

# ROAR!

An aerial photograph of a massive marathon crowd filling the Champs-Élysées in Paris. The Arc de Triomphe is visible in the distance at the top of the frame. The crowd is dense and colorful, stretching down the wide, tree-lined avenue. Various sponsor banners like 'RMC', 'MULTEX', 'asics', and 'GDF SUEZ' are visible above the runners.

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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 Mike Dean on 01702 552500 or [liaison@redlion-group.org](mailto:liaison@redlion-group.org).



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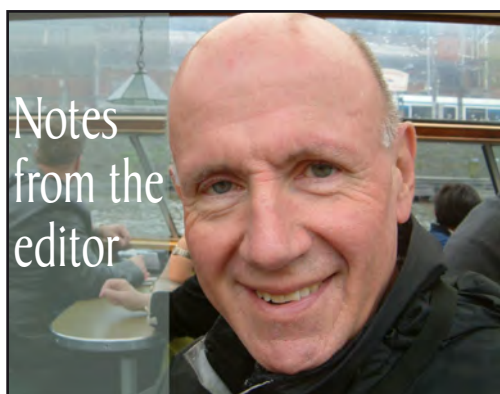
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*All may be well until you suffer a bout of pouchitis or catch a lurgy from infected water or untreated food on your annual summer or autumn break*  
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Well, it's goodbye to the Dean machine and hello to the Gaherty brigade. Mike Dean stood down as Red Lion Group chair and handed over to Morag Gaherty at the 2010 Information Day on 17 April. Morag, as many of you know, was co-editor of *Roar!* for several years and is a founder member and former liaison officer of the group.

Mentioning Mike brings me to a confession. I've always wanted to be

ling patients with problems and issues. It's Mike for PM, I say.

I've worked with him as Red Lion vice-chair for the past three years and chair before that – and the lobbying starts now. I've also very much enjoyed working with Margaret who was, as most of you know, Red Lion secretary until last year. Happily we won't be losing Mike's energy and pizzazz as he's staying on the committee as key link-up man and Red Lion liaison officer.

Another "Mr Energy" is Andrew Millis the new vice-chair. He's a relatively recent committee member (you can read about his latest pastime on page 7).

Andrew has been helping Tim run the website and last year started a free conference call service for committee meetings. Although Red Lion Notes Secretary Chris Lawton does a sterling job transcribing the contents of meet-

wife of GMTV Breakfast presenter/reporter John Stapleton. In her talk "The Pope and I" Lynn told us how her own experiences of FAP inspired her to launch the charity Lynn's Bowel Cancer Campaign.

In a lively, slide-assisted address she told us about her meetings with Pope Pius VI, the last pope, who also had FAP and Prince Charles whom she persuaded to say "bottoms and bowels" on prime-time TV. Lynn recently set up a European Cancer Screening Campaign in the European Parliament. Another Lynn-led event is "Dress Spotty Day" (see the photo on page 4) which encourages people to get regular cancer screenings and so "spot" any symptoms. The next Spotty Day is November the Fifth. So prepare for some razzle-dazzle. Contact [spotty@bowelcancer.tv](mailto:spotty@bowelcancer.tv) for more details.

You can read about the other talks given by Sue Clark, St Mark's consultant colorectal surgeon, and Dr Simon



*Mike Dean (right) shares a moment of mirth with two other Red Lion Group members at the 17 April Information Day*

Mike Dean. It's the apparently effortless way he organises everything from the smart, compact Red Lion packs he and Margaret Dean produce for Information Day, their speedy collection, delivery and despatch of each issue of *Roar* and Mike's thorough planning, preparation and leadership of Information Day. Another, lesser known aspect of Mike is the time he spends advising, helping and counsel-

ings, we thought we'd have to share around the other secretarial duties for another year until RLG member Sarah Bowes gamely volunteered at Information Day. Sarah's a university PA and a keen horse-rider, cyclist and Lindy Hop-per (a dance also known as the jitterbug).

This year's Information Day celebrity was Lynn Faulds Wood, the former BBC 'Watchdog' presenter and

McLaughlin, gastroenterology specialist registrar at Conquest Hospital, Hastings, later in this issue.

Once again the Day's afternoon workshops gave members a chance to talk frankly about their more personal niggles and problems.

There were open forums – or discussions groups – for male and female pouch owners and a special forum for partners too. Zarah Perry-Woodford,



St Mark's clinical nurse specialist, gave two very well-received workshops on diet and pregnancy and fertility for pouch-owners and there was some animated and constructive feedback in a workshop on the Medina catheter (available on prescription with the code M8730-5).



*New Red Lion Group patron, Lynn Faulds Wood (left) and husband John Stapleton*

Once again more than 90 of us thronged the Himsworth Hall on a sultry April day. Lynn Faulds Wood certainly raised the tempo with some of her more revealing video clips taken at



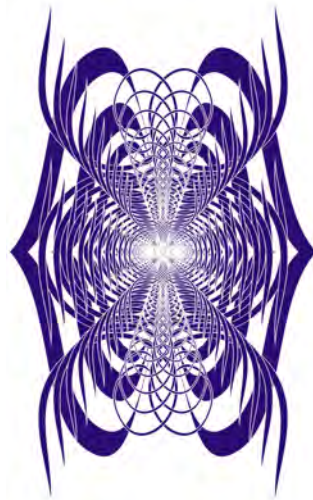
*New Red Lion Group Secretary, Sarah Bowes*

the European Parliament and Sue Clark handled a positively edgy question-time with aplomb. The raffle raised a record-breaking £209.

#### **A wider view of the web**

And now a few words of praise for *Roar!* co-editor Tim Rogers who does all these beautiful magazine layouts.

Last year Tim gave the website a stylish re-design and then doubled its capacity. This has given us far greater space – and scope – to express ourselves and carry our latest news, views and articles – and each edition of *Roar!* is posted six months after publication.



More and more of you are obviously logging on and I certainly get regular web-inspired emails and phone calls about, yes you've guessed it, catheters among other topics.

Talking of publicity, Simon McLaughlin and Zarah Perry Woodford wrote an article in a recent edition of the *British Journal of Nursing* about the key surgical and medical solutions to pouch problems.

The article highlighted Medina catheters and quoted from my article in the Christmas 2008 *Roar!* (Issue 39) about how it changed my life. It also mentions a certain pouch support charity called the Red Lion Group.

If anyone would like a copy of

Zarah's and Simon's excellent article please email me at [cbrowne@browne-media.co.uk](mailto:cbrowne@browne-media.co.uk).

#### **Two-for-one**

Sadly our patron Claire Rayner has had to leave us for health reasons. We are very grateful to the Harrow-based broadcaster, journalist and author for her 10-year-tenure with us and wish Claire and her family a very happy future.

In her place, we're very pleased to welcome the broadcaster Lynn Faulds Wood (see above) and our past president and former St Mark's clinical director Professor John Nicholls.

#### **...and finally**

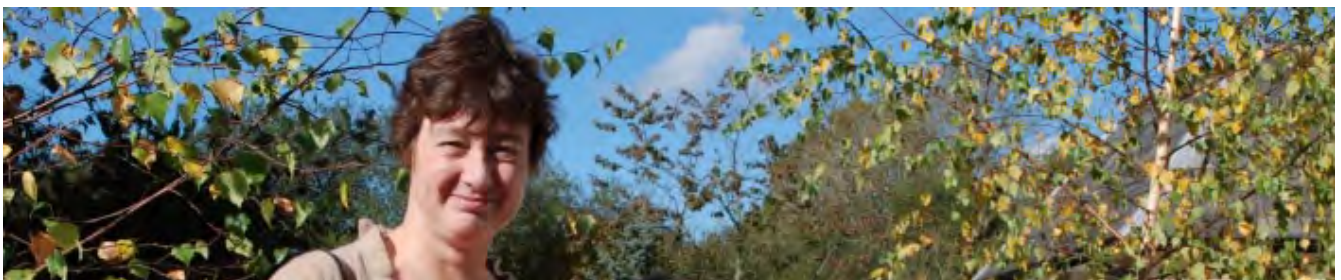
Another note for your diaries apart from Dress Spotty Day is the date of the next Information Day. It's Saturday, 16 April, 2011 and will be held once



*New Red Lion Group Vice-Chair, Andrew Millis*

again at St Mark's Hospital. We'll send you more details nearer the time.

Have a great rest of summer and happy reading!



*Founder member and New Red Lion Group Chair, Morag Gaherty*

## LETTERS

*Dear Sir*

I am coming up to 10 years with a pouch and I am pleased to say I haven't looked back after finding St Mark's Hospital.

I would just like to say that I do get tired most days and find folic acid

working abroad or have done so for extended periods. So can anyone give me the benefit of their experience of this, especially with regard to getting medical help when needed and the availability of public loos and the other essential hygiene measures all we pouchees are familiar with. The obvious thing which comes to mind is

And an emailed letter from the new Red Lion secretary Sarah Bowes:

*Dear Editors*

If colitis and Crohn's are being classed as auto-immune diseases (I thought this was the most likely theory but still unproven?) then might this explain why some patients suffer from dermatitis/eczema? I experienced very severe eczema on my hands at around the age of 15, and they are very, very sore at the moment.

The splitting on my knuckles and fingers is deep and has not healed in four weeks (my eczema usually causes me more embarrassment and pain than the gastro condition). I would be interested in any research linking psoriasis, eczema or dermatitis with colitis/Crohn's – are you able to point me in the right direction?

I notice when my IBD symptoms are less acute, my hand eczema and swollen, achy joints improve greatly. During my stay on St Mark's Hospital's Frederick Salmon ward a few weeks ago, I spoke to a couple of patients who coincidentally were experiencing the same extreme psoriasis and eczema as I was.

*Ed Chris Browne:*

*I too have had mild dermatitis on the inside (but not the outside) of my hands – flakyskin and small incisions. It's usually worse in winter, though tends to be intermittent throughout the rest of the year.*

*Has anyone else had similar symptoms to Sarah and me?*

tablets – I take one a day – do help. Giving in and having an afternoon nap also helps. I know I don't drink enough but I do try. Any tips from fellow pouch-owners would be useful.

But thank God for surgeons who carry on and try to find answers to our problems. Red Lion also helps so very much. So keep up the good work.

Best wishes from  
Jackie Brooks  
40 Northdown Close  
Maidstone  
Kent  
ME14 2ER

*Dear Sir*

I am a female pouch owner (not the best pouch that ever existed but I cope most of the time with Medina catheters) and, as I wish to see the world a bit, I am considering getting a teaching certificate so I can go to South America.

I am sure lots of pouch owners must be living and

how to take six or so months' supply of medication with you when you go.

I know a lot depends on the individual country but my choice of location will be based largely on these matters.

All information gratefully received.  
Thanks

Helen Bradshaw  
Helen.b24@virgin.net



## Bargain Book Offer!

If you'd like to know practically everything there is to know about pouches, colons, treatments and your unique inner workings. Now's your chance – thanks to a very generous offer by former Red Lion committee member and press officer Stephanie Zinser.

Stephanie is offering six copies of her book *The Good Gut Guide* (Thorsons, £10.99) for just £5 – or less than half the price. It's highly recommended reading.

Contact me (Chris Browne) on 07939 110842 or [cbrowne@browne-media.co.uk](mailto:cbrowne@browne-media.co.uk) to order a copy.



## Sweet fifteen

RLG regional rep Christine Jackson wrote about her pouch operation in an early issue of Roar! Here's her progress report

Some of you may remember a story I wrote in *Roar!* about my experiences of a pouch operation. Well, I just wanted to carry on and tell you what has happened 15 years after the op.

Just before the operation, when my children were aged only four and five, I was lucky enough to move house a few miles from my Mum and Dad. Without my parents help I could not

working a number of hours for the course in my local hospital alongside my GP. That was strange and I saw another side to my GP – in a nice way of course. My girls were adults by then and I could concentrate on MY life.

I then got a part-time job as a nurse in a care organisation in my area and managed to be promoted to head of care working in the office – as by then

to say when I can come in for a hip replacement op. I think it's only within the last six to nine months that the arthritis in my right hip has deteriorated so much that a hip replacement is the only thing that can be done.

I'm sick of painkillers but I can't walk at all without them (believe me I've tried to) and I feel very house-bound. My daughters have been great



have coped – as I was and still am a lone parent.

Fifteen years on I don't have much trouble with my pouch at all. I have even been discharged from seeing my consultant Professor Corbett who has retired anyway.

Every now and then it grumbles whenever I eat fruit and veg but for most of the time it is well-behaved. I'm lucky enough to have a great relationship with my GP too so if I have any problems he's always quick to help.

A few years ago I was lucky enough to go back to university and to complete a return-to-nursing practice course and then re-register as a nurse,

arthritis had started to kick in. Wow! I was wondering what I had been missing all these years.

It was fantastic being back as a nurse. With my life experiences and slightly older age, I found I really had something to give.

Lots of things had changed in nursing but it was a fantastic experience. Unfortunately I found that I just couldn't carry on and had to leave as working meant I was worse off financially, to be honest, and it put a huge strain on my finances.

Today I'm sat at home with my trusty stick by my side waiting for a phone call or letter from the hospital

and help me so much that I couldn't cope without them. However I can't go rummaging round car boot sales now and I can't even go out in the rain as the paths in the area are so slippery. I'm actually dreading, but looking forward, to that change in the quality of my life when I have had the operation. Apparently I will be in for three or four days as it's done by sedation (boy I need that) and epidural, so that makes the recovery much faster.

*PS: Christine's report was sent just after the last edition of Roar! So she has probably had her hip operation by now. We wish her a very speedy recovery and a more mobile future.*

## Footsore and fancy-free

Andrew Millis went to Paris in the spring-time for some romance, culture and, of course, French cuisine. Then he realised he had to run a marathon.

It may not sound particularly original to write an account of running a marathon. Many people try it and are sponsored by their friends – probably because the objective is to raise money from the sheer surprise that the ambitious runner would finish! In fact 95 per cent of those running the London marathon have the lure of sponsorship.

My story is a little different – for several reasons. First, selfishly I haven't raised any money for anyone or anything at all. My aim was to get the fastest time I could, and I did everything I could to achieve that. Second, I ran the marathon in Paris, not London. There was something really special about taking the Eurostar and staying in a hotel for a couple of nights. And, of course, I have a pouch to think about, and am the wrong side of 50! It is the age that's driving me to log my physical achievements in a year that will make them easy to remember – before the ageing process wins.

I have been running for about four years, but only seriously for the last two. Before that I went out once at the weekend, if I could be bothered when I woke up! I have read that it takes three to four years of running to develop the physiology and neurology changes to run fast for a long distance. The last two years have made a lot of difference to my times.

There are a number of training schedules on the net that show you how to prepare for running a marathon. Most are scary, with different speed/distance runs six days a week. So I ignored them. Fortunately I work about seven miles from home, and that is a brilliant distance to run. Twice a week I ran to work and back, and on Saturday or Sunday I went for a run that grew longer and longer. Since the end of September 2009 when I booked my place in the Paris marathon, I have run 790 miles and up to 47 miles-a-week.

Zara Perry-Woodford, St Mark's clinical nurse specialist, put me in touch with David Skinner, who has a pouch and has run marathons in London, Chicago and Berlin. I am indebted to him for his selfless support, coaching, tips and interest in my progress and achievements. Together with *Run-*

*ner's World* magazine, I learnt about shoes, clothes that get rid of sweat, carbohydrate loading and a massive list of preparations for the big day. I learnt that only 20-25% of the calories that are burnt up for running go into muscle contraction – the rest go in heat. How the longer runs are used to teach the body to create bigger stores of glycogen in the muscles and liver. I also experimented with Loperamide when running, and how long it would keep me from needing the toilet despite enjoying a big breakfast. I don't normally take Loperamide at all.

All the schedules build up your

running for 13 weeks out of a total of 16, then tail it off for the last three to ensure you are fully rested for the event. There were days when it was hard to fit in the necessary runs, i.e. when snow lay on the ground. The roads may have been cleared, but the pavements weren't and motorists don't tolerate runners in the road. I ran to work on Tuesdays and Thursdays, because your body takes 36-48 hours to replace the glycogen in your muscles, then chose from either Saturday or Sunday to run 14-21 miles. The longer distance took its toll and made me want to go to bed when I got home! Towards the





end of training, there was an organised half-marathon in Fleet, Hampshire, so close to my home that I could walk to the start – and I dispensed that in 1 hour 30 minutes 34 seconds. I began to get nervous as I packed to go to Paris, repeatedly humming the music of Chariots of Fire to myself.

As soon as I booked the marathon in September (unlike London, it is simply a matter of a few clicks on their website and a €57 (£50) fee but you do have to send in a medical certificate from your GP) I booked the hotel as close as possible to the start in the Champs-Élysées. I arrived in Paris on Friday, 9 April, to ensure I could do all that I needed to do and to recover from the day's travel well before the race on Sunday, 11 April. I found an Italian restaurant selling massive bowls of pasta for reasonable prices, and I took large boxes of Shreddies to

eat in my hotel room so as to build up carbohydrates. The target was 10g of carbohydrates per kg body weight per day for three days!

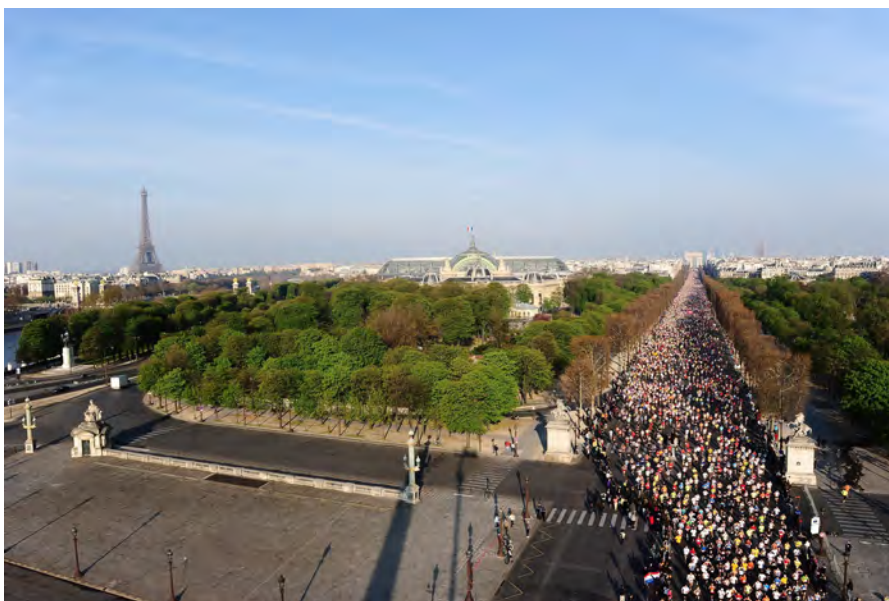
My pre-race nerves actually reduced my appetite which wasn't good as nerves can hit the stomach causing loss of absorption. That means weight loss, and the liver gives up its glycogen first as weight loss starts. Bad news! So Loperamide was judiciously taken. I had a planned dose of Loperamide close to the start of the race to help me through it.

On the morning of the race, I wasn't nervous at all, and was really looking forward to starting. There was a fantastic atmosphere at the start-line with the Arc de Triomphe as a backdrop. Music, people shaking hands and the runners throwing off their clothes ready for the race.

Although 40,000 places had been booked, I later learnt only 32,500 turned up. But that is still a lot of people to get behind a start-line.

After the gun, the kilometres flew

by quite well with my legs feeling great. Every kilometre there was a sign up, and every 5km there was a blue wire across the road which picked up a signal from the chip that everyone had fitted to their shoes. While at 21km, 30km and the finish, passing over those wires also triggered text messages to the numbers we specified before the race. The message gave the name, race position and time – really clever. I had one sent to my older son, and the other to my sister who was with me in Paris.



At every 5km there was a water stop but that was chaotic. People didn't see the benches of water bottles in enough time to "put indicators on" and move across to the side of the road. So on seeing the water you had to just dive across about 10 runners and hope the collisions were not too serious. Those that did grab bottles – and that was practically everyone because of the 18°C heat – drank some then half-heartedly lobbed the bottle in the direction of a bin. But it almost always missed and either hit the crowds by the side of the road or soaked them with flying water.

For at least 1km, we ran through a tunnel. It was lit but dark compared to the sun outside, and smelly! There was a scent of sweat from the several thousand runners that had gone

through before me! We also ran through Pont d'Alma, where Princess Diana was killed. I looked around for any new evidence I could send to the Daily Express.

At about 30km I started to get a little tired. There was a slight pain in my upper leg muscles – a tight feeling. It was not hard to ignore, and it never got worse. I think it was just telling me that I had run out of glycogen and the muscles were switching to burning fat, which produces lactic acid. At

around 38km, I had to stop for a pee. Everyone just went by the side of the road. No one cared! However, it took up precious time.

I had a target time of 3 minutes 30 seconds, which is an easy-to-calculate five minutes per kilometre. I was just about on track throughout – I had caught up the 60 seconds I lost from my target near the start. At one point I was 40 seconds ahead. At last the finish was in sight! But the pee lost me precious time, and the last 200 metres (the marathon is 42.195km) meant I finished at 03:31:00. Still, I was quite happy.

I finished 6,114th out of 31,566 runners. That's not too bad for a 50-year-old with a pouch to contend with. When I picked up the automated messages there was one from my son which said: "Well done Dad, I'm proud of you!"





## Sun brings rays of hope

After recent studies linking low levels of vitamin D to bowel cancer, new Red Lion chair Morag Gaherty advises exercise, plenty of high fibre and healthy living.

Summer is a good time to absorb vitamin D through your skin - though it may be best not to overdo the sunscreen - if research published in a recent edition of the *British Medical Journal* (BMJ) is to be believed.

It comes after medical experts expressed concern about the rising number of cases of rickets (the softening of bones in children) caused by

who have low levels of vitamin D are more likely to develop bowel cancer.

“The next step is to carry out new clinical trials to try to confirm whether vitamin D supplementation can reduce the risk of bowel cancer and whether there are any harmful effects of higher levels of vitamin D.

“But we need to emphasise that, for the moment, the findings need to

The research team said that although the latest study provides evidence of a link between vitamin D and bowel cancer, it does not prove that taking vitamin D supplements prevents the disease.

More studies are needed to find out the potential impact on other cancers and the effects of taking extra vitamin D doses, scientists said.



vitamin D deficiency and called for it to be added to milk and other food products.

Children with the highest levels of the vitamin had a 40% lower risk of developing the disease compared with those with the lowest levels.

Dr Panagiota Mitrou, science programme manager for the World Cancer Research Fund, said in the *BMJ*: “This is the biggest ever study on this subject and there is now quite a lot of evidence from studying populations that people

be treated with caution and they are certainly not enough evidence to suggest that we should be taking supplements to increase levels of vitamin D.

“The best advice for reducing risk of bowel cancer remains to stop smoking, maintain a healthy weight, be regularly physically active, to eat more fibre and less red and processed meats and to cut down on alcohol.”

Apart from sun exposure, eating oily fish and cod liver oil are good sources of vitamin D.





## Truths and myths about pouches

The talk given by Sue Clark, St Mark's colorectal surgeon, at Information Day was followed by one of the liveliest, most provocative question-and-answer sessions many of us have heard for a long time. It began with colon transplants, moved on to stem cell tissue and then pouches and fertility and ended with faecal transplantation. It makes for a riveting read.

In her talk Sue Clark said that although choosing to have a pouch was a wise choice for many people, they were never perfect. Pouches needed to adapt their lifestyles, faced higher daily outputs than non pouch-owners and sometimes faced occasional spells of pouchitis as well as one or two other sides-effects.

Here is a summary of the post-talk questions and answers.

**QUESTION: A Red Lion member with long-standing pouchitis said she had seen a TV programme about a woman who had had a total colon transplant. Would this solve her problem?**

Sue replied that only the small intestine – not the large – could be transplanted. Even then anti-rejection drugs were needed and it was very much a last resort – and a dangerous one for a number of reasons. Sue said reverting to an ileostomy would be a much better option if possible.

**QUESTION: Does having a pouch operation reduce a woman's fertility?**

Sue said it was not the colon operation but the removal of the rectum that reduced fertility. The reason is that taking out the rectum creates adhesions around the fallopian tube and ovaries.

The answer for women pouch patients who want to have children is to have an ileostomy and then an internal pouch created after they have had their family, she said.

**QUESTION: Could stem cell tissues be considered in the future or would ulcerative colitis reappear when your large bowel grew back again?**

Sue replied: "I think the problem is exactly that. Nobody understands why people get ulcerative colitis but it is something to do with the immune system and the contents of the gut. It is amazing, if you think about it: your

bowel is full of bacteria and foreign materials, stuff like chicken, peanuts, whatever you are eating. If you think about it, it is separated from your blood by fractions of a millimetre. If you injected that stuff into yourself, you would be exceedingly ill. Somehow or other our gut protects us from all this foreign material, bacteria, [and] it protects us from it even though it is only a fraction of a millimetre away from our bloodstream. Yet we do not have a terrible reaction all the time.

"The skin is the same: if you think about your skin - all the time you are touching horrible things and you are covered in bacteria and it is not far from your blood and the inside of you and you are fine, you are protected, you are not erupting. When something goes wrong with that mechanism, you get diseases. I am talking about the skin because eczema is thought to be very similar. Somehow that kind of balance of being able to tolerate foreign material on you or in you yet be protected from it goes wrong. That is what is thought to happen with eczema and it is also thought to be what happens with colitis."

**QUESTION: Is there a risk of pouch-owners who have had ulcerative colitis developing dysplasia [the abnormal development of cells on the surface of the cervix] or cancer?**

Sue replied: "No, is the answer. It is low...very, very low. One of the problems is that it is difficult to analyse it via the different groups. Overall the risk of cancer, having had a pouch, is in the region of one in a thousand. If you look at those who have had cancer, they have all fallen into the high risk groups. Therefore all I can say is it is low. Even if you have previously had cancer or dysplasia, it is still a low risk. But I have sort of turned it on its head and said, well, all the people who have

had cancer have fallen into that group so let us go on following those people up. The other people who do not have any of those risk factors, who do not have a previous cancer or dysplasia, do not have FAP, and do not have cholangitis [inflammation of the bile duct], nobody in those groups has had cancer and therefore we do not need to follow up these people.

**QUESTION: A Red Lion member asked if faecal transplantation was an option in pouchitis research.**

Sue replied: "I will tell you about this because I am interested to know if people think this is completely outrageous or not, but we have done trials including taking samples and trying different treatments and trying to work out what bacteria causes pouchitis.

"Part of the issue is that people with colitis and pouchitis may actually have different patterns of bacteria in their bowel," said Sue. The idea was that if the bacteria pattern could be returned to normal, it might help pouch-owners.

She said St Mark's Hospital was thinking of trialling faecal transplantation. "You get somebody who is normal and fine, who should have good bacteria, whatever the right balance of bacteria in their poo is, and you collect some of their poo, then you mash it up and then you give it by enema to the person who has the disease. It works in pseudonymous colitis... I think it sounds absolutely horrendous... I am not sure how it is going to wash with the ethics committee, or how it is going to wash with somebody," said Sue.

"If there is anybody here with pouchitis, would you contemplate having this done to you? The donor will be screened for visible infection and all the rest of it, but fundamentally what are people's attitudes? If you were really struggling with pouchitis, would you let us put somebody else's poo into your bowel?" she asked Red Lion members

When a lot of members put their hands up, Sue replied: "OK. That's very good," to much laughter.



*Sue Clark at Information Day*



## Have I got pouchitis?

Some signs of pouchitis are instantly recognisable – others are not. That was the theme of a talk given by Dr Simon McLaughlin, gastro-enterology specialist registrar at Conquest Hospital, Hastings, at Information Day

While most pouch-owners visit the loo four to eight times in 24 hours, about 50 per cent need to go at night and the majority can “hold on” for about an hour. A third of pouches need to take Imodium or co-deine to achieve this balance, said Simon.

Twenty to 50 per cent of former uc sufferers get pouchitis either once or in several spells. For ex-FAP sufferers the ratio was far smaller – with two to five per cent likely to have the condition, said Simon, a former St Mark’s Hospital consultant registrar.

### So what exactly is pouchitis?

It is inflammation of the pouch and usually means the pouch-owner has to go to the toilet more often than normal. More extreme cases of the condition lead to pouch failure and the need for an ileostomy, though the numbers are dwindling said Simon.

Recent studies show 90 per cent of owners can expect to have a pouch after 20 years. For those who don’t the majority have their pouch removed in the first one to two years. Ileostomy candidates usually keep their pouches in place – just in case. Before they used to have the pouch removed.

Referring to pouch failure, Simon said the key cause was pelvic sepsis which occurred in the link between the pouch and the anal canal. “If

your pouch works well, the chances are it is going to work well forever. Most people who lose their pouch will have problems with the pouch very



soon after surgery, be it troublesome pouchitis or be it pelvic sepsis. Again, with people who have pelvic sepsis, it may settle down after the operation or it may come back,” he said.

Another reason why patients forego their pouches was because they did not work properly for one reason or another. “They are just not happy with it and would rather go back to having a stoma,” said Simon.

### How can you prevent pouchitis?

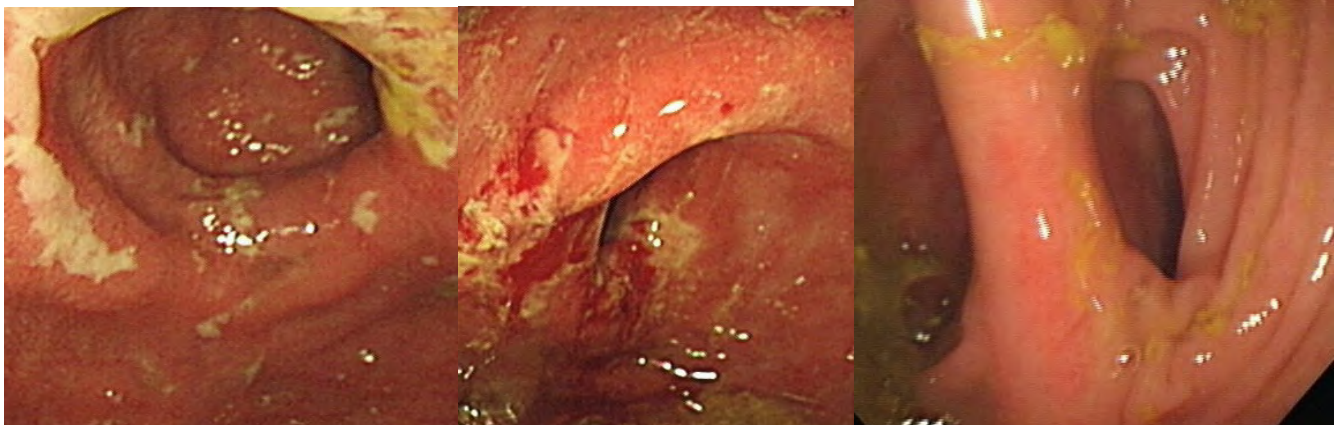
The answer is you cannot. “It is either going to happen or it is not,” said Simon. If you have primary sclerosing cholangitis (PSC) – chronic liver disease – your chances of getting pouchitis are far higher with a greater risk of problematic pouchitis, said Simon.

The best advice was to try to avoid taking regular anti-inflammatory drugs such as Ibuprofen, Nurofen, Voltarol and similar. Studies showed that it would be better for pouchitis sufferers who took regular anti-inflammatories to stop so the pouchitis could get better on its own. Although “if you need to take them because you have arthritis or something, you may not want to suffer by not taking them,” said Simon.

Here is a summary of a question-and-answer session after Simon’s talk:

### QUESTION: If I take Ibuprofen or anything like that, I bleed. What should I do?

Simon replied: “Well again that may be because it is causing inflammation in your pouch. They are called anti-inflammatory drugs but paradoxically they can cause bowel inflammation. They reduce inflammation in joints and produce anti-inflammatory chemicals in your body but they cause inflammation in your bowel, i.e.





stomach ulcers or ulcers in the small bowel. Thus I think the message is to say, oh, take anti-inflammatory drugs if you have a condition that requires them, but take something simple like paracetamol or codeine if you have just something like a headache.

**QUESTION: What are the symptoms and causes of pouchitis?**

“It is very similar to ulcerative colitis, which is inflammation of the lining of the pouch, just as ulcerative colitis is inflammation of the lining of the colon.

No one really knew the causes of pouchitis though there had been three studies into the condition – two from St Mark’s and one by Simon himself. “Basically what we are looking at here is trying to look at bacteria in pouches between people who did have pouchitis and people who did not,” he said.

“People have been trying to do this for 30 years, and there have been lots of studies on this but older studies, before these three, were basically people trying to grow stool on agar plates. We now know that that does not work very well; you can actually identify only about 20 per cent of bacteria in the gut in that way, so most bacteria in the gut are really difficult to grow, so

all those studies are rubbish, to be quite honest,” he said.

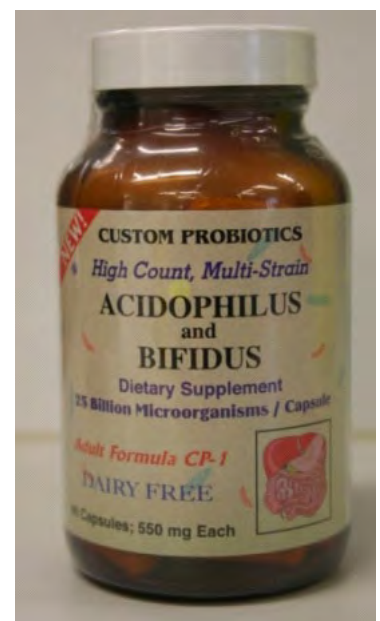
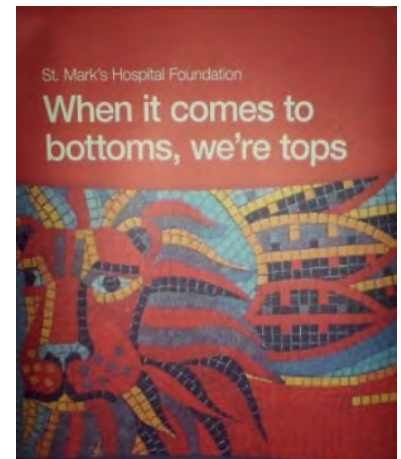
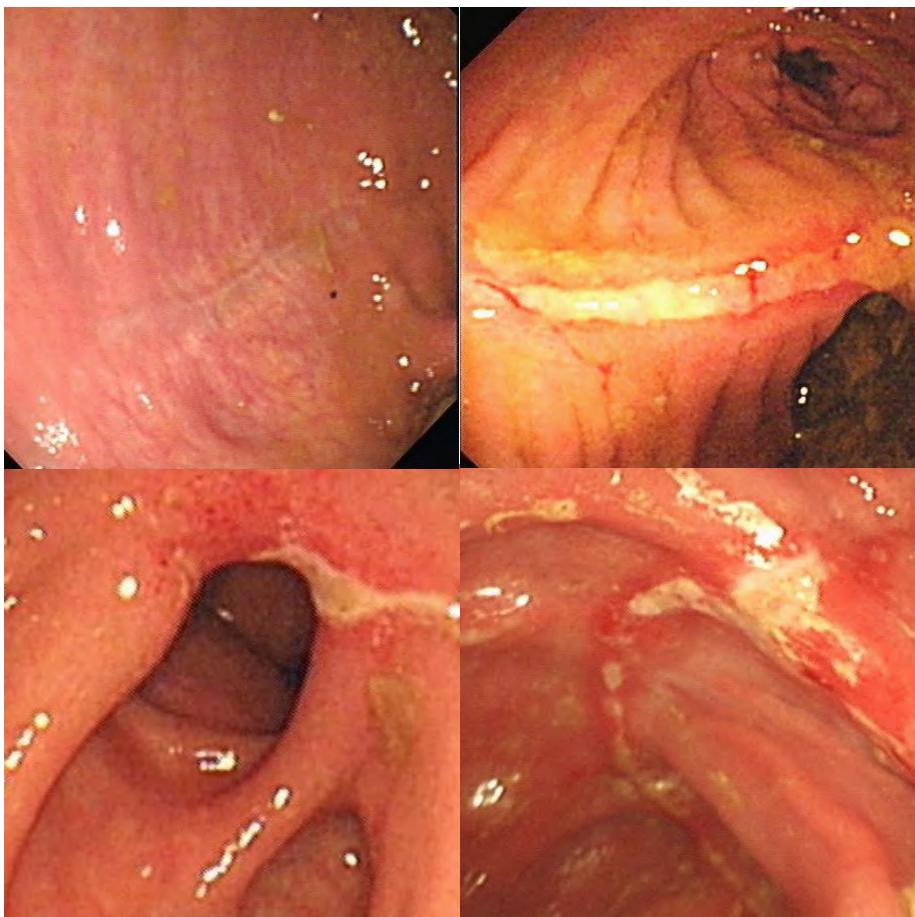
The three recent studies tried to find the causes of pouchitis by identifying bacteria from people’s DNA i.e. genetic fingerprinting. The bacteria did not have to be live, but you identified them from their unique DNA, and that is clearly the way forward, said Simon.

One study was from Matt Johnson, Simon’s predecessor at St Mark’s Hospital. It found that there was no difference between people who had pouchitis and people who did not, and “hopefully this is what we think is a very robust study where we did analyse them individually and in lots of detail.

“Therefore, although there is no difference in the actual bacteria of those who do and do not have pouchitis, there is a clear reduction in the diversities of the various different types of bacteria in people who



have pouchitis..... and people with ulcerative colitis have very different bacteria from those with FAP. I think that means you need two things to get pouchitis: (1) you need to have different bacteria already, and that predisposes you to get inflammation and (2) your immune system has to recognise those bacteria as foreign, so it is, if you like, over-reacting,” explained Simon.



## Chairman's and Treasurer's Reports

Here are the annual reports of outgoing chairman Mike Dean and treasurer Marjorie Watts presented at the Red Lion AGM on Information Day.

### Mike Dean

It gives me pleasure to address you today and there are a few points to mention.

First, Claire Rayner, our patron for the last 12 years, has now stepped down due to ill-health and the scaling down of her commitments and I would like to say a thank you for her support over the years. The group will now be looking for a new patron.

Second, I do not propose to go into detail about membership at this stage as this will be covered in our Treasurer's Report. However, I am pleased with our renewals despite the economic gloom.

Third, you may recall that last year I said it would be my final year as chairman of the Red Lion Group. That year has flown by, it just does not seem possible.

I would like to thank the committee and the St Mark's staff, and in particular Zarah Perry-Woodford with whom I have worked very closely, for all their help and continued support to me during my tenancy as chairman.

Fourth, we are still without a secretary and have scratched along for the last year. We desperately need someone to volunteer. After all it is your group! It is not an onerous task but any good organisation does need a good secretary. We cannot really go on without someone volunteering so I would ask you to search your heart and think "yes I could help".

Finally, I am willing to become an ex-officio member of the group and it goes without saying I will give as much help and guidance to the next chairperson as they want. I am also pleased to have met many of you over the years and I would also like to thank you for your support to me and the group.

### Marjorie Watts

I would like to thank Brian Withers for auditing the accounts again this year, it is very much appreciated. I also thank John White, the previous treasurer, for his help. It is so good to know he is at the end of the phone.

#### Income

Subscription income is £55 less this year, caused by a small reduction in

membership which was 279 compared with 285 at the end of 2008. Thank you to the 166 members who pay by standing order. This continues to be most helpful.

Donations are similar to last year and we are most grateful for the members and a company who have been able to further support the work of the Red Lion Group.

Sale of Red Lion merchandise including books was about half of the previous year. Please everyone remember to visit the table today to donate. There are some useful items to be had, including tea towels—everyone should have one!

Income from interest has reduced due to the very low rates during 2009. The Gift Aid amount is up to £700 and I would like to encourage you to complete a Gift Aid form, if you are a UK taxpayer and if you have not already done so. This will assist the Red Lion Group and does not cost you anything.

Information Day registration and raffle income in 2009 was up by over a £100 on the previous year as we had a particularly high attendance.

#### Expenditure

The cost of the AGM and committee meetings shows an increase for 2009 as cost of the AGM paperwork,

refreshments and raffle prizes was higher. Apart from the AGM, three other telephone committee meetings were held in February, August and November. The November meeting was at no cost as we used committee member Andrew Millis's conferencing facilities for which we are most grateful.

The lower figure for the printing and postage of Roar reflects the cost of two magazines produced in 2009 compared with three in 2008. Also the magazines were within the lower postage level.

General postage and stationery shows a slight increase.

The website was again without cost this year and has much information. Please see for yourselves by visiting [www.redliongroup.org](http://www.redliongroup.org).

The excess of income over expenditure for 2009 is £2,210 and your committee has donated £2,000 to St Mark's Foundation for use in pouch research.

This year's surplus of £210 after donation payments, together with the balance brought forward at the start of 2009, results in a final balance of £8,739.78 for the Red Lion Group.

Thank you for your attention if you have any questions for me or other committee members we will try to answer them.





## Check out that travel cover before it's too late!

Have you checked the small print of your travel insurance recently? If not I suggest you do so now – especially if you're about to go on holiday.

Most of the free policies offered by banks, building societies and travel operators are fine for the relatively healthy, illness-free holidaymaker, but not so good for the pouch-holder. Why? Because we automatically fall into what is known as the “pre-existing condition” category.

Put simply, it means we already have a medical condition that recurs from time to time. Which, quite bluntly, means we are more of a liability (or in other words expense!) to a travel insurer.

All may be well until you suffer a bout of pouchitis or catch a lurgy from infected water or untreated food on your annual summer or autumn break. Suddenly, you will need a course of tablets, medication or even hospital treatment to help you and your family cope with the rest of your holiday.

But if you don't have the right cover, your travel insurer won't pay for your treatment or tablets. Why? Because your problem is not just a one-off but a recurring one, which means it could happen at any time.

If you don't have the right cover, you and your partner or family could be forced to fly home early which will add yet more expense and hardship to your well-earned break – or else face the prospect of some very costly medical bills or an expensive stay in a foreign hospital.

But help is at hand, dear reader. For the Red Lion Group has set up its own special travel insurance with two companies. Leisure & Lifestyle Insurance Services (Tel: 08445 763029) gives travel cover for pouch-holders aged up to 70, while Freedom Insurance Services (Tel: 01223 454 290) covers those in the 70-82 age group – and the over-82s according to their circumstances.

Timely advice that's certainly worth heeding.

*Christopher Browne*

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*Page 14 – Self-portrait in Mirror*

Nick Winchester from UK

## 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,  
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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!

### 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:

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## Visit Our Website

[www.redliongroup.org](http://www.redliongroup.org)





