



The ileostomy & internal pouch
Support Group

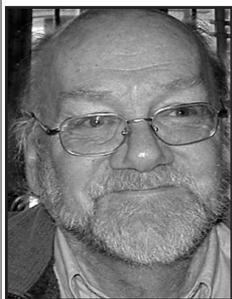
IA Manchester

Registered Charity: 1039256

newsletter

summer

issue 02-09



A Word from Your Chairman and Editor

For many of
you this will
come as quite

a surprise. For those of you who attended the recent AGM, I apologise in repeating my thanks and gratitude in your vote to appoint me the Chairman of the Manchester IA Membership . Both the Committee and, I am sure, the general membership are extremely grateful to Ian Hay, who has stood down for personal reasons and poor health. Ian took on a huge task on his appointment to the Chair having not only to establish an accurate Membership base but also the very necessary need to regularise the Manchester Account. Ian, and his wife Cath, spent considerable time in collating, balancing and finally closing the previous three years accounts successfully to validation with an

Independent Accountant. We all owe him our heartfelt gratitude and wish him well with his future plans.

And so we move forward. It is not my policy to advocate major changes to our Organisation - merely to build on our current status and to improve and highlight areas needing urgent addressing - such areas as our Young IA membership; Open Days and Visits; Guest Speakers; etc. I look to you - the Members - to make known to myself and other Committee Members those items you feel would benefit our Membership. Elsewhere in this Newsletter you will find articles and comments regarding :

- a. How to contact the Committee
- b. A proposed Salt's Visit
- c. An Open Day in October
- d. Web News and Internet News

So, I look forward to a greater involvement in issues of Manchester IA

Regards - *Chris Ainsworth*

NEWS FROM YOUR COMMITTEE

Journal Distribution

You will see from the Committee contacts box, elsewhere in this Newsletter that the Committee has changed - very slightly. Tom Fleming - the latest Member to join the Committee - has taken over from Anne Cross the job of Journals Distributor. This means that the National Office send to Tom the required number of Journals and inserts for the Manchester Membership. Having completed an envelope and label list for the 280+ distribution list - as well as a similar quantity of this Newsletter - the Committee meet at the end of each quarter and - literally - "stuff" the envelopes!

Hopefully - both Newsletter and Journal arrive in you mailbox shortly after the first of June, September, December and March.

NOTES FOR YOUR DIARY

PROPOSED MANCHESTER MEMBERSHIP AUTUMN MEETING

OCTOBER 17th 2009 FROM 10.30am

HOPE CHURCH HALL - VICARAGE CLOSE

A SPEAKER-APPLIANCE STALLS & more

COME ALONG FOR THE CHAT AND TO MEET AND SOCIALISE

MORE DETAILS IN OUR NEXT NEWSLETTER

**also IT IS PROPOSED TO VISIT SALT'S HEADQUARTERS - IN BIRMINGHAM
IN THE AUTUMN- WATCH THIS SPACE**



RADAR -

The National
Key Scheme
(NKS) offers

independent access to disabled people to around 7,000 locked public toilets around the country.

All Ostomates are entitled to a key which may be obtained free via your local Council - or by contacting your Stoma Nurse

IA MANCHESTER NOTICE BOARD

**Remember to visit the IA
Manchester Noticeboard now
in place in the General Wating
area - Area 1 - of
Hope Hospital**

***IA Manchester Committee are still
seeking suitable, interested and quali-
fied members to fill the vacant position
Young IA Representative;
Interested -? contact Chris Ainsworth
on 0161 798 8494
chairman@ia-manchester.com***

THE ANNUAL GENERAL MEETING

An Informal Account of The Annual General Meeting which took place on Thursday 30th April 2009 at Hope Church Salford

Many of you will no doubt remember the AGMs taking place in the Frank Rifkin Centre and other centres/halls, etc over the years. Once the facilities at Hope Hospital had become out of our reach we had to consider finding a suitable venue which was central to the majority, which also suited our purposes of open exhibition areas as well as a meeting place and within our budget to hire.

Hope Church - which stands at the junction of Lancaster Road and Eccles Old Road - had such a hall attached to the Church which suited our purposes.

So it was on Thursday 30th April last that Ian Hay opened the AGM for 2009. with his welcoming address in which he stated that for general health and private reasons he would be standing down at this meeting - as Chairman of Manchester IA. He had, he said, enjoyed his few years as Chairman and thanked the Members of the Committee for their support during his time in office.

In turn, the remaining officers gave their summarised reports of the previous year and Ian, as acting Treasurer, gave a summary of the financial accounts over a period of two years. His suggestion that we - as members- should now be seeking to use our funds for either research or education, etc. was well received.

Marlene Evans - whose report appears elsewhere in this Newsletter - once again expressed her anxieties over the lack of visiting officers in what is the second largest membership in England. Thanks were given to those who had purchased the Annual Draw Tickets which had resulted in a 'commission' of £205 for our funds. During the report on our Website and Internet use Chris pointed out that although more and more members were becoming 'Net-Aware' we mustn't forget those who are not 'connected'. The added facility of email addresses for members should make the passage of information easier when run alongside a lesser posted mail. Following the re-election of Officers who were to remain standing Ian proposed Chris Ainsworth to the position of Chairman and this was unanimously accepted. Following a short acceptance speech from Chris a presentation was made to Ian on behalf of the Membership.

An offer was made to Mr. Ralph Donner, present, to possibly stand for the position of Treasurer in the future. Mr Donner hasn't declined; however, he stated that he would not be available to meet and discuss until the end of June. A new member, Louise Breen, has expressed an interest in becoming our Youth Members representative and she was kindly, and enthusiastically thanked.

Following the formal closure of the meeting a informative and interesting short talk was given by Marie Hurst, an exponent of the Bowen Technique of Managing pain due to a variety of problems

The meeting closed with general discussion and social chat.



*An article submitted by Brian Roberts
(Held over from the previous Newsletter)*

Hi there, the last few months have been really busy as this support website continues to attract interest around the world. Several Professors and Companies conducting research surveys have been in touch recently asking for help in tackling various issues relating to ostomates and the products/services we use and I've also heard from several stoma nurses in different parts of the UK who are keen to learn more how to treat 'gay' patients with more understanding. One Hospital in London is even producing a special leaflet and I'm helping with this. I've had a few very distressing emails and letters from people too who feel so alone and isolated – one has attempted to take his own life because of depression and I wish I had resources to help but all I can do is reply and try and offer practical advice when I can.

With about 150 people's profiles on our website looking for someone to email and exchange views with from all over the world it's good to see how the internet is helping to make the world a little smaller. You don't need to be gay (or even help out when we're busy!) to email anyone if you read an interesting email as most are very pleased to exchange thoughts about life after surgery in other parts of the world so take a look if you have the internet – you may find a new email pal. One recent email came from a 30 year old man in Greater Manchester who had not heard of the IA at all and had only found my website by accident after using a 'Search Engine' – this isn't the first person in the UK who has never heard of the IA and it's a puzzle why they haven't as I was given all the information by Hope Hospital (now Salford Royal), perhaps the IA needs to get Notice Boards in all the hospitals in the UK, I know that I.A. Manchester is organising that now at Salford Royal but what about the others? I think that younger ostomates - are reluctant to join the IA as the image presents it is for older people – I know it's an issue that IA Manchester is concerned about and are doing their best to attract younger members to join in. Years of neglect and inactivity have left their mark on the IA and now it's a very hard job trying to attract a wider age range involved but I know IA Manchester are working on it...I mean, look at this - a piece in your magazine from a gay group!

www.gayostomates.org ~ www.gayostomates.co.uk ~ www.gayostomates.org.uk

Caring for Your Ostomy

By Pat Murphy, RN, CETN, Alexian Brothers Hospital

Here are some simple pointers for ostomy care. They may not be new, but sometimes it is good to be reminded of them. Good ostomy care habits can catch and nip problems in the bud—the rosebud that is.

1. Inspect your stoma and skin each time you change your appliance. Your stoma should be bright red, smooth and shiny. Inspect the lower edge especially well. Use a mirror if necessary. Look for any signs of irritation or bleeding—It may mean your appliance is rubbing there. Your skin should not be pink, purple or gray, even right next to the stoma. Although, when you first take your appliance off, you will notice some pink skin under pressure points. This is the same as when you take off your watch or a pair of stockings. This is normal. Also, inspect your skin in a sitting position to see if creases or low areas from around the stoma. This will tell you where to take special steps to even out the area when you put on your appliance. Stretching the skin to be smooth may be all you need to do, or you may need a dab of paste or one of the new seals like Hollishesive or Eakin.

2. Remember, a new stoma changes size for up to a year. Re-measure your stoma every time you change the barrier for the first six months and every month thereafter. Always re-measure if you are having a problem with leaking. Measure the stoma at the base from side to side and from top to bottom. Many stomas are oval. If you are cutting a skin barrier or a one-piece ostomy system, no skin should show when it is in place.

However, make sure the barrier is never touching the stoma. This is a bit tricky to do, thus manufacturers developed the seal allowing a slightly bigger opening to be made.

If your stoma is not perfectly round, do not trace and cut a round circle. Instead, make the barrier fit exactly. It should just miss the stoma, sealing down on the skin right next to it. Your appliance or barriers should not go over any red, wet mucosal tissue—the kind that forms the stoma. If you wear a pouch with a karaya ring on it, the ring should gently touch the stoma all around.

Even an “old” stoma can change size temporarily. It can change from round to oval if you are experiencing some abdominal distention or if you have gained weight.

3. Be sure you know the steps involved in treating sore skin. Many people use too much powder. This may interfere with the adhesion of the appliance and cause the problem to worsen. A tiny amount of powder should be placed on the sore area, and then wiped off with a dry tissue. It will stick where you need it; i.e., if you have wet, irritated skin, powder will protect it so the barrier will stick to it. A barrier will not stick to a wet surface. The barrier will then protect the skin against the output, and the skin will heal better under the barrier. If you use a liquid skin barrier—never with extended wear barriers, like ConvaTec's Durahesive or Hollister's Flexextend—it should be applied over the powder until you can no longer see any powder. Fan it dry quickly and then put on your appliance as usual. When treating any skin problem, always change your appliance more frequently than you usually do until the problem is solved. This is so you may examine the progress of the healing, and prevent and additional damage from occurring.

An Update on the Review of the arrangements under Part IX of the Drug Tariff for the provision of stoma and incontinence appliances - and related services - to primary care

The last consultation

In order to seek views on proposed new arrangement, the Department has followed a process of public consultation. The last consultation was published in September 2007. This consultation closed in December 2007 and we received responses from healthcare professionals, dispensing contractors and manufacturers, and a number of patient groups. A summary of the formal responses can be found at the same website address as the consultation itself.

A large amount of correspondence was also received from individual patients, their carers and Members of Parliament on behalf of their constituents.

Having considered the views expressed about the proposals set out in the consultation, the DH decided that it should meet with interested parties to discuss their responses - as this would allow us to explore approaches that would help to inform policy and, consequently, allow us to conclude the review.

These meetings began in February 2008 and we met with representatives from the NHS, patient groups, healthcare professionals and industry trade associations.

The discussions highlighted two key requirements: that patient care must be maintained and that any new proposals should be more affordable to dispensing contractors and manufacturers than those put forward in the September 2007 consultation.

Both of these requirements are in line with the Department's stated aims.

Next steps

Having listened to everyone's views, we are in the process of drafting a further consultation. This will be published in May 2008 - along with an Impact Assessment and Equality Impact Assessment - and will be open for 12 weeks.

2007-9

In the meantime, the Department trusts that users of stoma and urology appliances are reassured that no hasty decisions are being made and that the Department is taking into account the views of a wide range of interested parties - not least patients, whose ongoing care is of paramount importance.

**An Article by Marlene Evans
Visiting Co-ordinator and
Deputy Chairman
Manchester IA**

Our Membership Database stretches from Wilmslow in the South to the Rossendale Valley in the North, East to Ashton, Hyde, Stockport and West as far as Wigan. Comprising some 240 members, and growing, we are desperate to increase our complement of qualified visiting officers to support the Stoma Nurses in our Regional Hospital Stoma Departments. So what does it mean :

The Value of an IA Visitor

IA has been providing visitors to patients pre- and post-operatively since it was founded. Visiting is one of the most important services IA offers, as it allows patients to meet and talk to someone in complete confidence who has experienced a situation similar to their own. All patients and visitors are matched as closely as possible in terms of age, sex, type of surgery, occupation and interests.

IA offers a variety of training to its members who are suitable to visit. The training ranges from one day introductory sessions to the three-day 'Counselling Skills for IA Visitors' course, which is endorsed by WECT (UK) and the Royal College of Nursing Gastroenterology and Stoma Care Nursing Forum.

If you are interested please contact me ,
Marlene Evans for an informal chat on
0161 790 9380

(All information is strictly confidential)

**IA MANCHESTER
EXECUTIVE COMMITTEE**

**Chairman: Mr Chris Ainsworth
Tel: 0161 7988494
chairman@ia-manchester.com**

**Secretary: Mrs J Rose
Tel: 01204 535407
secretary@ia-manchester.com**

**Distribution : Mr Tom Fleming
Tel: 01706 822643**

**Visits : Mrs. M. Evans
Tel: 0161 790 9380**

**Committee : Mrs Anne Cross
Tel: 0161 442 9856**

**Newsletter/Website
Mr Chris Ainsworth
Tel: 07711578876**



NACC -

**Improving life for
people affected
by Colitis & Crohn's
Disease (IBD)**

**NACC has 30,500 members, 70
local Groups and over 1,000
active volunteers. NACC's infor-
mation and support services are
available to anyone affected by
IBD:**

**Weekdays from 1pm to 3.30pm
and 6.30pm to 9.00pm.
0845 130 3344**

SOME NEWS FROM ABROAD



World Ostomy Day 2009 will be celebrated on the 3rd October 2009 and the theme will be “Reaching Out” The aim of World Ostomy Day is to improve the rehabilitation of Ostomates worldwide by bringing to the attention of the general community and the global community the needs and aspirations of Ostomates.

Activities to promote awareness may include: educational programs, seminars, support meetings and demonstrations/displays; electronic information networks, newspaper and magazine announcements/advertisements and articles. Publication of informative handout materials and brochures: audio and video announcements and films; personal visits and lobbying activities; official government proclamations and joint activities with allies agencies and professional health Associations

Once again the Coloplast Merit Award will be an integral part of World Ostomy Day. The aim of the award is to encourage the spread of enterprising initiatives of national Ostomy Associations to member Associations around the world. The award has been developed in cooperation with IOA and has been presented since 1991. There will be 3 regional contests

• Europe • The Americas • Asia & South Pacific

As part of WOD 2009 there will also be an International Photographic Competition sponsored by Hollister. The World Ostomy Day Photo Contest. The theme of this competition is to indicate that having a Stoma does not stop Ostomates leading a full and active life. For example families on vacation, during work, sporting activities, spending time with children/ grand children volunteering in community organizations. There will be 20 winners for this competition from all parts of the world.