Summer 2003 **NEWSLETTER**





VOLUME 2 **ISSUE 5**

STOMA SUPPORT GROUP WORKING WITH ST MARKS AND NORTHWICK PARK HOSPITAL

Part of St. Marks Hospital Foundation Charity Registration No. 1088119



Bob's Hello



Hi everyone, the time has come for me to put pen to paper. It seems only yesterday that I was finishing the last one. I have some very good news; as you know, last year I suggested to the members that we become a registered charity. At the last AGM, it was discussed at great length and we were split 50-50. A suggestion was made to see if we could become a part of another registered charity, namely the St Mark's Hospital Foundation.

I presented our case to Sean Bonnington, Director of Development of St Mark's Hospital Foundation and he, in turn, put it before his Board of Trustees and I was called to give a presentation. I am very pleased to announce that on the 4th July 2003 it was passed and now we are officially a part of St Mark's Hospital Foundation.

What will this mean to us? What will it change? Fundamentally, there will be few changes and we will continue to serve all our members and anyone else who needs us, as we have done in the past. One major change will be that we will not have our own account at the bank. It will be linked with St Mark's Hospital Foundation, in a separate account earmarked "Inside Out".

We will, of course, be able to countinue to raise monies for Inside Out and for the Foundation and be more credibly accepted in the community. I see this as a perfect marriage for both of us as we will complement each other.

I hope that you all have had a great holiday and I look forward to seeing you at some of our events in our 4th year of existence.

Kind Regards Bob - Chairman of "Inside Out"

In a city restaurant: Open seven days a week, and weekends too.



Coffee Mornings

10.00am to 12 noon

In the Out Patients Department of St Mark's, Level 3

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.



Monday 1st, Tuesday 16th September

Wednesday 1st, Thursday 16th, Monday 27th October

Tuesday 11th, Wednesday 26th November Thursday 11th, Monday 22nd December

Quick Reference Food and Drink Chart

Key: F = Cause flatus O = May cause odour

C = Colostomy I = Ileostomy

L = May cause loose stool C = Requires chewing well

U = Urostomy

D = May discolour urine

All of the foods listed are permissible, (unless you have been otherwise advised by your doctor), but this is a quick reference of those which more commonly

provoke wind etc. Read the key to understand the symbols and remember that the same foods will not produce the same effect in all people - we are all different.

s is a	quick	
at		

A	0	1	11	K	-	1 11
FO (B)	C		U		С	I U
Apples		L		Kiwi Fruit		L
Apricots	<u>202</u>	L		L		
Artichokes	F			Lamb	C	
Asparagus	F	0		Lettuce		1
В				M		
Bananas	F	F		Mango		L
Beans (all types)	FLO	FLO		Mushrooms	F	F
Beef		C		N		
Beer	F	F		Nuts (all types)	C	С
Beetroot			D	0	J	· ·
Broccoli	0	FO	10000	Oil based salad		
Brussel Sprouts	F			dressing	L	L
Bean Sprouts		L		Oranges	L	L
Bamboo Shoots		Ĺ		Onions	OF	OLF
С				P	OF	OLF
Cabbage				TL.	_	
Cauliflower				Parsnips	0	0
Cereals				Peaches		L
Celery	Ŧ.			Peas	L	L
Chocolate	L L	L		Pears		L
Coconut	L	CL		Pineapple		LC
Coleslaw		C		Plums		L
	_	OF		Popcorn		L
Cucumber	F LF			Porridge		L C
Curry	LF	LF		Potatoes		С
D E				Prunes	L	L
				Q		
Eggs		OF		R		
F				Radishes	F	F
Figs	L	L	•	Raspberries		LC
Fish		0		Rhubarb	L	L
Fizzy Drinks	F	F		S		
G				Seafood	0	0
Gooseberries	L			Spinach	LF	Ĺ
Grapes	LC			Spring Greens	Santa .	O
Н	4	1		Strawberries		L
				Sweetcorn	ì	FL
î	W.	47 M	14	T	_	· L
			Č			Ti .
		13	2	Tomatoes	0	
			3/	Turnip	0	0

From your

Hello Everyone,

a great pity.

On a lovely summer's day like this I am indoors trying to think of something to write about. The brain does not work too well in this weather, or is it age? I do miss the bi-monthly meetings. Do you? When we had the meetings I did get to meet some of you, though, I must admit, not many because this is why the meetings were cancelled. Unfortunately, I find it very difficult to attend the coffee mornings so you are mostly names on a membership list, not faces of people to talk to which is

Perhaps I will see some of you on our trip to 'Clinimed', I do hope so. When firms have generously offered to take us on a visit to their factory, free travel with a free lunch and glass of wine, they deserve to be supported. Don't forget to let Bob or me know if you would like to come. Please don't let us down, just pick up the phone and let us know if you find yourselves unable to come. The trip is on Thursday 2nd October 2003 you should all have had notification about this from Bob. I'm asking you to let us know as soon as possible so that we let 'Clinimed' know how many to cater for.

We have a member who finds it difficult to travel to any of our meetings/coffee mornings. He wonders if there is anyone out there who would like to be his pen pal/e-pal. His name is Jason and his email address is:

JASONMOON4@active.co.uk.

I hope you have put the date of the next year's AGM in your diaries. It is on the 8th May 2004. The meeting will include an open forum with ostomists and a surgeon present, seminars on each type of stoma and a talk from a 'relevant' person. In the middle of all this will be a very short AGM!

Enjoy the summer and have a good holiday.

I wish you all the best of health

Diane Owen, Secretary

0208 2486684

Overseas

Bob has persuaded a new member, Martin Clarke from New Zealand, to tell us how he came to be a patient at St Mark's. It is quite a long and interesting story, so we have decided to serialise it in the newsletter. The first part appeared in the Spring issue whilst the second excerpt now follows. Anyone who did not see chapter 1 may have a copy of the complete story if they contact Joan Greenwood.



We took around two weeks to cover Belgium,
Luxembourg and Southern Holland and found
ourselves at a beautiful seaside campsite near Arnhem,
some twenty miles west of Amsterdam. I had been
starting to feel unwell again at that stage, and my
condition deteriorated rapidly after our arrival at the
camp - to the extent of having to make fifteen or
sixteen loo-visits daily. I made several calls to
Winchester Hospital over the next couple of weeks,
during which I was advised to increase the
Prednisolone intake - but to no avail. I went downhill
really fast and less than four weeks after setting out on
our European trip, I had to admit defeat, and we made
an uncomfortable and unpleasant trip back to
Winchester and the Royal Hampshire County Hospital.

I was admitted to their Victoria Ward at the end of May 2001, and with the exception of a one-week period in June, remained there until mid-July 2001. Throughout my sojourn at Winchester, the medical staff again tried to find a solution to my symptoms, but without success; it was a most frustrating couple of months as every conceivable test was undertaken, but no positive identification of the exact problem could be found. During this period my body condition experienced further deterioration and a weight loss of 3 stone from the norm caused me even more misery!

When I was transfered by ambulance to St Mark's Hospital in London, for what was clearly the best treatment available anywhere, I began an extensive programme of tests under Dr Alistair Forbes. He diagnosed 'Ulcerative Colitis' as the specific cause of

my difficulties, but confirmed that I had displayed, over the long months previously, anything but the normal symptoms of the disease! I was a 'problem child' (in middle age?!) - and for no apparent reason!

I remained at St Mark's for another seven weeks; at that time it was finally agreed by all concerned that every attempt to cure the problem medically had been unsuccessful, and that surgery to remove the Ulcerative Colitis from the colon was the only remaining option. Surgeon Richard Cohen stepped in to the equation, the operation took place on 21st September 2001, and it turned out to be a full colectomy; I thus ended up with a loop-ileostomy stoma, and commenced life with 'the old bag'!

I had faced the prospect of this major surgery in general, and the resultant stoma bag in particular, with inevitable trepidation. My confidence was greatly boosted, however, by discussion with other stoma patients who indicated that the bag, while causing inconvenience, was not a major problem. I found this to be the case, and with the unfailing support from the stoma nurse group, I was able to do everything I wanted to with confidence.

After lengthy recuperation from surgery, I was able to return to work early in January 2002; having not worked since April the previous year. I was thrilled to make this step - and the bank manager was quite happy about it as well!

Concludes in the next issue of Inside Out

Over the last couple of months we have had a few of our members pass away and our thoughts go with those who remain to mourn them. I found this piece when my father died and I would like to share it with you...........Bob

There's always another tomorrow, However hard the day.
There's always an end to sorrow, Time wipes our tears away.
There's always a reason for living, Though sad your heart may be;
There's always another horizon, Beyond the one you see.

Jo Sweeny's Baby.
Jo, an important
member of St Mark's
Stoma Care
Department.



Jessica

On the menu of a Swiss restaurant: Our wines leave you nothing to hope for.



Hotel brochure, Italy:
This hotel is renowned for its peace and solitude. In fact, crowds all over the world flock here to enjoy its solitude.

Chairman of "Inside Out" (Stoma Support Group) ~ Robet Azevedo-Gilbert

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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 drostomy 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 Hospi

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

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