something out of The Matrix (although of course that film wasn't released at that time). The surgery hadn't worked too well, and nothing would come out of the tube from my rear. An X-ray revealed that part of the pouch had adhered to my spine or something like that, so I had to go down again to have that sorted out.

By this time my surgeon had been through the wall of my abdomen three times so you can imagine it was a bit sore. This time the surgery worked and after a few days as I started eating solids I began to get movement from the pouch and so from my rear. Now I couldn't stop going! My sphincter muscle must have weakened so much it was hard to keep control, and the bed sheets ended up soaked a couple of times. Gradually I was able to hold on long enough to get to the toilet, but often it seemed that as soon as I got off the loo it was time to go again. After a couple of weeks, by which time I think I was going a bit crazy being in hospital, I was allowed home to adapt to my new pouch.

The first months were pretty rough. I still had discharge from where the mucus fistula had been and this took a long time to heal. This kept me off work for about four months. In this time I built up my strength and started walking longer distances and found I was able to hold on until I got to the next toilet. I was still sore though, as I got a lot of anal discharge during this time. I tried several creams to keep the area round my anus clean and non-irritated. There was a lot of itching too just inside the anus. This did get so bad at one point that I seriously considered going back to my surgeon and asking for the stoma bag back!

However, I persevered and over time the frequency of my visits to the loo dropped, although I was still going up to ten times a day and a couple at night, and I started to look forward to getting back to 'normal'. Every time I tried to be more active though, whether it was swimming or using a rowing machine, I seemed to get flare ups where I would get bleeding from the pouch and more frequent and loose motions.

> ...I persevered and over time the frequency of my visits to the loo dropped...

Neither the surgeon nor my doctor could see a relationship between the extra activity and the extra activity of my pouch. Yet it seemed to me that if I sat watching TV or playing games on the computer all day my pouch worked well, but if I pushed myself a bit and tried exercising, it would play me up.

This went on for a few years until my partner, Kristine, and I went to Hawaii in January 2000. This was the first time I remember being confident enough to go out without a piece of tissue paper in my underwear. I was more active - we went snorkelling and hiking across an extinct volcano and I had little trouble with the pouch. I should mention that through all this time I had played the drums in a local rock covers band and this had never caused me a problem. I think it may have helped being a drummer as of course I was seated, not standing like the guitarists. In 2003 I started studying for a degree with the Open University, which is by the by really, except to say that if my UC had continued unchecked I may not even have been here to do it.

> In 2005 I joined a gym and started swimming again with no noticeable affect on my pouch.

After the Hawaii holiday I built up what I was able to do. On a trip to Crete in late 2003 we hiked down the Samaria gorge, a trip of ten miles with, of course, no toilets to stop at on the way. In 2005 I joined a gym and started swimming again with no noticeable affect on my pouch. I still have to go to the toilet four

or five times an day, generally following meals, so the more frequently I eat the more I go, and usually once at night again depending on what I eat and how close to going to bed. I do still get a little bleeding and sometimes my motions are very watery and I do get sore round the anus at times. I have found that Acriflex works best for this. It heals the soreness and provides something of a barrier for next time I go.

I wouldn't say that life with an internal pouch has been a bed of roses. The first years were very rough and as I mentioned at times I considered asking for a 're-reversal'. But now I know what to expect and how certain foods and drinks will affect me, life does seem better. It is certainly 100% better than when I had UC.

I can still see the advantage of a stoma bag, or external pouch, as maybe life is less dictated by when you have to empty it, but I'm not sure how I would have got on walking ten miles in Crete. That was a long time between toilet stops and would a bag have over-filled?

> **I wouldn't say that life with an internal pouch has been a bed of roses. The first years were very rough...**

To me I suppose the real advantage is when it comes to swimming. I have the scars of my surgery but that does not prevent me getting in the pool for an hour. The frequency of visits to the toilet can be a problem - especially at work - but I just have to be prepared for that and work around it. I certainly do not consider my internal pouch to be superior to an external one, and I am aware that in years to come I may have to go back to a stoma bag.

I have had my internal pouch for ten years now - how many people have had them for twenty or thirty years, and how they get on, I don't know. Maybe someone else could enlighten us on that question. For now I am glad to be able to do the things I do that I was unable to do when I had UC, or when I had a stoma. If I had to go back to having a stoma tomorrow I would still be happy, just to not have the debilitating ulcerative colitis.

(Editor's note - Have you had an internal pouch for several years? If so, please contact me if you would like to share your experiences with our readers.)

Richard Armiger
Beds and North Herts IA

Rising to the Challenge: Colitis and Ileostomy - Before and After

Having received and read the IA Journal with interest since my ileostomy operation in 2002, I thought it was about time I wrote in telling a little of my own story.

My story starts about 20 years ago, soon after I had started going out with Wendy. I found that I started to need to dash to the toilet for no apparent reason and that I would occasionally have diarrhoea. As time went on I started to notice the occasional spots of blood when I went to the loo so made an appointment to see my GP and pretty quickly got referred to a consultant. After a number of tests, including a colonoscopy, barium meal and endoscopy, my condition was diagnosed as Crohn's disease. I was prescribed some oral tablets and given follow up out-patient appointments with the consultant.

Over the next 10 years I had many visits to the consultant and was prescribed numerous different tablet treatments. During the various visits to the consultant I had yet more tests and biopsies done, and sometime towards the end of this 10 year period had my condition diagnosed as ulcerative colitis - knowing this made more sense of the particular symptoms I was experiencing.

Wendy and I got married in September 1991 and she has, I am proud to say, been my strength and support throughout my illness.

Between 1995 and 2001, I had numerous accidents where I did not manage to make it to the loo in time, on train journeys, car journeys, and once while leading worship as a Methodist local preacher. It got to the point where I needed to know that there was a toilet available everywhere I went, and Wendy and I found that we could no longer go for long walks in the countryside. In June 2001, I had a severe flare-up of the colitis which resulted in me being admitted to Luton & Dunstable Hospital. Over the next three weeks I had a number of medical treatments, from intravenous steroids through to enemas, and daily blood tests and even a relatively new treatment for colitis called cyclosporine, used by transplant patients to knock out the immune system. All the time my inflammation count was on the up, and visits to the loo increased to around 17-18 times a day, each time passing blood with diarrhoea.

On Thursday 12th July 2001 I had an operation to remove my colon and to have an ileostomy formed. I remember coming round in recovery in some considerable pain and seeing a clear bag over my new ileostomy, with staples down my stomach where they had operated. My recovery did not go to plan - I contracted MRSA, which led to septicemia, spent three days in intensive care, had to have my heart restarted, the wound re-opened due to infection, and had pretty much every side effect to the treatment possible. In total I spent just over ten weeks in hospital.

Eventually in early September I got home with a drain still in place and my wound still slightly open. However the one thing that I had already noticed was the improvement in not getting that urge to go to the toilet. I learnt quickly that the ileostomy bag was pretty easy to change and manage, and apart from still feeling weak I found myself noticing an improvement in my quality of life, even in those early days.

Over the next year or so I had one or two leaks and switched from a one-piece bag to a two-piece system, including the use of strip paste, which has enabled me to be leak-free for these past five years. In November 2005 I had an operation to remove the remains of my rectum, having opted to retain my ileostomy rather that try an internal pouch.

Since the initial ileostomy operation, Wendy and I have managed to have a couple of foreign holidays, previously ruled out due to the severity of my colitis. I have set up my own business and successfully completed an MBA. Wendy and I now have two lovely (well, most of the time!) children, Jacob & Iona, who

Richard with his wife Wendy and their children, Jacob and Iona.

About to set off on the climb up Ben Nevis.

were born two years and five years after my operation respectively. So I can only say that, for me, having suffered from Crohn's disease and ulcerative colitis, an ileostomy has meant life has begun afresh, and has enabled me to do things that had simply become impossible before the operation.

In June last year, I joined four other people, plus two drivers, from my local Methodist Church, in attempting the National 3 Peaks Challenge. I think this was in part down to my turning 40 last year, and was definitely in response to having an ileostomy and wanting to prove that life has got significantly better for me since the operation. We set ourselves the challenge of completing the three peaks, Ben Nevis in Scotland, Scafel Pike in England, and Snowdon in Wales in under 48 hours. The challenge was to raise money for our own Church building project as well as supporting NACC and **IA**. We set off early on Monday 18th June for Scotland, and 46 hours later we arrived back at the foot of Snowdon, soaked through, tired and aching, but having completed the challenge which raised just over £6000 for the Church project, with 10% going to NACC who received £600, and **IA** who also received £600.

During the challenge I had to change my ileostomy bag once or twice whilst climbing. With the two-piece system I found that carrying spare bags and plastic bags meant I could quickly remove the full bag and clip on a new empty one. I then took the full bag with me secured in a nappy sack until I could dispose of it.

There is life after an ileostomy, and as I have found out, sometimes life in all its fullness. For me my personal Christian faith and the love, prayer and support from my church, family and friends has enabled me to cope and get through this roller-coaster of a ride these last few years.

I still have the occasional problems with the stoma, particularly with stomach upsets and sore skin, but these pale into insignificance when compared to the life that I can now lead with my wife and two gorgeous children.

Ben Nevis summit.

Sue Blackwell
Secretary - South East London & West Kent IA

Passage to India

Do you really think someone like you should go somewhere like that? This was the overwhelming response when I told people I was planning on going to India for a holiday.

'Someone like me' - slightly crazy, prone to doing things on a whim? - no, they meant someone with a stoma! There's an unwritten assumption that if you go to India you are going to eat or drink something iffy and get very sick - the ubiquitous 'Delhi belly' - but I figured that I at least wasn't going to have to sit on a manky toilet, unlike my travelling companion who didn't have the convenience of being colonically challenged!

The only time I really thought that India was somewhere I shouldn't go was when I started to look for a quote for travel insurance. I used the list on the IA website, but some companies wanted over £400, which was almost as much as my flight - for £400 I would have made sure I did end up in hospital just to get my monies worth! Happily, Direct Line was much more helpful and only charged me £69 - a bargain.

So after months of planning, and two weeks hoping that the spare bags I'd sent out to my friend would arrive in time, and sent via the 'diplomatic bag' no less which gave me more space in my suitcase for the essentials - shoes and clothes! We set off from Gatwick for the long schlep to India and touched down in New Delhi at 3.30 the next morning.

It was our first introduction to India - no air con, total disarray due to rebuilding, toilets that were best left alone, and people everywhere. We spent the first three days in Delhi. We did try and walk on the first day - big mistake! Not only was it very hot, but were there no pavements, and we were followed every step of the way by drivers offering to take us to all manner of places for 'only 10 rupees'. We soon decided to stick to hiring cars. This was also a cunning plan to avoid having to brave an Indian toilet (I'm adventurous, but not that adventurous!). I'm lucky and can go four hours or more without needing to empty my bag, so I could spend the morning sightseeing and have the car deliver me back to the hotel in time to empty.

Traffic in Old Delhi.

Old Delhi has to be seen to be believed: teeming masses of people struggling for road space with two-wheelers, autos, cycle rickshaws, and the ubiquitous cows. Noise in India is everywhere, indicators and brake lights seem to be in short supply, so sounding the horn is the way to let other road users know you are there. One of our drivers told us that to drive in India you need good nerves, good eyes, good luck and a good horn!

After doing some of the tourist sights in Delhi we set off for New Delhi station and the train to Agra. New Delhi station was...'different'! There were people everywhere, sleeping and sitting on the platforms, selling food and drink, and piles of luggage and packages upon packages tied up in hessian - it really was like something out of a film. When we eventually found the correct platform, after shoving numerous 10 rupee notes into helpful hands, we found that the Indian railway system is really quite organised. Having booked and paid for our tickets over the internet (a very frustrating, but real, introduction to India), our names were listed on the passenger list pinned up on the outside of the train carriage. Indian train stations are deadly if you can't carry your suitcase up and down mountains of stairs - if I didn't have a parastomal hernia before I went, I certainly would have had one by the time I came home! Agra was only just under three hours away by train, and we spent the journey trying to explain to the carriage attendant in pidgin English that we couldn't ring our doctor and get a prescription for tablets for his sick mother...

Agra is of course home to the Taj Mahal, and our room at the hotel looked out towards the Taj in the distance. The Taj Mahal is well worth seeing, nothing quite prepares you for seeing it up close, and it really is a remarkable building. Even though we were in a five-star hotel, it did suffer from frequent electricity blackouts, and a lack of water in the toilets every afternoon. I discovered this by accident after emptying a very full bag and then realising that the toilet wouldn't flush...disaster. I have to say the wee housekeeping men were very kind, and had been in and flushed it for me when the water came back on - that is what I call service.

The Taj Mahal.

After Agra we had to go back to Delhi to catch the train down to Hyderabad. We booked the Rajdahni Bangalore Express which took just over 22 hours. The train was late leaving Delhi and both my friend

Sue en route to Agra.

and I needed the toilet. Unfortunately she needed to wee so she had to brave the station toilet - I think she is still recovering from that experience. On the other hand, I could wait until the train came in before I emptied my bag (by now full to bursting), down the loo straight onto the tracks at Nizamuddin Station (oops!). We were safely ensconced in 1AC, in a two berth compartment complete with carpet, and a man came in after every meal to sweep the floor. Luckily they had both Indian and Western style toilets, although trying to balance and aim down the hole (while watching the tracks whiz past underneath) took a bit of practice - the ‘flush’ was a mere trickle so a good aim was vital! Food is included in the ticket price (only £41 to travel some 1600 kilometres) and I have to say I did worry a bit about how safe it was, especially when the meat turned out to be chicken on both days. But I figured - ‘what the hell, eat it and see what happens’ - and of course nothing happened, it was delicious. While on the train I missed a South East London & West Kent committee meeting, but I think I was excused.... well, I did work my holiday out so that I would be back for our October meeting - now that is dedication to **IA**!

Hyderabad was such a change to Delhi and Agra, the climate is much more bearable, and there were fewer cows on the streets, although we did see a chopped up camel, complete with head, for sale outside a butchers shop. After Hyderabad we travelled on the overnight train to stay with my friend in Bangalore for a week. Bangalore is the IT capital of India and is far more westernised than any other city. We had a lovely time, eating out in five-star hotels and restaurants, going to the beauty salon, shopping, and being driven everywhere by her driver.

On the way back to the UK we stopped for four nights in Dubai. It was during Ramadan, which is not the ideal time of year to visit. It was 40°C every day and I have a tendency to get dehydrated anyway, so not being able to drink anything in public during daylight hours was really difficult. Dubai was the only place where I had a problem with my stoma - drinking so much fluid back in the hotel in one go meant that it leaked, twice in one night, but my friend and I decided that the stains on the bed looked more like coffee so I was terrible and just went out and left it! As you can tell, I’m not one of those people who carries a bed sheet around with me - if it leaks, it leaks, and who really cares? The chambermaids have seen worse I’m sure, atlhough I did cross my fingers and pray that it didn’t happen again as I was down to my last base-plate. As you’ve probably guessed by now, I don’t believe in taking half a ton of extra supplies ‘just in case’. Even spending a day at the Wild Wadi Water park wasn’t a problem - my bag was flapping about in the water for all to see, but I was having far too good a time to care.

So is India somewhere someone like me (and you) should go? A resounding “Yes!”. Ok, we didn’t rough it - five-star hotels are so much more civilised, but we ate and drank at all sorts of places and had no problems. I had no problems with security at the airports - who cares who sees your spare bags, will you ever see those people again? And shock horror, I didn’t even take a travel certificate with me! Having a stoma shouldn’t stop you travelling anywhere you want to go, and I for one can’t wait to book my next holiday.

Dear Editor

Letters should be addressed to the Editor, **IA** Journal, PO Box 22, Great Yarmouth, NR31 6WA, to reach him no later than the date shown on page four (or e-mail to editor@iajournal.co.uk). The editor is not responsible for opinions expressed or advice offered in the letters. If a nom de plume is used, the name and address of the writer must be supplied. As space is limited within the Journal, the editor may condense letters, although every effort will be made to retain the meaning and tone of the original.

Terry Gallagher
email: terry.gallagher@ntlworld.com

In issue 199 (Spring 2008), Peter Grace writes that he gets blockages and is often unable to trace it back to something he has eaten. Peter, and I suspect many other **IA** members, is unaware, obviously, that food-related blockages only make up 10% of the total number of blockages. The other 90% are due to adhesion-related obstruction and are therefore completely unrelated to anything Peter, or anyone else experiencing the same problem, has eaten.

The problem is that adhesions form whenever abdominal surgery has been undertaken, and some people get more than others. These adhesions, scar tissue, join parts together which should be free to move, and so cause kinking or twisting in the ileum, leading to obstruction.

So if any of you get an obstruction, don't waste time trying to remember what you ate that may have caused it - it is far more likely to be due to adhesions. Obstructions due to these can happen at any time and are nothing to do with anything we ourselves have done or eaten.

Interestingly, if you have had internal pouch surgery (and I think the designations of 'internal pouch' and 'external pouch' are less confusing than using 'pouch' for both), you can still get adhesion-related blockages from the adhesions from all your surgeries. Those with an internal pouch are, in fact, more likely to suffer from these because of the extra surgeries required.

Elaine Bryant
email: elaine@ebryant1.wanadoo.co.uk

I read with interest the letter from Peter Grace in Issue 199 regarding blockages. I too suffer from these (and as I have come to realise now, so do others) but cannot cope in the same way as Mr Grace.

I have been an ostomate for three years, and now have a permanent ileostomy. I have had what I would classify as three very nasty blockages in that time, two of which have resulted in me being hospitalised. The last one, only a couple of months ago, was the worst of all, and it felt as if my intestine was about to explode, feeling as hard as a cricket ball, with only morphine giving me any respite from the pain. The blockage lasted for some 18 hours, and had to be very painfully internally manipulated which did free it up eventually. I was warned of possible surgery, as the blockage could have been due to adhesions. I was on a fluid drip for some 36 hours.

Again, like Mr Grace, I really could not put it down to what I had eaten, although with the last main meal having been pork, I haven't touched it again since!

For others who have suffered likewise in this respect, I wonder if they were advised by their surgeon of blockages being a 'regular' occurrence?

I also read Penny Stevens' letter with interest regarding tiredness - I thought it was just me being unable to sleep properly at night - visiting the bathroom to empty my bag being a frequent feature as well, no matter what precautions I take. I also suffer with primary sclerosing cholongitis (PSC) - relating to the ducts in the liver - brought on by my ulcerative colitis, which also adds to my tiredness factor. My only solution at the moment, as my life is pretty hectic, in looking after a home, a 91 year-old father, and frequently two grandchildren, is to work through it. But oh, the delight of an evening when my partner and Dad are in bed and I have my 'afternoon nap' at about 9pm!

Thank you for listening to me on the above - this is the first time I have written in. Although I can talk reasonably well to people about being an ostomate and be upbeat about my situation, I still have trouble coming to terms with the change to my body form, (albeit that I have gone down a dress size since my operations!). My partner is not concerned about this, but I continue to be - I don't know how I get over this.

Mrs. Kath Robertson
147A Wetherby Road
Harrogate
North Yorks
HG2 7AA

Are there any members of **IA** who have experienced a very dry condition with the 'adhesive' on their ileostomy bags?

I have used the same product for the past eight years without any problems but a couple of months ago, whilst changing the bag, I was startled to find this area completely devoid of adhesive, and the area closely around the stoma disintegrated.

I have seen my stoma care nurse but she has been unable to say why this has happened. I've tried other bags but the dryness and disintegration of the vital area

The next edition

IA Journal 201 (Autumn 2008) will be published on 1st September 2008. Final date for editorial contribution to be received is 4th July 2008.

around the stoma are still there, albeit to a lesser degree with some of the samples I have tried.

My ileostomy became 50 years old in May, so I am wondering if it might be my skin in that area 'objecting' to being covered with adhesives for the past 50 years!

I would appreciate any views or comments from **IA** members, particularly those who have stomas of long duration.

Thank you to all the good people involved in producing our **IA** Journal - I read it from cover to cover, especially the readers' letters!

Barbara Miles
Devon

In reply to Dennis Bell's letter (J.194), I, like his wife, had a rapid onset of ulcerative colitis (UC).

My symptoms started whilst on holiday in France, and on returning to the UK I went to see my doctor who said I might be having problems with haemorrhoids. As my symptoms got worse, I went back to him and after examining me he referred me to the hospital. The surgeon there told me I had severe proctitis and took a biopsy to see if I had cancer. Luckily I did not. Then I saw a doctor who gave me suppositories and medication.

Unfortunately I was not getting any better, and eventually I was taken by ambulance to hospital and given an emergency operation, when my colon was removed. A few days later I was told it was UC. I was then in my mid-sixties but luckily I was told I could have an internal pouch, so after several more operations I got rid of the stoma and settled down with my internal pouch.

In a previous **IA** Journal, people's experiences with an internal pouch were requested by Rachel Hayward (**IA** Internal Pouch Group), so here are mine :

Straight after the final operation, I suffered with dreadful irritation of the anus to the point where I was in tears. Using various creams didn't help me but taking codeine helped me to cope. I then wondered if I could be suffering from candida and took steps to try and cure this. As time went by I gradually had less irritation, although like most internal pouch patients I still have problems with it and also soreness. My control of the bowel has always been good, only having had three or four accidents, and I think in those cases there was a bug going around that I had caught.

I eat very little dairy produce and am careful with my fat intake. All meat and vegetables have to be very tender otherwise I have a pain in my right side as the food goes through. I do not eat salads or nuts. If I drink alcohol on an empty stomach I have to rush to the loo. I sometimes feel very cold but this sensation passes quickly. I occasionally cough when an acid taste comes into my mouth - reflux I suppose. The only other things I have had are very slight rheumatic pains - I know this could be to do with aging but it is also connected with UC sufferers.

Despite all the above minor problems, I am told that I look very well by people who know me, and I consider myself very lucky compared to many other sufferers with digestive complaints.

Emma O'Brien
Owenreagh Cottage,
Magheramore Road,
Dungiven
BT47 4SP
email: obrienemma@hotmail.com

Ulcerative Colitis (UC) was diagnosed for me at 27 when in Australia in 2000. The specialist who diagnosed it had quite interesting suggestions as to why I had been such afflicted, including 'catching' it from one of the many flatmates I had who suffered UC or Crohn's disease, and/or the build-up of adrenalin as a result of retiring from competitive swimming (another thing in common with same flatmates!).

I returned home to Ireland two years later in the grips of the 'mother-of-all flare-ups' during which I experienced secondary arthritis, anterior uveitis, erythema nodosum, secondary vasculitis, and mouth ulcers. This culminated in an episode of viral encephalitis during which I was fortunate enough to be given the last ICU bed in Northern Ireland during Christmas 2001, and the last rites. Thankfully, despite the doctors informing me of the possibility that I had Behcet's Syndrome, the prognosis was good and with prolonged corticosteroid treatment along with Colazide (Asacol & Pentase having not been effective), and a diet consisting of plain food, Elemental 028 drinks, and Forceval multivitamins, things eventually improved.

The following five years were dotted with flare-ups around stressful times (e.g. the days leading up to my wedding day), and often according to the seasons (Autumn & Winter being the worst of times). However, for almost two years I enjoyed excellent health whilst living a highly-challenging management consultant job in London. I was beginning to think the doctors had got it wrong, that I didn't have UC at all, and had just been unlucky for a time. Then the highly-challenging became highly-stressful and I thought an 'escape to the country' (i.e. back home!) would bring good health and it did for a time. When holidaying in Brazil however, things completely broke down and I knew that my colon wasn't coming back from this flare-up. Upon my return to Ireland in April 2006, I had no choice but to have my colon removed a few weeks later.

Recovery was swift - I had a new lease of life, I wondered why I hadn't had the surgery years previously, and I returned to work with only slight dehydration and minor blockages. Seven months later, a single-banded adhesion caused the last metre of my small bowel to become necrotic and it had to be removed. This surgery proved to be harder to deal with, probably because of the shock of it, and whilst I knew I was lucky to be alive, severe dehydration, major blockages and restricted mobility still often plague me. My attempts to go back to work failed and I became very down. My husband and family helped me with the 'Emma Get Well Programme' (EGWP), and I began to feel much better.

Last Christmas, the excruciating pain from what I thought was another banded adhesion turned out to be the result of an ectopic pregnancy. I had to have open surgery to remove the pregnancy and tube and I was completely devastated, mainly as a result of not even knowing I was pregnant and desperately wanting to be. Doctors told me that the fact that I had had two previous abdominal surgeries put me at a higher risk of this happening. By chance, whilst in hospital, I was fortunate to meet ladies who had close friends and family members with stomas and who had very positive experiences following their ectopic pregnancy. This has helped in coming to terms with what has happened, and I would be very grateful to hear from others who have had similar experiences.

Lisa Cooke
Via email

NatWest
Liverpool City Office
60-13-19
Norfolk + Suffolk IA - The Ileostomy + Internal Pouch Support Group - Three Hundred + Fifteen Pounds —
£315.00
CHARITIES TRUST
AVIVA FUNDRAISING ACCOUNT
⑈000588⑈ 60⑆13⑆19⑆ 45137358⑈

As a committee member of Norfolk & Suffolk **IA**, I put in a number of hours of my own time in support of **IA**, and I very much enjoy this voluntary work.

My full time job however, is as a Deputy Support Services Manager for Aviva Legal Services (many still know Aviva as Norwich Union!).

Norwich Union runs a scheme called Volunteer Plus. As an employee, if you do voluntary work in your own time for your local community, you can submit an application to Norwich Union under this scheme, provided you meet certain criteria (such as a minimum number of volunteer hours worked per month). If your application is successful, you are awarded money for that work in recognition of your commitment to the local community through your volunteer work. The money is payable to the organisation you volunteer for. In my case, that's Norfolk & Suffolk **IA**, and this year I was awarded a cheque for £315 payable to my local **IA** which will help us support our members.

If you work for Norwich Union, or you work for an employer that runs a similar scheme, fill in those application forms. If you don't try, you don't get, and every little helps (as some well known brand says!) - but it's true.

Angela Bamber
Via email

I've had an ileostomy for over ten years, and am also wheelchair dependent. It's coming up to my 50th birthday, and I decided that all things considered, I've had, and continue to have, a very good life.

Hence I wanted to mark my half century in a special way, so I'm undertaking a

‘Tandem Skydive’ on June 8th. I’m raising sponsorship money to go towards the British Heart Foundation as so many of my family have been affected by and died of heart disease. I wish I could divide the sponsorship between all the charities that I feel a link to, but alas, that is not possible.

There is a sponsorship form for my skydive that people can contribute to on-line, and hence I was wondering if you’d be prepared to put a note about this venture of mine into the **IA** Journal? Maybe it would encourage others to see that life needn’t stop if you have an ileostomy.

If you look at my web page, you’ll find a photo of me there, along with all the dates. The link to my web site can be found here www.justgiving.com/Aberration. The online sponsorship page will be staying open until August.

Having contacted the stoma appliance makers, I’ve been advised to protect my stoma with a cap, but otherwise all the pouches, flange, etc. should be fine. If they can withstand such pressures, then they must be able to withstand virtually anything!

By coincidence, when I registered to do this skydive, I needed to get a form signed by my GP. To cut a long story short, the GP found out that I’m suffering from hypothyroidism, and has started me on treatment. I’m greatly relieved as I’d been feeling extremely tired and my memory was getting terrible, but it had never occurred to me to go to the GP; I’d just assumed it was all part of the ageing process. So, in a way, there’s an added bonus that has come out of my doing this skydive.

I’d be extremely grateful if you would put some information about my skydive in the **IA** Journal, along with the sponsorship address, as I’m trying to raise £5000 and have a long way to go!

John Chatwin
email: johnchatwin@tiscali.co.uk

For 35 years, until earlier this year, I had been able to use ether solvent to remove karaya gum from my good old-fashioned rubber bags for re-use, and to take the gum away from the stoma area.

Now, just because some idiots have decided to sniff the stuff, Brussels, in its wisdom, has decided that it is far too dangerous a substance for us plebs to use, so, hey ho, we’re denied it without anyone checking why it was so important to responsible people like us in the first place!

I have, of course, tried a number of solvents from different suppliers, but removal from rubber does seem to present particular problems, and indeed some of these, and acetone, seem to attack the rubber itself.

If there are any dinosaurs reading this who still use this unfashionable equipment (which does stay on for up to a week!) I’d be very interested to know if they’ve any ideas, or, if in the same position as me, would they like to exchange electronic mail addresses to share information on products.

Arlene Colwell
email: c.and.a@mac.com

France calling - Bonjour!

Since my article “Opportunity Knocked “ appeared in the Winter 2007 **IA** Journal, I have had another ex-pat ileostomist in France contact me. It made me wonder if indeed there are any more ileostomists who subscribe to, and maintain close links with, **IA** in the UK and receive the Journal, but at the same time use the French healthcare system as a resident out here, and perhaps even have joined the French patient associations and go to their AGMs. So, my question is simply, “is anybody out there?”

France is of course a huge country, but I thought it might be useful to have a point of contact for any eventuality, and even exchange useful information and support each other if necessary. What do you think? I live in the Lot region and my e-mail address is shown above.

Vincent Cummins
32 Lambshear Lane
Lydiate
Liverpool
L31 2LA

I was diagnosed with ulcerative colitis (UC) back in 1993 and it took me two years to get back to something like normality.

Then I was made redundant after twenty years with the same company. After numerous jobs, some of which I had to give up because of flare-ups, I managed to do the London Marathon whilst in remission, for the British Digestive Foundation.

Late 2005 and early 2006 was a bad time with my UC, and after a colonoscopy I was asked to consider surgery. I eventually had a total colectomy in August 2006. I can’t praise my surgeon, stoma nurses, and hospital staff enough for the treatment I received at the Countess of Chester Hospital. I have gradually built myself up and I am planning to run the New York Marathon next November. I would like to run to support **IA** and to maybe inspire others to show you can get back to a healthy lifestyle, given time.

Clive Curteis,
email: c-rcurteis@tiscali.co.uk

My stoma has very little projection and I am leaking from time to time.

Before I approach my doctor about having it altered to project further, has any reader had this operation who could tell me what their experience was?

Miss A. Jenvey
(Member of Hants & IOW IA)

I had my ileostomy formed in January 2005. My stoma care nurse at the Queen Alexandra Hospital in Cosham was wonderful, and the other members of the stoma care department there have also been really helpful to me.

I attended my first local **IA** Annual General Meeting which was held at the Holiday Inn in Tichfield, and which I think was a resounding success. I found the talk by the nurse (who had travelled all the way from Hereford) interesting and informative - it seemed everyone who was present was listening attentively, especially when the question of company remuneration came up.

I met the divisional secretary (Nick Moon) for the first time, who was ebullient and friendly. I also caught a few words with people I hadn't seen for a while, and met the representatives from Salts who were nice and helpful.

Needless to say it was a busy few hours. Towards the latter part of the meeting, there was a raffle which I had entered albeit with meagre offerings. But the prizes were lovely and to my surprise I won one.

All in all, the 2008 AGM was an enjoyable time, and I felt privileged to be part of the support network that **IA** offers. It was nice for me to feel the support of other members who had had similar experiences of stoma surgery, and to share what happened to me in surgery, both downsides and upsides.

Thanks to everyone who was there - it was great to meet you all.

Roseann Kealy
Via email

I had a loop ileostomy in December 2006. Since then I have not had a decent night's sleep.

I empty my bag at least three times a night. Admittedly I am a very light sleeper so I wake before the bag is full, but I wondered if there was a way I could reduce the output at night since I am beginning to feel exhausted. I have tried Imodium at the standard dose, but have not found it helpful.

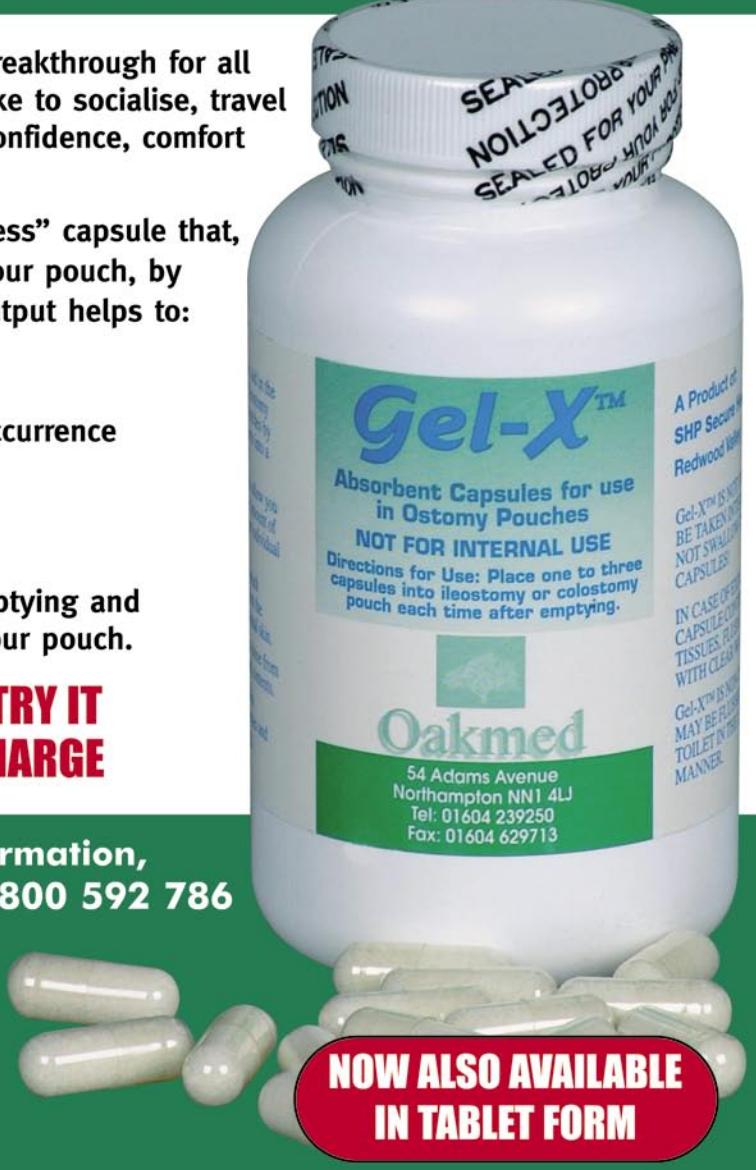
I would be very grateful for any advice fellow ostomates might be able to provide to me with at the following email address: rkealy@gmail.com.

Eileen Lawlor
10 Ellesmere Court
Bundoran
Co. Donegal
Ireland

I would like to express my thanks to the three ostomates who replied to my letter in the Winter Journal (J.198).

The tips they gave me worked very well for ballooning and odour. I now release the top of the pouch from the flange just a tiny bit to empty the pouch of wind, and I am using Dansac Nodor S, an odour neutralizer - 10 drops into the pouch to deal with odour. Also, I was subconsciously blind to the fact that some foods cause gas and I was eating all of these, particularly salads, eggs and fish, and so I'm trying to modify my diet.

On a lighter note, recently I have been having weird dreams. When in 'rem' (rapid eye movement) sleep, I get this overwhelming urge to pass wind and no matter how I try it doesn't happen. Then I wake up and realize that my rectum was stitched up two years ago - is this 'the phantom of the oh-phart-ha'?



Peter Machin
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Walderslade
Kent
ME5 0NP

Thank you for the **IA** Journal. I really find it a good read.

I have had my ileostomy for 48 years and I know from experience that any sport, activity, or career is possible. I would like to thank and congratulate all the writers of letters and the editor for the excellent selection of the same - they are so informative and entertaining.

In the last Journal (J.199) there was a gentleman who informed everyone that he went to the loo four times a day - now you wouldn't see that in 'Town & Country' magazine! Another contributor stated that he went into a sex shop to purchase an anal vibrator (as a substitute for the hard plastic dilator the hospital provided for his J-Pouch) - fancy dropping that into conversation on a social evening. Then there was the young man who goes behind a bush when out walking to empty his bag - I immediately thought of him walking in the Sahara Desert and saying to his guide, "Sod the Pyramids - find me a bush".

I am not in any way being derogatory or making fun of anybody - I just think that all your contributors are fantastic. Becoming an ostomist has not only changed our lives physically, but also mentally. We now openly discuss things that were previously taboo, and humour is always the best medicine.

Once more, thank you all very much.

(editor's note - may I also add my own thanks to all contributors - please keep them coming in!).

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I have been an ileostomist for two years now and enjoy receiving my **IA** Journals. I find the letters very interesting.

I am surprised when I read of the problems ostomists have with residual rectal stumps. Can anyone explain why some ostomists have this removed and some still have their rectal stump after six or seven years, causing them problems?

I had my residual rectal stump removed two years after my ileostomy, but found no information about this procedure in any **IA** Journal. I feel it would have helped me if I could have read about what this operation entailed before my surgery.

Penny Stevens
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Farnham
Surrey
GU9 0HR
email: philip.stevens2@ntlworld.com

In the previous issue of the Journal (Spring 2008 - no.199) I had a letter published on page 74 in which I offered to send a copy of the 'good' foods that I can eat and the 'bad' foods that I cannot.

Many members responded via my email address which was also published at that time, but for the benefit of those without email, I will welcome any further correspondence by letter to my postal address above.

Edna Podmore
6 Woodland Rise
Sutton Coldfield
West Midlands
B73 6EL

At the age of 32 years, I was given a colostomy, due to cancer of the bowel. For 31 years I used an irrigation system, which meant that I did not have to wear an appliance, and was relatively free to enjoy a 'normal' life.

Two years ago, following a colonoscopy, it was discovered that there was further damage to my colon and a decision was taken to remove it completely, and perform an ileostomy.

This has taken a lot of adjusting to in terms of diet and body image, and I was just feeling comparatively secure again when I started to have problems with indigestion, stomach cramps and nausea. After a blood test, etc., I was diagnosed as a coeliac, and I am therefore unable to have gluten, wheat, or milk and milk products. This, again, is going to take a lot of adjusting to, as many gluten free products are fibre rich which of course does not suit the ileostomy. In addition, it is important to maintain a nutritious diet, in view of bones and immune systems, so I am feeling somewhat overwhelmed with complicated information.

I wondered if anyone has both these problems and could help in any way, and advise me on diet, etc.? A reply via the **IA** Journal (which incidentally is a life-saver!), or direct by email - emp.podmore@btinternet.com - would be much appreciated.

Alison Wood
29 St. Buryan Crescent
Cheviot View Estate
Newcastle upon Tyne
NE5 3XF

I wonder if anyone with Crohn's disease (CD) suffers with acne or similar skin condition?

I'm aged 27 and have had CD and an ileostomy for eight years. Generally my CD is controlled except for a bad few months last year, but I find if I have a sensitive stomach for a day the acne on my face and back really flares up.

I don't want to take medication for my skin and risk a flare up of CD in the stomach - I prefer to control it with cream, but wonder if anyone else has had similar experience? I find that both the acne and tiredness are the most frustrating to deal with.

Is there a connection between CD and acne or skin conditions? I would like to hear from people with similar complaints.

Keith Woan
Secretary - IA Central & North
Lancashire

At our AGM last March, our secretary of 35 years, Mary Hogarth, retired from office and I was elected as her successor. A brief history of Mary's involvement with **IA** is as follows:

Mary, as she preferred to be known, had her ileostomy formed in 1965 and in March 1966 joined the nearest branch of **IA**, which at that time was Manchester.

As the number of local people with ileostomies increased it was, in February 1973, that the Preston branch of **IA** was formed as a sub-division of Manchester and Mary took up her post as secretary - a position she has held ever since, a total of 35 years.

When changes were introduced by the Charity Commissioners in 1994, Preston amalgamated with Lancaster to form a charity in its own right known as “**IA** Central & North Lancashire”. As the Lancaster branch also had many members in in Cumbria, the geographical area, from being a small local area based on Preston, was dramatically enlarged - the membership too - but Mary took it all in her stride. To add to her workload, she also accepted the position of Chair and for the past 14 years has acted in both capacities.

In the past 35 years Mary has befriended and counselled many people and her phone line was always open for anyone to discuss their worries or problems, or just to have a friendly chat. Having just celebrated her 85th birthday, Mary decided it was time to ‘drop down a gear’ so has handed over the secretary's reins although she has expressed a wish to continue in her role of Chair.

In the photo, Mary is pictured receiving her honorary membership certificate from Mr. M. M. Mughal, ChM, FRCS, President of **IA** Central & North Lancashire. Besides her certificate, Mary also received a gift of a cut glass crystal vase and a large bouquet of flowers.

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What a lovely tribute to the life and work of Joyce Parsons (**IA** Journal Spring 2008, page 36).

I first met Joyce as a student nurse in 1962. She came to our training school at

Harold Wood Hospital and talked to us about her ileostomy, and also showed us her stoma. I then worked alongside her when I was a staff nurse on the surgical wards - she taught me so much and was always available if we had a problem, or if a patient needed help at home.

Sometimes we would end up in occupational therapy with a sewing machine adjusting clothing for a patient to accommodate their appliance. This was in the days before the stoma care nurse when we were allowed to give complete care to our patients!

Little did I know that I would then develop problems myself and become a patient of Mr John Talbot at Harold Wood Hospital. In 1977 I was diagnosed with Crohn's disease and underwent a total colectomy with ileo-rectal anastomosis, a relatively new procedure then. Joyce was there and gave me so much support. This helped me for 18 years and I met up with Joyce a few times at hospital reunions.

I started having more problems and surgery, and eventually was referred to St Marks and had an ileostomy in 1997. Once home, I met up with Joyce again and went to visit her a few times - she gave me so much encouragement and support. I recently met up with Joyce as she was in the same residential care home as my mother, and it was a pleasure to be able chat to her.

A truly remarkable lady who I will always remember.

Barbara Markham
Visiting co-ordinator - Humberside IA

It is with great sorrow that we have to report the death of Fred Knapp on 25th January.

He had been our treasurer for sixteen years and was made an honorary member when he retired two years ago but remained a committee member. At our committee meetings and our Annual General Meeting he presented and explained the financial statements and would always give his considered opinion on matters that arose.

Lilian and Fred helped at meetings and supported social events such as the coach outings and visits to the mini-cinema. Fred arranged the evening meals and helped to provide the entertainment at the Christmas parties.

Our thanks are due to Fred for his service to Humberside **IA** over a long period and our heartfelt condolences go to Lilian who, we are pleased to hear, will continue to take part in our meetings.

People will remember the big man with the big smile at the entrance to members' meetings - he will be sadly missed.

The **IA** Journal is available on tape free of charge for visually impaired members. For more details contact the Journal Editor.

Out and About

National Council 2008

Members of North East **IA** waiting to welcome delegates at National Council 2008 in Newcastle on March 29th and 30th.

Photograph from:

Roy Savin, Stourbridge ***IA****.*

IOA Award

At the International Ostomy Association Congress in Puerto Rico in August 2007, the Coloplast Merit Awards for World Ostomy Day entrants were announced. A special award was given to Sligo General Hospital where a multi-disciplinary team worked in partnership to promote Healthy Bowel Week by organising a week-long series of events for patients, staff and the public in the main foyer of the hospital.

The event was advertised widely via posters, e-mail, the media, shopping centres, health centres and hospitals. The team included stoma care services, gastroenterology, nutrition & dietetics, oncology, ostomates and ostomy support groups, the Irish Cancer Society, quality & health promotion, general surgery, paediatrics and local schools.

Anne Demick (centre) can be seen here presenting the award to Dolores Kivlehan (right - health promotion) and Susan Moore (left - stoma care nurse specialist) at Sligo General Hospital. The IOA team judging the awards recognised the creative team work and innovative actions that made this such a successful event.

Devon IA

Sid Brissenden (left - chairman of Devon **IA**), Yvonne Evans (centre - senior stoma nurse, Royal Devon & Exeter Hospital), and Ian Daniels (right - consultant colorectal surgeon and honorary President of Devon **IA**) are seen receiving a gift of a noticeboard from Devon **IA**. It was paid for under the matched funding scheme, and will be used to highlight local meetings, and the research work led by Mr Daniels in colorectal surgery.

Dumfries & Galloway IA

At this year's National Council, Derek Oliphant (right) and John Scoular (left) made a presentation to David Eades (centre) on behalf of Dumfries & Galloway **IA**. This was our way of saying thank you for all his help over the years. The gift was rather special, being a bottle of malt whisky with a label which read the "Eades Malt". It also had "David" in bold letters so that no one else could claim it!

South East London & West Kent IA

Three members of our committee stood down at our AGM recently after almost 70 years between them. Pictured (left to right) are Pam Thompson (retiring chairman, and former local secretary) Ken Holdaway (retiring former treasurer), and Audrey Walker (retiring committee member).

Norfolk & Suffolk IA

Under **IA**'s matched funding scheme, Norfolk & Suffolk **IA** purchased 15 Valley cushions for patients' use and distributed these between East Anglian hospitals at Norwich, Cambridge, Ipswich, Kings Lynn, Bury St. Edmunds and Gorleston. Each individual cushion was inscribed with the **IA** logo and the group's name, as can be seen in the photos.

Pat Allington (second from right) presenting cushions to nurses at Heath Road Hospital, Ipswich.

Tracy Woods (centre) presenting cushions to nurses at the Queen Elizabeth Hospital, Kings Lynn

John Smail (second left) presenting cushions to nurses at the James Paget Hospital, Gorleston.

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