

ROAR!



ISSUE 34 • SUMMER 2006

Roar! is the newsletter of the Red Lion Group
St. Mark's Hospital • Watford Road • Harrow • HA1 3UJ

Regional Reps

Here is our current list of regional reps with home telephone numbers — please feel free to contact your local rep and get acquainted.

If you would like to be a regional rep, please contact Marion Silvey (phone number on inside back page).



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Meet Zarah Perry-Woodford

Anyone who met Zarah Perry-Woodford at April's 2006 Information Day might have thought they were seeing double. For both she and her twin sister Vashti were spotted helping out with the seminars and selling raffle tickets.



All very confusing. However Zarah assures us that it is she and not Vashti who is the pouchcare specialist at St Mark's Hospital, speaks at Red Lion committee meetings and helps organise key events. Even though her sister works two corridors away as the hospital's pain nurse specialist.

Zarah and Vashti are local girls. They were born at Northwick Park Hospital and lived in the area for six years before moving with their family to Trinidad where they spent the rest of their childhood and schooling.

After passing her 'A'-levels Zarah returned to the UK to become a nurse. She got a job at Stoke Mandeville Hospital the famous spinal injuries centre in Aylesbury, Buckinghamshire. She graduated from university with a nursing diploma and joined the Royal Air Force Nursing Service.

Zarah's next post was at the Royal Defence Medical College at Hasar Hospital, Portsmouth followed by a spell at Birmingham's Selly Oak Hospital where she helped open a patientcare centre using the combined skills of NHS and Forces nursing staff.

Her first St Mark's post was as a senior staff nurse on Frederick Salmon ward in 2002. She then moved on to the hospital's stomacare and finally pouchcare departments. Apart from keeping fit and going to the gym (see pictures of her half-marathon exploits on pages 4 and 5), Zarah is an animal-lover and the proud owner of two cats and a pair of friendly house rabbits.

Her Grand Plan for 2006/2007 is to:

- Publish a fatigue survey into the causes of tiredness among pouchees. Some of you have already been involved in this.
- Draft a guide to pouch problems like pouchitis, diet difficulties and loperamide control and the best ways to handle them
- Set up new outpatient clinics at St Mark's
- Hold pouch patient study days
- Raise the level of pouchcare backed by telephone and in-house support



What makes Information Day so special? Gather round and I'll tell you. Apart from hearing the wisdom, clarity and ideas of speakers like Professor John Nicholls, Kay Neale and Julia Williams it's the chance to meet up with fellow pouchees, share problems and find new ways to improve our daily lives.

That's my view and I have a sneaking suspicion it may be yours too. A unique example of this occurred during the workshop for male pouchees. We were talking amongst ourselves when a fiftysomething Red Lion said he was amazed to find himself sitting between

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between them

four people who'd had eleven abscesses between them since their operations.

"I've heard of unpleasant conditions like fistulas, pouchitis and severe soreness but not abscesses," he said. The famous four then told him exactly what it was like to have one, how they coped with it and the best sources of treatment.

My point is that if our friend ever has an abscess – and perish the thought if he does – he will now have some

insider tips to help him cope with it – thanks to Information Day.

I'd like to put diet second on my list of I-Day Specials. None of us really has all the answers to what we should or shouldn't eat. Even though we may have picked up a few clues after a disastrous late-night dinner or two or that liquid lunch when England won the Ashes.

The do's and don'ts of diets were covered by at least three speakers on 8 April. One gave us the benefits of eating natural as opposed to processed foods, a second dealt with the importance of calorie counts and the third told us which foods to avoid. Sweet corn and nuts were two of the worst culprits.

The third of my I-Day Specials is Knowledge. We get a lot of comfort from the hard facts – particularly when they err in our favour. We know for instance that while most pouch operations are successful, at least 30 to 40 per cent of us have problems like pouchitis afterwards. The truth can hurt, but at least it's the truth. Knowing we are not alone can make those less palatable truths easier to bear.

You can read all the reports and AGM details later in this edition of *Roar!* But for now a big thank you to all those who came to St Mark's Hospital this year. It was great to see you and I hope to meet up with you again next year.

Getting the message across

We've got a rival. Yes, there's another group with a magazine called 'Roar'. It's not a charity like we are, but the students of Kings College London. KCL as many of us know has close links with St Mark's so I wonder – dare I say

it – if they pinched the name from us.

It was our new membership secretary Inez Malek who came across this flattering 24-page imitation. However that's where the similarity ends really. For the mag's spring edition has a page of 'Hunks' and 'Babes'. Though I wouldn't describe the pictures as particularly Hunky or Babe-like as they are all in rather dull sepia-toned colours.

His and Hers are not something that Tim Rogers and I would ever contemplate of course. Well, we might contemplate it but we'd never do it – and even if we did we'd make sure that all the photos were in magnificent glossy technicolour!

KCL is more political than we are – as you'd expect with a union newspaper – although like us it has three editions a year. It also has an internal rival called 'Boar'. A dismissive headline in the

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March issue says 'Students Boared of Roar' and refers to it as 'modestly printed in black-and-white on two A4 pieces of paper and found in Roar distribution bins'. With an emphasis on the bins.

I'm very glad none of you has brought out a newsletter called 'Bore'. Though perhaps you have and you're not telling us about it. A few years ago we had a junior edition of *Roar!* called 'Paw' – ha, ha, ha – for young people with pouches. But isn't this name game getting just a little bit catchy. After all if we were a rowing club we might call our magazine 'Oar', while a golf club might call theirs 'Fore' and so it goes on.

Anyway just to make life a little more interesting I'm awarding a half-case of wine to the person who comes up with the funniest selection of 10 titles rhyming with *Roar!*.

Your entries will be judged by the committee. So please send them to me at 89 Fulwell Park Avenue, Twickenham TW2 5HG.

I can hardly wait.

The Nike Milton Keynes Half Marathon

The Red Lion Group's pouch support specialist Zarah Perry-Woodford and Sarah Varma, a member of the St Mark's Hospital stoma care team, bravely ran the Nike Milton Keynes half-marathon to raise funds for the group...Michael Dean reports.

It was in early February that Zarah decided she wanted to do something positive for charity and coerced her colleague and friend Sarah into contemplating running a half-marathon. Neither of them had ever done anything like it before but their minds were made up and they began an arduous training regime with regular workouts in the gym and evening runs.

Our story begins on Saturday, 12 March, 2006. It's 5:30 am and the alarm sounds. I throw off the covers and sniff the air. It smells cold. I give Margaret a nudge – "time to get up" I say. We part the curtains and look out of the bedroom window. It's still dark and the moon is shining, everything is glistening and, yes, it is cold. "Milton Keynes the land of the roundabouts beckons," I cry as we head off along the M25 and the M1.

The host venue for the half-marathon is the campus of the Open University, a large, sprawling site on the outskirts of Milton Keynes. We arrive a bit earlier than planned, although there were a few brave bodies already there and it was still freezing cold. I rang Zarah to find out where she had got to. "We were feeling hungry so we dropped into McDonalds should be with you soon," she said. Anyway she arrived together with Sarah, Zarah's boyfriend



Sarah and Zarah (right) wave to spectators

Martin and her sister Vashti and husband Jamie. I looked at the small car. "You all fitted into that?" I asked. Zarah grinned impishly and nodded.

We headed to the registration-point to check in. There were hundreds of runners and supporters milling around. They had come from all over the country and the atmosphere was electric. We had already decided that we would go to a couple of vantage-points along the route to cheer on our intrepid pair and needless to say we got lost.

By the time we had reached the first one they had already gone by and a bunch of stragglers were bringing up the rear.

We'd also lost touch with Vashti and the lads so we headed off to another

vantage-point collecting a few other lost souls en route. There we met up with a lonely marshal and, with much stamping of feet to keep warm, waited for the runners to appear.

The first to arrive at the bottom of the steep slope was a long way ahead of the field and obviously determined to finish the 13-and-a-bit miles in just under two hours so we were told. We clapped and cheered the front-runners as they reached the top of the incline to give them as much encouragement as possible, shouting "Come on boys and girls give it some wellie" as they still had three miles to go. All the time we were

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looking out for our lonely runners.

A few hours had passed and still there was no sign of them. The field was beginning to thin out and the supporters who had originally joined us were long gone, their runners having already moved ahead of the pack. Now it was just Margaret and me alone with our thoughts. Suddenly at the foot of the slope we saw two familiar faces. It was our doughty duo. We waved and they waved back with big grins on their faces. We shouted "Not far to go" in an encouraging but not altogether truthful way.

Once they had gone by we rushed to the finishing line to make sure we had a grandstand view to welcome them home. Strangely enough we also met up with the companions we had managed to lose earlier in the race – so we all stood at the finishing line to cheer them in.

One by one the runners started to appear looking exhausted but triumphant. The loudspeaker was announcing them in number order when suddenly our two friends appeared. They



A relaxed-looking duo celebrate with friends

were running hand-in-hand to make sure they finished together. “We’ve done it!” they cried as they strutted over the finishing-line. The girls may have been shivering and shaking but they had fulfilled their dream.

After they had collected their medals we headed back to the cars. Margaret had the forethought to bring hot drinks and sandwiches and, of course, the obligatory biscuits. By the time tea was made Sarah and Zarah were ensconced

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in the back of their car under a pile of duvets. The hot tea was very welcoming for everyone, but now it was threatening to snow and we were glad to be on our way home.

Both our runners did extremely well. Their training regime may have been tough but it enabled them to raise more than £700 of much-needed funds for the group.

If you have any fund-raising tales – however big or small – from your area we’d love to hear from you. Just email or send us a small article or letter and we’ll publish it. Tim and Chris (our addresses are on the back of Roar!).



Information Day Presentations

The following ten pages contain two presentations from the Red Lion Group information day 2006. The first is **Ileo Anal Pouch and Diet** by June Beharry. The second presentation was given by Zarah Perry-Woodford and is about **Pouch Problems: Hints and Tips**.

ILEO ANAL POUCH AND DIET

June Beharry
Gastroenterology Dietitian
Oxford Radcliffe Hospitals NHS Trust
John Radcliffe Hospital

Function of the colon

- re-absorb salt (sodium)
- re-absorb water
- forms stool
- fermentation
- synthesize vitamins (Vit K)

Post op Guidelines

- improve nutritional status
- light, soft and low fibre
- adequate fluid and salt intake
- regular eating pattern
- re-introduce fibrous foods after 4 wks in small quantities & well chewed
- “restore eating confidence”

What should you eat to maintain a healthy body?

- In most cases - a healthy balanced diet
- CHO (55% - 60%)
- Fat (30%)
- Protein (15%)
- 5 food groups

5 Food Groups

1. Fruit and Vegetables
2. Breads, cereals, rice, pasta and potatoes
3. Meat, fish and alternatives
4. Milk and dairy products
5. Fats and sugars

1. Fruit and Vegetables

- Excellent source of many vitamins, minerals and antioxidants
- Aim for as much variety as possible
- Aim for 5 or more serves every day – determine individual tolerance

1 serve =1medium sized fruit (eg apple, banana, peach, orange)
 =2 small fruit eg satsuma, plums
 =2 tablespoons vegetables
 =1 small glass fruit juice
 = 1 small bowl of salad

Low Fibre

↑ Fresh tinned or stewed:
Apples, cherries, grapes,
melon, banana, plums,
pears, peaches, plums
(avoiding pips skin & pith)
Carrot, beetroot, courgette
lettuce, spinach,
squash, pepper,
swede, broccoli or
cauliflower florets,
skinned cucumber and
tomato, turnip

High fibre

↓ Berry fruits, dried fruit,
unripe bananas, kiwi
fruit, grapefruit,
rhubarb, mango,
oranges
↓ Beans and pulses,
chick peas, split peas
↓ Brussel sprouts, peas,
mushrooms, cabbage,
garlic, green beans,
okra, onions, leeks and
sweetcorn

2. Bread and Cereals

- Starchy foods provide us with energy
- Excellent source of fibre and B vits
- Cheap and easy to prepare
- Base each meal around
- Opt for lower fibre choices if required
 - Eg. Sweet potatoes, pasta, noodles, scones, baguettes, crackers, cous cous, rice krispies, corn flakes,

3. Meat, fish and alternatives

- Protein is essential for growth and repair
- Excellent sources of B vits, iron and zinc
- Try to have lean and low fat versions where possible
- Eg lean meat, poultry, fresh fish, oily fish, eggs, soya products, pulses, nuts, eggs
- 1 – 2 serves day

4. Milk, dairy foods and alternatives

- Most abundant supply of calcium – major “at risk” nutrient
- Also good sources protein and energy
- Low fat versions have the same amount of calcium
- 3 serves day =
 - 1 glass (250ml) milk
 - 1 pot yoghurt
 - 1 matchbox (30g/1 oz) cheese

5. Fats and sugars

- Limit animal fats
- Restrict fats/sugar if excess weight is a problem
- Practice good oral hygiene
- Beware of hidden fats and sugars
- Become a label reader

Fluid Intake

- very important (rehydrate well)
- thirst is not a good indicator of your hydration status (too late)
- high pouch output loses a lot of water, salt and potassium
- aim 8 - 10 of cups of fluid per day

Types of fluid

- Rehydration drinks (sports drinks with added salt, dioralyte, WHO)
- keep tea, coffee and water to < 4 cups/day
- limit fruit juice + sugary drinks
- Encourage water



Special dietary considerations

- calcium intake
- vitamins and minerals
- hydration
- high energy



The Dysfunctional Pouch

- erratic eating habits
- high caffeine intake
- high alcohol intake
- high fibre diet
- high fat intake
- poor fluid intake
- sorbital intake
- irritable bowel syndrome
- food intolerance
- pouchitis
- probiotics



Probiotics

- “good bugs” in the digestive tract
- Gionchetti *et al.*, 2000 showed that 85% of patients with chronic pouchitis remained in remission after taking high dose probiotics
- pouchitis associated with lack of “good bugs” (Lactobacilli + Bifidobacteria)- VSL#3
- yoghurt, Yakult, Actimel, capsules

- Vary in their efficacy
- A small increase in bloating or flatulence when you first start is normal
- Try to take both *Bifidus* and *Lactobacillus* and *with food preferably*
- Trial for several weeks- 3 months

Foods that thicken output

- rice and rice cakes
- pasta and white bread (fresh)
- mashed potato
- apple sauce
- smooth peanut butter
- marshmallows and jelly cubes
- banana (ripe)

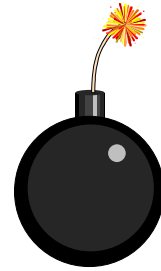
Increase wind and odour

- broccoli, sprouts, cabbage
- onion, garlic, leeks, asparagus
- beans
- spicy foods
- carbonated drinks
- beer
- eggs
- differing individual tolerability



Increase pouch output

- pulses and leafy vegetables
- high fibre fruit and veg
- wholegrain cereals
- nuts and sweetcorn
- alcohol, fruit juice and caffeinated beverages
- chocolate
- fatty foods
- food intolerance



Optimizing Pouch Function 1

- Don't skip meals, eat small meals regularly
- Include foods that thicken output
- Avoid eating and drinking at same time



Optimizing Pouch Function 2

- healthy eating, freshly cooked CHO
- fruit and veg to tolerance
- consistent fluid intake throughout the day
- probiotics / prebiotics
- limit foods that cause irritation e.g. spicy

Optimizing Pouch Function 3

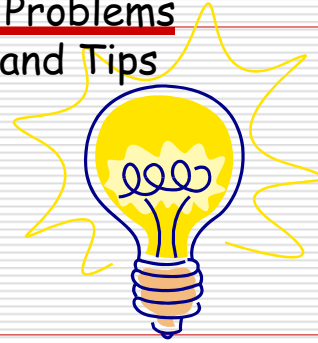
- limit food that increases output
- limit foods that cause gas
- chew food well
- if active overnight aim to finish eating early in evening
- get formal assessment from dietitian - in exceptional cases - exclusion diet

Good nutrition and
healthy eating
make a difference!



Zarah Perry-Woodford
Specialist Nurse - Pouch Care
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Pouch Problems Hints and Tips



A Normal Healthy Pouch

- ☐ Undergoes changes within 6 weeks following closure of the ileostomy
- ☐ 'Normal adaptation' to 'colonic type mucosa' this can take up to two years!

Common Complications or Problems

- | | |
|--|---|
| <input type="checkbox"/> Pouchitis/pre-pouch ileitis | <input type="checkbox"/> Gastrointestinal infection |
| <input type="checkbox"/> Poor bowel function | <input type="checkbox"/> Obstruction |
| <input type="checkbox"/> Fistula formation | <input type="checkbox"/> Dehydration |
| <input type="checkbox"/> Difficulty emptying pouch | <input type="checkbox"/> Diet problems |
| <input type="checkbox"/> Sore perianal skin | <input type="checkbox"/> Wind problems |
| <input type="checkbox"/> Pelvic infection | |

Hints and Tips to Resolve Problems



Pouchitis

- ☐ Inflammation of the bowel mucosa of the internal pouch
- ☐ Occurs in up to 50% of patients and patients may be affected in varying degrees of severity
- ☐ Usually occurs in patients who have had surgery for ulcerative colitis rather than FAP.

Clinical Pattern

Setti-Carraro et al (1994) established 3 categories that patients fall into as early as 3 months following closure of ileostomy.

Clinical Pattern

- ☐ 50% - never develop acute inflammation or episodes of pouchitis.
- ☐ 40% - experience episodes of acute inflammation which settle with treatment or spontaneously. These patients experience pouchitis at varying intervals which are sometimes prolonged episodes.
- ☐ 10% - Chronic pouchitis.

Signs and Symptoms of Pouchitis

- | | |
|--|---|
| <input type="checkbox"/> Sudden onset | <input type="checkbox"/> Fever |
| <input type="checkbox"/> Frequency > 12 times | <input type="checkbox"/> Feeling generally unwell |
| <input type="checkbox"/> Passage of blood | <input type="checkbox"/> Vomiting |
| <input type="checkbox"/> Abdominal pain/cramping | <input type="checkbox"/> Dehydration |
| <input type="checkbox"/> Urgency | |

Diagnosis of Pouchitis

- ☐ Contact pouch nurse or GP
- ☐ Review signs and symptoms
- ☐ Rigid pouchoscopy/endoscopy
- ☐ Flexible pouchoscopy/endoscopy
- ☐ Biopsy/Histology

Note - this is ideal but not realistic
Can be diagnosed based on symptoms and endoscopic appearance of bowel mucosa.

Treatment of Pouchitis

Antibiotics usually a 2 week course

- ☐ **Ciprofloxacin 500mg B.D**
- ☐ **Metronidazole 400mg T.D.S**

Not so common treatments:

- ☐ 5 Aminosalicylates eg. mesalazine, asacol, pentasa
- ☐ Steroids eg. prednisolone

Poor pouch function

- ☐ Frequency > 10/per 24 hours
- ☐ Urgency - inability to defer urge to defaecate
- ☐ Leakage of mucus or stool
- ☐ Incontinence

Possible Causes of Poor Function

- ☐ Gastrointestinal infection
- ☐ Pouchitis
- ☐ Pre-pouch inflammation
- ☐ Pre-pouch obstruction
- ☐ Pelvic infection
- ☐ Pre-pouch stricture
- ☐ Incomplete evacuation due to narrowing or a remnant of rectal type tissue.
- ☐ Weak sphincter muscle
- ☐ Functional inability to evacuate pouch

Investigations

- ☐ Rigid endoscopy
- ☐ Flexible endoscopy and multiple biopsies
- ☐ Pouchogram
- ☐ Evacuating pouchogram
- ☐ Small bowel follow through
- ☐ Anal ultrasound
- ☐ Ano-rectal physiology
- ☐ Pouch compliance

Gastroenteritis

- ☐ Frequency
- ☐ Nausea and vomiting
- ☐ Abdominal discomfort (not acute pain or distension)
- ☐ Dehydration

Causes of Gastroenteritis

- ☐ Ingestion of suspicious food
- ☐ Foreign travel
- ☐ Contact with another person with similar symptoms
- ☐ Diet change
- ☐ Medication change

Investigating gastroenteritis

- ☐ Clinical history
- ☐ Full blood count
- ☐ Stool culture

Early Signs of Dehydration

- ☐ Increased liquid output from pouch
- ☐ Decreased urine output
- ☐ Dark coloured urine
- ☐ Feeling tired or lethargic
- ☐ Dizziness, dry mouth, headache
- ☐ Increased thirst
- ☐ Dark sunken eyes
- ☐ Cramps
- ☐ Low, rapid volume pulse

Rehydration Tips

- ☐ Rehydration drinks- Electrolyte mix, Lucozade sport drinks, bovril or marmite
- ☐ Add salt to meals
- ☐ Take loperimide or codeine before meals
- ☐ Drink water, tea or squash in addition to rehydration drinks
- ☐ Do not eat and drink at the same time
- ☐ Eat starchy, carbohydrates.

Foods and Associated Symptoms

SYMPTOM	FOODS
Increased stool	Fibrous foods, pulses, beans, leafy green veg, raw veg, wholegrain cereal/breads, nuts caffeine, fruit juice, fried foods, chocolate and milk
Decreased stool	Bread, rice, pasta and bananas
Anal irritation	Spicy foods, nuts, seeds, coconut, citrus fruits, raw veg
Wind	Onions, beans, beer, fizzy drinks, cabbage
Odour	Fish, onion, garlic, eggs

Pre-pouch obstruction or stricture

- ☐ Frequency of very liquid stool
- ☐ Reduction or no output from pouch
- ☐ Nausea and vomiting
- ☐ Abdominal pain
- ☐ Abdominal distension

Managing obstruction

- ☐ Drink fluids only until symptoms settle
- ☐ If symptoms become severe see G.P or go to local A&E department
- ☐ May need intravenous fluids
- ☐ Surgery is avoided at all costs

Investigations

- ☐ Small bowel follow through
- ☐ Pouchogram
- ☐ Flexible endoscopy

Stricture of the Ileo-Anal Anastomosis

- ☐ Caused by scarring at the join between the pouch and the anal canal
- ☐ Occurs in 40% of patients who have had a stapled anastomosis
- ☐ Frequency, Urgency, Leakage
- ☐ Feeling of incomplete evacuation

Investigations

- ☐ Digital examination in the outpatient department
- ☐ Confirmed on examination under anaesthetic

Treatment

- ☐ Dilatation of the stricture in the outpatient department or under general anaesthetic
- ☐ Patient may be advised to continue to use a dilator at home for a short period of time or long term

Biofeedback (anal physiology)

May be considered:-

1. Weak sphincter muscles
2. Inability to evacuate pouch

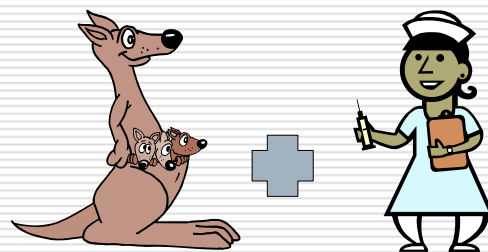
Sore Perianal Skin

- ☐ Keep perianal area clean and dry
- ☐ Have regular baths; use a bidet
- ☐ Use moist wipes and pat dry
- ☐ Avoid rubbing, itching
- ☐ Avoid perfumed soap or talc
- ☐ Wear loose cotton underwear
- ☐ Always apply a barrier cream
- ☐ Consider thickening the bowel with loperimide or codeine

Conclusion

- ☐ It is advised that you get to know your body, know your pouch and know where to get help if you need it.
- ☐ Remember your doctors, GP or pouch nurse are there for support and guidance.
- ☐ Persevere, relax and enjoy the freedom your pouch can bring you!

Still Unsure?



The Perils of Parking Tickets and Spilt Beer

Bill Shepherd battles with parking bureaucracy, but benefits from being prepared.

Some of you may remember that about five or six years ago I was persuaded to write a couple of articles for *Roar!*, by our then pouch nurse Julia Williams and Morag Gaherty on the subjects of Radar keys, parking and the congestion charge and they affect people with varying degrees of incontinence.

So what were the MPs going to do about it? I wrote to 12 MPs, most, but not all, came back through my MP, Peter Lilley. Some of those said that they believed that we could apply for a Blue Badge and that I should go down that line. I had two replies from the then transport minister, Lord Gus McDonald. In one of his letters he told me that there was to be a committee set up to examine the needs of more groups of people to see if they should be added to the list of those entitled to have a Blue Badge and that I would be informed about the results in the very near future.

At around this time NACC branches in a number of cities and a Scottish county had come to an arrangement with their local police. Police and traffic wardens seeing a locally agreed card in the windscreen, unless they could see that you were milking the system, could give a little understanding to the owner's plight. It worked very well in some areas like Cambridge, Huntingdon and I was never challenged in the St. Albans area. Then of course it was spoiled by the government allowing the use of parking attendants, most of whom were not interested in these local agreements and I am told that most of them fell by the wayside.

So, armed with a letter from my doctor, the letters from the MPs, who said they thought I could apply for a Blue Badge, and a very well put together letter from Peter Cartwright of

NACC, who described the rush for a toilet due to "explosive diarrhoea". So with all this invaluable backing I trundled off for my meeting with the council representative responsible for the Blue Badges, only to be treated with "I phoned your wife last night. You are not entitled: you can walk." Yes, I said, but at the times when I need the Radar disabled toilet, I need to get as close as possible to the toilet as then is the time when I really do have trouble walking, without looking a bit like a clown with my knees tied together. I showed her

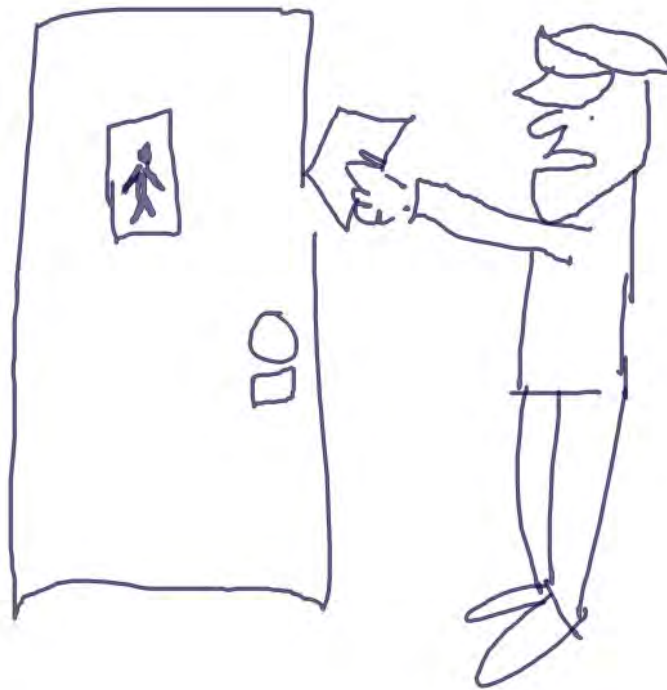
refurbish the disabled toilet which was being used as a paint store. They have done all of this, repainted the walls and even put a Radar lock on the door and a new water heater as well. As I said, they could not have done more for me.

Five years down the line I, as a result of a parking ticket, have been invited to join the list of consultees. I have asked that our vice chair, Mike Dean, could be accepted to represent the Red Lion Group and this has been agreed by the under secretary of state, Karen Buck MP.

Last September I took my wife Sue up to the London Eye. We stopped in West End Lane, West Hampstead, to ask where I could buy a congestion charge ticket. I asked a shopkeeper, who didn't know, and then a ticket attendant, who didn't care: she just shouted at me "Pay and display, pay and display". So I said I'd better go then, and thought no more about it. Sue had tried to speak to her as well, but also had no real response. In October I received a fine for £100 for non-payment of a parking ticket that had never been given, either to Sue or myself. My wife had been

sitting in the car all of the time and would have seen if a ticket had been issued.

I phoned Camden Council, the issuing area. They told me to put anything that I wished to say in a letter. They said the parking attendant has no leeway: they must issue a parking ticket if you are in a parking space. In my letter I asked what if I had asked where the nearest disabled toilet was? Like most of us from time to time I need to know the answer to that question in a bit of a hurry. Their answer to that was you would have to take it up with the Parking Ticket Adjudicator and see what



I'm giving you a ticket Mr Shepherd. You've been parked on that loo too long

the letter from the minister, but even that made no difference. "Try again when the law is changed", she said, "goodbye".

My company, Walkers Crisps, where I am a lorry driver, could not have been more helpful. The initial "You should take early retirement", was later withdrawn and replaced with the comment "I've never seen you looking so well, what can we do to help you?" During the last five years I've worked night shifts to keep me out of heavy traffic and more recently worked at the London depot where my managers have persuaded our landlords to

they say. At this point they reduced the fine to £50 for 14 days agreeing that the ticket may not have been served properly, but should I appeal and lose, the fine would go back to £100. They also sent me a copy of the 'notice history report', which told me that all of this was for just **one minute**.

"While I appreciate that it was not your intention to park in contravention of the parking regulations, there is no grace period for motorists in a pay and display bay during controlled hours" – Camden Council

Upon receiving the second letter from Camden I wrote to my MP Peter Lilley to see if he had come upon this before, as when I looked it up on the Internet it said most places give five minutes, except Westminster which will only allow three. In one of the letters I received it said that the government is to try to equal out all of the rules so that the public will know where it stands.

"Please note that if the adjudicator believes that you have behaved in a vexatious, frivolous (for asking where a toilet is) or wholly unreasonable manner, they can award costs." – Camden Council.

Peter Lilley also wrote to the then Transport for London Commissioner, Bob Kiley who replied (you'll like this) that there are almost 100 stations that have toilets; unfortunately, many of these toilets are not in use. Why tell us, especially as he also says that it could be seven years before they can be brought back into service? Does 2012 ring any bells? My wife says that this comment was recently used on the television. In truth it is some time since I used the underground. I do have a certain fear of being trapped, getting off a train in a hurry, only to find that this is one of the stations that does not have a toilet, only to see the train heading for the next station that may have. I also carry a quite large holdall that hold a complete change of lower half clothes as well as a number of pads. I do understand the need to have security, but I don't want to be stopped and asked all of the questions "Where are you going?" "What's in your bag?" "Will you please empty your bag?", like my niece was a few weeks back, three times in one day (although that was apparently because she was travelling on her own to the States...).

When I spoke to the members, at Morag's suggestion, a few years ago, I

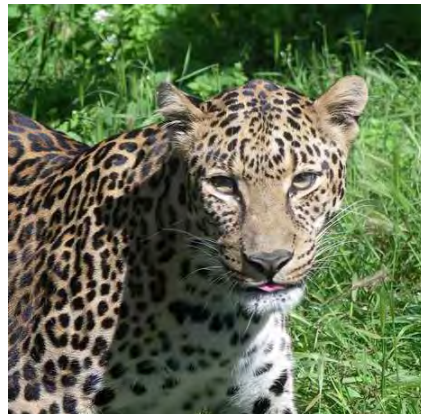
asked if you would like me to follow up anything I had written in the earlier article. A number of you came to speak to me, and I was surprised how many of you felt the same fears that I did. Being trapped in the tube was by far the most feared. Someone told me that they were embarrassed by loosing control on a bus and the Mickey being taken out of them; even the driver made a big thing of the bus having to be taken out of service as it was "due to you, this bus is unhygienic". He probably wanted an early night anyway. Someone else had a

long walk home one night because they had an accident while suffering during a bout of pouchitis and couldn't call a taxi because they knew that they smelt so bad that they would not be allowed in the cab if it came.

It did have its good side at a celebration depot dinner one night when I had a full pint knocked over straight into my lap. It really was a total accident, but I'd be willing to bet that I was the only one that had a complete pair of trousers and underwear with me, both in my holdall and in my car.

Big Cats

In August I am looking forward to a visit, once again, of the Santiago Rare Leopard Project, a private collection of big cats at Welwyn. It is owned by a gentleman who is in the rare breeds project, helping to conserve the world's most rare and endangered leopards.



As the project is licensed to open to specialist groups only for a limited number of days each year, I am privileged to be able to attend through the Wildlife Art Society. Although I go on the 'painting' days, I rarely do very much sketching and usually end up taking photographs instead because the opportunities there are so good.

Although they haven't an African lion – being a rare *leopard* project – they do have a mountain lion called Tamar, who came to them from a closed down zoo in Devon. Tamar purrs like a kitten and loves having her ears stroked but only by those who really know her well, i.e. the owners and a very well known wildlife artist who is a great supporter of the project. I wait until she is well away from me before I would even dare poke my camera through the little peephole

especially made for the purpose! It is difficult to take in how quickly these cats can move – every bit as fast as your domestic puss. But their teeth are much longer!

A lovely lunch is laid on for us on our days at the Santiago, with a variety of delicious salads and naughty sweets, which I can tackle without difficulty – not just the sweets but the salad as well! At the moment I am busy trying to lose weight but I also lose willpower at the same time!

It is wonderful to be able to enjoy these experiences and to feel well. I am ever grateful to everyone involved in my surgery, which has made it all possible.

I will probably have some more photos of the Santiago animals when I go again in August. I was given kind permission by them to reproduce them here.

If anyone would like to know more about the Santiago, you will find more pictures and information on the website: www.pantherclub.co.uk/Georges/santiago/santiago.htm.

Christine Lawton



Red Lion Group Annual Reports

Chair

This year has been so full of incident that it's difficult to know where to start my chairman's report. Everything that could have possibly happened to a small but perfectly informed charity seems to have taken place in the last 12 months – apart from outright civil war or the consecutive resignations of the chairman, vice-chairman and secretary.

Anyway let's keep it simple and start with a few tributes. As most of you probably know by now, our former chairman and committee member Brian Gaherty died suddenly in the summer. Our sympathies go out to his wife Morag who like Brian has been a stalwart member of the committee since day one. Brian who with Morag and a few others was a founder-member of the group was one of the nicest and gentlest people you could ever meet.

I will always remember his humour and the cartoons he drew for *Roar!*. One of them showed a pouchee about to be examined with the caption 'The Endoscopy is Nigh'. It's witty, it's timeless and it's typically Brian. I'm sure you will all join me in wishing Morag Gaherty – who has gamely decided to stay on the committee – and their two young boys all the very best for the future.

As most of you may remember I called 2004 The Year of the Lioness. Well, just to be completely different, I'm calling this year The Year of the Lioness Mark II. It's not that I'm prejudiced against my fellow lions. Far from it. It's just that many of this year's main events have involved women. First of all Jo Wagland, St Mark's pouch support specialist, left for a similar post at University of Southampton Hospital at the end of 2005. Jo was a co-opted member of the committee and a key organiser of several Information Days and we'll all remember her kindness and bright personality. We wish Jo, her partner and their baby daughter a very happy future on the south coast.

The second all-women's event occurred when Marion Silvey said she would have to give up her post as membership secretary for personal and health reasons. Many of you may have spoken to or emailed her – even if it was about a forgotten subscription – and

we'll all miss her helpful manner and quiet efficiency. When I mentioned this to Inez Malek, a former secretary of the group, she said she might be interested so long as the post didn't need a degree in physics. I assured her that it didn't and she volunteered to take on the role. A very big thankyou Inez – and welcome home. As most of you know by now, Jo's replacement is Zarah Perry-Woodford. It didn't take long for Zarah to get into her stride so to speak – for last month she and Sarah Varma from St Mark's stoma care department ran in the Milton Keynes Half-Marathon. They not only finished but raised valuable funds for the group. Both of them have been helping to organise today's event so our warmest thanks and congratulations.

Sorry if this sounds a little like an Oscar winner's speech, but I'd like to add another word of praise for Julia Williams, a former St Mark's pouch specialist and one of the founders of the Red Lion group. She returned to St Mark's last year as lecturer and programme leader at the Burdett Institute and has been a real boon to us – using her organisational skills to find speakers and help set up today's event.

But to leave our Lioness theme for just one moment, I'd also like to thank a very energetic and hard-working male lion. Much of the preparation for today's event is down to the vice-chair and former chairman Mike Dean. He and his wife Margaret, our honorary secretary not only put together all our smartly-produced Info Day packs, sourced speakers and did much of the liaison for today's event, but also sent out all the subscription reminders and the various editions of *Roar!* – something they have been doing for the past three years.

Another large 'thank-you' note to the rest of the committee for combining their various note-taking, editing, information-providing, book-keeping and membership liaison skills with such aplomb during the year.

Three more items. Please keep the letters and articles coming for *Roar!*. It's your magazine and the more feedback Tim and I get the better it will be. Second, we are updating the website. It's looking a little dated at the moment so we've appointed an IT man at no

cost to ourselves to give it a fresher, more up-to-date look. We'd welcome your ideas on this too.

We've also been extending our stoma care and pouch department network throughout the UK. We are now in touch with 50 hospitals. The next target is Wales. I don't know which part of Wales, but Mike Dean certainly knows as he is helping to coordinate this useful campaign with representatives from Dansac and Osteomart.

So let's look forward to another year of successful fund-raising and above all support for fellow pouchees, their partners, relatives and friends. For that's what Red Lion is all about – helping each other over difficult and sometimes critical stages of our lives.

Thank you all very much for spending a sunny Saturday at St Mark's – and you never know we may even be able to call 2006-2007 the Year of the Lion for a change.

Christopher Browne

Membership Secretary

Membership of the group remains around the 320-mark which is very encouraging news. Part of the reason is the very high turnout at last year's Information Day. Whenever this happens it seems to have a spin-off effect on membership. This year's subscription renewals were only £100 down on last year.

The other membership news has been the recent handover of the secretary's role from Marion Silvey to Inez Malik. Inez, who as some of you may remember was Red Lion secretary for several years, plunged straight into her new job by contacting all the Red Lion reps (some of you are here today) to find out how the local groups were faring and to note any changes of address or phone number.

It goes without saying that we are very grateful for the efficient way Marion did the job. It certainly helps to make Inez's role that little bit easier. Although most new inquiries about the group are handled by Mike Dean and Zarah Perry-Woodford, Inez will run the database and handle all membership and subscription matters.

Inez Malek and Christopher Browne

Information Day Report

How often do we hear the phrase ‘too much information’? Two, three, four times a week perhaps. How easy it is to get carried away by a story that means just a little bit more to us than it does to everyone else. The result? A few tell-tale groans from our audience.

The one time we can comfortably get away with it – aptly enough – is Information Day. We can happily shed our inhibitions and talk about our problems knowing that the more we share the more widely we are appreciated. Perhaps we should rename the event ‘Too Much Information Day’.

Roll up to St Mark’s! Unburden your inner fears! Mention the unmentionable! You get the drift I think.

For talking about our timeless tummies is like switching on a handy stress buster – something we are rarely able to do with friends and neighbours as Stephanie Zinser so succinctly puts it in her book ‘The Good Gut Guide’*.

One speaker who never gives us too much information is Professor John Nicholls. Every year the Red Lion president passes on the latest news and data on pouches and bowel research. A quick scan of your responses to this year’s ID on 8 April shows we simply can’t get enough of the Prof’s gastric gems.

Almost a third of the 80 Red Lions who came to St Mark’s Hospital, Harrow, said they left wanting a lot more from Prof Nicholls. One said he wished he could have spoken for an hour instead of his customary 40 minutes. Another said: “Professor Nicholls should be given considerably more time for questions and answers – given his standing and expertise in the whole spectrum of bowel disease.” While a third added: “There is so much valuable data in Professor Nicholls’s talk but not enough opportunity to cover it all!”.

A blatant case of too little information then. Although Tim the editor and I would love to print the Prof’s talk in the current *Roar!*, it is in Powerpoint and thus not really newsletter-friendly. However the committee plans to give our president a greater hearing at next year’s Information Day.

You can read all about two of the other talks in this, the Information Day edition, of *Roar!*. The first ‘Dieting and pouches’ was about the Do’s and Dont’s of Food and Drink – two key topics for

pouchees. The speaker June Beharry, a dietitian from Oxford’s John Radcliffe Hospital, bravely stood in at very short notice for another speaker who pulled out at the last minute. So a very big thankyou to June.

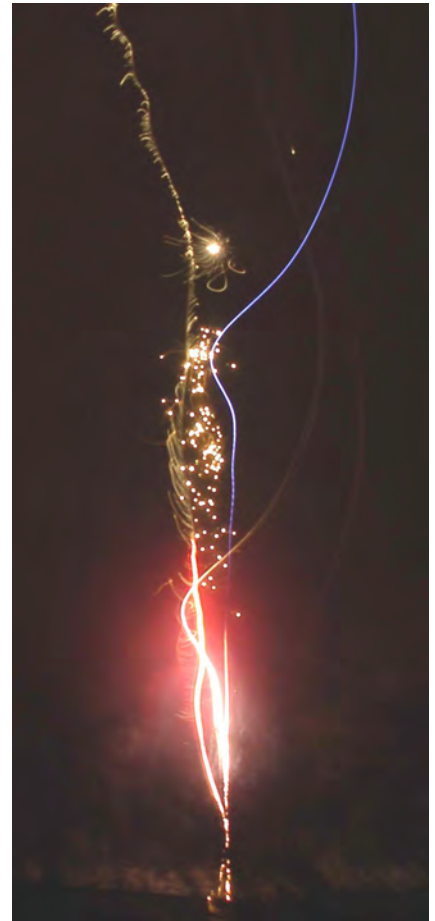
The second ‘An overview of pouch surgery’ was given by Zarah Perry-Woodford, St Mark’s Hospital’s pouch care specialist. What a lively, upbeat talk it was too. Not bad for someone who was suffering from a sore throat and had never given a public speech before!

Our warmest thanks to all the other speakers and workshop leaders – Ann Brownbill who spoke about personal well-being, Julia Williams, Kay Neale, Trish Evans, Mike Dean and Chris Lawton. Not forgetting of course the ‘A’ Team who set it all up – Mike and Margaret Dean, Julia, Zarah and the St Mark’s stomacare team.

We’ll call next year’s Information Day the Nicholls Special. After all you can’t have too much of a good thing.

*The Good Gut Guide by Stephanie Zinser (Thorsons) costs £10.99

Christopher Browne



Please support the Red Lion Group

Registered Charity number 1068124



All donations, however small, towards expanding the work of the group will be gratefully received. If you would like to send a donation please make your cheque payable to The Red Lion Group. And send it to: **The Red Lion Group Treasurer, Mrs Marjorie Watts, 11 Meadow Way, Upminster, Essex, RM14 3AA**

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Join the Red Lion Group

- Newsletter three times yearly with all the latest news, views and events
- Membership is £10 (£5 for hardship cases, and free for under 16s) per annum
- Write to Liaison Officer at the address above for a membership form

Write for Roar!

Have you had any interesting or amusing experiences that you think other people with pouches might want to read about in the Red Lion Group's newsletter *Roar*!?

We are particularly looking for pouch-related articles, but we are happy to publish practically anything.

Perhaps you've taken up a new hobby since having your pouch

operation? Or are there any clever little tricks or diet tips you've picked up that you'd like to share? We'd even be willing to publish an article about why having a pouch was a bad idea.

Even if you've never been published before please send us something.

You'll get the satisfaction of seeing your name in print and you may give hundreds of

fellow pouch people an insight into an aspect of their condition they hadn't noticed before. Most important of all you'll make the life of the newsletter editor a little bit easier.

If writing articles isn't your scene we are looking for other things too, including cartoons, crosswords and jokes.

With your contribution we can keep the newsletter bursting with life and make reading about pouch issues fun and stimulating.

Tim and Chris

