Autumn/Winter
2004
NEWSLETTER

INSIDE OUT

VOLUME 2
ISSUE 10

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

Hello friends, well the summer is nearly over or did it ever begin? I for one went away and visited family in Portugal and enjoyed the sun, sea, fresh vegetables, fresh fish, pastel de natas and the wine. I am back, replenished and ready to start again. I hope that you all had as an enjoyable holiday as I did.

As you can see from the layout we have increased our size, (thanks to Fittleworth), and hopefully we will give you a lot more information into which you can delve. To help us put a newsletter together from which you can get the most out of it we need your ideas on what you want to see in it. We can fill it with lots of things but they may not be what you want to read.

Please could you let Joan, Diane or me know what you would like in your newsletter.

I am sorry to say that Grace Miller, who had suffered for a long time with bouts of illness that has meant frequent stays in hospital, has passed away. Our thoughts go out to her family.

Clare Bossom, had a bay girl on the 26th June, at 10.34pm, weighing 8lbs $3^{1/2}$ozs and has been named Fay Olivia.

We are now agents for CUI WEAR, they make undergarments and swimwear for both ladies and gentleman. They are unique in that they have little pockets inside the garment into which you can put your bag, and so have that added security. If you do wish to make an order you can do it through us or you can ring them direct on freephone 0800 279 2050 and quote IOU 256 or online at www.cuiwear.com and quote the same reference IOU 256. We will then receive the commission in the Inside Out account.

You can find the swags showing the texture and patterns of the different cloths in the Stoma Care Department, the Outpatients Department or on our board in the entrance to St Mark's.

I hope you enjoy our new look and please let us know what it is that you would like to see inside these covers.

Best Wishes
Bob
Chairman, Inside Out

Inside Out Coffee Mornings

In the Out Patients Department of St. Mark's, Level 3
10.00am to 12 noon

We are there to enable you to seek advice about your stomas, or if you just want a good old chin-wag and a cup of tea or coffee, then you are more than welcome.

October	Wednesday 13th, Thursday 28th
November	Monday 8th, Tuesday 23rd
December	Wednesday 8th, Thursday 16th
January	Monday 10th, Tuesday 25th
February	Wednesday 9th, Thursday 24th
March	Monday 7th, Tuesday 22nd
April	Wednesday 6th, Thursday 21st

A Letter from your Secretary/Treasurer

Dear fellow `Ostomists`

As I sit at my desk writing for our 'winter' issue of 'Inside Out', the sun is shining, the sky is blue and it is hot. Yes, I am in England; in fact I am in Harrow, only a couple of miles away from St.Mark's Hospital. I remember when I had my 'op' in July 1999 the weather was the same as this, very hot and sultry..

What have we to come? Weather wise, who knows; we might have an 'Indian summer' or 'Arctic conditions' or anything in between! We have, of course, got Christmas!

Looking back, we had a very successful Open Day and AGM (as reported in our summer newsletter) and will be having another one in May 2005, exact date will be announced when bookings for the hall are verified. The date may be announced in this edition, in the 'Stop press', if not it will be in our next edition.

In our Chairman's letter, Bob mentions the arrangement with CUIwear; they had a stall at our Open Day. I saw many of you talking to the owners, I'm not sure how many of you bought items - I did. I bought a swimming costume and was so pleased with their personal attention and with the costume itself. It's brilliant, I feel a million dollars when wearing it. They didn't have my size so I placed an order that was supposed to take two weeks to arrive. I was going on holiday the following Saturday and they got it to me in time! I hope that many of you will support us as agents.

The Jazz Extravaganza was brilliant; it was just a pity that there were so many empty seats causing us to make just £662 which will not go very far between ourselves and research into Crohn's, Cancer and Colitis. With all the work involved I cannot see us running another Jazz evening, which is a pity, because those people who attended thoroughly enjoyed themselves and would support another one.

Whenever this edition of 'Inside Out' arrives through your door, I hope that you will have had a lovely summer, not only with an enjoyable holiday but also with good health.

My best wishes to you all,

Diane
Secretary/Treasurer

Am I really the only one?

I cannot believe that I really am the only Stomatist who admits to hating their Stoma. Much as I hate it, I never lose sight of the fact that without the skill and care of the distinguished surgeon who performed the operation, I wouldn't be around even to moan about it. The problem is that I didn't know that he was going to give me one that has a mind of its own and spends half of its time thinking up ways and means to thwart and aggravate me, and the other half putting them into practice. And, to make matters worse, it listens to my 'phone calls'. When a former colleague 'phones to arrange a luncheon for a group of us, which is a regular occurrence and one where I particularly want to look my best, I know that even though for at least two days prior and during the lunch, I will have only eaten the stodgiest food available. However, just before we leave the restaurant, I will have to disappear for ages and my friends will be wondering out loud if I am alright.

What particularly annoys me is that I have to wear fuller skirts than I would really like (due to one of its idiosyncracies).

This Stoma of mine works 24 hours a day, not as the leaflets say - either once in the morning or afternoon or evening. Because of this, I find that irrigation will not work for me.

There are a number of ways in which it regularly causes me trouble but I will not bore you with them. Unfortunately for me, mine was one of those ineligible for a reversal.

So, I am stuck with it and will presumably still be the only one moaning, unless you know differently!

JEMG

Inflammatory bowel disease – key facts

Dr Simon Gabe, Senior Lecturer and Consultant Gastroenterologist, St Mark's hospital, London.

Patients with inflammatory bowel disease, IBD (ulcerative colitis and Crohn's disease), often have many questions but can be afraid or even too embarrassed to ask them. Here are some of the common ones:

- What it ulcerative colitis and Crohn's disease?
- What causes it?
- Will I be able to work, travel, and exercise?
- Should I be on a special diet?
- How will other people react to my illness?
- Will this change my life?

What is Ulcerative Colitis?

Ulcerative colitis is a disease of the large intestine (colon). There is inflammation and ulceration of the innermost lining of the bowel wall. It looks much like a burn on the inside of the bowel. Tiny open sores, or ulcers, form on the surface of the lining, where they bleed and produce pus and mucus. All this makes the colon empty frequently causing diarrhoea (sometimes with blood) and crampy abdominal pains. The inflammation usually begins in the rectum and lower colon, but it may also involve the entire colon. When ulcerative colitis affects only the lowest part of the colon (the rectum) it is called ulcerative proctitis. If the disease affects only the left side of the colon, it is called limited or distal colitis. If it involves the entire colon, it is termed pan colitis.

What is Crohn's disease?

Crohn's disease can affect any area of the gastrointestinal tract, including the small intestine and colon. Again there are areas of ulceration and inflammation in the bowel wall, but the symptoms can be different if other areas of the bowel are affected. When the small bowel is affected, there is more abdominal pain and nausea or vomiting than diarrhoea.

What causes IBD?

Although considerable progress has been made in IBD research, we do not yet know the cause of these diseases. Studies indicate that the inflammation in IBD involves a complex interaction of factors: the genes the patient has inherited, the immune system, and something in the environment. Foreign substances (antigens) in the environment may be the direct cause of the inflammation, or they may stimulate the body's defences to produce an inflammation that continues without control. Researchers believe that once the IBD patient's immune system is "turned on," it does not know how to properly "turn off" at the right time. As a result, inflammation damages the intestine and causes the symptoms of IBD. That is why the main goal of medical therapy is to help patients regulate their immune system better.

How common is IBD?

It is estimated that as many as 150,000 people in the United Kingdom are affected by either ulcerative colitis or Crohn's disease. The frequency of ulcerative colitis has been fairly stable over the last half-century, but over the same time frame there has been a substantial rise in Crohn's disease.

Ulcerative colitis is generally a disease of the young. Most cases are diagnosed before age 30, although the disease can occur at any age. Crohn's disease is also similar as it can occur at any age but usually presents in adolescents and young adults (mainly age 15 to 35). In another much smaller group of patients, the disease develops between the ages of 50 and 70.

Is IBD inherited?

We know that IBD can tend to run in families. Studies have shown that up to 20 percent of people with ulcerative colitis will have a close relative with either ulcerative colitis or Crohn's disease. However, there does not appear to be a clear-cut pattern to this inheritance. Recently, an important breakthrough was achieved when the first gene for Crohn's disease was identified. The researchers were able to pick out an abnormal mutation or alteration in a gene known as Nod2. This mutation, which limits the ability to fight bacteria, occurs twice as frequently in Crohn's patients than the general population. At this time, no method is available to screen patients for this gene. There is also no way to predict which, if any, family members will develop Crohn's disease. Much more work is being done in this area and St Mark's hospital is involved in some of this pioneering work.

Emotional stress & coping with IBD

People with ulcerative colitis accept the diagnosis with a wide range of emotions. Some people are angry for a time, others feel relieved that they now know what it is that has made them ill. Everyone is different. Each person with the disease must adjust to living with ulcerative colitis in his or her own way. There should be no guilt, no self-reproaches, or blame placed on others as you come to grips with your illness. There are resources and information available, such as local support groups and IBD education seminars. No one with ulcerative colitis should ever feel alone.

Because body and mind are so closely interrelated, emotional stress can influence the course of ulcerative colitis. Although people sometimes experience emotional problems before a flare-up of their disease, this does not imply that emotional stress causes the illness. There is no evidence to show that stress, anxiety, or tension is responsible for ulcerative colitis or Crohn's disease.

Coping techniques for dealing with IBD may take many forms. Attacks of diarrhoea, pain, or gas may make people fearful of being in public places. In such a situation, some practical advance planning may help alleviate this fear. For instance, find out where the toilets are in restaurants, shopping areas, theatres, and on public transportation ahead of time. It also helps to talk about any problems or concerns that you have and, if in doubt, don't be ashamed to ask.

Ulcerative Colitis

What medications are used to treat ulcerative colitis?

Currently, there is no medical cure for ulcerative colitis. However, effective medical treatment can suppress the inflammatory process. This accomplishes two important goals: It permits the colon to heal and it also relieves the symptoms of diarrhoea, rectal bleeding, and abdominal pain. Three major classes of medication are used today to treat ulcerative colitis (see Table).

What is the role of surgery in ulcerative colitis?

Anyone reading this article is bound to have undergone surgery for their inflammatory bowel disease. In general, around one-quarter to one-third of patients with ulcerative colitis are resistant to medical therapy or have a complication resulting in surgery. This operation performed involves the removal of the colon (colectomy). Unlike Crohn's disease, which can recur after surgery, ulcerative colitis is "cured" once the colon is removed.

Depending on a number of factors-including the extent of the disease and the patient's age and overall health, one of two surgical approaches may be recommended. The first involves the removal of the entire colon and rectum, with the creation of an ileostomy or external stoma (an opening on the abdomen through which wastes are emptied into a pouch, which is attached to the skin with adhesive). Today, many people are able to take advantage of new surgical techniques, which have been developed to offer another option. This procedure also calls for removal of the colon, but it avoids an ileostomy. By creating an internal pouch from the small bowel the surgeon can preserve bowel integrity and avoid a stoma. You should be aware, however, that patients with a pouch do not have an entirely "normal" bowel function. If you wish to know more about this procedure, please discuss this with your doctor or stoma care nurse.

The role of nutrition

There is no evidence that any particular foods cause or contribute to ulcerative colitis or other types of IBD. Once the disease has developed, however, paying special attention to diet may help reduce symptoms, replace lost nutrients, and promote healing. For example, when your disease is active, you may find that bland, soft foods may cause less discomfort than raw vegetables, spicy or high-fibre foods.

Crohn's Disease

What medications are used to treat this disease?

As with ulcerative colitis, the same drugs can generally be used although there are some differences (see Table)

What is the role of surgery?

Two-thirds to three-quarters of patients with Crohn's disease will require surgery at some point during their lives. Surgery becomes necessary in Crohn's disease when medications can no longer control the symptoms. It may also be performed to repair a leak in the bowel or relieve a blockage that has developed. Generally, the diseased segment is removed (resection) and the two ends of healthy bowel are joined back together (anastomosis) but it is not unusual for a stoma to be formed. While resection and anastomosis may allow many symptom-free years, this surgery is not considered a cure for Crohn's disease, because the disease frequently recurs at or near the site of anastomosis.

An ileostomy also may be required when surgery is performed for Crohn's disease of the colon. After the surgeon removes the colon, he brings the small bowel to the skin, so that waste products may be emptied into a pouch attached to the abdomen.

The role of nutrition

There is no evidence that any particular foods cause or contribute to Crohn's disease or other types of IBD. Once the disease has developed, however, paying special attention to diet may help reduce symptoms, replace lost nutrients, and promote healing.

When Crohn's disease is active, soft, bland foods may cause less discomfort than spicy or high-fibre foods. Except for restricting milk in lactose-intolerant patients, most gastroenterologists try to be flexible in planning the diets of their Crohn's patients. A healthy diet should contain a variety of foods from all food groups. Meat, fish, poultry, and dairy products (if tolerated) are sources of

protein; bread, cereal, starches, fruits, and vegetables are sources of carbohydrate; margarine and oils are sources of fat.

Research studies

A number of different research studies are being undertaken at St Mark's hospital for patients with ulcerative colitis and Crohn's disease. If you are interested in participating, please ask your doctor if there are any studies that would be appropriate for your condition.

Table: Treatments used in IBD

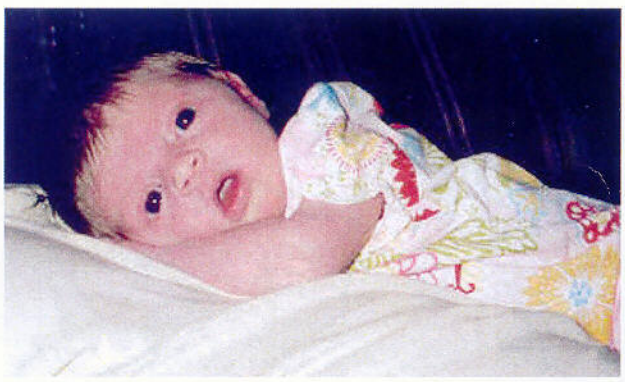
Treatment group	CD	UC	Examples	Action
Aminosalicylates	✓	✓	Mesalamine (Asacol, Pentasa) Sulfasalazine	Used for mild to moderate episodes of ulcerative colitis & are helpful in preventing relapses
Steroids	✓	✓	Prednisone Budesonide	Used for moderate to severe disease. They affect the body's ability to create and maintain inflammation. Can be very effective for short-term control but are not recommended for long-term use
Immunomodulators	✓	✓	Azathioprine 6-MP Methotrexate	These drugs alter the immune cells' interaction with the inflammatory process. Patients need to be monitored closely with blood tests when taking these medications.
		✓	Cyclosporin	This is being used in severe ulcerative colitis and is preventing some patients from requiring surgery. Requires close monitoring.
	✓		Infliximab (Remicade)	This is an antibody that binds to a key immune protein that plays a role in inflammation (TNF). It can be used in patients with Crohn's disease who have had an inadequate response to conventional and immunomodulatory therapy.
Antibiotics	✓		Metronidazole Ciprofloxacin	These can be helpful in active Crohn's disease as well as help treating any abscess or fistula that has developed.

CD = Crohn's disease, UC = ulcerative colitis

Sarah's Piece

Clare and I would like to inform you all that there is now an update on our stoma care service. Over the past year we have been working hard on planning and implementing a stoma care nurse led service, which has now been up and running since January 2004.
The aim of the clinic is to provide an informative and supportive service in a relaxed atmosphere to all ostomists within our local community (Harrow Borough). We provide continuing care to newly discharged patients and to those who may have lost contact with a stoma nurse.
The clinic offers ongoing support, practical help, advice, and information on stoma problems, including skin care, colostomy irrigation, psychological and sexual advice. We can also provide a support garment measuring service and information on support groups and networking.
The clinic is appointment based only and referrals can be made via your G.P. All local G.P. Surgeries are aware of the clinic due to the support by the "Friends of St Marks" who kindly sponsored our information leaflet, which has been distributed to all G.P surgeries.
This has been an exciting new project for Clare and myself, which we believe, enhances the care provided within St Marks and Northwick Park Hospital.

Sarah Varma
Stoma Care Nurse Specialist



Fay Olivia
Clare Bossom's baby

Medical Histories

I am reliably informed that these are actual entries on hospital charts by doctors!

- The patient has been depressed since she began seeing me in 1993
- She stated that she had been constipated for most of her life until she got a divorce
- Patient had two teenage children but no other abnormalities

Useful Contacts

Chairman ~ Bob Azevedo-Gilbert
256 Merlins Court, Alexandra Avenue
South Harrow, HA2 9BZ
020 8426 5203
insiedout.bag256@btinternet.com

Vice Chairman ~ Barry Kindred
020 8423 7845

Secretary / Treasurer ~ Diane Owen
020 8248 6684
insideoutbag170@aol.com

Editors ~ Henry & Joan Greenwood
020 8248 4740
hjgreenwood@lineone.net

Ileostomy & Internal Pouch Support Group
0800 018 4724

NACC
01727 830 038

Urostomy Association
0800 018 4724

British Colostomy Association
0800 328 4257

CUI Wear
Underwear + Swimwear for ostomists
0800 279 2650 Quote Ref IOU256

Want to join the support group?

If you have a colostomy, ileostomy or a urostomy and you would like more information, please complete the form below and send it to:
Clare Bossom & Sarah Varma c/o Stoma Care Department, St. Mark's & Northwick Park Hospital, Watford Road, Harrow, Middlesex, HA1 3UJ

Name _____

Address _____

_____

Postcode _____ Telephone _____