ISSUE 45 • SPRING 2012

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 David Skinner on 01708 455194 or by e-mail at liaison@redliongroup.org.



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Please support the Red Lion Group



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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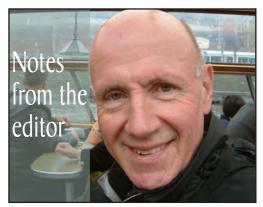
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Page 6 – Running by John Nyberg from Denmark
Page 10 – Buckingham Palace by Christine Lawton (Red Lion Group)

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Back cover: Trooping the Colour by Christine Lawton

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The London Olympics is one thing, but you can read about two other frenetic feats in this sporty, spring issue of *Roar!*. The Red Lion Group version of the London Olympics, perhaps, except one event was in Berlin and the other in Cumbria!

You can also read the moving story of pouch owner Roz Prescott, daughter-in-law of the former deputy prime

minister, John Prescott, and how she juggled the birth of her first baby with a prolonged outbreak of uc. Her account has appeared in several national newspapers, which all helps to give greater recognition to the hidden, and as we all know, often over-secretive world of the colon.

Roz, who is a BBC TV producer, is leading a campaign to raise more funds for colon research and to encourage sufferers to add their names to a National Register and give them access to the best and latest sources of research and help.

If you'd like to meet Roz and hear

all about how she's been coping with life as a pouchee, she'll be our guest speaker at Information Day at St Mark's Hospital, Harrow, on Saturday, 12 May.

Information Day – a date to remember

Information Day promises to be a great day in many other ways too.

First of all, we've decided to change the format to make it

livelier, more sociable and interactive (see the recent Information Day and membership renewal letter from vice chairman Andrew Millis).

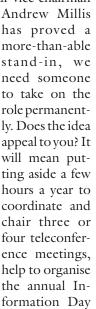
We'll be starting off with a midday buffet to get us all in the mood for an afternoon of pithy anecdote, personal experiences and the latest news about pouches. It'll give us a chance to mingle and meet up with many new and notso-new members of the group. Mark's consultant colorectal surgeon, Sue Clark, will give us a rundown of the latest events in pouchdom.

Then there's the interactive part. We've included a slots for a questionand-answer session for us to pose questions and hear it from the experts, followed by three workshops for male and female pouch-owners and partners to talk about some of the more intimate moments that happen to us at one time or another.

Then to end the day on a high note, we've arranged a trip to a local Pizza Express where we can swap names and addresses, favourite bands or make plans to meet up later in the year.

Would you like to chair the Red Lion Group?

As some of you may know, our chairman Morag Gaherty had to step down last year for medical and personal reasons. Although our vice chairman





There's a fascinating line-up of speakers too. We'll hear about keyhole surgery and how it works from St Mark's laparoscopy surgeon Janindra Warusavitarne. The prize-winning gastroenterologist Dr Ailsa Hart will talk about the alternatives to pouch surgery, while Red Lion president and St and act as point-of-contact for the rest of the committee – who are all very friendly and helpful I may add!

If the idea appeals to you, please fill in a nomination form at the AGM on Information Day.

Meanwhile I look forward to seeing you on 12 May.



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Millis's city breaks

Marathons are a mere excuse for some European sightseeing, says RLG vice chair Andrew Millis.

Before you think this is just another article written by a pouch owner lucky enough to run a marathon and showing off about it, there are three items of interest I should like to share with you. First the event was only made possible by Ciprofloxacin, the antibiotic used to help combat pouchitis, as I will explain later on. Second the article contains a warning about going to sports injury clinics. Finally there is a good aesthetic reason why you should make Berlin your next destination for a weekend (or longer) city break.

Attracted by the prestige of the Berlin marathon, I had booked to do it in 2010, but had had an injury to my left foot (this also showed up as pain in my right knee as my right leg tried



Our very own action man, Andrew Millis

to compensate). As this was only five weeks before the event, I wasted no time in going to a sports injury clinic. There, a well qualified podiatrist (foot specialist) diagnosed a collapsed bone/ tendon which forms the arch of the foot, and that I needed orthotics (specially designed plates inside my shoe to correct my foot and posture) not only immediately but for the marathon too. The specialist said they normally take three months to adapt to; but as I only had five weeks, she designed a programme of running with these orthotics in my running shoes. So far so good-except I had been relieved of £380 for this pleasure.

Off I went on the long training runs necessary be-

fore a marathon, but soon found the orthotics gave me blisters like I've never seen before. They were giants and very sore! I have never had even a mark from my running shoes before, so to be in different pain thanks to these orthotics was no joke. So I took them back. While the clinic sent them back

> to the manufacturer, I carried on running without them. I had got used to them, and without them my back must have adjusted in some way. The day after a run without them, I could barely move. After every so many feet of walking it was as if someone had put a knife into my back. Putting on socks took half an hour! So, off I went to the doctor who gave me an anti-inflammatory which did the trick, but only by the day of the marathon. I didn't stand a chance, of course, and although I started, I dropped out after 20 miles unable to walk - let alone run.

Fast forward to September 2011. Again I lined up at the start of the Berlin marathon. This time I had done my training, without the orthotics, which have since been binned. The only thing that had gone wrong was a flare-up of pouchitis, which rendered me weak and losing weight fast. I lost almost a stone - weight I could ill afford to lose. I obtained two weeks of Ciprofloxacin from my doctor, which fixed the problem in 24 hours, and helped me to gain weight. I took it right up until the day of the marathon. And of course the pouchitis started to come back soon afterwards, but I didn't care then - I had done the marathon and finished it (3 hours 18 minutes 40 seconds, in case you wondered).

And now for the fun bit. Berlin is a fantastic place. It is cheap (my four



nights in a spotlessly clean three-star hotel in central Berlin-just a walk from the start of the race - and my British Airways flights from Heathrow cost £420 all-in) and moving around the capital on the excellent buses, trains and trams cost $\pounds 6$ a day for unlimited travel. Nowhere else has as much history from the 20th century as Berlin, and it is all accessible. Remnants of the famous Wall exist, as well as open-air museums of the rise of Nazi party propaganda. Famous monuments have been rebuilt, and stunning architecture which wasn't destroyed in the two world wars has been restored. Loads of older history too - nearby Potsdam boasts the beautiful Sanscouci palace built by Frederick the Great, in a magnificant park. You can see the whole city from the 205-metre high tower in Alexanderplatz, built by the Communists during the cold war to spy on the west, and shop in the modern shopping centres.

Even if you are not interested in the marathon, it's a great place.



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LETTERS

How to avoid the football effect

I was looking back to the problems of wearing a stoma at night recently. Because it is on the right-hand side of the body looking down, you had to lie on your right side. If you lay on your left, the bag sort of hung awkwardly, with the big risk of it pulling off as it gotheavier. And if you lay on your back, the waste from the stoma just puddles around the join between the bag and

your skin and causes irritation. And as for lying on your stomach – forget it! Some nights, some waste gets onto the filter and clogs it. Wind then can't escape, and blows up the bag like a football. While you sleep, the adhesive gives way and you wake up realising you have leaked during the night, and you need to change the sheets. Lovely!

Of course the pouch solves all of these problems, but does it? How many people don't always wake up when they need the lavatory? How many people with pouches subconsciously think they can harmlessly release wind while they sleep without remembering they have a pouch and there is likely to be a little leakage with it? How many people wake up in the middle of the night and feel no sensation at all - only to go back to sleep and find in the morning it

had been a signal or wake-up call to go to the toilet, albeit of short duration. Only for the brain to say to the pouch "we've woken him up but he hasn't gone to the toilet, so the consequences are his look out". Not many partners are happy with this.

So you then put pads into underwear to absorb anything unwelcome, or just as an insurance policy. But they are not cheap, and you can't get them on prescription. Although the pads are readily available at pharmacies or online, you can only buy them in very large quantities such as batches of 50 and while some hospitals will hand out a few, you can't expect to get them automatically. You may also find the pads don't offer sufficient protection, and you need some other bed protection to be on the safe side?

Are any readers familiar with any of this? And how many pouch-holders sleep through those signals to go to the lavatory at night?

I would be very pleased to hear from anyone who has had similar experiences. Please send your replies via a "Letter to the Editor".

Name and address supplied



PSC and pouchitis

I have a pouch and primary schlerosing cholangitis – commonly known as PSC – which is a liver disease linked to ulcerative colitis. I was told that I had a higher chance of suffering from pouchitis when I had my pouch, and just a few months after I started using it, I had lots of problems which were diagnosed as pouchitis.

I have been on rotating antibiotics for just over a year now to treat it and will need to do so for the foreseeable future. I would be very keen to hear other people's experiences with pouchitis and if anyone else has PSC.

> Sophie Robinson Forest Hill, London

Can anyone help?

Dear Editor

I have had ups and down with my pouch since day one in 1989 but did manage a more normal life than before with ulcerative colitis.

Over the past 10 years things have been getting a lot worse, with bad outbreaks of cuts around the bottom and not being able to eat as much as before. Also I have problems with arthritis caused by the many injections into my joints to help with my ulcera-

tive colitis.

Can anyone let me know if any Red Lion Group member with a pouch has had to have a hysterectomy?

Just to fill you in, since last September my iron results kept getting lower and lower and I had pain again in the legs, which was a lot worse at night time. The last time I had this, my serum iron (the iron that goes around your body) was low. Also the skin around my back passage has been getting worse.

I know I have a wound there which will never heal properly but my skin is starting to break down more and more, making it very uncomfortable to sit again and walk far, and also very very painful when going to the loo.

I was put on antibiotics, which I had a reaction to – pain in the joints and my legs, with shin splints.

I was also told to in-

crease the number of anti-acid tablets I take to two in the morning instead of one. This might help the output to be less acidic and so burn my bum. I was also put on Imodium syrup to try and make the output a little bit more formed, so that I would not have to go to the loo quite so much. None of these measures has worked.

Then, would you believe, I was on the loo one Sunday night and I felt as though my insides were dropping out. Yes, I suffered a prolapse.

After seeing my surgeon, who referred me to a gynaecologist, the outcome is that I have got to have a hysterectomy of some kind.

Nothing is ever easy with me be-

cause of my internal pouch. My two doctors have decided they need to operate together, and will try to get the same anaesthetist that I normally have (well the one that did the nine operations I had between 2010 and 2011). I had two anal fistulas.

They have both spoken to different colleagues to try and find out if anyone they know has done surgery with someone with a pouch. So far no one has.

Until they get me under, they do not know what they will find. It is not

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known what has attached itself to other parts of my gut. They have to do a big cut down my tummy again so they can have a good look.

They may have to take out ovaries or the whole lot. The problem is that they have to give me a permanent ileostomy. To do this they need to disconnect my pouch so that they have enough to bring out to make the ileostomy (I do not have much of the small intestine left, this is what the pouch was made of). It may mean that they have to take out the pouch altogether; this would be major surgery and that is why it is taking time to sort out just who they need in the theatre.

The timing of the operation may be delayed because some of them have got holidays booked, lucky things, but at least they will be refreshed.

I'm not looking forward to this at all. I shall be glad when it's all over. If you can help please let me know.

Many thanks.

Name and e-mail address supplied

Marathon woman

Fundraiser extraordinaire Jane Dalzell ran the recent Great North Run and raised £511 for the Red Lion Group. Not only that but the Cumbria-based runner is going to do it all over again with a superfit friend at the 2012 event. Not bad for a 67-year-old!

Do you like to keep fit and if so what's your favourite activity – a bracing weekend walk, regular visits to the local pool, perhaps, weekly aerobics classes or an exercise video in the comfort of your own home?

Ask Cumbria-based Jane Dalzell how she likes to keep active and

she'll reply going for runs. Though we're not just talking about any sort of run here. but the world's largest and most famous halfmarathon, the Great North Run.

A n d that's not all. Jane hastrained for and competed to have a pouch operation at St Mark's Hospital in May.

An extraordinary family indeed! For Lisa, who lives in Ewell, Surrey and has two ileostomy bags, is the mother of six children. "Lisa's been absolutely brilliant. She doesn't let her illness interfere with her life at Championships in Dublin.

However to go back to Jane for a moment. He pre-race plans were slightly marred by a knee injury. "I couldn't do too much training because of a problem with my knee and I had to be satisfied with running from one telegraph pole to the next as part of my



final preparation for the event. But the atmosphere of the race was absolutely brilliant. Everyone in the crowd seemed to be cheering me on which helped to make it all very uplifting and the whole day even more worthwhile," she said.

Jane plans to run for us again with her

in four of them, the last time in September 2011 when she joined 54,000 other entrants at the start of the Newcastle-upon-Tyne event – at the age of 67!

Just to add a little lustre to Jane's achievement, the intrepid sexagenarian raised £511 for the Red Lion Group – her niece Lisa Green, who has Crohn's Disease, is an RLG member and is due

all. She just gets on with bringing up her large family and never sits back and moans about her difficulties. It's her example that made me enter the race and raise money for the Red Lion Group," said Jane.

One of 40-year-old Lisa's other passions is Irish dancing and she is about to compete with one of her daughters in the World Irish Dancing friend Jan Miller, a coeliac's disease sufferer, in this year's Great North Run.

A dynamic duo indeed! You can sponsor Jane and Jan who'll be running on 16 September by visiting www.justgiving.com/Jane-Dalzell0

Congratulations Jane! We very much appreciate your efforts and your very kind donation to the group.

Christopher Brown

John Prescott reveals his bedside manner

When Roz Prescott lay seriously ill in hospital, it took a hug and a few words of comfort from her father-inlaw to help her make a crucial decision.

Just weeks after giving birth to a baby daughter, Roz Prescott, daughterin-law of the former deputy prime minister, told hospital doctors she wanted to die.

Roz had been suffering from ulcerative colitis for two years and her symptoms had got so bad that she couldn't eat, had to go to the loo up to 20 times a day and was in pain most of the time.

So just after her husband, David, took her to London's St Thomas's Hospital for the second time, Roz begged her doctors and nurses: "Leave me alone. I just want to die."

"Even though I had my new baby, Ava Grace, I was so mentally and physically worn out I couldn't face any more pain," the 33-year-old TV producer told the *Daily Mirror*.

Her next visitor was her father-inlaw, the former Labour deputy prime minister, John Prescott. "He saw from my face what had happened and gave me a huge hug. I just let it all out. And John held on to me until I had sobbed it all out. He said: 'We're all here for you lass and we'll look after you. Your little girl will be here waiting when you're better," she said.

After an ileostomy operation, Roz found it difficult to adapt to her new bag. However, she later had a pouch operation and her situation improved.

Roz has been campaigning to

set up a national register for uc and familial adenomatous polyposis (FAP) sufferers and recently visited George Osborne, Chancellor of the Exchequer, to appeal for more funding for research into IBD-related diseases.

"IBD is not rare – one in 400 people suffer from it in the UK – so why aren't we talking about it. We need to stop being shy about it because it could happen to anyone," she says.

Roz will be guest speaker at Information Day on Saturday, 12 May, this year.

• Rozand the Prescott family are Crohn's and Colitis UK ambassadors.



Just look what you can find at your local Tesco – not!

Red Lion Group Liaison Officer David Skinner discovers a novel way of avoiding an accident.

I went to bed with good intentions. On one of the nocturnal occasions I needed the loo I would go downstairs and take my bog in a bag into the garden and, well, garden test it I suppose is the phrase.



I awoke again at 4.10 am, for my second loo visit and once again I planned to conduct my long-awaited experiment in the garden...hoping it wasn't a full moon, as I might find explaining this activity to my neighbours a tad difficult.

Peering through the kitchen window onto my verdant lawn I couldn't understand why it was well, not verdant ...good grief that looks like snow, the outdoor thermometer showed -3°. Unashamedly, I hurriedly picked up my bog in a bag, tightened my dressing gown and scurried upstairs to my centrally heated bathroom.

So how does the bog in a bag work? First it is very light to carry and it can also be easily slung across the back if you want to take it with you on a long walk.

It is simple to set up and very stable. All you do is unfold it – you can easily do this blindfolded although that is not compulsory (but might add to the overall experience) – and then remove its central cover which doubles as the seat.

The second step is to place the disposable bag which collects the waste over the seat, pushing the bag down into the hole that remains by taking off the seat cover.

There is no third step. It is now ready to use – it is that simple.

I found it quite comfortable to sit on, 10 even 15 minutes wasn't a problem; perusing several pages of *The Independent*, even if it was about a quarter to five in the morning. I would say that for those with a fuller bottom it might be on the small side, but remember the bog in a bag is not there to replace the toilet in your bathroom, it is there for when there is no other toilet. I also found the gap between my bottom and the bottom of the bag on the shallow side but will not make the same mistake twice! A small hand sanitiser which you can buy from Boots would come in be very useful.

This is an excellent piece of kit for us pouchees and I commend it to the House...I really must stop watching the Parliament Channel!

If it was a choice between a 400yard round trip to a toilet block in pitch black darkness with rain and wind cheering you up to boot, I would choose the bog in a bag every time.

I am not to sure I have the bravado to use it on the eastbound District Line platform at Tower Hill Tube Station though...or even if it would be legal. Perhaps someone can let me know how they get on!

The B-in-a-B costs £19.95 plus VAT and you can find a stockist on http://www.boginabag.co.uk/buy-boginabag-products.aspx



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Another innovative product from

Fiona finds the feel good factor

Intimacy was the missing link that persuaded Red Lion Group member Fiona Winning to swap the bag on her belly for a pouch.

What are the chances of two women of similar age who work in the art department of a prison having an ileostomy? About one in several thousand I would guess.

Well that's what happened to me and I only found out about our shared experience during a chance conversation. My colleague, who I shall refer to as Mary, told me she had a six-month-old loop ileostomy while she was being treated for bowel cancer. I, on the other hand, had been an ileostomist for 13 years after a long spell of ulcerative colitis.

A few weeks later we had another chat, this time in the intimacy of the art department's store cupboard! This time Mary asked me why I hadn't had my ileostomy reversed to a pouch.

I said I had been put off by some of the reports I had read about pouches and was concerned about possible incontinence. Money was another facpsychologically I didn't feel accepting or comfortable enough in myself to risk being rejected – because of the bag on my belly.

After telling Mary my story and shedding a few tears, I made a mental shift from "no, never" to "maybe I can".

A few months passed before I did anything. For change can be scary and many of us tend to avoid it if at all humanly possible. But then I had done the groundwork and knew about Denial and the Change Equation. Even though like many practitioners sick pay situation and, finally, Googled St Mark's Hospital for its postal address. Then in November, 2009, I put pen to paper. Dear Robin Kennedy, I wrote, remember me from your time at Yeovil...

I was sent an appointment on Christmas Eve to discuss the operations and ask questions. Farah came with me, bless her. By this time I had made up my mind to go ahead with the surgery. I met Miss Sue Clark [St Mark's consultant colorectal surgeon] the following month for a further discussion and to confirm whether I wanted to go



ahead. It sounds a funny thing to say but I was aware that there was a degree of blind faith that everything would be OK. It seemed

It seemed a long wait for a date, but it gave me time to get fit before the operation, my boxercise sparring partner being an HM Prisons gym instructor. Thanks Steve!

The ileoanal pouch was made in Sep-

Finishing touches: Fiona Winning in her studio

tor with the prospects of two operations with convalescence periods, no partner to rely on and no savings. What chance was there?! Finally, I didn't relish going back into hospital after the difficult recovery period I'd faced when I had my ileostomy operation.

I was a healthy, fit and resolute ileostomist. I was also a single parent, able to work as a counsellor, trainer and, for the past five years, teacher in a prison environment. I was able to pursue my own art practice, eat most of what I liked, swim, go to the gym, socialise and travel.

But then I made what felt like a confession. Something that had eluded me all this time was an intimate relationship. Deep down and I can dish it out, I am not so good at heeding my own advice.

Then things started to happen – as if sub-consciously prodding me. The skin around my stoma began to itch and I had a few flange leaks. Then when I went on holiday to Gozo with my daughter Farah and sister and watched as they languished in the sun in their bikinis, it dawned on me how fed up I was feeling with the bag on my belly. I realised I wanted to be rid of this plastic attachment. In short, I wanted my belly back!

I did some research on the internet, looked at medical procedures, read various testimonies, changed my mind several times, talked to my daughter, got information about my tember, 2010 and taken down in July, 2011, so it's still early days yet. On a good day, and there are more of them than bad ones, I believe I made a good choice. It's now a case of managing my pouch and making the most of my new life. I am a person who doesn't do things by halves, so I quit my job in May and was then given 10 months to move from my accommodation. Bring it on, I say...

My final verdict: I was pleased that I was able to make my own choices about all this. However I believe there are people happily living in loving relationships who manage the medical and visual circumstances connected with ileostomies. I have huge respect for them.



Contact the Red Lion Group

CHAIR

We are looking for a new Chair. Does the idea appeal to you? The job requires a few hours a year to coordinate and chair three or four teleconference meetings, help to organise the annual Information Day and act as point-ofcontact for the rest of the committee. See page 3 for more details.

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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

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www.redliongroup.org



Ideas, Ideas, Ideas and More Ideas Yes Tim Rogers and I thrive on them for it's ideas that make Roar! the readable package we like it to be.

Whether it's something that happened to you on the way to work, an interesting holiday or personal experience, an insight into your life with a pouch or a lively letter, please don't hesitate to send it in.

But then if writing articles isn't exactly your favourite pastime, we are always looking for cartoons, jokes, crosswords and competition ideas too.

That way we can keep your news-

letter bursting with life and information and make reading about pouch issues fun and stimulating.

Please send your articles, letters and ideas to:

> **Christopher Browne** Roar! 89 Fulwell Park Avenue Twickenham TW2 5HG

or roar@redliongroup.org

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