

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.



BEDFORDSHIRE

Carol George Sandy 01767 263092

CLEVELAND & NORTH YORKSHIRE

Christine Jackson Saltburn by the Sea 01947 840742 chrisjacks1960@btinternet.com

ESSEX

Peter Zammit Benfleet 01702 551501

HERTFORDSHIRE

Susan Burrows St Albans 01727 869709

NORFOLK

Sandy Hyams King's Lynn 01485 542380

NORTHERN IRELAND

Sharon Hendron Lisburn 02892 661559

WILTSHIRE & DORSET

Bernadette Thorn Salisbury 01722 327388

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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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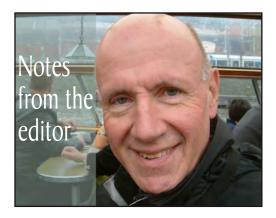
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Do you pay for your prescriptions and, if so, how much? £20,£30 or even £50 a month perhaps? Even if it's £20 – or £22.20 for three prescriptions to be precise – it's a hefty sum to pay out.

Some of us get our prescriptions

free. I got mine after showing my GP two Roar articles about our then chairman Dr Martin Peters. Martin wrote about how he managed to get a medical exemption (MedEx) certificate after telling his GP that a pouch is an internal version of an ileostomy or external stoma.

However the law is an ass on this issue. The Prescription Act says anyone with an ileostomy should not have to pay for their prescriptions as they have a stoma that "needs an appliance or continuous surgical dressing". Thus implying we do not fall into that category. Or do we?

The Act is misleading. Surely a pouch is a type of appliance (the dictionary calls it a "device"). Or a man-made version of the large colon. Thus, I would argue, it should fall into the exemption or non-payment category.

I've spoken to at least 15 members of the Red Lion group who don't pay for their drugs and medication – and there are others too some of whom used Dr Peters' articles to convince their GPs and local health authorities. No doubt some of you have tried and failed.

Quite frankly the Prescription Act is a national disgrace. Far too many people with serious conditions have to pay for their medication. Some cancer patients for instance (although, as diabetics are exempt, I don't have to pay for my insulin).

The law must be changed -- and it is up to groups like ours to lobby the

Government and the Department of Health to get the rules changed. A point made very forcefully by St Mark's Hospital pharmacist Yee Chee Cheung at this year's Information Day (See her article on page 4).

So are there any other ways we can save money on prescriptions? Yes, is the short answer. You can do it via a pre-payment certificate (PPC). It works best

if you need four or more prescriptions every three months or 15 plus a year. Which will cost a minimum of £29.90 or £111.

You can pay your annual fee outright or in 10 monthly direct debits. So even if you have four prescriptions



a quarter or 15 a year – and most of us have considerably more -- you save money. Order your PPC from http://www.nhsbsa.nhs.uk/Health-Costs/2131.aspx, phone 0845 850 0030 or fill in a FP95 form – available from many pharmacies and local surgeries.

You know it makes sense!

Better informed

I always come away from Information Day feeling better informed after such a vibrant forum of knowledge and medical data. This year was no exception. It began with a tribute and presentation by Red Lion chairman Morag Gaherty to Mike Dean who was our chairman, liaison officer and Information Day organiser extraordinaire for many years.

Then there were four exceptional speakers -- with three of their talks featured in this issue. Each item was followed by lively questions from a large and animated group of members, families and friends on such issues as diet, childbirth and faecal transplants (see Dr Jonathan Landy's article on page 7).

Once again more than 60 of you attended, some from as far away as Scotland, Yorkshire, Northern Ireland and even Italy. It was a sunny, goodhumoured day with an extra dimension -- six workshops that gave members

and families a chance to speak freely and frankly about more personal issues such as coping with a partner's pouch worries, various work, social and travel problems and living with a Medina catheter.

We're planning an equally dynamic programme for Olympic year – 2012. And, to help you plan ahead, we'll be sending out the booking forms several months beforehand. So log on to the website www.redliongroup.org and watch this space for more details about the talks and highlights!

I look forward to seeing you there.

HAVE YOU ALWAYS WANTED TO BE AN EDITOR?

If so, now's your chance. After several years editing Roar with Tim Rogers, I've decided to move on and let someone else

have a go. You don't need an MSc in physics, you meet and talk to a lot of interesting people and you have the satisfaction of seeing your work in print at least twice a year.

You'll need an interest in writing, pouch affairs and a few spare evenings to put it all together. If that all sounds attractive, do contact me on cbrowne@ brownemedia.co.uk or 07939 110842 and we can discuss it.

For now, thanks for several years of enjoyable feedback and some very feisty letters. It's been emotional!

Have a very happy rest of summer. *Christopher Browne*

Keep taking the tablets

Codeine or loperamide? Ciprofloxacin or Metronizadole? All too many of us have faced a nagging decision about which drug to take for a pouch problem or a spell of pouchitis. But, happily, help is at hand. St Mark's Hospital's Pharmacist Yee Kee Cheung gave us an Information Day guide to the best drugs and when to take them. Here are her findings.

In her talk, "Drugs and Pouches", Yee Kee Cheung said the main drugs the average pouch-owner uses are loperamide and codeine.

These two drugs help slow the pouch's motions and so prevents frequent loo visits. They also help us to absorb water and the daily nutrients our bodies need.

Loperamide can be taken in "quite high doses" of up to 16mg four times a day, she said, and it is relatively safe with no long-term side-effects. The average codeine dose, on the other hand, is 30-60mg four times a day

and can cause drowsiness.

To get the best effects, said Yee, pouch-owners should take both drugs 30 minutes to 1 hour before food

Pouchitis

As bacteria is said to be the main cause of pouchitis, the recommended treatment is to take antibiotics twice a day for 1-2 weeks. In more severe cases it can be taken for a period of a month or even several months, she said.

The main antibiotics are metronidazole, ciprofloxacin and augmentin. One of metranizadole's side-effects was a metallic taste in the mouth. Users should also avoid alcohol while taking it. Anyone who is prescribed ciprofloxacin should avoid direct sunlight and use sun creams during hot weather,

she said. Users sometimes experience inflammation in the tendons – mainly the Achilles.

The other antibiotic, augmentin, can cause nausea, vomiting and diarrheoa. It also contains penicillin, so those with penicillin allergies should mention this to their doctor before taking it, said Yee.

If antibiotics do not help to control a spell of pouchitis, pouch-owners could try probiotics, which, she said, is a food supplement rather than a

drug. VSL3 is the most trialled or investigated. It contains eight strains of bacteria and can help those with severe pouchitis who are in remission with antibiotics. Probiotics can be bought without a prescription from pharmacies and health stores.

Breast-feeding and pregnancy

Yee advised pregnant women to avoid complementary or herbal medicines and, when taking medication or drugs, to consider using creams or enemas instead of tablets. When family, or what your plans are after you have had your baby and whether you want to breast-feed," said Yee. When a pouch-owner plans ahead, she and her partner can then gauge which drugs are safe and which are not, said Yee.

Prescription charges

Anyone who lives in Scotland, Wales and Ireland does not pay prescription charges. In England the current charge is £7.40. One good way to save money on charges is to use a pre-payment scheme, said Yee.



breast-feeding, women on a drugs regime should take them after they have breast-fed to minimise exposure to their baby.

"There are drugs we know that are definitely not safe in pregnancy and some drugs that are known to be safe. However, there are lots of drugs in the grey area where there is lots of conflicting data about whether or not it is safe," said Yee.

"Always discuss this with your doctor if you are planning to start a

Pre-payment cards can be obtained by filling in an FP95 form from your local pharmacy or GP's surgery.

Pouches are not currently included in the Department of Health's medical exemption certificates list. "This list is very limited. There are lots of chronic conditions patients may experience that require very regular medication and they are not eligible for free prescriptions, so this is a list in desperate need of revision by the Department of Health," said Yee.

Colonic irritation

Pouchitis has a nasty habit of creeping up on those of us with even the most trouble-free pouches. However the Nasty P can be controlled, as St Mark's Hospital Research Fellow Dr Jonathan Landy revealed in a talk at the 16 April Information Day.

Pouchitis is inflammation of the pouch – no more, no less – although its technical name, idiopathic pouchitis, is a little more complex. There are several other types of the condition known as secondary pouchitis, said Dr Landy.

The causes of the latter include infections such as clostridium difficile, although very few have so far been reported at St Mark's, he said. Another cause is drugs, namely Ibuprofen and Diclofenac, and Nicorandil which is used to treat heart disease. Pouch-owners who have a reaction to radiation may also contract pouchitis, said Dr Landy.

He said American researchers believe autoimmune diseases - when the body's immune system attacks itself - can lead to pouchitis. In a few cases, patients with long-term ileostomies get a condition called diversion pouchitis, with the faecal stream by-passing the pouch and undoubtedly causing lack of nutrients in the area.

Another condition that causes pouchitis symptoms is coeliac disease. It is important for anyone with pouchitis to find out whether they have the milder coeliac disease instead of pouchitis, said Dr Landy.

Whenever a pouch-owner has pouchitis he or she is physically examined and their case notes studied by their consultant, he said.

Pouchitis facts and figures

Recent studies reveal that up to 50 per cent of those who have had a pouch for more than five to 10 years have an episode of acute pouchitis. It usually lasts less than four weeks and responds to a course of antibiotics. It hardly ever happens more than three times in a year and chronic pouchitis affects 10 to 15 per cent of pouch-owners, said Dr Landy. Though it very rarely happens to those who had familial adenomatous polyposis (FAP) before their pouch

operation.

The most likely period for a pouchowner to have pouchitis is the two years after his or her operation, although it can occur any time up to six years or more after the op, said Dr Landy.

So how does someone with a pouch know whether they have pouchitis? The symptoms, which can be traced via an endoscopy or biopsy findings, are usually an increase in stool frequency, urgency or abdominal pain – "and occasionally rectal bleeding, although most patients we see with pouchitis do not have bleeding, and

a fever can occur but not necessarily all patients have it," said the St Mark's research fellow.

Although research into pouchitis is ongoing, there are no confirmed theories about why it happens, said Dr Landy. One theory is that it is an extension of ulcerative colitis as it, too, is inflammation of the bowel and has similar symptoms to uc.

The response times to antibiotics used to treat the two conditions were very different and the medications used to control uc were not that effective for pouchitis.



Vital St Mark's research work needs funds

You may or may not have heard of the phrase "faecal transplantation" (FT). Anyway FT - as you'll find out below - is the theme of one of two vital studies that are being carried out at St Mark's Hospital. The other is the causes of pouchitis.

The research and results of these two projects could prove life-changing for current and future pouch-owners.

However, like many important studies, one of them, the Faecal Transplant study, is in urgent need of funds. The Red Lion committee has agreed to send a sizeable donation to help and is seeking other ways to raise funds and donations towards this major research.

On the next two pages, St Mark's Hospital Research Fellow Dr Jonathan Landy describes what exactly this crucial research is all about, what the teams have achieved so far and what their aims are.

If after reading this, you have a fundraising idea you would like to suggest – or a donation you would like to make – the committee and St Mark's would love to hear from you. Please contact Red Lion Group Secretary Sarah Bowes-Phipps on 01727 875156or sarah.bowes@live.co.uk

1. Study into the causes of pouchitis

Almost one third of patients with ulcerative colitis (UC) will require surgery to remove their diseased colon. As mentioned in the proceeding paragraphs, the operation of choice for these patients is the ileal pouch-anal anastomosis pouch (IPAA).

Unfortunately, up to half of UC patients will develop inflammation in the ileal pouch, known as pouchitis, after surgery. This is an inflammatory condition which affects the lining of the pouch and is characterised by increased stool frequency, bleeding, stomach cramps and urgency - the feeling that one must rush to the bathroom to avoid an accident.

Pouchitis only occurs once the pouch is functioning with faecal content and the gut's natural bacteria passing into it. It is responsible for around 10% of pouch failures necessitating the removal of the pouch and the formation of a stoma - an artificial opening in the bowel created by a surgeon to collect waste. The bowel is diverted and placed on the abdomen. This requires the patient to wear a bag or a stoma appliance and emptying it daily.

Currently, there is a lack of understanding about what drives pouchitis. Previous studies, including a recent study (see above) by our group, suggest that its onset is encouraged by:

- Bacteria, through an imbalance of the bacteria present in the pouch;
- The patients' own immune system;
- The function of the natural bar-

rier of the gut lining.

Patients' immune systems and their natural gut barrier functions are thought to



play a significant role in how their bodies respond to bacterial imbalance in the gut.

Addressing the challenge

We propose to study changes in the natural barrier function of the pouch lining as well as the key cells that determine the immune response. This is with a view to assessing their roles in the breakdown of tolerance and the onset of inflammation in response to the bacteria present in the pouch.

This study will:

- 1. Enhance our understanding of the key mechanisms responsible for development of pouch inflammation and the factors responsible for inflammatory bowel diseases as a whole;
- Contribute to our knowledge of new potential targets for treatment.

Patient recruitment

Patients undergoing IPAA surgery will be recruited from St Mark's surgical unit. We aim to recruit 10-15 patients with UC undergoing this type of surgery. Mucosal biopsies (samples from the gut lining) will be

taken from ileostomy and pouch mucosa at the time of the closure of the ileostomy.

Post-operative patient monitoring

• A pouchoscopy will be performed at six months and a year

- following ileostomy closure and samples from the pouch lining taken.
- In addition, patients will be assessed:
- Clinically using the Pouch Disease Activity Index;
- Endoscopically and histologically at each interval following ileostomy closure.

Samples will be analysed to look at the anchors, known as tight junctions, that link the cells of the pouch lining together, maintaining the barrier function. In addition, the following will also be assessed:

- The type and the function of dendritic cells, using laser technology;
- The natural chemicals produced by the immune system that determine the type of immune response the body makes that is tolerance or inflammation.

We hope this will enlighten us on how patients' immune systems and natural gut barrier functions react when the make-up of gut bacteria is compromised, thereby encouraging pouchitis, and that with this knowledge we will be able to contribute to the design of new therapeutic targets for this group of patients.



2. Faecal transplantation

Our group at St Mark's Hospital has spent over 20 years investigating the causes of pouchitis. We have recently shown a different, less diverse composition of gut bacteria in pouches of ulcerative colitis patients compared with FAP pouches and in particular in pouches of ulcerative colitis patients with pouchitis.

Interactions between the immune system and the bacteria in the gut are likely to be important factors in the development of inflammation. Dendritic cells in inflammatory bowel disease are increasingly recognised for their function in regulating intestinal immune responses. Dendritic cells continually survey the gut contents, enabling tolerance of good bacteria and recognising harmful bacteria. Our group has accumulated knowledge of the role of dendritic cells in regulating inflammation in the gut in response to bacterial signals.

A probiotic treatment for chronic pouchitis has been shown to help prevent pouchitis. This probiotic has been proven to increase the diversity of the

Faecal transplantation has been used effectively to treat *clostridium difficile* colitis, which is thought to be due to a reduction in bacterial diversity and antibiotic selection of harmful bacteria. Faecal transplantation has been shown to change the bacteria in the gut of patients to the healthier composition of the stool donor.

We aim to assess the changes in the balance of the pouch bacteria and the immune system responses following faecal transplantation in patients with chronic pouchitis. The objectives of the study are to:

1. Show that faecal transplantation is an effective means of improving the diversity of the gut bacteria and reducing the presence of antibiotic

resistant bacteria

2. Demonstrate that increasing the diversity of the bacteria will lead to a reduced inflammatory immune system response and a reduction in pouch inflammation.



We propose to study the immunological and microbiological effect of faecal transplantation in patients with chronic pouchitis, assessing the effect of faecal transplantation on the bacterial sensitivities, the diversity of the pouch bacterial

community and the effects on dendritic cell function.

Patients with chronic pouchitis will be identified. Patients and their nominated donor will be fully informed of the aims and process of the study verbally and by written information sheets and consent will be obtained. We aim to recruit 15 patients to the

is on den- disease in g

study. Healthy donors will be screened for potentially transmissible illnesses.

What happens next

Stool donors will be asked to provide a stool sample prior to faecal transplantation. Then 30g of stool will be mixed with 50ml of sterile saline and homogenised; 30ml of donor faecal suspension will then be instilled via a tube passed into the stomach. The tube will be removed and the patient will immediately resume a normal diet and general activities.

Bacterial DNA will be extracted for analysis from the donor stool as well as from biopsy samples from the patient before and four weeks following faecal transplantation. For patients in clinical remission after four weeks, stool samples will be taken monthly for analysis for a further two months after faecal transplantation. Dendritic cell type and function will be analysed from biopsy samples before and after faecal transplantation and the natural chemicals produced by the immune response in inflammation will also be assessed.

Desired outcome

We feel that the results of this research will have important implications for pouchitis therapy in a number of ways. Faecal transplantation could reduce the exposure of patients to long-term antibiotics and their potential side-effects, and by decreasing or treating bacterial resistance reduce pouch failure secondary to medically-refractory pouchitis.

It is also possible that the results may lead to new treatments for the management of inflammatory bowel disease in general. This study will have

significant implications on the potential opportunities for the use of faecal transplantation as a treatment for pouchitis and other inflammatory bowel diseases, potentially leading to clinical trials of faecal transplantation in the near future and clinical application within five to 10 years.



gut bacteria and has also been shown to cause dendritic cells to become more tolerant and reduce immune system signals that trigger inflammation. However, clinical experiences of probiotics for pouchitis are disappointing.

Increasing the diversity of the pouch bacteria and reversing the selection of resistant bacteria may reduce the immune response and prove an effective treatment strategy for pouchitis. One way to increase bacterial diversity is by faecal transplantation.

The Clark clinic

How well do you know your pouch? Far better than anyone else - after all it's yours and it has played a key part in your life since you first had it. But there are many other aspects to pouchdom – as Sue Clark explained in her lucid Information Day talk "Pouches – why and how". Here are 10 of them.

Fact One:

Bottoms up!: Better medication and drugs like Azathioprine mean that when operating on children pouch surgeons can sometimes keep that vital last foot – the rectum. "In adults what tends to happen is that ulcerative colitis in the remaining colon – ulcerative proctitis – makes life pretty miserable and the function is pretty poor and generally you need to remove the rectum as well," said Sue.

Fact Two:

Old and new: The old-fashioned way of removing the large bowel before the first pouch in the mid-1970s was the ileostomy. "You bring the end of the ileum out through the abdominal

Hospital, Harrow, in 1978. He was assisted by his registrar Mr John Nicholls, one of the Red Lion Group's patrons and until recently St Mark's Hospital's clinical director.

Fact Five:

There are three types of pouch, the S-pouch, J-pouch and W-pouch. See diagram at bottom of page.

The first, the S-pouch, was devised by Sir Alan Parks and John Nicholls (see previous fact). The second, the W-pouch, looks like a multi-seamed rugby ball, is the largest pouch and is very tricky to make. Which is why most surgeons use the J-pouch which has fewer seams and is less prone to leakage.

Fact Seven:

Temporary ileostomy: Most pouch-owners have temporary ileostomies between their first and second pouch operations. This allows the newly-formed pouch to settle and thus helps prevent leaks after the pouch is closed.

Fact Eight:

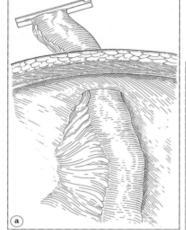
Failure rate: Approximately 15 per cent of pouches fail, according to figures taken over a 15-year period. Previous uc sufferers are more likely to face pouch failure than those with FAP. This is because those with polyposis have no inflammatory problems "and therefore are less likely to get inflammation of the pouch – pouchitis – and are much less likely to get inflammation around the anus," said Sue. Patients with failed pouches invariably need a permanent ileostomy.

Fact Nine:

The average pouch-owner goes to the loo six times in 24 hours – five times in the day and once at night.

Fact Ten:

Rashes are not uncommon among uc sufferers. They are known as *erythema nodosum* - or large red blotches which usually appear on the legs - and *pyoderma gangrenosum* or random purple-red patches. "I think people have a range of skin rashes because they are ... debilitated, malnourished and chronically ill.... When you have had your bowel removed, they tend to be less bad and are also treatable," said Sue.







wall and then you turn it slightly inside out to make a little spout (See illustration above).

Fact Three:

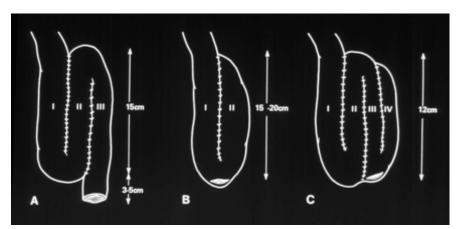
FAP facts: A small minority of pouch-owners have FAP before having a pouch fitted. The vast majority – just over 85% – have ulcerative colitis

Fact Four:

First pouch: The first pouch was formed by Sir Alan Parks at St Mark's

Fact Six:

Cuff links: What does the "cuff" refer to in pouch surgery? It is the lower 1-2 centimetres of the rectum and joins it to the anus. Cuffitis is when this area is inflamed which occasionally happens to patients with ulcerative colitis.



Ring my bell

New Liaison Officer, David Skinner, recounts how he was persuaded to allow himself to be elevated to the dizzy heights of the Red Lion Group Committee.

My new telephone brrrrr brrrrrd, brrrrr brrrrr'd, it didn't trill, cheep or play sounds, it was a proper piece of communications kit from the 1950s. A

black Bakelite job, its lead ofbrown cabling would not have looked out of place on a baby's Arran jumper. The shiny dial meant no more listening to tiresome menus. No more pressing "1" if I want to renew my insurance policy, or "4" if I need to hear the whole list again, no buttons you see. Perfect.

"Yes" I said into the mouthpiece. No answer, I could hear a lot of crackling

and static. It reminded me of the old black and white war films when the fighter pilots were talking to base and their RTs [radio telephones] were on the blink.

My mind was whirling; Andrew was asking me to be the Liaison Officer of a Wild Life Club that specialised in lions. Absolutely fantastic, I accepted on the spot, "Delighted" I shouted over the static. Must be good for at least one safari a year I thought. It had been years since my last trip to South Africa but I was already looking forward to my next.

Of course going on safari this time would be a very different kettle of fish. No colon to keep me company and emptying the old pouch in the bush would be more than a little problematic, what if a lion caught me with my pants down.....liaise I said to myself.

I eagerly awaited my first committee meeting - Andrew had said this would be by telephone conference. I wasn't convinced Betty was up to this (I'd named my new telephone by now) but I'm sure Betty and I would muddle through somehow. Several people



David Skinner: RLG's new liaison officer

introduced themselves but the static and crackling down the line was playing havoc with my listening ability and I only kept getting snatches of words... action day...day of action...fighting funds...commitment...progress... constitution.

All this was providing a lot of food

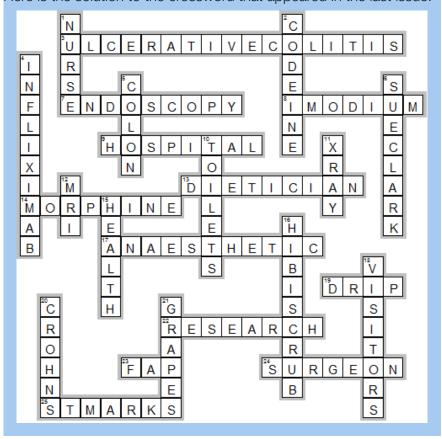
for thought, I mused, not one mention of safaris or wildlife.

Then a slightly Caledonian-accented voice said ".....and that concludes the meeting of The Red Lion Group." I dropped the receiver, open-mouthed and in deep shock, it would appear that I had got my self immersed in some Scottish nationalist independence group...by mistake.

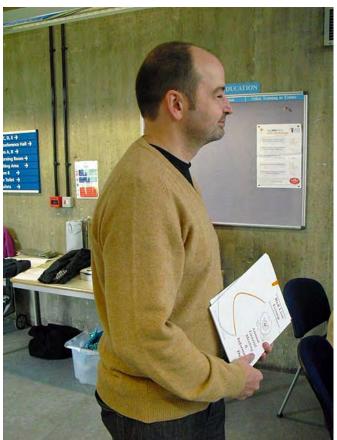
David was diagnosed with ulcerative colitis in 2000. He had his colon removed in April 2008. Six months later, accompanied by his ileostomy bag and double hernia, he ran the Chicago marathon. He blames his appalling time of 4 hours 28 minutes on the 29°C heat. Thanks to the blinding surgical skills of Sue Clark and her team and the staff of St Mark's, David is now the proud owner of a new pooch. They often go for long runs and are both very happy together.

Crossword Solution

Here is the solution to the crossword that appeared in the last issue.



Photos from 2011 Information Day
Christopher Browne borrowed Andy Watts's camera and took these photos to record some of the happenings at Information Day in April.







Clockwise from top left: (1) Watching brief: Steve Bowes-Phipps, husband of Red Lion secretary Sarah, waits for the next speaker. (2) Red Lion cub: Nine-year-old Olivia Jobes from Leeds, who had her pouch op aged four, with her parents, Richard and Helen, in the St Mark's Hospital gardens. Is this a world record? (3) Is it a medical instrument, a microphone or a bottle of wine? Red Lion vicechairman Andrew Millis (right) presents Dr Jonathan Landy with a bottle of red (4) Question time: St Mark's research fellow Dr Jonathan Landy makes a point during his Information Day talk on pouchitis.



Contact the Red Lion Group

CHAIR

Morag Gaherty
16 Hill Brow
Bearsted
Maidstone
Kent ME14 4AW
Tel: 01622 739034

Kent ME14 4AW Tel: 01622 739034 Fax: 020 7691 9527 chair@redliongroup.org



TREASURER
Marjorie Watts
11 Meadow Way
Upminster
Essex
RM14 3AA
Tel: 01708 5012

Tel: 01708 501273 treasurer@redliongroup.org

NEWSLETTER EDITORS



CLINICAL NURSE SPECIALIST

Zarah Perry-Woodford St Mark's Hospital Northwick Park Watford Road Harrow HA1 3UJ Tel (work): 020 8235 4126 pouch@redliongroup.org



VICE-CHAIR

Andrew Millis 142 Tavistock Road, FLEET GU51 4HG Tel: 01252 623674

vice-chair@redliongroup.org



CONTENT
Christopher Browne
89 Fulwell Park Avenue
Twickenham
TW2 5HG
Tel: 020 8894 1598



EX-OFFICIO
John White
44 France Hill Drive
Camberley GU15 30

Camberley GU15 3QE Tel: 01276 24886 john@redliongroup.com



SECRETARY

Sarah Bowes-Phipps 84 Centaurus Square Curo Park Frogmore St Albans AL2 2FH

Tel: 01727 875156 secretary@redliongroup.org

LAYOUT
Tim Rogers
30 Amberley Gardens
Epsom KT19 0NH
Tel: 020 8393 6968



Lorraine Howell 125b Welldon Crescent Harrow HA1 1QJ Tel: 020 8723 4801 lorraine@redliongroup.org

PRESIDENTSue Clark

NOTES SECRETARY

Christine Lawton 19 Nathans Road North Wembley HA0 3RY Tel: 020 8904 7851

notessecretary@redliongroup.org

LIAISON OFFICER

roar@redliongroup.org

David Skinner
23 Halcyon Way
Hornchurch
Essex
RM11 3ND
Tel: 01708 455194
liaison@redliongroup.org



PATRONS







Lynn Faulds Wood

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 Christopher Browne 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 newsletter bursting with life and information and make reading about pouch issues fun and stimulating.

Please send your articles, letters and ideas to:

Tim Rogers
Roar!
30 Amberley Gardens
Epsom
KT19 0NH

or roar@redliongroup.org

Visit Our Website www.redliongroup.org



