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Urostomy Association

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The Colostomy Association

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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 form 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 (Inside Out)
Diane Owen, 170 Malvern Avenue, Harrow, Middlesex, HA2 9HD

Winter
2010
Newsletter

INSIDE

OUT

Volume 4
Issue 3

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

Dear Friends,

I must apologise for my delay in putting this together, it is that I've been rushed off my feet just lately. I am trying very hard to keep my feet on the ground and my nose above the waterline.

I came back from Portugal with very good intentions of putting on our Fashion Show in the Harrow School during October of this year, but due to our economic climate, we have had to postpone the show until next year, so watch this space! Why you might add? Well I and the committee feel that it would be good to show, especially those of you who have just been the recipient of a stoma, that life doesn't have to change, you can still achieve what you want to in life and that there is a whole range of fashion available to help you achieve this.

Our aim as a support group is to provide you with the means of whether it is product knowledge, information regarding how Harrow PCT is causing issues with prescriptions, or how the new white paper could affect how you may be treated in the future. We are certain that there will be cuts in public spending even though the government has promised that spending on the NHS will be protected.

The white paper implies that the GP's will take a greater control of their budget, especially as the PCT's & SHA's are being disbanded within the next couple of years. How might this affect people with stomas? I know that GP fund holding had no harmful effect on the provision of stoma care and appliances, now I believe things will change.

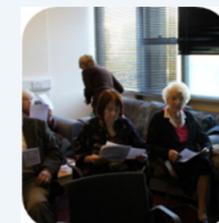
Primary Care Trusts (PCT's) up and down the country have already begun to process and identify the most cost effective stoma, continence and accessories products for their GP's with the intention of producing a limited list

from which they can prescribe from thus keeping their core costs down to a minimum, as they believe this will be a saving. Unfortunately, as they are not the recipients of stoma products etc, they are unaware of how this may have a knock on effect i.e. an appliance may not suite all, skin irritation and odour problems, just to name a few possible issues.

Stoma Care Nurses are very proactive in ensuring that the needs of individual stoma patients are understood and are being met. They have where possible, influenced the consultations over the years to protect you as stoma patients to continue to have access the products you trust and feel confident with and enable you to have a good quality of life.

Remember if you do find that you start to have problems in receiving any of your usual items after the so called hand-over from PCT to GP budget control, do get in touch with your stoma care dept and ask if they can intervene on your behalf with a letter stating why you are in need of that particular item or quantity.

The findings from the survey, which you all so kindly filled in for me are just being finalised for publication, which we could not have done without the help of Claire Taylor of the Burdette Institute and Simon Gabe Consultant MD, and our own Stoma Care Dept at St Mark's. We were able to present our findings to the Grand Round which happens each week at St Mark's where a number of departmental leads and consultants come and listen to presentations on the latest findings in the medical world.



cont..//

We now have to take this to the next stage which is to see how we can improve on what is already set up i.e. nursing while in hospital to after care once a patient has left the hospital.

St Mark's is in a privileged position as it is recognised not only throughout the UK but also worldwide, and in my eyes should be setting the benchmarks for the rest to follow and not the other way round. This can only be done if it listens to those who have gone through the ordeals and are having to deal with their new way of life. Hence I am meeting up with Mr Jarindra Warusavitarne, General Surgeon and overseer of the Stoma Care Department and Jo McCarthy, head of Nursing for Surgery to see if we can improve on what is already in place. I will of course keep you updated not only via our newsletter but also on our website which you can find on www.iossg.org.uk hot gossip page.

For those of you who were able to make it to our AGM on the 21st of October, where we talked about the latest on the Live Consultation and how it is affecting us on a day to day basis, especially as Harrow PCT is the only PCT that is making stoma patients life more difficult by implementing their interpretation on the final outcome of the consultation which came into effect in April of this year. We in Harrow have had to live with the demands since September of last year. I am scheduled to have a meeting soon with both the head of Pharmacy, Anna Jenkins, Head of Complaints Helen Butler, and the Chair of the PCT Dr Gillian Schiller to talk over a number of issues that are affect some of you. I am hoping that they will listen to reason. It is not we, as stoma patients are not unreasonable or that our appliances and accessories are life threatening, but they do restrict our quality of life, and by putting what I think are petty restrictions to try and save what are a few pence in regards as to the main budget of Harrow PCT. Hopefully we will have some more positive news in our next newsletter, but in the meantime you will be brought up to date through our website and our coffee mornings which you will find updated in this edition.



We also spoke about our Information/Open days which we have been holding every year, and whether to continue in the same light, by

that I mean do we continue to hold it every year or should we do it every two years? I would like you to tell me and your committee what you would like to see happen. Do you find them helpful? Do you find the speakers are covering the areas that you would like to hear about, or are there subjects that you would like them to talk about? Please let me and your committee members know, you can either write to me or send an email to me at: bob@iossg.org.uk my address is on the back of the newsletter.



Finally, I mentioned that this will be my last year in office as your Chairman. I will be standing down so that someone else can bring in new ideas, add to the ethos of how the group runs and in how it can continue to support stoma patients, new and old.

Firstly it has been an honour and a privilege to have served the group over the last eleven years (twelve) by the time I hand over. I have gained so much from you all and I hope I have been able to pass on my knowledge to those of you who have needed it.

This does not mean that I'm walking away completely; you cannot get rid of me that easy, sorry! I would like, as the MP's put it, spend a little more time with my family. I will also be able to update our website with the information I have gathered over the years, four boxes full, which is waiting for me to scan. I just do not have the time at the moment and the idea of our website is to keep you updated with what is happening, the changes in the medical world plus the never ending government changes which have an effect on our every day to day lives.

I can only do this by having the time, I'm sure you will understand. But hey, we still have to find someone who is willing to take up post. I will of course introduce him/her to all those I have met and who they can talk to for guidance. So come on, put on your thinking caps and come up with some names who you feel you would like to represent you!

A Merry Christmas to you all and a Very Happy New Year.

Kind Regards

Bob

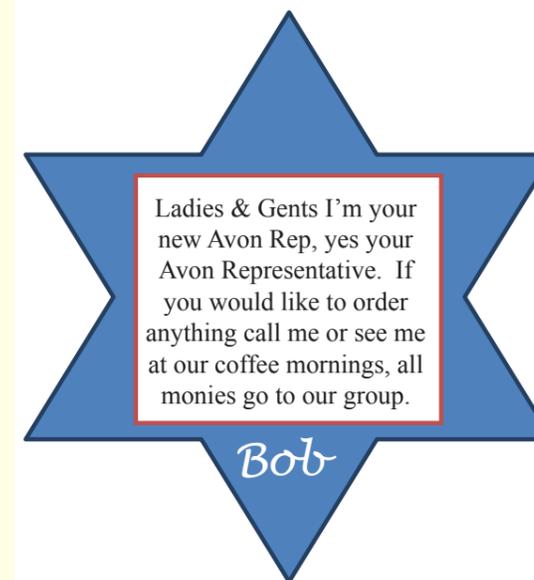
INSIDE OUT

2011 COFFEE MORNINGS

from 10am to 12pm

January	Tuesday 18th	Fittleworth
February	Wednesday 2nd Thursday 17th	BBraun ConvaTec
March	Friday 4th Monday 14th Tuesday 29th	Pelican CliniMed Hollister
April	Wednesday 13th Thursday 28th	Ostomart Salts
May	Friday 13th Monday 23rd	Oakmed Dansac
June	Tuesday 7th Wednesday 22nd	CliniMed Convatec
July	Thursday 7th Friday 22nd	Fittleworth BBraun
September	Monday 5th	OakMed

Follow the sign to our meeting room



Ladies & Gents I'm your new Avon Rep, yes your Avon Representative. If you would like to order anything call me or see me at our coffee mornings, all monies go to our group.

Bob

Newsletter Editor Wanted

Is there anyone out there who would like to take over the rewarding role of Editor for our Newsletter?

The role involves receiving the articles that are sent in and fitting them into a template. Additionally, feel free to revamp it - its your newsletter and you know what you would like to see and what would help other stoma patients. Please come forward - I know there is a budding news editor out there who is itching to get a chance to have a go!

Please contact me at: bob@iossg.org.uk

OR

Telephone 0208 428 4242

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Hi there fellow 'Inside Outers',

It seems incredible that Christmas is nearly with us again. Why is it that as you get older time seems to pass so quickly? It seems as though it was only a couple of months ago that we were celebrating New Year!

It was good to see some of you at the AGM last month. When I was talking through the financial report one issue that was discussed was the large amount spent on food for our Open Day! Well of course it wasn't our usual Open Day, it was a dinner to celebrate our 10th anniversary at the Masonic Lodge in Northwick Circle – so all was explained. The AGM was held separately at the Windsoc Club in South Harrow (with food of course!) after the end of the financial year. Because this AGM was so late I'd forgotten what had happened the previous year (and so had Bob!).

As I am on the subject of money – you know what's coming next – your membership fees, £5, are due next month. If it helps, I have standing order forms available for you to use, if you would prefer to use this method, then please let me know.

It was a great pity that the fashion show had to be cancelled because of the lack of support. Bob had spent a lot of time organising the evening, and it was with much regret that we had to cancel. We lost about £300 cancelling but would have lost a lot more had we had gone ahead.

I send out over 200 newsletters. I wonder why members (in the loosest term because to be a member you should have paid your £5) don't support events that Bob and the committee organise. The 10th anniversary dinner only had about 20 members in attendance. OK the newsletter gives you info re your stomas but even if you have a stoma you are entitled to a night out!

Two New Year resolutions to add to your list for 2011 – (i) please pay your membership and (ii) support the one or two events that are organised for the group.

I finish by wishing you all a Happy Christmas and a prosperous New Year.

Diane

INSIDE OUT ACCOUNTS 1/4/09 - 31/3/10

<u>Income</u>	<u>1/04/09-31/03/10</u>	<u>Expenses</u>	<u>1/04/09-31/03/10</u>
Carried forward	£1,625.90	AGM (Food, drinks etc)	£897.58
Donations	£735.00	R A-G / general expenses	£1,441.81
Manufacturers donations	£700	Envelopes	£52.83
Membership	£260	PMT (printing)	£358.80
	<u>£3,320.90</u>	Eurooffice	£109.91
		Ace	<u>£12.80</u>
			<u>£2,873.73</u>
	Balance 31/03/09	£1,625.90	
	Income	<u>+£1,695.00</u>	
		£3,320.90	
	Expenditure	-£2,873.73	
	Balance 31/03/10	<u>£447.17</u>	

I remind members that these accounts are audited through St. Mark's Foundation and I just take the relevant information from the accounts. Please note that without the manufacturers donations we would be in a sorry state. Bob's expenses (R A-G) cover all sorts of expenses including postage and costs incurred when Bob adds to/deletes/amends the website. Bob has moved to another website 'manager'. The website is brilliant and we should be very grateful to Bob. If he charged by the hour we would be in a sorry state. The accounts also show a quarterly payment of £135 for the website.

Inflammatory Bowel Disease

Background to IBD

Inflammatory bowel disease (IBD) is the term given for two chronic (life long) diseases, Crohn's disease and Ulcerative Colitis. Both diseases can cause inflammation in the gastrointestinal tract. In particular, Crohn's disease can cause inflammation anywhere in the gastrointestinal (GI) tract, from the mouth to the anus. In contrast Ulcerative Colitis causes inflammation in the large bowel (colon) only. See figure (1) for diagram of the GI tract.

About 250,000 people in the UK currently have IBD; that is 400 people per 100,000 population. Furthermore, it is thought that IBD affects 5 million people worldwide, with a greater incidence in the western world. The number of people diagnosed with IBD increases every year, and IBD can strike at any age.

Causes of IBD

The precise cause of IBD is unknown, but it is commonly believed that IBD occurs in individuals who have particular genes that make them more susceptible. Added to this there is an abnormal reaction of the immune system to bacteria in the gut or something in the environment. As the exact cause is still, somewhat unclear, this can in turn make management of these diseases challenging.

Diagnosis

The common age for diagnosis of IBD is between 15-35 years of age. This is the time when mostly people are likely to be in education; completing A levels/GCSE or attending university; or in employment; trying to build a career or alternatively building a family; getting married and having children. Ultimately this time period (between 15-35 years of age) is important in anyone's life, with all of the above life changing events happening. It is easy then to appreciate that a diagnosis of IBD during this time period can be difficult to come to terms with.

Remission & Relapse

IBD is a life long remitting relapsing disease, which means that the disease goes through episodes of active disease and periods of inactive disease. These episodes happen as a matter of disease course, and can be difficult to predict. However, many sufferers do report that they have identified triggers for their disease relapsing, such as a stress.

It is important to recognize that sufferers differ and are individual in their own disease & so the number, frequency and severity of relapses can vary considerably from person to person. So too can the treatments used and the manner in which patients respond to them.

During periods of active disease (relapse) sufferers can experience symptoms which including diarrhoea (up to 20 times per day), with bleeding and urgency, abdominal pain and weight loss due to loss of appetite and/or abdominal pain.

Other symptoms can include tiredness or lethargy as well as eye, joint, and skin problems related to the



Treatment Medical & Surgical

There is no cure for either disease. Medical therapy for both diseases is aimed at reducing inflammation, and sustaining full remission long term, with the ultimately aim of improving the quality of life of patients. Medical treatments for IBD have advanced considerably in the last 2 decades, with newer treatments available. The ranges of medication that can be used include oral, intravenous (through a vein) and rectally applied medication to reduce the inflammation and induce remission of the disease. Many patients will require some form of long term medications to control their disease.

Surgical intervention is seen as curative for ulcerative colitis, when the colon is removed. However, surgical resection of Crohn's disease does not offer a cure, meaning that any resection (removal of the active segment of inflamed bowel) is limited as the disease may re-occur over a period of time.

Support

Support from family and friends are invaluable to people who suffer from inflammatory bowel disease. Above all, people diagnosed with IBD need support from those closest to them, so that they can continue with a normal life as well as managing their disease adequately. This can be a difficult balance to strike, but one which is most definitely achievable.

Support from those closest is vital to allow the person with the disease to be cared for when unwell (assistance around the home/kids etc), but equally as important to provide encouragement and support to return to normal life during periods of good health or remission.

The healthcare team looking after people with IBD also has a vital role to play in support. Care for people with IBD is a team approach, and people with IBD can expect to be looked after by doctors (medical and surgical), nurses, dieticians, and in some cases counselors.

It is important for the person with IBD to have a good relationship with the main team members and ensure that there is clear, open access to care when needed, especially as periods of relapse can not be predicted. Advice about diet, possible medical and/or surgical interventions is best checked with the team as otherwise the person can gain conflicting and often confusion information.

Support from groups such as Crohn's & Colitis UK (formally NACC; www.nacc.org.uk) and CICRA (Crohn's in Childhood Research Association; www.cicra.org) provide a sound reliable source of information for sufferers and their families, particularly during the early stages of diagnosis, but are valuable throughout the disease course.

When people have had surgery for their IBD, other groups such as IA (Ileostomy and internal pouch support group; www.the-ia.org.uk), Colostomy Association (www.colostomyassociation.org.uk) and of course the Inside Out stoma support group provide invaluable support networks for people to access at their wish.

Life

Most of the patients that I look after with IBD have achieved their desires in life, whether it is in education, employment or family, despite their diagnosis of IBD. It is necessary to appreciate and acknowledge this and drawn upon all the support available (as detailed above).

Marian O'Connor
Lead IBD Specialist Nurse
St. Mark's Hospital & NWLH NHS Trust

