Summer 2008
Newsletter

INSIDE OUT

Volume 3 Issue 8

STOMA SUPPORT GROUP WORKING WITH ST. MARKS AND NORTHWICK PARK HOSPITAL
Incorporated with St. Mark's Hospital Foundation Charity Registration No. 1088119

Bob's Hello!

Dear Friends,

I'm sure all of you have been in a situation where you are not sure if you are coming or going as you have so many things happening at the same time and you are not sure which one to start, then the phone goes and someone asks you about one of the other ones and so on and so on. Well that's where I am at this moment in time.

We are coming up to our ninth year of our Open/Information Day's (7th June) where I hope to meet as many of you I can before the end of the day. We will have our manufacturers there for you to see if they have any new products for you to try out.

This year will be slightly different in that we will not have any of our consultants in to talk to us, but we will have Lynn Foulds-Wood, known for her TV reporting and later campaigning for bowel cancer awareness. Lynn was a sufferer of bowel cancer and came through the other side and has made it one of main purposes in life to bring to the fore front how people can help themselves and at the same time challenge those in power to re think how cancer patients can get a better deal.

We will also have Karen Butler from Harrow Primary Care, to bring us up to date on what has been happening with the Live Consultations in regards to stoma patients and their needs and afterwards you will be able to ask questions.

Our thoughts are with the families of those who have recently lost their loved one. There are also a few of our members that seem to be going through a period of illness which is dragging them down a bit. Hopefully with the sun coming out and the flowers in full bloom and the leaves on the trees starting to sprout that they will start to feel better.

I look forward to seeing as many of you who can make it on the day.

Kind Regards **Bob**

Dear ‘Inside Outers’,

Well, here we are again. The clocks have gone forward one hour; the weather, although a bit mixed, is slightly sunnier and warmer. I certainly feel brighter with the lighter evenings and warmer weather; I think most of us do.

Many thanks to those of you who have sent me your £5 membership or have paid by standing order – quite a few more than last year but still only 45 members out of the 215 names on my list who receive our newsletter; that is about 20%. The £5 helps towards the cost of producing and sending out the newsletter 4 times a year, well worth it I think. Again, I remind you that you can pay by standing order and I will send you a form on request.

I am very disappointed that I will not be able to attend the AGM/Open Day on 7th June this year. I really enjoy meeting you and putting names to faces. You have probably not heard of the UK School Games that is a government initiative to search for ‘budding’ athletes for 2012. The 1st event took place in Glasgow in 06, the second in Coventry in 07 and this year it will take place in Bath. For my sins I am involved in selecting and leading a swimming team from England East and have an orientation weekend on the 7/8 June that I have to attend.

It is a pity because listening to Lynn Foulds-Wood would be very interesting. Also, to hear what Karen Butler from Harrow Primary Care has to say about ‘Live Consultations’ could be even more interesting. Come with your questions ready: how the changes suggested would affect your life; how you would not have coped without the help of the stoma nurse etc. This will be your chance to ask leading questions – remember Karen Butler has not got a stoma so therefore has not experienced life with one.

I hope that, if you have access to a computer, you are using our website – it is brilliant and our thanks should go to Bob for all the time and effort he has put into it. (www.iossg.org.uk)

Keep well and I’ll be thinking of you all on the 7th!

Diane

Secretary/Treasurer

Inside Out

Coffee Mornings

In the Out Patients department of St Marks, Level 3
10.00am - 12.00pm

We are there to enable you to seek advice about your stoma, or if you just want a chat and a cup of coffee or tea then you are more than welcome. We are fortunate to have visits from manufacturers at some Coffee Mornings - please see below. This is an excellent way of viewing the latest products and/or simply chat to the experts.

Thursday 12th June	**Closed over August**
Monday 23rd June	**Wednesday 3rd September**
Tuesday 8th July	**Thursday 18th September**
Wednesday 23rd July	

EDITOR'S PAGE

With the main holiday season almost upon us and many members expressing concern about adequate holiday insurance here is some welcome news: **Inside Out Stoma Support Group Travel Insurance**

Travel insurance for **Inside Out Group** members has been designed for use by customers about to have a stoma or who already have a stoma as a result of any of the following:

Ileostomy – Colostomy – Urostomy – Pouch – Mitrofanoff or PEC's

Historically customers with any medical condition have found finding quality cover at a reasonable price difficult. Some insurance companies when faced with a customer with a medical condition have in the past declined to offer any cover at all. Some still do. Other insurers whilst agreeing to offer cover have loaded premiums by 100 or even 200 percent.

Leisure & Lifestyle Insurance Services working with underwriters **Millstream** and specialist medical screening providers **Mediquote** believe that by properly understanding a medical condition you can better ascertain the true risk of a claim being made. Being more scientific in respect of the frequency and cost of potential claims means underwriters should be able to set their premiums accordingly.

We consider that there is a higher risk of claims being made by **Inside Out Group** members, most likely for holiday cancellation following an abnormal routine investigation or a complication in the post operative phase. The cost of medical treatment if required whilst away on holiday may also be higher. That said we do not think that the increased risk is huge so premiums for **Inside Out Group** members are only loaded by 15 percent on our standard rates.

Other factors affect the calculation of premiums such as the age of the customers or the destination being visited, most people are aware that it is more expensive if you are travelling to North America, however we have set out some premiums examples below:

- A Single Trip policy for an individual aged between 18-39 travelling to Europe for up to 17 days

  Standard premium £19.23 **Inside Out Group** £22.62

- An Annual Multi-Trip policy for a couple aged between 40–54 with worldwide cover excluding North America

  Standard premium £130.55 **Inside Out Group** £153.59

The premiums quoted are for Gold cover. The premium for Annual Multi-Trip insurance includes 'Enjoy Life' Benefits, a range of Concierge, Lifestyle, Travel and Healthcare services the normal retail price for which is £49.95 per year for an individual and £64.95 for a couple or family.

New Developments: What is happening?

Article for In Touch Magazine

Inflammatory bowel disease (IBD) incorporates Crohn's disease and ulcerative colitis. Also microscopic colitis or collagenous colitis are inflammatory bowel diseases, but are much less common. We still do not know the cause of these conditions, but developments are occurring all the time: from genetic predisposition to novel treatments. I will focus on some of the questions that we are debating at the moment about treatments and also touch on the developing field of intestinal transplantation … not as treatment for IBD, but as treatment for the extreme situation when a patient's intestine fails completely.

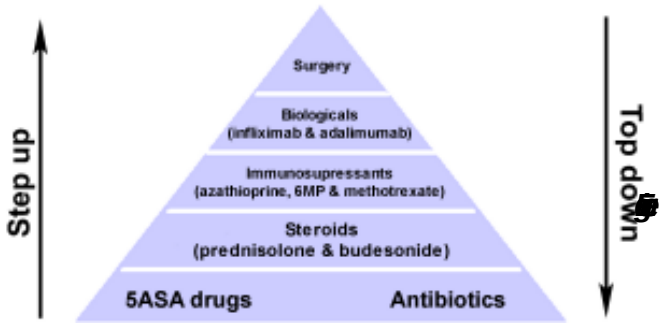
Step-up or top-down?

This is a serious question that is being asked by the world's experts at the moment with respect to the treatment strategy for inflammatory bowel disease.

Step-up refers to the classic treatment approach, a progression of treatment intensity as a patient's disease becomes increasingly severe or resistant. Top-down refers to the early introduction of intensive treatments, including "biological agents" and immunosuppressive drugs, with the aim of avoiding complications and improving quality of life, starting from the assumption that these drugs may interfere with the natural history of the disease.

In many respects the question of step-up or top-down is not new as it has been debated for a number of years: going in hard with powerful treatments at the beginning of the disease in order to prevent relapses. However, the right treatments were simply not there as invariably going in hard with strong treatments meant using high dose steroids. We have known about the problems of using steroids for some time and therefore try not to use them unless absolutely necessary. Equally we are well aware that steroids may quell the fire of a flare up, but they do not put the fire out completely. In this respect they do not alter the natural history of inflammatory bowel disease as flare ups continue to occur causing a degree of damage to the intestine each time.

Fortunately there have been many new developments in the treatment of IBD over the past 5-10 years and potent new medications with acceptable side effect profiles have been developed, which *may* alter the course of the disease. It is suggested that giving these treatments early on may be better than the traditional way of treating the disease.



1: The "step-up" & "top down" approaches to the treatment of Crohn's disease

The conventional pyramid treatment strategy for induction of remission in Crohn's disease is reflected in the current guidelines that recommend a "step-up" approach, with patients initially receiving oral 5ASA treatment (mesalazine, mesalamine or sulfasalazine) or antibiotics (ciprofloxacin or metronidazole). If there is no response or if symptoms worsen, patients are advanced to receive steroids (prednisone or budesonide). Immunosuppressive agents (azathioprine, mercaptopurine or methotrexate) are then added to the treatment regime in patients who are steroid resistant, allowing the steroids to be decreased or stopped. Infliximab tends to be used in moderate to severe refractory disease.
Some of the new drugs that are re-kindling this debate include infliximab (Remicade) and adalimumab (Humira). These drugs act on an inflammatory mediator called tumour-necrosis factor alpha (TNFα) and are conventionally reserved for patients who have failed both corticosteroids and the steroid sparing drugs. Infliximab and adalimumab are antibodies that block the effects of TNFα. TNFα is a substance made by cells of the body which has an important role in promoting

inflammation. By blocking the action of TNFα, infliximab reduces the signs and symptoms of inflammation.

What about other similar conditions?

Rheumatoid arthritis has many similarities to Crohn's disease, but simply affects a different part of the body (the joints and connective tissue). In this condition it has been shown that the early introduction of infliximab together with methotrexate is better at treating early rheumatoid arthritis than single therapy with either treatment.

Is there any evidence?

A recent study published in the Lancet in February 2008 compared 'Step Up *vs.* Top Down' treatment in Crohn's disease. They demonstrated that the combination of infliximab with immunosuppressives at disease onset was better than the current standard approach. This was both in terms of treating a flare up and preventing further flare ups.

So, why don't we do this now?

There are many good reasons why treatments don't just change after a single study. In particular, there needs to be overwhelming evidence of benefit and one study, however convincing, could be a fluke. In addition, the top down strategy involves giving 'aggressive' treatments to all patients at the beginning and since over 50% of Crohn's patients have a mild disease over time, this will expose them unnecessarily to powerful medications. At the moment we do not have any good markers which enable us to identify high-risk patients, but once these are known then this may be the way ahead. Finally, there are still discussions about the long-term safety and the high costs of powerful medications such as infliximab and other biological treatments, and caution is the sensible approach. Thus while it seems attractive to use powerful biological treatments early in the course of the disease, caution is generally advised for the moment.

In ulcerative colitis the same argument holds as for Crohn's disease, although there is less evidence for treatment by the top down approach. Thus at the moment the step up approach is the accepted treatment protocol.

High dose mesalasine in ulcerative colitis:

If you have ulcerative colitis, have you noticed that when you have a flare-up that your doctor is advising you to have higher and higher doses of Asacol or Pentasa treatments in the place of steroids?

High dose mesalasine may prevent the need for steroids.

Sulphasalazine was the first drug to be used for the treatment of ulcerative colitis. The early trials showed that the higher the dose used the more effective it was, but the side effects became worse. It was then realised that many of the side effects were from the part of the drug that contained sulphur and as a result and sulphur-free drugs were developed (mesalazine, olsalazine and balsalazide). There have now been a number of studies to look at the effective dose for these drugs in the treatment of ulcerative colitis and these have shown that mesalasine (Asacol and Pentasa) works more effectively at higher doses (up to 4.8 g/day), particularly in patients having a flare-up. This dose is double the usual treatment dose that was recommended for a flare-up. In addition, combined treatment with tablets and suppositories or enemas is more effective in treating a flare-up. These mesalazine drugs appear to have dose-related benefits without dose-related side effects.

Mesalasine may prevent colon cancer in ulcerative colitis & Crohn's

One new finding about these mesalasine drugs is that they may prevent the development of colon cancer in patients with ulcerative colitis and Crohn's disease. We have known for some time that patients with ulcerative colitis and Crohn's disease affecting all or most of their colon are at higher risk of developing colon cancer, which is why colonoscopic surveillance programmes are recommended after 8 years of having the disease. A study published in 2005 from Nottingham suggested that patients who were taking the 5ASA drugs (sulphasalazine, mesalasine, Olsalazine and Balsalazide) were significantly less likely to develop colon cancer. More research needs to be done here, but this looks interesting and most doctors now suggest continuing treat-

ment rather than stopping it, even when the disease is not active.

Intestinal Transplantation

Did you know that it is possible to have an intestinal transplant? I must start off by saying that this is by no means an ordinary treatment, but an extraordinary treatment only to be considered in exceptional circumstances when there is no alternative. Nevertheless it is possible. At present (and for the foreseeable future) this is considered in patients with intestinal failure. Equally, the term intestinal failure may be odd – you have almost certainly heard of heart failure, kidney failure but the term intestinal failure is not usually used. Intestinal failure is when there is not enough functioning bowel to absorb enough nutrients or fluids to keep alive. In this situation you lose weight and become very thin. The only option is to have intravenous nutrition (a sterile feed that goes directly into your veins). This intravenous nutrition can continue at home for patients and can be given long term. However, when complications occur, patients become eligible to be considered for an intestinal transplant. It may seem strange that this sort of extreme treatment (intestinal transplantation) is more commonly performed in babies and children than in adults. Babies are more prone to developing liver problems when they have intestinal failure and this makes transplantation the only possible treatment to save their lives.

Worldwide around 200 intestinal transplants are currently per year and around 1,500 have been performed since 1985. It is therefore early days for this extreme treatment. Two-thirds have been in babies and children and one third in adults. In adults this has been performed in patients with Crohn's disease as well as other conditions. In the UK, there have been a total of 18 adults transplanted. The survival rates after an intestinal transplant are increasing and are currently quoted at around a 60% chance of surviving 5 years after the transplant. This may not seem very good, but it will improve with time as the treatments used to stop rejection continue to improve. Nevertheless, it is reserved only for patients whose outlook is poor without a transplant.

There are three types of intestinal transplant that can be performed: (1) an isolated small bowel transplant, (2) a combined liver and small bowel transplant, and (3) a multivisceral transplant, which is usually involves transplantation of liver, small bowel and stomach, although kidneys, pancreas and bladder can also be transplanted.

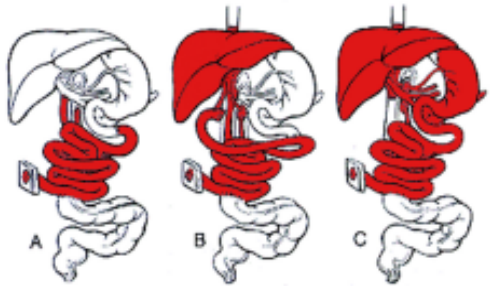


Figure 2: A. Isolated intestinal transplant. B. Combined liver and intestinal transplant. C. Multivisceral transplant.

Ask your doctor about new treatments for your condition

As you can appreciate there are continuing advances for patients with inflammatory bowel disease and other bowel problems. This is a rapidly changing field, so be sure to ask your doctor about new treatments that may be appropriate for your condition. Some of the newest treatments are performed as clinical trials. These are safe and have all been approved by an appropriate ethics committee, implying that they are not putting you at any undue risk. Various clinical trials are always underway at St Mark's, so if you are interested let the nurses and doctors know and they will tell you if there is a trial appropriate for your condition.

Dr Simon Gabe
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Co-Chair of the Lennard-Jones Intestinal Failure Unit

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