

ROAR!



ISSUE 33 • NEW YEAR 2006

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

Regional Reps

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

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



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Let Christine Put You in the Picture

If you want a new image speak to Christine Lawton – literally. For our notes secretary has been using her photographic skills to produce some exclusive Red Lion greetings cards.

Christine and her Leica camera are virtually inseparable on outings, holidays, social and official events – and to very good effect. For she has produced some eye-catching images of birds, animals and country life (see the examples above and below).

Though the cards are a little late for Christmas 2005, you could use them for next year – or an upcoming birthday, wedding, anniversary or any other event that appeals. The cards cost £1 each or £5 for six (plus p&p) and Christine is generously donating 70p each to the group. You'll see more examples of Christine's work through out this issue of *Roar!*

Order your cards from Christine on 020 8904 7851 or email her on christinelawton@aol.com. Very many thanks and a Happy New Year Christine.

Christopher Browne





Greetings comrades and co-pouch-holders and a very happy new 2006. I bring you tidings of great joy. After a vexing few weeks trying to find a new membership secretary, the committee got a seasonal surprise. Our former secretary Inez Malek said she was willing to do the job. Phew! We can throw away all those recruitment ads we drafted for *The Times* and *Daily Telegraph* (not). We can also shed several thick Christmas coats of anxiety.

I'm sure you'll all join the committee and me in welcoming Inez and give her every encouragement in her new role. We are very grateful to her. We are

studies at the University of Bath show that tablets carrying traces of the Class C drug may help relieve the symptoms of uc and Crohn's disease

equally grateful to Marion Silvey who has done the job for several years with quiet aplomb—and, I may say, unerring efficiency. She also helped save my skin.

With more bravado than sense perhaps I said I would set up new contacts with hospital stomacare departments. However I found that despite countless voicemail messages I got just two positive replies. Marion was more successful. When I men-

tioned my dilemma to her she bravely said she would carry on the task and managed to set up a database of interested hospitals.

Thank you very much Marion and our warmest wishes to you and your husband for the future.

Top Marks

St Mark's Hospital is known as brand leader in the pouch trade. Jo Wagland was until recently its stomacare nurse specialist. She was also a co-opted member of the committee—our medical consultant if you like. Jo has now moved with her husband and tiny daughter to a similar post at the University of Southampton Hospital (see Mike Dean's tribute on page 7). Good luck Jo. We'll miss you.

Her successor is Zarah Perry-Woodford, a member of the St Mark's stomacare team. We'll soon be inviting her to join the Red Lion committee as a co-opted member. Our very best wishes Zarah and we look forward to doing business with you.

The Cannabis Connection

Did any of you read the reports about cannabis and uc in the *Daily Telegraph* (yes, that paper again) and *Gastroenterology* magazine?

They said that studies at the University of Bath show that tablets carrying traces of the Class C drug may help relieve the symptoms of uc and Crohn's disease. Experiments with canniboids—extracts of cannabis—showed that they help the body recover from some of the side-effects of these two diseases and can also heal the lining of the gut.

As most of us know, steroids and surgery are the usual way to treat these

conditions. Despite intensive research at St Mark's, the Oxford Radcliffe Hospital and Imperial College, London, there is currently no cure for either, although leading gastroenterologists like our president Professor John Nicholls believe there will be one for uc in five years' time.

Information Day 2006

It'll soon be that time of year again. Yes, Information Day is on Saturday 8 April this year, so get out your pens and pencils and write it into your diaries and calendars. We've got some great speakers, all the latest research on uc, polyposis and pouches and a series of workshops so you can really get down to the nitty-gritty about your problems and experiences.

I live, breathe and almost eat chunks of the the pithy prose that you pouchees and readers send

Prescriptions for Success

I sent out at least four pairs of Red Lion letters to help clinch free prescriptions for RLG group members. I hope they worked. Please let me know how you got on by emailing cbrowne@brownemedia.co.uk

Lively Letters

I hope all of you manage to read Susan Walls's delightfully written article about uc, HRT and the menopause. It's based on Susan's own experiences as well as some intensive research she has done on the subject.

The article should provoke some lively letters so keep 'em coming. You know Tim Rogers and I live, breathe and almost eat chunks of the the pithy prose that you pouchees and readers send us.

As Tim is doing the layout and I am doing the content for the next two Roars, please send all letters to me at 89 Fulwell Park Avenue, Twickenham, Middlesex TW2 5HG.

Life After Brian

Morag Gaherty pays tribute to her husband—founder member and former chair of the Red Lion Group.

I would like to thank everyone who took the time to contact me after the article I wrote in the last issue of *Roar!* about Brian's death. I was very touched by the number of calls, letters and e-mails from you all, expressing your sadness and telling me how much inspiration you took from him over the years. I know he would be pleased to know that he had helped even people he had never met.

Bob, Tom and I continue our day to day lives. I am so proud of how well the boys have coped so far. Both are sad to have lost their Daddy, but they have

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carried on being the boys they always were. Every now and then we have a cuddle and a bit of a cry, and then they pick themselves up again.

It can be disconcerting for strangers: I pity the number of postmen and meter readers who have had the door opened to them by Tom. They inevitably ask "Is Mummy or Daddy in?", to which they get the cheerful reply "Daddy's dead!", before he dashes back to the TV or wherever. That certainly puts a strain on the subsequent conversation.

This weekend I took the boys to visit the grave for the first time since Brian died, at their request. They think he is buried in a lovely peaceful location, and I'm glad they approve. In due



course, they will help me choose the wording to be put on a headstone, which will be another way for them to be close to him.

On a practical level, I am coping well, and am lucky that Brian left me financially secure, so that we do not need to think about moving home or

The trouble is,
people expect
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and weepy all the
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And that stops
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me going out to get a full time job. I have found, however, that there are many unexpected emotional issues, and am considering going for bereavement counselling to deal with these. The trouble is, people expect you to be all sad and weepy all the time, which is not

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how I feel at all. And that stops me from discussing my real concerns with them. Talking to someone impartial will hopefully help with this.

Thank you all once again for your kindness and consideration. I hope to be back writing more material for *Roar* in due course, when I feel ready. Thank you also to Chris for taking over the reins on the newsletter during this time for me, and to the rest of the committee for their invaluable support as well.



Living With a Pouch—Or Had I Forgotten?

Christine Lawton reflects on the positive effect a pouch has had on her life.

In March 2001, I had Jpouch surgery at St Mark's Hospital after years of UC and after 23 years with an ileo-rectal anastomosis, which was the result of removal of most of my colon because of extensive UC. After repeated bouts of UC in what was left behind, and spurned on by some biopsy results, my surgeon and I agreed that I would be better off without the rest of my colon and I was consequently offered the choice of having a Jpouch or a permanent ileostomy. After much agonizing and research, helped, I have to say, by the Red Lion Group, including the late Brian Gaherty, who was a great help and support to me and whose unstinting work for RLG will always be fondly remembered, I opted for the Jpouch, which, thank you to everyone involved at St Mark's, has been a resounding success.

For over 40 years I have written verbatim Pitman's Shorthand, for which, longer ago than I care to remember, I gained a certificate for 230 words a minute. All my life I have been a verbatim shorthand writer, beginning my career taking the official record in jury trials, for two years in the House of Lords Hansard and also tribunals, arbitrations, company meetings, courts martial and disciplinary hearings for the police and the military. My job involves obviously sitting for long periods and taking breaks only when a break is announced. Consequently I wondered whether my new pouch would allow me to do this again, or whether I should be forever at home transcribing tapes.

After a trial run, I found my pouch worked like a dream and I didn't need to ask for comfort breaks in between those that were scheduled. I am happy to say I have never had to ask for one. I find I can cope with journeys to and from work, even long bus journeys which I sometimes take into London instead of the train, just for a change of scenery. I do all my transcribing at

home so I don't have to travel every day, but even if I had to, I feel I could cope with it. I still carry round a small supply of cotton wool, which I find helps with soreness, although I rarely get that these days. Sometimes I eat a cake or something which is too sweet and that will start a bit of irritation but it soon goes away.

I find I can eat practically anything, although I do find some types of chocolate send my pouch into over-drive, as does cinnamon, which I dislike

This can be very handy at times!

When I attend information days and hear the lectures about what happens to one's body in the process of receiving a Jpouch, I can hardly believe I am one of those patients.

Besides my work, I have many other interests, including painting and photography. I have started to make greetings cards from my photographs and would like to sell some in aid of RLG, so please look out for some when you come to the next informa-



anyway so I do not find that any hardship.

I also find that I can carry my working briefcases, etc, without a problem and sometimes they can be quite heavy. In fact I can carry very heavy weights and have always been able to do this, although I wondered whether the Jpouch would make a difference. Maybe doctors wouldn't recommend it but it has never had any ill effect on me.

I think it took about 2 years, really, for my pouch to reach perfection and it has improved even more since then. It seems to have a bigger capacity and thus quite a long time can pass between the desire to empty it and the imminent need to do so.

tion day.

Being a Friend of the Royal Botanic Gardens, Kew, I pay frequent visits there and go on many of their walks and coach outings. I can cope with a three hour journey without any urgent need for comfort stops. I also visit London Zoo where I have studied animal drawing and still keep up practice with a group of artistic friends. I also visit art galleries and go to the meetings of the Harrow Art Society. I find all these things very stimulating and I like to keep my brain active as they say it helps to combat ageing! However, I do feel younger now, at 59, than I did at 29 when I was suffering from UC.

I'm still pinching myself!

Collision Course with the Menopause

HRT or not HRT? That is the question that Susan Walls wrestles with.

A few years ago, my GP made me a promise: the autumn of my life would be golden. As I got older, he said, my immune system would be come less reactive, the pouchitis would improve, and I'd feel stronger, fitter and less tired.

It all sounds plausible. But he missed out a fundamental part of growing older, at least for women. There's a dirty great boulder blocking the path to these mythical golden years—and it's called the menopause.

If you're a woman with ulcerative colitis, you already know that hormones have a major effect on the course of your illness, for better or worse. Some UC and pouchitis sufferers feel fantastic during pregnancy; others develop the first symptoms of disease when pregnant. Some women feel ill around the time of their periods; others feel better than usual. Hormones cause upheaval. But if you think it's hard to live

with them, just try living without them for a bit.

I crashed into menopause a couple of years ago, around my 45th birthday. No warning—just one big bleed, and that was it: bye-bye hormones. Then came the hot sweats, the panic attacks, the grumpiness and all the other unpleasant stuff that happen when you remove the sex hormones oestrogen and progesterone from a woman's body. But if the woman's body in question happens to also have an auto-immune disease, the results can be catastrophic. For me, the hot sweats didn't matter much – I was up all night with pouchitis and sore joints anyway.

Around the time of my menopausal crash, I happened to interview a top-notch gynaecologist, Professor Mark Brincat, who runs the Depart-

ment of Obstetrics and Gynaecology at St Luke's Hospital in Malta. He's also a member of the International Menopause Committee. Professor Brincat told me two things that I think you ought to know. The first is that having an auto-immune disease pre-disposes a woman to have an early menopause. The second is that your immune system needs oestrogen to function smoothly.

The exact role of sex hormones in auto-immune disease is complex – every hormone has a different effect on

brain sharp, your libido firing, and your immune system running smoothly. What's more, oestrogen has a protective effect against some cancers – notably bowel – and continuous combined HRT can protect against endometrial cancer. But anything that has an effect will have a side effect. And oestrogen's powerful effects need to be balanced against the increased risks of some diseases, particularly breast cancer and possibly strokes.

In Summer 2002, an American study into the effects of HRT on post-menopausal women was stopped early, because of increases in breast cancer, heart disease, stroke and blood clots among the women being studied. The abrupt ending of the Women's Health Initiative (WHI) caused an international hoo-ha. Clinicians and scientists nervously re-scrutinised their data. New guidelines were issued. The press went into a

feeding-frenzy, and stories about killer hormones appeared in every newspaper in the developed world.

Now the dust has settled on the fallout from the WHI study, it's worth examining the considered reactions to it, so. An RCOG (Royal College of Obstetricians and Gynaecologists) study group recently recommended women should take HRT for five years only. But many of the eminent clinicians who took part in the study group disagree with that decision. Professor John Studd is one of them. He describes the five-year figure as 'nonsense'. He and many other doctors believe that the WHI study was flawed in every way. 'The WHI used a wrong population, of the wrong age; treated them with the wrong hormones, and then came to the wrong conclusions about their own data,' he says.



a different part of the body's immune system. But several studies have shown that oestrogen has a direct influence on inflammation-causing chemicals: as oestrogen levels fall, the amount of these chemicals increases in the body.

So the big question is, should you take HRT? For me, the answer was an unequivocal 'yes'. Within days of starting hormone therapy, I felt better than I had in years – not only did the pouchitis disappear, but I felt bouncier, happier and calmer. Within weeks, my skin looked better too.

But the downside of HRT therapy will not have escaped your notice. Before you reach a decision on HRT, you need to do a cost benefit analysis, taking into account your family history, and what you think is important for quality of life. Oestrogen keeps your skin young, your bones strong, your

For starters, most of the women on the study were too old to be starting HRT – they had an average age of 63, and almost a quarter of them were over 70. Interestingly, all the women in the study who suffered heart and stroke problems were in the 70 plus age group.

Then there's the matter of the type and dosage of HRT. The WHI women were given the equine oestrogen, Premarin (whereas most doctors in Europe prescribe estradiol, which is the human version of the hormone). And all the 20,000 women in the study were given the same dosage. 'One dose can never be appropriate for all patients,' says Professor Studd. 'Different women require different doses by different routes, with different combinations of different hormones for different symptoms with different surgical status, and for different ages.' Finally, the WHI women were given a combination of Premarin and continuous progesterone, which means they got the same, combined, dose every day (rather like taking the pill).



Most doctors don't recommend this type of HRT, and certainly don't routinely prescribe it for elderly patients – especially not fat, unhealthy ones. Amazingly, most of the WHI women were overweight, and almost half of them were on hypertensive drugs. 'They were

years of taking the hormone. This risk is about the same as drinking alcohol every day; being overweight; having a late pregnancy; a late menopause; or not having any children at all (and when was the last time you read an article about how not having kids will give you cancer?).

HRT may not be for everyone, but it certainly worked for me. If you do decide to take it, you'll probably need to play around with the dose and delivery system. I find a gel works best, with progesterone tablets for ten days a month. You may also need to find a sympathetic GP. I've got a new one, who sees HRT treatment as an important tool in managing my auto-immune disease.

If you'd like to discuss any of the information in this article, you can contact me at:

susanwalls@jungle9.freemove.co.uk

Have you had any experiences of uc, HRT and the menopause? If you have, we'd really like to hear from you with a letter to Roar! Please send it to Christopher Browne, 89 Fulwell Park Avenue, Twickenham, Middlesex TW2 5HG.

not a healthy population and not at all comparable with the patients usually treated with HRT in the UK,' says Professor Studd.

Most doctors agree that appropriate HRT raises your risk of getting breast cancer by 1 in a 1,000, after 10

Farewell to Jo

Red Lion vice-chair Mike Dean pays tribute to St Mark's Hospital's Jo Wagland—former RLG committee member, pouch specialist and friend

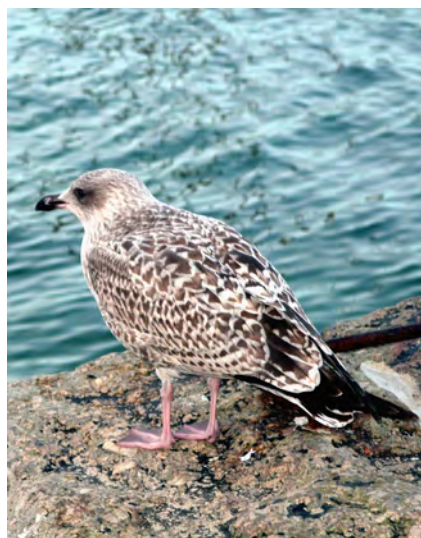
When Julia Williams our first Pouch Nurse Specialist left us three years ago to take up a new post I wondered who would follow her, but my fears were allayed when she introduced Joanna Sweeney as her replacement.

Jo and I hit it off straight away and we became very close associates. Over the last three years we built up a very good rapport and indeed Jo has been outstanding in the promotion of the Red Lion Group. We have often had some very strange phone calls when she has tried to enlighten me as to the intricacies and vagaries of bums and motions.

This has not always endeared me to my colleagues at work, but then again the look on their faces has been priceless. Yes, to many people the subject is still taboo and to quote from the "Good Life" when Margo referred to it as "nasties" this still holds true today even amongst our more broad-minded generation..

Anyway I digress, after a year or so in the post Jo then became Joanna Wagland and a little Wagland shortly followed, young Jessica. Even though Jo changed her hours, being a busy working mum, she still continued to be available at the end of the phone for anyone who needed professional advice, irrespective of whether they were a RLG member or had just seen our posters or website and were in desperate need. She worked tirelessly arranging speakers for our information days and I must say there have been a few hitches along

the way but there you are that is life as they say.



Jo and her husband decided that with the addition of Jessica they wanted a change in lifestyle away from London, hopefully around the New Forest area, and Jo has secured a new post at Southampton University Hospital.

It has been great working with Jo and we will certainly miss her contribution. Although

Jo is not based at St Mark's she still has the RLG very much to heart and will continue to champion the Red Lion Group in her new position.

Mike Dean

Living with Rita

Sandy Hyams looks back on ten years living with Rita.

Ten years ago this summer, Stromboli the Stoma was superseded by Rita the Reservoir*. Put like that, the process sounds easy and straightforward—but we know better, don't we? A decade on, memories of the pain and discomfort of the early days have faded. Life, though it will never be completely "normal" again, is enjoyable once more.

Shortly after my pouch operation someone, who was two years down the line (and should have known better), told me that that was as good as it gets. I had to inform her that she was wrong.

The agreed consensus was to try a food once to gauge the effect and, if it was adverse, to attempt it again a few weeks later. To my regret, over-indulging in fresh fruit was nearly my undoing that summer.

Garlic, onions, strong blue cheese, mushrooms, sweet corn, nuts, coffee and wine (the usual suspects): all were taken in small amounts with varying degrees of success. I never left home without disposable cleansing wipes and a barrier cream.

For the first couple of years I was

was shocked out of my complacency by a bout of pouchitis. A course of antibiotics quickly sorted me out. However, I was plagued with it for two or three years, every six months or so. I kept a supply of the antibiotics in my travelling medicine bag, just in case (it's still there, unused five years later). Unfortunately, the medication gave me thrush, so I also had to take *Acidophilus* in conjunction with the antibiotics. Trust me, it works.

I still take medicine to slow down or thicken my output, though one tenth of



Yes, the frequency and urgency of visits to the loo had diminished after two years, but other things had improved with time too.

At the start I kept a meticulous record of what and when I ate—and my reactions. Up to 12 visits a day was the norm for the first few weeks. Now it is five or six times daily. Ten years ago professional advice on diet was sadly minimal—trial and error seemed to be the only solution. (However, since then the Red Lion Group has produced the booklet *Healthy Eating for People with Pouches* with the backing of Dansac.)

careful of what I ate, and then I grew more adventurous. I can now eat or drink practically anything I want, and delight in cooking my husband's favourite meals, including exotic hot and spicy dishes. I still avoid raw onions—but then they always did give me indigestion.

Cheap, coarse wine also affects me—a good excuse to indulge our passion for fine Spanish wines. Sometimes after dining out I suffer that old familiar sore bottom, but not often and Sudacrem soon alleviates it.

Nearly two years after surgery I

what I needed initially. Just two codeine phosphate tablets and one Loperamide each day seem to do the trick. Leakage was a problem in the early days as well as the occasional "accident". Thankfully, these episodes are few and far between now, although I continue to wear panty liners for that added security. Explosive noises at times are still an embarrassment when using loos away from home, an ongoing problem that will probably never be solved—unless readers have any suggestions.

I wonder if I am unique in not having to have annual check-ups. After

five years my surgeon decided that I didn't need them, although of course I could always contact him if there were any problems.

So, what are my thoughts after ten years of living with a pouch? I can eat and drink what I like. My body image (forgetting the spread of middle age-

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plus!) is positive. I can wear clothes that I didn't dare with an ileostomy, including a bikini in hotter climes. And I can travel without all the paraphernalia that I needed with a stoma.

Reading about the tales of woe, the continuing pain, pouchitis or leakage, the emergency trips to hospital, that some pouch patients have had to bear, I realise how lucky I have been. Rita the Reservoir is no flash in the pan, but a success story.

*Stromboli was so-called because he was always erupting; Rita because my digestive system had to be re-educated



Polyposis Day will be too good to miss

What happens when an event attracts too many people?

The organisers panic, call a series of meetings and then cancel at the last minute. Unless of course they're Mike Dean. When a recent St Mark's Hospital event was threatened by overspill, Red Lion's vice-chair coolly put on a second event to cope with the extra people.

The St Mark's Polyposis Registry had expected 80 to turn up to its first-ever Information Day. Then, to its surprise, 140 applied. "We couldn't turn all these people away so we arranged to hold another event in May this year.

It just so happens that 80 is the maximum number that health and safety rules will allow us in the hospital area,"

says Mike who ran the event with his wife and Red Lion secretary Margaret.

The event was held on 12 November and led by Kay Neale, the Polyposis Registry's registrar. It featured six talks and six lively workshops on coping with FAP – familial adenomatous polyposis.

Among the speakers was Registry director Professor Robin Phillips who discussed surgical options for FAP, Kay Neale who spoke about the genealogy and risks of inheriting FAP, Ripple Man on 'Polyps and You' and nurse specialists Sandra Burke and Jacquie Wright on FAP's causes, effects and after-care.

Despite the overspill there are still spaces for the second Information Day. To find out more log on to www.polyposisregistry.org.uk.

Christopher Browne



Margaret Dean



Mike Dean



Professor Robin Phillips, Polyposis Registry Director

Letters

As a pouchee of 13 years, I felt I had to pass on this amazing new cure for sore and itchy bums. In 1992 I had surgery at St. Mark's under Professor Nicholls for ulcerative colitis, and was given a new lease of life with a pouch.

This worked very well for about the first five years, give or take the odd bout of pouchitis. I was able to eat most things that were previously banned. Then gradually over the next five years things started to go wrong.

I was becoming more explosive at toilet times, with certain foods irritating my bowels, especially spicy foods and nuts. This got to the point that I was being forced to spend more and more time in a hot bath, as this was the only thing that gave me relief,

All the barrier creams that St. Mark's had given me to try had not worked. In some cases they caused more irritation than before.

I became so sore that my bowel movement ceased to function properly due to the pain caused by the inflamed area. St. Mark's then tried every X-ray

and scan possible to find out the cause of this problem, but to no avail.

I was now forced to drastically alter my diet because so many things were causing blockages and great pain. At this time I was using zinc and castor oil cream to try and relieve the soreness, until one day when I ran out of the stuff, my wife suggested I try some Germoline ointment instead.

I did, and the result has been amazing. I know I sound like a salesman for Germoline, but a little dab after every visit to the toilet has meant no more soreness or irritation.

My bowel movements have consequently become more regular, and although certain foods such as mushrooms, peas, sweet corn and nuts still cause me a problem, they do not cause any pain now.

While I do not know if this situation will stay the same in the future, I felt that I had to pass this on to anyone suffering from the same problems that I had.

Received via the website.

Get it in Your
Diary Early!

Red Lion
Group
Information
Day

Saturday
8 April 2006

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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- 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

Visit Our Website

www.redliongroup.org

Write for Roar!

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

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

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

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

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

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

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

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

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

Tim and Chris

