
Summer 2004
NEWSLETTER

INSIDE

OUT

VOLUME 2
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

Wow! What a fantastic day we had on the 8th May. We had between 80 to 100 people come in to the Open/Information Day. To look, listen and have their say. A big thank you to our manufacturers, speakers, caterers, members of the committee and your good selves who made it worthwhile.



It's when things like this come together that I get a buzz, knowing what we are doing is absolutely right and worthwhile because it brings together manufacturers and stoma nurses, and you can see new products and ask for medical advice in a relaxed atmosphere. We will make this an annual attraction, especially as we have not had so many people at our AGM before.

The Jazz Extravaganza was a great success, both the Dean of St Mark's Hospital, Mr Alistair Forbes and the Mayor of Harrow, Mrs Lurline Champagnie, were toe tapping all the way through the evening. The Mayor was kind enough to pull out the winning tickets of our summer draw: 1st prize of £250 went to Mr R. Johnston, 2nd prize of £100 went to J. Seymour, 3rd prize of £50 went to J. Edmunds, 4th prize to N. Kindred and the last prize went to E. Spivack. A BIG THANK YOU to all of you who came on the night, bought raffle tickets and to those of you who helped out on the night.

Best wishes, Bob

Chairman of Inside Out

In memory of John Mason

Sadly, John passed away earlier this year. He and his lovely wife Doreen were regulars at our coffee mornings and he will be fondly remembered for his wit and stories. We gratefully acknowledge the donation made by his family and friends. Our thoughts are with Doreen and hope that we will continue to see her at our coffee mornings.

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.

July Tuesday 6th, Wednesday 21st
August None due to vacations
September Thursday 2nd, Monday 13th, Tuesday 28th
October Wednesday 13th, Thursday 28th
November Monday 8th, Tuesday 23rd
December Wednesday 8th, Thursday 16th



A Letter from your Secretary/Treasurer

Hello, once again, and welcome to this our 'Summer Newsletter'. Did I meet you at the Open Day on the 8th May? Were you the handsome gentleman in the brown jacket or the striking lady in the floral dress? I met a lot of interesting people at the Open Day, some were members, some were non-members whom I hope are going to become members. It was a very interesting day. This will become an annual event so if you missed this one, make sure you attend the next one.

Manufacturers were showing their wares and giving advice to those requiring it; coffee/tea/cold drinks were available all day long; a lovely buffet lunch was provided; there were three very interesting talks and a question/answer session - and it didn't cost you a penny! or rather, lots of pennies if you bought some raffle tickets or tickets for our 'Jazz Extravaganza' at the Winston Churchill Hall in Pinn Way, Ruislip.

We need your support if we are going to help the research into 'Crohn's, Colitis and Cancer'. These are the three C's which have been the cause of the majority of us having

'stomas'. Both the raffle and the 'Jazz Extravaganza', we hope, will make us money for this research. We were lucky when we had our 'ops', research helped us benefit considerably from those of you who have had your stomas for some years.

Holding our AGM at midday during the Open Day, proved successful. The last three AGM's have been very sparsely attended and it was great to see so many at, what is generally anticipated to be, a boring meeting. I do not think that it was boring, but, maybe I am biased!

Remember: any comments, questions, answers, items of interest would be welcome by our editor, Joan, telephone number and e-mail address on the back of this newsletter.

At the moment it doesn't seem as if summer is approaching, but the calendar tells me it is so! So, here's wishing you happy holidays in the sunshine whether it will be on our shores or abroad.

With Best Wishes

Diane Owen (Secretary)



Letters to the Editor

We have received a very interesting communication from Eric Midson of Slough, one of our members. His story is rather interesting and we feel that you would like to hear about it.

Eric was born in 1927 with Hirschsprung's disease. This is a congenital disorder affecting the bowel, tending to run in families and occurring about four times more often in boys than in girls. He considers it a 'dreadful complaint'. He was 22 before he heard of St Mark's hospital in City Road where he came under the care of Sir Nauton Morgan "who gave me a Colostomy and later a Sigmoid Colostomy". Later, he was under Sir Alan Parkes who advised him that a reversal was not an option; he then had a Ileostomy.

Eric writes of the primitive appliances he was offered in those days. Firstly "a plastic box like a lunch box with a rubber bag hanging below the box, held on by an elastic belt", this he rejected. "Next was a belt with three buckles and four holes in the front with a saucer fixed by four knobs and padded with cotton wool gauze". This was also rejected. He was treated by Mr James Thompson and later by Mr Cohen. All of these surgeons he describes as extremely pleasant to know, they put his mind at ease. Being a devout Christian he feels helped him to live through his problems and not to become suicidal.

In addition to all those options already mentioned, about six years ago he had a Urostomy. He is an Insulin dependant diabetic and partially deaf. He regrets not having heard of St Mark's Hospital earlier and thanks everyone at St Mark's for their professionalism though he is still wistful about the demise of the position of matron.

Despite all of Eric's problems, he still works tirelessly raising money for Cancer Research with stalls at fetes and with his collecting box in various shopping centres.

He really is admirable.



Norman Stevenson (Independent Financial Adviser) 0208 429 8516

normanstevenson@cathedral-ifa.co.uk

As a financial advisor I always end a client meeting with my standard expression "I'm pleased to have been of help - do please feel free to introduce anyone you know who might benefit from the services I offer". Having used my catchphrase recently with a client who is a member of "Inside Out" he kindly took me to one of the regular coffee mornings at St Mark's.

There I met Chairman Bob and I also had the opportunity to meet and speak to a very positive and enthusiastic bunch of people. As an Independent Financial Adviser I get to know clients and help them plan for those dreams - whether it's the holiday of a lifetime, that dream car, a new conservatory or simply financial security. Some, because of health issues, just want "to get their house in order". Everyone has financial needs - and if you speak to an Independent Financial Advisor they will act on your behalf and give choice - it's a very personal service.

Good Luck and enjoy the summer!

Helpful Hint

Barry tells us that the adhesive used by our various manufacturers is not identical and that one may be more suited to you than another. His idea was that if this is a problem for you, causing soreness, ask another supplier for a sample of their wares so that you may try them out. If that is not successful try yet another supplier.

WE FEEL THAT THE FOLLOWING PAGE WILL BE INTERESTING TO ALMOST EVERYBODY!

Dear Joan,

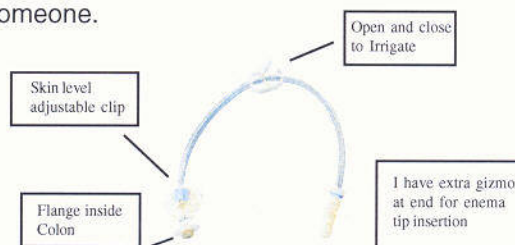
My name is Glenda Simmons, we met at the Information Day on Saturday 8th May. I must say a huge thank you to everyone involved, I feel overwhelmed by the helpful and useful exchange of information that took place, and feel that I 'belong' much more to this kind of Support Group, than any other I have so far encountered. I have sent my joining form and fee off and a small monthly donation by BACS, I hope this will help.

I am attaching an article about my Personal Profile and a picture of the PEG tube that I have inserted into my Sigmoid Colon so it gives a better idea of how it is done and what it looks like. Mr Cohen has made an excellent job of it, although I recently had a little complication and had to have the tube changed under general anaesthetic.

It is completely healed and fully functioning, for which I am so Grateful.

Thanks to all those who gave advice and tips to help with the few difficulties I do still have, I even bought the Eurax Cream on the way home to see if it will ease the incessant itching I suffer from!

Many thanks again, I hope this proves to be of some use to someone.



Personal Profile of Bowel Incontinence - PEC Procedure by Glenda Simmons

I have battled with bowel incontinence for some 28 years, after suffering a third degree tear at the birth of my first child, which my GP had repaired on the assumption that I would be fine. It took 5 years of feeling alone, frightened, worried and ashamed before I managed to tell my GP what was really causing the anxiety I was being treated for.

I was referred through the Royal London Hospital to St Mark's Hospital, where several tests were done and I had a Post Anal Repair. Unfortunately, the repair made the incontinence worse, but in those days there was nothing more that could be done. I had suffered from constipation from childhood and I noticed these were the times when passive leakage was worst, so it became a regular thing to juggle food, fibre and laxatives together in order to keep the constipation away and keep the incontinence to a minimum.

At the age of 50 the constipation became chronic and the incontinence was happening 10 or more times a day and was only controlled by unpleasant manual evacuation.

The local Hospital Consultant referred me back to St Mark's where I had similar tests carried out again and given the bio-feedback treatment. Sadly this didn't work for me, and other medicinal remedies were tried but the only thing that worked was rectal enemas. These were time consuming, messy and extremely painful. The alternative was a full Colostomy which is something I could not personally accept.

My consultant Nurse Specialist, Prof Christine

Norton and Colorectal Surgeon Mr Richard Cohen, proposed a new technique called Percutaneous Endoscopic Colostomy - PEC procedure. This uses a small standard PEG (Gastrostomy) tube inserted into the Sigmoid Colon through which I would irrigate enema and water to wash-out the lower bowel whilst sitting on the toilet as normal. I knew immediately this would be much more acceptable to me and decided to go ahead.

The PEC procedure is minimally invasive and can be done under local anaesthetic via Colonoscopy, although my own was carried out under General Anaesthetic for other reasons. I now irrigate my bowel once a day using one fleet enema followed by 500ml of boiled water. It is quick and easy to use, pain and strain free. It takes 20 minutes from start to finish. The tube is taped neatly to one side when not in use and I hardly know it's there.

The PEC has proved to be a highly successful, minimally invasive surgical procedure which is a very attractive and safe alternative to a Colostomy for Continence.

A Message from our lovely Stoma Nurse, Clare Bossom

Sarah and I would just like to Thank the committees' for their hard work at the Open Day and the time and effort that you all put in leading up to it. I thought it was a great turn-out and it was run very professionally and smoothly.

Thank you team
Clare



Chairman ~ Bob Azevedo-Gilbert

256 Merlins Court, Alexandra Avenue
South Harrow, HA2 9BZ
020 8426 5203
insideout.bag256@btconnect.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

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:

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 _____



A service as unique as you are



No two people are the same
Fittleworth appreciate this

Call **0800 378846** now to request a FREE
information pack or complete the form below and
return to:

Fittleworth Medical, Freepost, Rudford Industrial
Estate, Arundel, West Sussex, BN18 0ZZ

Name.....

Address.....

Telephone.....Email.....

Supplying all your stomacare needs