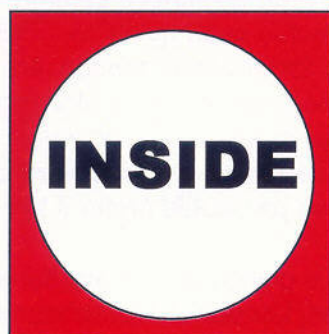


Autumn/Winter  
2003  
NEWSLETTER



VOLUME 2  
ISSUE 6

STOMA SUPPORT GROUP INCORPORATED WITH ST MARKS AND NORTHWICK PARK HOSPITAL  
Part of St. Marks Hospital Foundation Charity Registration No. 1088119



## Bob's Hello



Hi everyone, yes, it has been a very long time since I last put pen to paper and I'm sorry for the delay. Hopefully, we will get back on track and bring the newsletter back on schedule.

Well, what's been happening since we were last together? On September 29th, Barry and I were invited to a reception held by the Mayor of Harrow, who was the representative of the Queen's Jubilee award to voluntary groups for all the work they do in the community. We, the group that is, were nominated and even though we did not make the final award winning band, we were invited to a "Thank You" supper from the borough.

This month we held a Christmas Fair with the Windsock Club, to raise some money for our appropriate groups. It was very nice of those of you who made the effort, especially those who came from the other side of London. Joan and I kept our peckers up with an ample supply of coffee and mince pies and we managed to raise £60. In 2004, we have a very full calendar. In May, we have our AGM and at the same time, we will be holding an Open Information Day where some of our manufacturers and other groups will have their stands for all to see. In addition, there will be a couple of speakers followed by a question and answers session at the end of the day. Once we have the programme worked out, we will let you know.

In June, we will be holding a Jazz night to raise funds for our group and St Mark's Hospital Foundation, with which we are now incorporated.

This reminds me, we are now at the time when subscriptions are due, so please, could you let me have the completed standing order forms back. Thank you to those who have already sent them and for those who prefer to send cheques, would you please make out the cheques to "**St Mark's Hospital Foundation (Inside Out)**". This will ensure that the funds will be put into our account.

A few of our members have been going through the mill lately and this has kept me busy, checking on them. I hope that they and your good selves kept well over the Christmas and New Year period and that Santa brought you what you wanted. I for for one will be going into hospital just after Christmas for a small op. This does not mean that the coffee mornings will not continue in my absence, as they will be manned by other members, who will look forward to seeing you.

Best Wishes to you all till the next time.

Bob - Chairman of "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 stoma, or if you just want a good old chin-wag and a cup of tea or coffee, then you are more than welcome.

**January**

Tuesday 20<sup>th</sup>

**February**

Wednesday 4<sup>th</sup>, Thursday 19<sup>th</sup>

**March**

Monday 1<sup>st</sup>, Tuesday 16<sup>th</sup>, Wednesday 31<sup>st</sup>

**April**

Thursday 15<sup>th</sup>, Monday 26<sup>th</sup>

**May**

Tuesday 11<sup>th</sup>



## From your Secretary

Dear Inside-Outers,

The time has come for a few words of wisdom from your secretary. A problem - I haven't got any!

What have we done since I last wrote a few words to you. Not a lot! Coffee mornings are the mainstay of our organisation for the moment. These are very important for members and new members, to join in discussions with other "Inside-Outers" and manufacturers about their problems. Don't forget that members have been through the same problems as you; with specific problems Bob, our chairman, can usually find someone with a similar problem. It's a small room and a bit of a squash sometimes, but you will be made very welcome and a hot cup of coffee or tea will be thrust into your hand in a couple of minutes. (Follow the signs displayed in St Mark's outpatient department.)

A group of us went to Crawley to the Clinimed factory. We were given coffee, shown around the factory to see how the "bags" were made, they also provided a lovely lunch and then a talk about new products in the pipe line, using our expertise, listening to our problems and adding our names to their list for trials of any new products. All in all, a very interesting day. A big thank you must be given to all those at Clinimed who made us so welcome.

Anyway I hope you all had a very Merry Christmas and a Happy New Year.

Best Wishes for 2004 (It is already four years since the millenium, doesn't time fly when you're fit and well, and having fun.)

Diane Owen, Secretary

With our Spring Newsletter, we hope to start a "Question & Answer" column, with more than one answer to each question. This is mainly for those who, for whatever reason, are unable to voice their problem at the Coffee Mornings. If you have a problem or need advice, do write or call us. Questions & Answers will have the initials only of the participants unless you would prefer it to be otherwise.

Bob is going into St Peter's Hospital, Cleveland Street, London W1 telephone 0207 636 833 on Monday 12th January and could be there for up to 2 weeks. Are we going to allow him to be bored?

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### How to handle a Black Eye - Norma Herrmann

My black eye really was caused, quite respectably, by a door. If you are young, handsome and male with a black eye, you will probably be thought to be some kind of sporting hero. However, if you are, like me, female and more than middle aged, you are likely to be shunned and feared as dangerous. Here are a few rules. Firstly, make sure you are immaculately dressed at all times. If you nip down to the shops in your gardening clothes with a black eye, your switch card will be taken away and every loop and line of your signature scrutinised. Five-pound notes you offer will be held up to the light! Next, never chat to strangers in a queue or smile at anyone, or they will back off expecting you to ask them for money. Do not walk through the streets with too much shopping, or they will think you are the bag lady.

The thing about having a black eye is that it is very easy to forget you have one. I did this in a large supermarket where I saw a bag of 20 frozen sausages had burst open and spread over the bottom of the freezer. I said to the assistant that if they were being thrown away, my dog would rather like to have them at a bargain price. Of course, I had forgotten "the eye". A heated debate took place between staff members, on the subject of the impossibility of bags splitting in freezers. Who had done it? In the end, my dog was granted the sausages, and I the benefit of the doubt, in spite of the black eye, which showed I was surely guilty.

The week ended with a lovely meal in an Italian restaurant in Brighton. Someone in our group ordered a bottle of wine which nobody wanted. The waiter re-corked the bottle and told me to take it home. Picture the scene: there is me, walking for some reason several steps from my family, as if alone, clutching an open bottle of wine, with a black eye, in the middle of the Pavilion Gardens....Surrounded by fellow sufferers.

### SPECIAL QUOTATION

"I can handle everything that God throws at me. I just wish he had less confidence in me".

**MOTHER TERESA**





# Overseas Experience

We continue with the 3rd and final instalment of Martin Clarke's story. Once again if you have missed any and wished you hadn't telephone Joan Greenwood on 0208 248 4740

As had been indicated by the medical and surgical teams at the St Mark's, my quality of life virtually returned to normal as a result of this initial surgery-the premise of removing the problem rather than treating it certainly had significant merit!

A hitch occurred at Easter 2002 when the small intestine twisted behind my stoma - with very painful consequences! An emergency operation took place at St Mark's to solve that particular difficulty, and fortunately access to the problem area was able to be achieved through the stoma itself.

Mr Cohen kept me under further observation as 2002 went by, and it was agreed that it was appropriate for a "pouch" operation to be undertaken; this second major operation took place successfully in May 2002. Though my stoma remained, it was hoped that, if all went according to plan, a reversal of the ileostomy could be considered a few months later. All did go according to plan - and as the pouch had formed and healed well, the ileostomy was "undone" in September 2002, one year less one day after the colectomy. Having had three planned procedures and one unplanned procedure (and many nights in the Frederick Salmon Ward of St Mark's!), it was an anniversary for us to celebrate!

Since the reversal (and the associated removal of the ileostomy bag) I have felt really well. I have gained strength and I certainly seem to be pointing in the right direction - to the extent that my Gill has suggested that a diet may now be appropriate! It has been discovered that I have a hernia in my abdominal wall as a result of the intrusive surgical procedures; this is causing no difficulties at this time and though it will be necessary to rectify it at some stage, it will not be considered in the short-term. Apart from that, I take Loperamide twice a day to slow down the activity of the gut, I wear pads for the minor leakage that occurs occasionally, I make internal gurgling noises from time to time and I make loud noises in the toilet about five times a day - but if they are the four major legacies of my illness, then they are comparatively easy to live with as a "pouchie"!

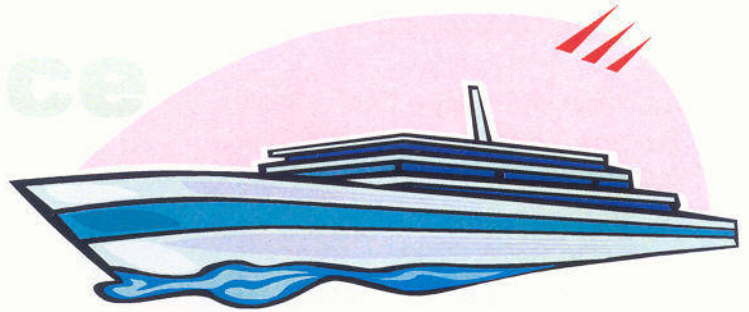
Some general observations on my experiences are perhaps of interest:

Excellent treatment from the NHS in general, and from GPs, the South Infirmary, The Royal Hampshire County Hospital and St Mark's Hospital in particular.

Total professionalism from Richard Cohen, Alistair Forbes, and their numerous colleagues in the medical, surgical and nursing areas at St Mark's.

Support from my employers at MOD at Andover, who allowed me to remain employed on a temporary basis, despite all my hospital comings and goings!

Acknowledgment of being very lucky to have come through the turmoil satisfactorily.



I have been asked on a number of occasions to what extent life has changed since my first problems nearly three years ago - and it has, inevitably, in a number of ways. Our "OE" plans referred to earlier have gone a bit awry, but flexibility in our planning for this once-in-a-lifetime trip was always going to be required! Gratitude for the super care and attention we have received from everyone involved in my illness will not fade - as we have been unable to express appropriately our appreciation. Fortunately Gill and I have always faced things with a grin (on the basis that we are generally unable to change what's coming our way!) and that joint sense of humour has certainly helped us to try and remain positive through some of the darker days. There is no doubt that we have a different outlook on life. We have always tried to enjoy the life we have, but somehow we do face each day as if it were more important than previously, and appreciate each day for what we do and what we can look forward to doing - and there's lots to do!

I was born in the UK (ironically at Wembley Park, not far from St Mark's) but have lived in New Zealand for the last thirty-five years - where I met that girl of mine! Our circumstances have thus been a little more difficult for us because the majority of our family and friends live a trifle inconveniently at the other end of the world - but it has resulted in our always-special relationship between ourselves becoming even more special; our two grown-up daughters have also been the cliched "towers of strength" and their short-distance and long-distance love and support have also helped me immeasurably. I do not believe that I could have got through without my family.

Would we recommend people to go through what we've been through? Of course not - but if it happens to you, be aware that there is nothing to fear and you can emerge at the other end almost as though it hadn't happened! Now when shall we book that cross-channel ferry.....

## Funnies

A flight attendant's comment on a less than perfect landing: "We ask you to please remain seated as Captain Kangaroo bounces us to the terminal"

After a real crusher of a landing in Phoenix, the flight attendant came on with, "Ladies and Gentleman, please remain in your seats until Captain Crash and the Crew have brought the aircraft to a screeching halt against the gate. And, once the tyre smoke has cleared and the warning bells are silenced, we'll open the door and you can pick your way through the wreckage to the terminal".





**Chairman of "Inside Out" (Stoma Support Group)**

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**Editors ~ Henry & Joan Greenwood**

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## Useful Contacts

**Ileostomy & Internal Pouch Support Group**

0800 018 4724

**NACC**

01727 830 038

**Urostomy Association**

0800 018 4724

**British Colostomy Association**

0800 328 4257



**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:

Claire Bossom - Sarah Varma c/o Stoma Care Department, St. Mark's & Northwick Park Hospital, Watford Road, Harrow, Middlesex, HA1 3UJ

Name \_\_\_\_\_

Address \_\_\_\_\_

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



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