

Roar!



Produced as a courtesy by Dansac Limited

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

New Committee is Go!

The Red Lion Group had a second annual meeting on Saturday 27 April 1996 at St. Mark's Hospital's new home in Northwick Park. Tim Rogers was there to see what happened.

Julia Williams became the new Pouch Support Nurse at St. Mark's Hospital earlier this year. One of her first missions was to revitalise the Red Lion Group, and to this end she set about organising a second annual meeting, on a par with the meeting held in Syon Park two years ago to launch the group. Once again Dansac kindly stepped in to fund the event which took place at the new home of St. Mark's in Northwick Park Hospital, Harrow.

Mr Nicholls gave an informative and entertaining talk about the development of the pouch operation (complete with full-colour slides - not for the faint-hearted!). Julia

Williams then gave a brief talk about her role as the newly-created Pouch Support Nurse and her hopes for the development and growth of the Red Lion Group.

She was followed by Morag Pearson who went through some simple guidelines and tips on a subject dear to many pouch owners' hearts: diet.

After a delicious buffet lunch eaten in glorious sunshine on the balcony of the Himsworth Hall, the group split into workshops to brain-

The New Committee

Chairman	Dr Martin Peters
Treasurer	Peter Johnson
Secretary	Monica Melling
Liaison Officer	Morag Gaherty
Vice Chairman	Tom Deans
Vice Secretary	Inez Malek
Social Secretary	Sarah Myers
Newsletter Editor	Tim Rogers
Press Officer	Christopher Browne
Fundraising	Bill Worthington

storm future plans for the Red Lion Group. After tea a committee was elected and they agreed afterwards to meet up on Saturday 22 June to take things forward.



Dr Martin Peters



Peter Johnson



Monica Melling



Morag Gaherty



Inez Malek



Sarah Myers



Tim Rogers



Christopher Browne

In This Issue...

Rachel Abedi on how pregnancy affected her pouchp. 4
Christopher Browne investigates complementary medicinep. 2
Morag Pearson on eating your way to a better pouchp. 3
Lettersp. 6

Refreshing the parts others cannot reach

Drugs, medication and operations are today's answer to colon problems. However the future may lie in medieval apothecary jars, primitive healing and Chinese herbalism, *Christopher Browne* discovers.

Government Warning. Modern Medicine Can Damage Your Health. Such gloomy slogans often catch the eye of passers-by in London's Docklands or Brixton High Street.

Luckily, there is little evidence to support such a claim. The truth is that a blend of modern medicine and complementary cures can be an inspiring aid to recovery.

So let's stand up, shake off all negative thoughts, and spell out the unadorned facts.

We have all had surgery of one kind or another. The result is we've all got a unique, private part to be proud of, a part which we are not

Alternative therapies have surprisingly effective results

ashamed to own up to.

Perhaps you woke up in St Mark's, City Road, with a Nicholls W-pouch, or else found yourself in Frederick Salmon ward experiencing the after-effects of a Thompson J-pouch.

Some of us tell our friends about our PPPs (private, personal pouches), all of us tell our loved ones and a few of us tell our employers, employees, tutors, work colleagues or drinking companions.

Another feature we have in common is that we all want to get better. We may have had periods of codeine or loperamide dependence, a revision or two, perhaps an examination under anaesthetic. Such experiences are a vital part of the recovery process.

Although we may not like having to rely on drugs, medicines or operations, we are happy to comply if it makes our life easier and more bearable.

But, hark, there may be other more natural ways to help us through these tricky periods of rehabilitation.

If you had mentioned alternative or complementary medicines ten years ago, I would have chuckled and murmured: "Cranky, superstitious nonsense."

Ten years later, I am a different man. Older, and certainly wiser. For since my two operations, I have come across a number of alternative therapies which have had surprisingly effective results.

So let us look at these natural cures a little more closely.

First there is *homeopathy*. Most of use have heard of this alternative remedy. The principle is that an illness is a symptom and treatment should be holistic i.e. aimed at the whole person. Remedies are made up of small doses of natural substances that, in larger amounts, produce symptoms similar to the illnesses they set out to cure. These remedies stimulate the patient's immune system and help the body heal itself.

A recent St Mark's patient who had proctitis is convinced the homeopathic tablets she took before and afterwards helped to relieve the pain of her two operations.

The royal family are perhaps the most famous advocates of ho-

The royal family are perhaps the most famous advocates of homeopathy's healing powers.

meopathy's healing powers.

Healing. This is the most ancient form of medicine. It involves one individual (a healer) transmitting energy into another, a rite performed among many a prehistoric tribe. The energy then enters various healing zones and in many cases leads to complete or near-complete recovery.

I have been to several healers

and have noticed marked changes in my condition. You do not have to believe in any particular faith, just let yourself go and be relaxed enough to accept the healer's energy flow.

If you wish to see a healer in

Like healing, reflex therapy releases energy into specific healing areas and hastens recovery.

your area, you can contact the National Federation of Spiritual Healers (0932 783164). Member-healers rarely ask for money, just a donation to charity. Interestingly the NFSH has never been sued by a dissatisfied customer.

There are other healers - some famous, some quietly anonymous - who may be recommended to you by friends or relatives. Rates vary from £15 to £25 an hour. Even if, after the first consultation, you never go again, you won't have lost anything - apart from the cost of a good dinner!

Reflex therapy. This is not unlike healing. Using the feet, the reflexologist is able to penetrate the two nervous systems (central and autonomic) and relax muscle and nerve areas that were previously tense or strained.

Like healing, reflex therapy releases energy into specific healing areas and hastens recovery. I have found reflex therapy particularly effective in getting over the two pouch operations.

Reflex therapy - often called reflexology - is a superb remedy for back pain, too. You may have had lingering problems after your operations. A few visits to your local reflex therapist could be the answer to all that.

Acupuncture is a system that

Continued from previous page

penetrates pressure points in the body using tiny needles. This opens up and relieves stressed and damaged areas, waking up the brain's own pain-killers, known as endorphins. Acupuncture, which was first developed in China, has a growing following in the West.

Among other popular complementary cures is *aromatherapy*, in which the therapist uses scented oils on selected areas of the body, helping to reach the parts the others cannot reach!

Many people also find *herbal* remedies help cure the body of its ailments, complementing their daily food intake with natural herbs, minerals and vitamins.

Psychotherapy and *counselling* can help with post-operative stress and sleeping problems, while *meditation* and *massage* are proven aids to relaxation and pain relief.

If you want to find out more about *complementary cures*, you will find individual practitioners in your

the most ancient form of medicine...performed among many a prehistoric tribe

local Yellow Pages or at health centres in your home town or village.

There are some centres and complementary curers who overcharge and overplay their qualifications. But you can usually spot these after the first visit or two. If in doubt, see if the practitioner belongs to an official association or governing body.

Your doctor might have some useful ideas. More and more of today's GPs prescribe alternative medicine for their patients. My GP, for instance, is a practising acupuncturist.

So, if conventional medicine has not quite worked its magic, or you would like another, more natural second opinion, why not give complementary medicine a try?

You will not be alone. In 1995, five million British patients consulted complementary practitioners.

Top Diet Tips

Morag Pearson, the St Mark's dietician, gives some sound advice on eating your way to a better pouch

When planning their diet, a pouch patient should ask themselves two questions: "How am I going to achieve an adequate nutritional intake?" and "How will what I eat affect my pouch?"

Nutritional intake

When considering the first question you must bear in mind that it is desirable to take a varied and well balanced diet, and vital to take plenty of fluids and keep salt levels up.

Typically you should drink 6 to 8 cups of fluid a day (1½ to 2 litres) in the form of water, tea, coffee and unsweetened fruit juices. You should also add a teaspoon of salt to your food every day because without a colon you are at risk of not absorbing the salt your body needs to stay healthy.

There are times when you need to be extra careful about keeping your fluid and salt intake up. These are when you are suffering from vomiting, diarrhoea or excessive perspiration due to hot weather or exercise, and also during the first few weeks after surgery.

At times like these increase your fluid and salt intake, and if necessary take oral rehydration fluid (you can buy sachets of powder for this from your pharmacist).

As always, if the condition is severe, or persists, seek medical help.

Eating and your pouch

As far as the effects eating has on the pouch there are no set rules. Pouch function is often just as affected by your eating pattern as it is by individual foods. If you think your food is adversely affecting your pouch keep a food and symptom diary.

It is worth retrying problem foods - they may not cause you problems after a while. But always bear in mind that variety is essential for good health.

Eating patterns

Obviously bowel frequency increases with the number of meals eaten. If you feel you are suffering from going to the loo too often try consuming no more than three meals a day. If you are troubled by getting up in the middle of the night to empty your pouch try eating your last meal of the day earlier, and perhaps make your largest meal of the day at lunchtime.

Food effects

Different foods have different effects on different people. What may cause one pouch patient a problem may not bother another. However, the following guidelines make sense for many pouch patients.

Thickening

Soluble fibre thickens the consistency of the stool and therefore reduces frequency. This can be found in oats, peas, beans, lentils and barley. Insoluble fibre holds fluid but encourages faster transit time, thus increasing frequency. This can be found in wholemeal bread and wholegrain cereals.

Increased output

Foods which increase output are: alcohol, caffeinated beverages, citrus fruit, chocolate, beans, leafy green vegetables and raw fruits and vegetables. Another culprit is sugar which attracts fluid into the small bowel through osmosis causing a larger, more watery stool.

Decreased output

The following foods decrease bowel output: bananas, rice, cheese, creamy peanut butter, tapioca, white bread, potato and suet pudding.

Avoiding wind

Chew your food thoroughly and cut down on fizzy drinks if you are troubled by wind. Wind can also be caused by talking too much during a meal!

From Rome to Raphael

How pregnancy and childbirth affected *Rachel Abedi's* pouch

Knowing that many pouch owners have trouble conceiving, I feel almost guilty that my baby began more by chance than design, his existence more the result of a romantic weekend in Rome than of concerted effort.

However, once I discovered that I was pregnant, all sorts of questions began to worry me: would my pouch, created three years ago, be squashed by the growing baby? Would my absence of colon limit the baby's nourishment? Might the pouch be damaged during childbirth? If I opted for a caesarean section, would the incision hit adhesions, and the wound heal properly given my already extensive scarring?

These worries might sound silly now, but they were pretty real to me at the time, so I decided to see a private specialist obstetrician for ante-natal care. My anxiety about being treated as a 'normal' mother-to-be on the NHS was heightened when I attended an ante-natal clinic at my local hospital. At each visit, I was seen by a different junior doctor, none of whom seemed to know about pouches, let alone any pouch problems associated with pregnancy.

In the end, the cost of private care was too high, and actually proved unnecessary. I asked to be put on the books of a consultant obstetrician at the local hospital, who reassured me with his knowledge of my situation, helped by an informative letter from my pouch surgeon.

The hospital consultant explained that one risk of having a caesarean was that an adhesion might accidentally be cut (the pouch itself is too far behind to be in the way), perhaps making swift additional surgery necessary to fix my

digestive plumbing. However, an advantage of being at a large NHS hospital was that surgeons would be on standby in case that happened. I still preferred this option to the risk of rupturing an adhesion during labour.

Pregnancy had no effect whatsoever on my pouch, certainly in the early months. The baby settled to the left of my central scar, perhaps because adhesions to the right (where the stoma had once been) left him too little space to manoeuvre. This meant that my belly looked a little odd, and the scars didn't stretch as much as the skin, but it felt fine.

I had to go to the loo (pouch) a little more frequently during the

abdominal surgery. But the rumoured agonies of natural childbirth were utterly horrifying to the uninitiated. Stitches in my tummy I can cope with, but *there* - no thank you! Better the devil you know...

I was fully conscious during the birth, although numbed from the diaphragm downwards by an epidural. Giddy with hope and anticipation, I giggled all the way through the operation, and was able to welcome Raphael as soon as he made his grand, if undignified, exit (or should I say entrance?). The epidural also meant that I did not have to recover from a general anaesthetic, which was a blessing.

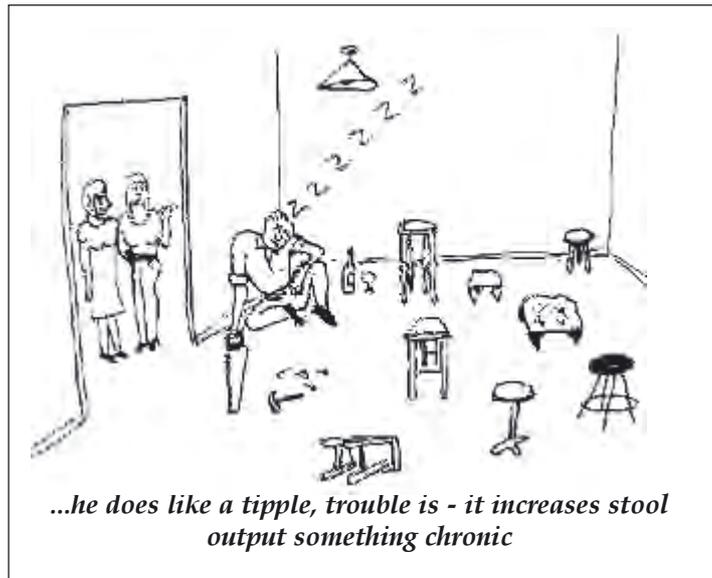
I then spent five days in hospital, standard for post-caesarean recovery, during which I learned the basics of baby care under the much appreciated supervision of the nursing staff.

A close eye was kept on the wound, and the transition from drip to fluids to solid food was made slowly, because this had been problematic after pouch surgery.

The point where the caesarean scar crossed the long central scar took a little longer to heal than elsewhere, but six months on is almost invisible. Because of the scar tissue, I may only be able to

have one, or at most two more caesareans, but a hat-trick will be quite sufficient.

My life now is unrecognisable from my 'pre-Raphaelite' period, but the pouch has remained efficient and trouble-free. Obviously, women must make their own decisions about pregnancy and childbirth, guided by medical expertise, but I hope that my experience will help to reassure and encourage. My journey from Rome to Raphael was not a difficult one, and now I am thoroughly enjoying the fruit of my (lack of) labour.



...he does like a tippie, trouble is - it increases stool output something chronic

last month or so of pregnancy, but the consolation was that I did not suffer from constipation, which is otherwise common during pregnancy. My diet remained the same, with the addition of multi-vitamins and more fluid, and I put on weight as normal.

I must admit to feeling great relief when my pouch surgeon recommended an elective caesarean, although I could have opted for natural childbirth had I really wanted to. Somehow I felt unperturbed by the prospect of an operation - I was after all an old hand at



Editorial

None in one?

Is the debate on whether patients should have a two-stage pouch operation, or have it done all in one, being won by the proponents of two-stage?

When the pouch operation was pioneered twenty years ago at St. Mark's Hospital patients underwent two operations, one to form the pouch and a second to close it.

In the period between the operations the pouch was allowed to heal by forming a 'loop ileostomy': a section of the small intestine about the pouch was pulled out onto the surface of the skin and cut across its cross section forming two stomas: one leading out from the small intestine and one leading in to the pouch.

These were both enclosed by an

ileostomy bag and the pouch was allowed to heal much more quickly because it did not receive any stool.

A large number of patients still have the operation done in two stages like this, but as the operation has become perfected many surgeons have tried performing it in one stage.

Although the pouch will not heal as quickly because it starts processing stool practically from day one, the idea of only performing one operation, thus saving much time and effort, is quite attractive.

However many surgeons, in-

cluding one of the pioneers of the pouch operation, Mr John Nicholls, have come to the conclusion that all-in-ones aren't worth it. Patients having the operation done all-in-one are more likely to encounter problems and tend to take longer to get used to their pouch.

At least with the two-stage approach patients can take things one step at a time and only start making use of their pouch once it has fully healed and is in a fit state. A second closure operation may be more hassle and take time, but it is probably worth it.

Nicholls for President

Action was the name of the game at the Red Lion Group's first committee meeting

The highlight of the Red Lion Group's first committee meeting on Saturday June 22 was an impressive action plan drawn up by liaison officer Morag Gaherty and former patient Brian Gaherty.

And action was the order of the day, setting the tone for a lively and good-humoured meeting that was attended by eleven committee members, friends and associates and ably chaired by Dr Martin Peters.

Morag's Action Plan - or MAP - was an ideal blueprint for the committee's first official meeting. Its aims are to encourage communication between pouch-holders, provide information and support, monitor surgical and medical advances, run social and fund-raising events, and raise public awareness of the Red Lion Group.

One of the group's priorities is to set up a network of local groups.

These would give the Red Lion Group a solid foundation. They would also enable fund-raising and membership drives to be held locally as well as nationally.

Christopher Browne, who was elected Press Officer, agreed to sell the Red Lion Group to the news media. Two encouraging signs were articles about pouch surgery in the Guardian and The Oldie. Christopher said he would contact the journalists concerned.

Another major theme was public awareness and the need for the Red Lion Group to attract the attention of both doctors and hospitals. Morag agreed to set up a database of medical contacts in order to widen the group's sphere of influence and patient support.

The committee decided to invite John Nicholls, Consultant Surgeon at St Mark's, to be the group's

honorary president, with Red Lion founders Celia Myers and Rachel Abedi, honorary vice-presidents, as a tribute to their work in setting up the Red Lion Group.

The need to raise funds to give the group a sound financial base was discussed and Bill Worthington appointed a fund-raising officer. The Red Lion Group will have an annual subscription of £5, with concessions for cases of hardship.

Membership and enrolment forms are to be sent out to existing and new members (see inside this newsletter).

After a most encouraging and vocal start - with refreshments provided by Dansac - a second committee meeting was arranged for Saturday 7 September at St Mark's Hospital. Another annual meeting has been provisionally booked for Saturday 26 April 1997.

Letters

Dear Editor

I was diagnosed in February 1995 as having familial adenomatous polyposis (FAP). I was lucky because it was diagnosed by chance without any family history.

FAP is a hereditary genetic disease usually, but occasionally there are spontaneous cell mutations setting off a new strain - I fall into that category. My children have a 50:50 chance of inheriting it.

My consultant advised me to have pouch surgery because it was a question of *when* rather than *if* one of the thousands of polyps would turn cancerous. Well, I took the only sensible route and am now a member of the Red Lion Group!

FAP itself is a very rare disease, and a spontaneous mutation must be rarer still. I wonder if there are any other patients in a similar position, having had a pouch for preventative reasons?

*B Gaherty
Hertfordshire*



**Roar! Letters Page
20 The Maltings
Green Lane
ASHWELL
Herts
SG7 5LW**

**e-mail:
timr@dircon.co.uk**

Dear All

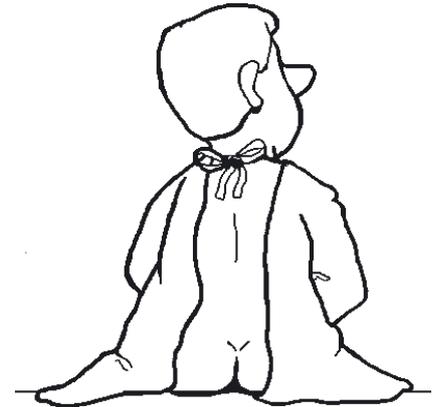
Please help us to help you

We are two final year undergraduate dieticians from Surrey University, investigating dietary habits and problems commonly experienced by people with ileo-anal pouches.

As you know, there is limited dietary information available for patients with pouches and with your help we would like to amalgamate and make use of your knowledge and experience.

By way of a questionnaire we aim to identify the following:

- symptoms commonly caused or aggravated by dietary factors
- specific foods to which you attribute symptoms
- foods you routinely avoid in order to prevent symptoms
- foods you find beneficial in alleviating symptoms



Your input will help us to formulate dietary guidelines based on your experiences which will, in turn, be beneficial to both yourselves and new group members, helping you achieve enjoyment from a varied and balanced diet.

Around the end of the month, we are aiming to pilot our questionnaire among a few willing participants, with a view to expanding the survey to include all interested members before Christmas. We envisage publishing our findings in the Spring of 1997.

We are excited about the prospect of working with you and look forward to receiving some valuable answers and comments from you.

*Yours sincerely
Julie Lanigan and Heidi Tang*

Please support the Red Lion Group



All donations, however small, which would go towards our ever increasing administration costs will be gratefully received. If you have found this newsletter useful and wish to ensure that we have the funds to produce future issues, please send a donation to: **The Red Lion Group Treasurer, Mr. P B Johnson, 7 Chelston Approach, Ruislip Manor, Ruislip, Middlesex, HA4 9RY.**

Annual Meeting is Stormed

No, the Annual Meeting was not stormed by riot police (not this year, anyway). There was storming of a different kind as the meeting split into four groups, put their thinking caps on and asked themselves "Exactly what is the Red Lion Group all about?"

Brainstorming Group 1

What do you hope to gain from the group?

Getting to know people in similar situations · General information about soreness/discomfort and tips and updates · Share common problems and solutions · Have a good moan! · Receive newsletter · Information for GPs · Motifs/badges · Fund-raising · Directory of people in the group

How would you like to see the meetings develop?

General meetings once a year in London · Local meetings in own area to meeting people nearby

What format do you think the meetings should take and how often should they be held?

Annual committee meeting · Other speakers from outside · Patient speakers · Information between surgeons brought back to support group · An opportunity to find out if people are happy with treatment and care given



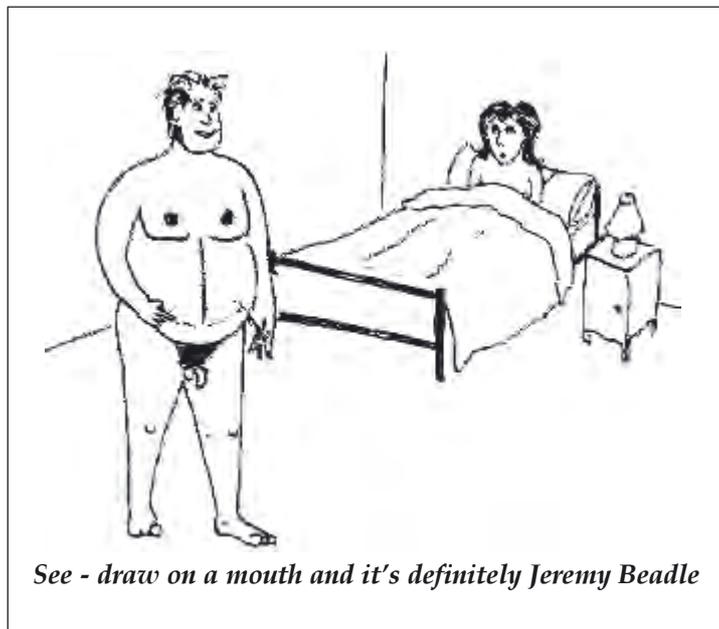
Ideas

More local groups in communication with main group · Co-ordination with other pouch support and Crohn's/colitis groups · Continuation of newsletter · Counselling courses for members of Red Lion Group · Offer information to hospitals performing the pouch operation

Brainstorming Group 2

What do you hope to gain from the group?

Friends · Support information · Advice · Shared experience · Understanding · Support to enable self help and motivation · Counselling · Variety of topics



See - draw on a mouth and it's definitely Jeremy Beadle

How would you like to see the meetings develop?

Big meeting twice a year · Crèche Family support · Regional meetings Hot-line

Help line at specific times · Regional list contact · Local membership list

What format do you think the meetings should take and how often should they be held?

Publicised well in advance, e.g. through IA Journal · Splitting into smaller groups · Handouts of speakers' talks · Separate room · Questions on topics for meetings

Ideas

Fund-raising · Socials · Run in London Marathon · Swimathon

Brainstorming Group 3

Refer patients to Red Lion Group in Out Patients · Annual general overview · Different location? · More notice of meeting · Individual pre-op information · Make database of patients available to local reps · Frequent newsletter addressing non-

surgical problems · Geographically / county based · Contact name male/female for each area · Raising profile of the group and surgery, especially in local District General Hospitals · More pre-op information, condensed into booklets · Small informal meetings · Job-sharing of committee roles · Induction meetings for new patients - not repeat information to "old" patients · Make slides available to present locally · Need liaison person on committee

Brainstorming Group 4

Do we need a Red Lion Group?
Yes

What do you hope to gain from the group?

Support and information · News and developments · Talking shop

How would you like to see the meetings develop?

Social area meetings · Area groups not based on counties · Annual national meeting ·

Ideas

Members' forum · Panel discussion

Join the Red Lion Group

Why not join the freshest and fastest-growing pouch group around, for just £5?

To continue to receive newsletters and be kept informed of future events you will need to join the Red Lion Group. Anyone is welcome to join, especially people with pouches or people considering having the pouch operation.

The membership fee is £5, and a form should have been included with this newsletter.

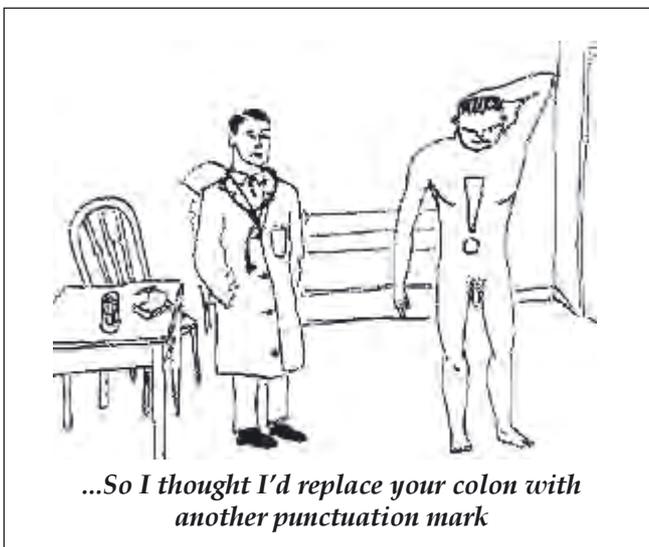
If you need extra forms please write to the Liaison Officer including your name and address and ideally a stamped address envelope:

Red Lion Group
20 The Maltings
Green Lane
ASHWELL
Herts
SG7 5LW

Don't forget to sign up any other people you know with pouches! The membership fee is waived in cases of genuine hardship. Please write with details to the address above if you can't afford to pay to join.

On the other hand if you can afford to pay more, please send a donation to the Treasurer (see previous page).

The Red Lion Group is entirely funded by voluntary donations, and we need your help to get even bigger and better.



Red Lion Group on the Internet

Check out our site on the World Wide Web:

<http://ourworld.compuserve.com/homepages/timrogers/REDLION.HTM>

You can get a message to the Red Lion Group via e-mail on:

timr@dircon.co.uk

There are two newsgroups on the Usenet which cover discussions about pouches:

alt.support.crohns-colitis
alt.support.ostomy

If you know of any other pouch-related sites on the World Wide Web please let us know and we'll include them in the next newsletter.

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 like scuba diving 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 (but not too many of those please).

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

You'll get the satisfaction of seeing your name in print, 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.

If you can't draw but have what might be a great idea for a cartoon please let us know. We'll get our resident artist on the case rightaway. (His work is scattered throughout this issue.)

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



Paws and Effect

It's competition time. The Red Lion Group needs a slogan. Here's a chance to put your creative powers to work. Quite simply we need a catchy phrase to go with the logo of the friendly lion. First prize will be a year's free membership of the Red Lion Group.

All slogans will be printed in the next newsletter, so here's your chance for fame as well as fortune (well, free membership at least).

Here are some examples to get your creative juices going:

- 'Red Lion Group, Helping People with Pouches'
 - 'Red Lion Group, Don't Just Sit There'
 - 'Red Lion Group, We Don't Just Scar: We Care'
- (OK that's enough bad slogans - Ed.)

Send your entries to:

Slogan Competition
20 The Maltings
Green Lane
ASHWELL
Herts
SG7 5LW

Closing date is 20 September 1996