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**Ileostomy & Internal Pouch  
Support Group**  
0800 018 4724

**NACC**  
01727 830 038

**Urostomy Association**  
0845 2412 159

**The Colostomy Association**  
0800 328 4257

**CUI Wear**  
Underwear + Swimwear for ostomists  
0800 279 2050 Quote Ref IOU256

**Ostomy Lifestyle Helpline**  
0800 731 4264

### Attention! Important! Please Read:

Whilst every care has been taken to ensure that the information in this publication is accurate and complete, the contents of this newsletter are provided for general information only and should not be relied upon for any specific purpose. Inside Out Stoma Group accepts no responsibility for the accuracy or statements made. Anyone acting upon them does so at their own risk. We recommend that you consult your stoma nurse or doctor before changing your procedures.

## Want to join the Support Group?

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

Name \_\_\_\_\_

Address \_\_\_\_\_

Postcode \_\_\_\_\_ Telephone \_\_\_\_\_

Annual membership subscription £5.00. Cheques payable to "St. Mark's Hospital Foundation"  
Diane Owen, 170 Malvern Avenue, Harrow, Middlesex, HA2 9HD



Spring  
2012  
Newsletter



Volume 8  
Issue 1

**STOMA SUPPORT GROUP WORKING WITH ST. MARK'S AND NORTHWICK PARK HOSPITAL**  
Incorporated with St. Mark's Hospital Foundation Charity Registration No. 1140930

Dear Friends

This is my first hello as Chair and a big thank you to you all for giving me this opportunity, although Bob is a tough act to follow!!! But he has promised that he will be there for on-going support every step of the way.

A big thank you to you Bob and I think that I can take the liberty of sending it from all the committee and all our group members. As Bob mentioned in the last newsletter his role has changed to Newsletter Editor. Much work has already gone into it, as negotiations (which are his forte) with Fittleworth who have agreed to give us more coverage, which means that we can provide more variety and exciting reading.

In this our spring issue, three individuals have given us the privilege of an insight in their personal journey which allows us to share experiences and so help each other on what can be a difficult journey.

Sarah

### Message from Lisa;

Hi Ya!

Just to let you know that even though I am not with you all at the moment, as I am now working at UCLH in the stoma care department, I am still thinking about, with the help of Bob and the department, setting up a support group here in UCLH, working along the same principles as Inside Out in St Mark's.

Lisa



# Dear Inside Outers

**I'm back!**

I've left you in peace for the last 2 issues; no nagging about memberships fees (re those of you who haven't paid this year). However, if you feel like putting a cheque in the post to me (address on the back page) please make the cheque payable to St. Mark's Hospital Foundation. DO NOT PUT 'INSIDE OUT' ON THE CHEQUE. The bank doesn't like it!

## How are your bowling skills? Ten Pin Bowling

We would like you to join your committee for some fun and laughter on Thursday July 12th 2012, 7pm, for games at the Park Royal Bowling Alley, a short walk from Park Royal Underground Station. The committee tested out the venue and had a riotous evening.

The committee have also decided to have another Open Day this year. It will be on Saturday 13 October 2012 at St. Marks.

Please put these two dates in you diaries now! I must warn you that the car park personnel will not give any concessions with regard to car park charges so perhaps it might be beneficial to use public transport.

I hope you are all keeping well and warm in this threatened cold spell. The flowers don't know whether they are coming or going. My camellia bush is in full flower, two months early, whereas my daffodils are just peaking through when other gardens have got daffs in full bloom. It's crazy!

Keep well

Diane  
Secretary/Treasurer



## Editorial correction to the newsletter volume 7 issue 4 - To prevent dehydration for the high output patient

I must apologise for an error that occurred in our last newsletter edition volume 7 issue 4, "How to prevent dehydration for the high output patient." I inevitably stated that Lisa Smith, who wrote the article for me was the Lead Nurse in the Intestinal Failure Unit St Marks, was in fact a Staff Nurse on that unit. I hope that this has not offended anyone concerned!

Bob (Editor)

# Coffee Mornings

DATE	DAY	Company	Location
15th March	Thursday	B Braun	IFU Lev 9 NWPH
30th March	Friday	TBA	Post Grad Lev 5 St M
10th April	Monday	CliniMed	Post Grad Lev 5 St M
24th April	Tuesday	Pelican	Out-Patients Lev 3 St M
9th May	Wednesday	ConvaTec	Out-Patients Lev 3 St M
24th May	Thursday	Patients Knows Best	IFU Lev 9 NWPH
8th June	Friday	Hollister	Post Grad Lev 5 St M
18th June	Monday	Oakmed	Post Grad Lev 5 St M
3rd July	Tuesday	TBA	IFU Lev 9 NWPH
18th July	Wednesday	Fittleworth	Post Grad Lev 5 St M
6th September	Thursday	CliniMed	Post Grad Lev 5 St M
21st September	Friday	Dansac	Out-Patients Lev 3 St M
1st October	Monday	B Braun	Post Grad Lev 5 St M
16th October	Tuesday	ConvaTec	Out-Patients Lev 3 St M
31st October	Wednesday	OstoMart	Out-Patients Lev 3 St M
15th November	Thursday	Coloplast	Post Grad Lev 5 St M
30th November	Friday	TBA	Post Grad Lev 5 St M
17th December	Monday	Hollister	Post Grad Lev 5 St M

Come along for an informal chat over a nice cup of tea/coffee and biscuits

10:00am till Mid-day

Follow the signs to the Venue



# A DATE FOR THE DIARY!



## This Year's Open / Information Day will be held on the

**Saturday 13th October 2012**  
**The Himsworth Hall**  
**Level 6 of St Mark's Hospital**

Come along and see some old friends and have a chat  
Come and see all the manufactures gathered under one roof  
showing their new products

Come and join in the very informative workshops  
Tea /Coffee, soft drinks, biscuits available through the day and  
a Snack Lunch

Come to our AGM to hear what we have been up to and what we  
plan for the future!

**Doors Open: 10:00 am - Finishes: 4:00 pm**

**We look forward to seeing you all on the day**

# Bile Acid Malabsorption

After being diagnosed with bowel cancer in April/May 2009; being treated with chemo therapy and radio therapy in an attempt to shrink the tumour and then being operated on in December 2009, I became one of the some 17,000 patients that are treated annually with radiotherapy to the abdomen and pelvis area. It would appear that nearly everybody gets bowel upsets during radiotherapy, but these usually settle after treatment. However, about half of all long term survivors develop ongoing problems.

As a member of this group I found that my bowel movements did not return to what they were before surgery; I would move from diarrhoea to constipation in a matter of six to twelve hours; acid reflux was a constant, almost daily problem and I was having to attend to my colostomy pouch on numerous occasions during the day and night. To say that all this is added up to a problem would be an understatement.

Early in 2011 Dr Arshi Denton, the oncologist who was treating me at Mt Vernon Hospital arranged an appointment with Dr Andreyev at the Royal Marsden Hospital, and a past member of staff at St Mark's, in London. Dr Andreyev organised for me to have a breath test which indicated that there was no bacterial problem in the gut. He also performed a gastroscopy and satisfied himself that all was fine in that department; and happily it was. He then arranged for me to have a SeHCAT scan at the Royal Chelsea and Westminster Hospital in London.

A week later and Dr Andreyev was telling me that I was suffering from a condition called Bile Acid Malabsorption. In my simple terms it meant that bile was called for from the liver and the gall bladder and introduced into the stomach to help with the digestion of fatty foods: Over many hours this bile travelled with the food through the small intestine. At the very end of the small intestine there is a short "specialist" section of the small bowel which extracts the bile, and via the blood stream returns it to the liver.

For some of us this "specialist" section was removed when the cancerous length of the colon was removed, or for many of us that "specialist" section was damaged by radio therapy: this means that the bile is not removed from the food. Unfortunately, or possibly fortunately for other important reasons the body does not pass bile which then tends to build up in the gut; and it is all this bile that causes all the ongoing problems which makes life so miserable for so many.

Once diagnosed Dr Andreyev put me onto medication and had me talk to specialist dieticians that work closely with his gastroenterology department and are involved in the research that he and his team are carrying out. The change due to this medication and in particular the very low fat diet (the more fat you eat the more bile your body has to produce to process it) to which I was introduced was nothing short of a miracle.

And it is an extremely low fat diet. Evidently, on average the daily fat consumption per person in the United Kingdom is 220 grams. In the United States it appears to be 320 grams. I have been cut back to 40 grams.

Within four days of starting the diet the diarrhoea/constipation disappeared and although I have not returned to the regularity of the pre stoma era my stoma pouch requires much less attention during the day and only rarely at night: and I have no acid reflux. The problem has literally disappeared.

After a long period of "misery" I am back using the underground and able to drive to the South coast; and far, far less concern about all the typical problems with my pouch.

This dramatic improvement is solely due to unique work done by Dr Andreyev and his team. He is the only specialist in the UK specifically appointed to treat patients with damage caused to the bowels by radiotherapy. In fact world-wide there are only a couple of other gastroenterologists who have published papers in this field.

At the Marsden the research team includes specialist dieticians, nurses and a data manager. They work closely with radiotherapy oncologists, cancer surgeons, nursing staff, radiographers and a wide range of professionals involved in the support and care of patients who are having or have completed radiotherapy.

**Derek Baker**

# Need a helping hand?

Have your supplies delivered direct to your door



- A dispensing centre local to you
- Opening hours 8am to 8pm  
Monday to Friday,  
9am to 1pm Saturday
- Quick, discreet and reliable service
- Complimentary accessories with each order
- Comprehensive sample service
- Overseas Emergency Cover -  
World Assist Alliance

World Assist Alliance programme  
for our customers abroad on  
holiday or business

## National Service, Locally Based

### SPECIALISTS IN HOME DELIVERY OF MEDICAL APPLIANCES



We have a range of information sheets available, please tick the relevant boxes for those that you require.

Stoma Cutting Template  Living with a Stoma - Hints and Tips  Common Stoma Problems   
Dietary Advice  Travel Passport  World Assist Alliance

Name: (Mr/Mrs/Miss) .....

Address: .....

Postcode: .....

Telephone No: ..... E-mail: .....

Alternatively, you can send a text. Please text **HANDS** (capital letters) plus your **name, phone** and/  
or **email** address with your request to **88802**

STMARKS

Fittleworth  
FREEPOST, Hawthorn Road, Littlehampton, West Sussex BN17 7LT  
National: 0800 378 846 Scotland: 0800 783 7148  
www.fittleworth.com caring@fittleworth.com



## Abdominal exercises following Stoma forming surgery

### Pelvic Tilting

- Lie on your back on a firm surface with knees bent and feet flat on the bed.
- Pull your tummy in, tilt your bottom upwards slightly while pressing the middle of your back into the bed and hold for two seconds.
- Let go slowly.
- Repeat ten times daily.



### Knee Rolling

- Lie on your back on a firm surface with knees bent and flat on the bed.
- Pull your tummy in and keeping your knees together, slowly roll them from side to side.
- Repeat ten times daily.



### Abdominal Sit-ups

- Lie on your back on a firm surface with knees bent and flat on the bed.
- Place your hands on the front of your thighs and pull your tummy in.
- Lift your head off the pillow.
- Hold for three seconds, then slowly return to starting position.
- Repeat ten times daily.



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# Q & A

Dear Fellow Ostomists,

I've received some questions via email and felt that we should pass these on and perhaps generate further Q & A in our newsletters in future. Please do not hesitate to respond to questions you see or if you have a particular issue that you would like to have some advice on.

**Q)**

Please could you advise me, my stoma keeps prolapsing, it does not always go back, and I have a hernia and at times I am finding it very uncomfortable. Should I use a hernia belt and if so which one can anyone recommend?

**A)**

## **Prolapse**

Ileostomy This not uncommon complication can be found alone or in association with a parastomal hernia. Chronic prolapse can cause irritation, bleeding, and even stoma necrosis.

## **Colostomy**

Prolapse is more common in loop colostomies, especially loop transverse colostomy. It is thought to develop in patients with obstruction because of the discrepancy between the size of the colon and the defect in the abdominal wall. It is not common to have a parastomal hernia in association with colonic prolapse.

## **Urostomy**

A prolapsing Urostomy is prone to trauma and poses problems with appliance attachment. The usual aetiology is inadequate fascial fixation; it occurs in up to 10% of cases. Should the stoma become so prolapsed that it causes difficulty with appliance attachment or trauma, any excessive protuberance may be trimmed off surgically and the resulting deficit over sewn.

## **Hernia**

As reported by research parastomal hernia is a complication affecting around 20-30% of stoma patients who have stomas and are more common around colostomists than ileostomists or urostomists.

It can be defined a parastomal hernia as a bulging of the peristomal skin indicating one or more loops of bowel through a defect around the stoma into the subcutaneous tissues. This often presents in a visible swelling, and contributing factors are obesity, gender, age siting of a stoma or a chronic cough.

Hernia support belts/pants are a non-invasive way of managing a hernia. There are many companies, but it about what you as the individual feels comfortable with. Read all the literature first to decide whether a belt would be beneficial or whether underwear garments would suite better. There are different styles which for women can be made with lace putting on a feminine touch and can also be tailor made.

## **Companies**

Coloplast  
Sash  
Sportex  
Salts  
Pelican  
OstoMart  
CUI Wear

It would be good to have some feedback from those of you that have managed this complication of wearing a support garment.

## My Tail by Robert Twelvetrees

Hi yah folks

My name is Bob Twelvetrees and I am a Urostomist. In 1992 I was diagnosed with cancer of the bladder and after four years of various treatments including Chemotherapy, it was decided that the best course of action would be to take out the bladder completely.

In August 1996 I had my bladder, prostate and ureter removed which was quite a shock to the system. After several weeks of complications, including an abscess on the wound which necessitated having the stitches and clamps taken out, the scar left to heal from the inside out, (no pun intended). I was eventually discharged from hospital, but with MRSA, which was treated at home daily by the District Nurses with strong antibiotics. In all it took nearly 12 months to recover, but with the help of my family and close friends I remained positive and determined to get myself back to being me.

So it was June 1998 my wife and close friends took ourselves off to the Austrian mountains for a "holiday". I knew I was really OK when we went for an eight hour trek over the mountain paths, taking the cable car to the top of the mountain traveling down, (although there were many paths up as well as down).

After a few months my wife and I decided it was time to get back to our hobby of Ballroom and Latin American Dancing, as in our late teens and early twenty's we were competition dancers. This has been a boon to keeping fit – after a night of waltzing, fox trotting, quickstepping, tangoing etc. You know you have made it, and we have continued to dance at least once a week to this day, and as I am now 79th year, I feel that this is somewhat of an achievement.

I also try walking at least once a day. I have never made a secret of my urostomy and my five grandchildren have all seen my stoma and were fascinated by it when they were younger. They were always very careful of my stomach when I played with them. They are all teenagers and more now as it is fifteen years since the operation.

I have also had great support from the Inside Out Stoma Support Group. We are very lucky in Harrow to be able to spend time with other ostomists especially at the coffee mornings, where we can learn from one another to help get over our little problems that we all get from time to time. Also to have visits from the various manufacturers who let us know about all the new appliances and accessories that are available on prescription to all stoma patients.

So the key is to stay positive, determined and as active as possible, letting you have a life back. I know that this is not always the case for everyone, but self-determination is a must.



**Bob and Pauline**

# Top to Tail

## by Azmina Verjee

Once upon a time, long ago when I was almost 10 years old, I started having symptoms of what turned out to be Crohn's disease. My GP didn't investigate; there were no protocols or referral guidelines in those days, and given its relative rarity, Crohn's simply wasn't on the radar. So my abdominal pain and altered bowel habit were put down to school-related stress and the GP sent me on my way.

As time passed, new symptoms developed; my lips became swollen and sore, and if I ate or drank anything acidic, especially citrus fruits and their juice, my mouth would sting.

My GP thought this could be an allergy, and so he wrote out a prescription for anti-histamines, and again sent me on my way. A year or so later when at a routine dental check up, my eagle-eyed dentist spotted fissures and ulceration deep into my gums. Alarmed, he referred me to the Eastman Dental Hospital without delay.

At the Eastman arrangements were swiftly made to biopsy my gums under local anaesthetic. The biopsies triggered a referral to a Professor of Paediatric Gastroenterology over at St Bartholomew's Hospital, John Walker-Smith. He was known, as many professionals are, by his initials JAWS – terrifying to a young child! After various diagnostic investigations, all of which will no doubt be familiar to you, I finally received a diagnosis of Crohn's disease – by now I was 14.

Initially I was prescribed oral Asacol, but the medication brought me little in the way of relief. The diarrhoea and abdominal cramps and went from bad to worse, and before long, I was going to the toilet 20 times during an average day. At school, I was spending more time in the toilet than in the classroom. I was prescribed prednisolone (steroid medication), which thankfully brought respite, but also impaired my growth and thinned my bones. So whilst my classmates were growing noticeably taller, my height stood stubbornly still. Fast-forward to today and I'm still no taller than the average 12-year old, and I've had a couple of premature broken bones along the way.

Another treatment I tried was the polymeric diet (consuming pre-prepared nutritious liquid drinks only). When the dear dietician told me these drinks tasted like delicious milkshakes, I wish I'd known to add a hefty pinch of salt! These days, the drinks come in 99 flavours and every colour of the rainbow, so we're fortunate and rather spoiled for choice.

Many people with Crohn's end up needing surgery at some point, and in this respect, I was no exception. By the time I'd reached university, I was in a bad way with a perianal abscess and a fistula (in my case, a tunnel running from rectum to skin).

During the early 1990s, Infiximab (an anti TNF alpha compound used to treat fistulae today) was still just a twinkle in a test tube on a laboratory bench, so when metronidazole (antibiotic treatment) failed, the surgeon's knife was the only option. The full details are too gory to be aired before the 9pm watershed, but to summarise; my first operation left me faecal incontinent, housebound and entirely dependent on care from others.



My early 20s were a haze of wound infections, daily district nurse visits, incontinence and the worst kind of pain imaginable. I could barely walk, let alone bathe myself or get dressed. I only left the house to go to the hospital, and the long journeys there and back were a struggle. 2 hours in the outpatient clinic waiting room, 1 hour waiting for a blood test, another hour waiting for medication to be dispensed; it all took its toll. The strain on my family was extensive and eventually, my exhausted mum gave up her job to look after me full-time. So there I was, back in nappies at the grand old age of 21. Meanwhile, my friends were out in the big wide world, starting their first jobs, buying their first homes and enjoying living independent adult lives. The contrast was stark and depressing; most days I wished I was dead.

My lifeline was my district nurse, Lian Panetta, who patiently and generously looked after me for almost 2 years. One day, she told me she had heard about a specialist hospital tailor-made for the likes of me, called St Mark's Hospital. Today, someone in an unfortunate situation could just Google, but the internet was in its infancy back then and my only source of information was the local public library, which wasn't exactly replete with books on fistulae!

At St Mark's Hospital, a wonderful giant of colorectal surgery, Peter Hawley, defunctioned my colon and created an end Ileostomy for me. The operation took place on July 2nd 1997, and I still mark the day upon which my life as a 'bag lady' began.

Being a bag lady, as I call it, hasn't always been easy. My stoma is hyperactive and makes unbelievably loud rude noises. I've been incredibly lucky not to have skin problems, but my bags do sometimes leak. When I'm stood at the supermarket checkout with faecal matter running down my leg, it doesn't matter that the liquid has escaped from my bag rather than from my bottom, because the panic, shame, smell and mess are exactly the same.

When I was 25, a surveillance colonoscopy revealed some high-grade dysplasia (pre-cancerous cell changes) in my now de-functioned (redundant) bowel. I was also still plagued by cramps and discharge, despite being on Azathioprine (immunosuppressant medication). So on April 21st 2001 I had an elective panproctocolectomy (removal of colon rectum and anus) and thankfully, I've not been back inside an operating theatre since.

I discovered Inside Out Stoma Support Group shortly before I had my panproctocolectomy, and I became an instant devotee. There can't be many illnesses that are as embarrassing and socially isolating as Crohn's disease. I've never once overheard a conversation in public about a perianal fistula or a leaking colostomy bag, yet people do talk openly about other conditions; chatting away about their diabetes or arthritis whilst waiting for a bus.

That's why the Inside Out Stoma Support Group is so important. In the company of Inside Outers, you can speak the otherwise unspeakable, and nobody will bat an eyelid; everyone knows, understands and accepts. And if you're not feeling talkative, there's no pressure at all to speak; you can simply 'be'. So please do pop in to one of our regular Coffee Mornings at St Mark's and join us for a cup of coffee or tea.

