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

Patron Wishes Members a Happy New Millennium

10 January 2000

Dear Morag

Thank you for the latest issue of Roar!, which is splendid. And I do hope that you and all readers who are involved with the Red Lion Group have everything they want for the coming year and the coming century!

Yours very sincerely

Claire Rayner

It's AGMTime Again!

Morag Gaherty looks forward to welcoming many Red Lion Group Members to St Marks on Saturday 15 April...

Final arrangements for this year's AGM and Information Day on 15 April 2000 are now well underway. As you might expect with a "David Irving-James Production", everything is being planned with military precision, and I hope this year's event will be our best ever.

and return to David no later than **5 April 2000** if you wish to attend. With the advance warning in previous newsletters, I hope you have remembered to keep this day free in your diary, because it promises to be an Information Day with a difference.



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You are being asked to send a cheque for £12.50 per person when you return your invitation. Let me stress that this is *not* a charge for the event, and your cheque will be returned to you on arrival. It is simply held so that if you cancel without notice, Dansac will be reimbursed for the wasted food. If you find you are unable to attend, and give either 48 hours notice or a valid reason for shorter notice, your cheque will be returned to you by post.

Unfortunately we had a lot of wasted food and expense as a result of non-arrivals last year, which is why we have had to implement this safeguard. For those who were put off by the exorbitant car parking fees, I am happy to report that we have arranged a huge discount if you buy a prepaid ticket - see the enclosed invitation and elsewhere in the newsletter for more details about this and other aspects of the big day.

In the information pack you will receive on arrival, you will find a plan of all the toilets in the vicinity of our event. We have had unpleasant plumbing problems arise in previous years which could have been

avoided with sensible use of the toilets. Please spread yourselves around these, and don't all use the same few loos - I don't need to tell you why not!

If you come across a dirty toilet, the important thing is that this is sorted out as soon as possible, otherwise the situation will rapidly deteriorate, and this is what we want to avoid. For this reason, David has been volunteered (in the best Army tradition!) as official Bog Buster, latrine orderly, sanitary adviser, toilet monitor, call it what you will. Please report all toilet problems to him as soon as possible, and he will nip in with his array of cleaning products to remedy matters.

Obviously, he can only go into the gents, so he will be delegating "women's problems" to one of us. Bearing in mind how busy we committee members all are on the

day (especially David), if you would be willing to take on this unenviable but necessary task for either the gents or the ladies, we would be eternally grateful.

So please roll up your sleeves



and muck in! (OK, I don't think we need to go quite that far, but you get the idea).

Resolution to be Voted on at the Annual General Meeting on 15 April 2000

To accept a limited amount of paid advertising in *Roar!*, the quarterly newsletter of the Red Lion Group.

This resolution does not cover the details of how the advertising will operate, to enable us to keep our options open for the future. The aim of accepting advertising is simply to increase our overall revenue, so that membership fees will not have to rise in the forseeable future to cover our costs.

I have the following ideas in mind:

A four page centre page supplement with a maximum of 16 adverts per issue, so that you can simply remove it if it offends you.

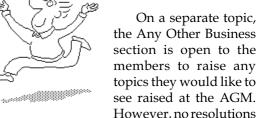
Two rates (which could be decided at the meeting): a commercial rate for companies advertising rel-

evant products such as barrier creams, and a lower rate for members who wish to advertise their own unrelated businesses.

At the top of each advertising page, a clear

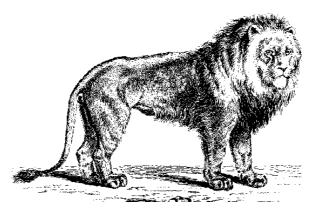
statement that an advert does not represent an endorsement by the Red Lion Group, so as to maintain our clear independent stance.

There will be an opportunity for a few minutes' discussion of these and any other good ideas relating to advertising put forward by the members. We are pressed for time, and so suggestions and prices can only be discussed in general terms.



can be voted on in this section, as these would contravene the advance notice rules to which we are legally bound. If you would like the committee to consider your AOB issues before the AGM, please do contact me as soon as possible so that I can disseminate this information amongst the various committee members.

Morag Gaherty



Editorial

Firstly, many thanks to those of you who took the time to complete last quarter's survey on the subject of our quarterly mailings to you. As you will see from the results starting on page 9, it seems we are generally getting it right, which is excel-

lent news. However, I had hoped for more response from those who don't usually complete the surveys, because what we *don't* usually hear is often more enlightening than what we do.

We will listen to your comments, and try to incorporate the most popular suggestions if possible. However, for those of you that asked for more Editorial, I can promise you now, you are going to be disappointed! You hear far too much from me already, and I'm not going to make it more. I'd like to hear more from you, your personal experiences and any other articles you think might interest us. Do I have to beg? Oh well, here goes then...

As ever, we do want to hear more in particular from those whose pouch has ena-

bled them to live a perfectly normal life. We know you are out there, but people contemplating surgery may get an unduly negative impression from our newsletter because we so rarely hear from you. Not everyone wants to read about medical histories - we want to hear about the sports and hobbies you have taken up, the places you have been to and

other such things. Tell us how your pouch has empowered you, to use the trendy term.

The subject of advertising was raised in the survey, and most people were in favour of it to a limited extent, as a way of increasing our



funds, as you will see from the results. A resolution to accept advertising will be voted on at the AGM, and you will find a copy of this on page 2 of the newsletter, together with a few details about precisely what form this could take.

As you will see from the agenda, the morning workshops are designed to give you a chance to talk about something other than pouches. One workshop is being taken by the lady from House of Colour, who will give advice on the colours that suit you, and how to co-ordinate these. Those of you that have met David will realise that he

has already been to one of these himself!

Another workshop is being given by Claire Bateson, a qualified chiropodist and reflexologist, on the health benefits of reflexology. There is a short introduction to this alternative therapy on page 15, to help you decide whether this workshop may be for you. Unfortunately, there will not be time for a practical demonstration, unless Claire asks for a guinea pig!

The third workshop is an opportunity for partners to talk about living in the shadow of pouch surgery or an ileostomy. We know that there is a great deal of trapped

emotion amongst partners, and welcome the opportunity to help partners as well as (prospective) pouch owners come to terms with the situation they find themselves in and perhaps to make new friends. The Red Lion Group prides itself on providing support to *everyone* affected by this surgery, not just pouch owners themselves.

My Story by Dorothy Simpson

Dorothy had her pouch surgery (in 1986 and 1987) at St Marks City Road, with both stages performed by Prof Nicholls. She had had ulcerative colitis for more than 20 years.

I found the "Finding the Cause" article on the front page of *Roar!* (issue 14) most interesting because at the start of both my pregnancies I suffered from severe diarrhoea. After the first three months of my first pregnancy in 1963, this settled down with no further trouble.

However, with my second pregnancy, I had severe, constant diarrhoea which could not be studied or treated because of possible harm to the baby. The diarrhoea continued after the birth of my son in 1966, until I had lost a lot of weight and my GP became concerned.

Over the next 20 years, I suffered from pain and bleeding - all that goes with ulcerative colitis, plus erythema nodosum. I was a District Nursing Sister at that time (SRN), and had to retire from my work that I loved.

I had an ileo-rectal anastamosis in Sunderland, but continued to need frequent to ileting. My two consultants got together to discuss this, and the upshot was that I was referred to St Marks.

I had surgery (a W pouch) performed there shortly afterwards, and eventually began to feel better. The worst part of the surgery - apart from the pain - was having an ileostomy. It made me feel degraded and depressed, and it leaked constantly. It was a thing I always said I'd never have!

About three years after my

pouch surgery, I completed a 43 mile walk, non stop across the North Yorkshire Moors, the "Lyke Wake Walk", and raised £100 for the Friends of St Marks. I completed it in 16 hours, and I'd do it again if I had the opportunity, even though I will be 61 at my next birthday.

I can't compare my life now to what I was like before surgery. I

could not walk as my joints were so swollen and painful. At one point, I was in a wheelchair. Now I am as active as when I was nursing. I'm having a few pouch problems at present, but these will be sorted.

I can honestly say that having a pouch was the best thing that happened to me during the worst years of my life.



What is Homeopathy?

As we have mentioned in previous issues of the newsletter, conventional (known as allopathic) medicine controls disease for the most part by using symptom suppressant drugs. Very often these drugs have unwanted side effects, and sometimes these side effects are actually worse than the problem for which the drug was being taken!

If you are wanting to avoid medication, or wish to minimise unwanted side effects from allopathic drugs, you may want to consider homeopathy. Homeopathy is now taken more seriously by the mainstream medical establishment, and most chemists sell homeopathic remedies, as self prescription is perfectly safe.

From our own experience, a visit to a homeopathic practitioner is well worth the expense (consultations usually cost around £20), as you get advice tailored to your specific circumstances plus a stronger selection of remedies than are usually available at the chemist. Treatment is not really as simple as the little booklets in the chemist imply, and you can easily waste money on tubes of pills if you don't really know

what you are doing. Our baby Bob had an unexplained facial rash for some months which our homeopathic practitioner cleared up within 24 hours. Since then, she has helped with his teething and earache. Certainly, my immediate reaction now if any of us is ill is to talk to Theresa first. We have not yet had to go back to the GP.

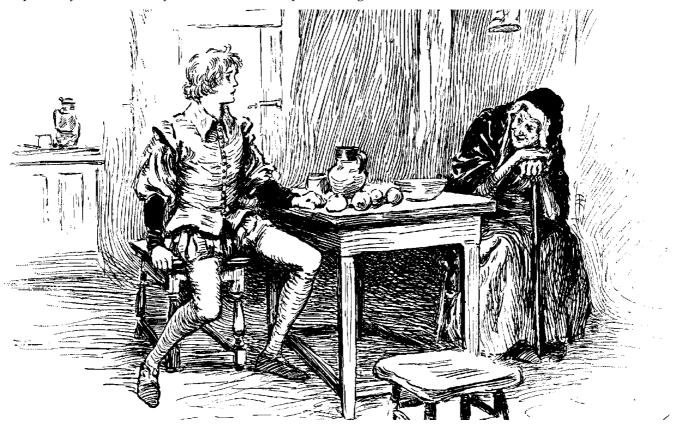
You may think homeopathy is only effective for relatively insignificant illnesses, but this is not the case at all. The following quote on the subject of homeopathy is taken from the website http://www.unc.edu/~aphillip/www/vaccine/dvm1.htm, which is backed up with detailed source references, including those from government statistics:

"Historically, homeopathy has been more effective than "main-stream" allopathic medicine in treating and preventing disease. In a U.S. cholera outbreak in 1849, allopathic medicine saw a 48-60% death rate, while homeopathic hospitals had a documented death rate of only 3%. Roughly similar statistics still hold true for cholera today. Recent epidemiological studies

show homeopathic remedies as equaling or surpassing standard vaccinations in preventing disease. There are reports in which populations that were treated homeopathically after exposure had a 100% success rate-none of the treated caught the disease."

The following extract is taken from the website mentioned in the Relevant Internet News section, and provides a brief understanding of homeopathy:

"Homeopathy is working with your body to produce long term stronger health. Homeopaths believe that homeopathy provides a way for your body to heal itself. Many health professionals feel that allopathic medicines are suppressive and push illnesses further into the body where later they emerge in worse health problems. Homeopathy is not about suppressing a symptom, but stimulating the body's natural curative powers. Taking homeopathics never causes a person to build up a tolerance. On the contrary, Homeopathy can enable the body to have greater immunity, less allergies, and quicker recovery



Contact_

My background is that I had UC for about 4 years, but it was very severe, and my surgeon (Mr Gerald

Kane), who had just returned from the States are seeing the Kocks operation decided that I would be a good candidate for it. I was his first Kock's patient (March

1980), so there were no support groups for me, and it was a matter of trial and error as to what I would be able to eat, and how to cope with my new system.

I eat a very limited diet and never have any salads, vegetables or fruit and so far have survived for 19 years like this. I must say that as the pouch gets older, it does get a bit more fragile, but I am very careful about my eating habits. I find it is necessary to wear an appliance now as the valve does leak, and I feel safer with my mini pouch.

I am now 57 years old, married

Request for Tombola Prizes

At this year's Information Day on 15 April, we will be holding another tombola to raise funds for the Red Lion Group. Committee members and reps have already generously donated some prizes for this, but if you have any unwanted gifts at home which you would be prepared to offer as prizes, we would be very pleased to receive them.

Please bring them along as early as possible in the day and hand them over as you check in. Thank you in advance for your generosity!

The tombola will be held over the lunch break. Every ticket ending in 0 or 5 will win a prize!

29, and a dear granddaughter of nearly 3. I am fortunate because we all live in the same town, and so I am able to see them almost every week. I am a House Mistress at a private school and am responsible for running the boarding establish-

ment which houses 60 girls from Grade 3 to Grade 12.

I am very active and I try and get a game of bowls in once a week, and I swim regularly during the summer. I recently did a course on Tai Chi, which I thoroughly enjoyed. Apart from these outdoor activities, I

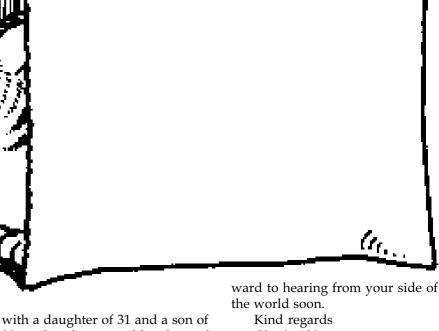
also enjoy sewing. It would be wonderful to be able to correspond with ladies who are in a similar position to myself and hope that the information that I have given you will be helpful. I thank you for your interest and caring,

and look for-

the world soon.

Glenda Alder

If you would like to correspond with Glenda, you can contact her at College House, Currie Road, Durban, 4001, South Africa, or via email on galder@dgc.kzn.school.za



Letters



Roar!Letters Page
"Arcady"
16 Hill Brow
Bearsted
Maidstone
Kent
ME14 4AW

gaherty@bigfoot.com

Dear Newsletter Editor

I would like to take this opportunity to tell you how much I enjoy and look forward to my copy of *Roar!* Although my friends and family have been so supportive since the onset of my illness, nobody can really understand what having a pouch is like. I find it such a comfort to read about other pouch owners' problems and experiences.

Thanks for the great work you and everybody who works on the newsletter does.

Valerie Vaughan

Ed: We often receive complimentary comments like these, although we don't usually publish them in the newsletter, in case it seems like we are boasting. However, a change is as good as a rest, they say, so please allow us a moment to rest on our laurels! The newsletter is only as good as the material we receive from our members, so do please take the time to write to us and to send in interesting pieces you come across in the media.

Dear Newsletter Editor

My particular experience is probably more complicated than most. Although I already had mild colitis, life saving surgery was needed due to a blood clot which formed in my colon. My entire colon ruptured and I ended up in intensive care for three days, and stage one of my surgery lasted $2\frac{1}{2}$ months.

I also had two life threatening blood clots on the brain, which caused a stroke, and loss of the use of my left arm. I am now on warfarin for life.

No diagnosis was reached, although fingers have pointed to the contraceptive pill. I would be interested to know if anyone else has had the same experience.

My arm is now back to normal, although it is very slow and clumsy. Since stage 3 of my pouch surgery, life is getting back to normal as well.

Victoria James

Dear Newsletter Editor

When advised it would be best for me to have pouch surgery for my ulcerative colitis, like many other patients (I assume), I was completely devastated. My first course of action was to find out more - I wanted to talk to anyone who had been through "it" and survived.

So I phoned the local rep for NACC, to which I belong, and asked for help/information about any known survivor (!) that I could talk to. The reply was "I don't know of anyone - sorry, can't help you!". Anyway, I have survived, although I'm only half way, waiting for the final stage to be done.

Maybe it would be a good idea for the Red Lion Group to contact NACC and tell them about yourselves, because *Roar!* has definitely helped me. I found you through my stoma nurse. Keep up the very good work.

So far I have learned that when I get pouchitis, I stop taking all dairy products. I use sweetened soya milk in my tea. This really does help and



when I suffer from joint pain-mainly in my legs - I stop eating wheat products and within 48 hours I am much better. I try not to have too much wheat anyway, but sometimes situations overtake you. I do hope these tips help someone.

Jackie Brooks

Ed's comment: NACC head office is aware of the work of the Red Lion Group, and we are on each other's mailing lists. However, we unfortunately have no control over whether that information is passed down to local branches. Many of our members are also members of NACC or ia (or both!), so if you are please do talk to your local rep to make them aware of the work done by the Red Lion Group and maybe even write in to their magazines.

Dear Newsletter Editor

I am 47 years old and had ulcerative colitis for 15 years. During this time, I tried lots of different medication. The UC was kept under control, but I believe I just learned to live with the symptoms. To this day, I can honestly say I have forgotten what it is like to be well.

In the early part of 1998, I was very unwell, and by March of that year I was admitted to hospital. I was going to the toilet 15 times a day, passing blood and mucus. By the end of the first week in hospital I was on Pethidine injections, and a week later I was advised to have an ileostomy.

After the operation, when the dressing was taken off, I had an infection in the wound. This left me with a two inch hole in my abdomen, which had to be packed and dressed every day and took three months to close. This left me with the infection MRSA. I not only had a bag for my ileostomy but a second bag for a mucus fistula. I was back in hospital a couple more times that year, still on steroids and Asacol.

In December 1998, the decision was made to have the second stage of the procedure, as this would remove my rectum and the bag I had for the mucus fistula. By January 1999, I had a J pouch with a covering ileostomy.

When the dressing was removed, I once again had a wound infection. The wound had to be opened and packed again, but split open one week later. It was closed with about 12 tension sutures which had to stay in for 6 weeks. All of this time I was still on steroids and a very high dose of pain killers.

Since then I have had unexplained vaginal discharge, pelvic pain (which I still get to this day) and discharge, including blood, from my back passage, plus my ileostomy bag filling up with blood. I have had tests for stomach ulcers, because the doctor was unsure where the blood was coming from.

I have had all the tests: MRI, pouchogram, ultrasound, CT and white cell scan. All came back negative.

The next hurdle was coming off the steroids, which left me very depressed. Now I have discovered I have an overactive thyroid, but this is not yet under control, despite the medication I am taking. In addition, after more abdominal and back pain, an IVU scan revealed kidney stones.

Two years down the line, I am still waiting to have the third stage of my operation, as I need to get the thyroid under control and off the steroids (on which I seem to have become dependent) first. The low pelvic pain, and pain and discharge from the back passage are still there, so I feel very weak and tired. I have found the counselling organised by NACC very helpful, but I cannot see the light at the end of the tunnel.

If there is anyone who may share the same problems as me, it would



be nice to speak to them, as I feel so alone.

I have spoken to Julia Williams, Morag Gaherty and David Irving-James, and I would like to thank them all. I am now considering a second opinion, but I am so confused. I just don't know what to do for the best. What I have written is only half of what I have been through, but it has helped me writing my feelings down and someone reading them.

Veronica Shaw 01708 552547

Ed comment: The last paragraph of this letter encapsulates perfectly why we include many personal experiences in the newsletter, although some members do not find them helpful. Hopefully Veronica will seek a second opinion from a pouch specialist, and will find some treatment that works for her. Many of us only realise how lucky we are when a story like this is printed.

Readers Survey Results

In our Winter issue, we decided it was time to find out whether *Roar!* and *Paw!* are developing in the way our members want them to. So our last survey asked you for your views on these. We received 61 replies before the deadline for this piece.

On the whole, your comments were very encouraging and we particularly appreciated those who took the opportunity to thank us for the work that goes into putting the newsletter together. It is a time consuming job, but one which gives a great deal of satisfaction because we know how much support our members get from it.

The first two questions related to how many people read your copy of *Roar!* and Paw! This was meant to mean how many people *in total*. I am not sure how many respondents misinterpreted that as people *other than yourself,* but at least three did so, because they told us no-one read them (but were still able to offer opinions about what they would like to see more or less of!). Anyway, the results are in Table 1:

Table 1

The main thing that leaps out from this is that Paw! is not very widely read, and this will prompt a review as to whether it is a worthwhile venture. This is a shame, because the idea of Paw! was not just to provide a simple newsletter for children with pouches (of which there are a few in the Red Lion Group), but also to provide something for the children of pouch owners to look forward to when the quarterly mailing of Roar! comes through. For this reason, Paw! is designed to be a fun activity sheet for any child, so pouches and surgery are not mentioned at all. If you have children of the right kind of age, and have not looked at Paw!

before now, please let me urge you to do so.

It may be that we will continue to produce Paw!, but only mail it to those who specifically ask for it. This will require a separate mailing, but the additional costs of this are unlikely to be higher than the current cost of printing a copy for each member. *Your comments are invited on this.* In the meantime, I am afraid there is no Paw! with this issue of the newsletter.

All of the subsequent questions related to *Roar!*, and the results are analysed below.

The next thing we asked about was whether we have got the tenor of the newsletter right. Only 1 (2%) of you thought *Roar!* was too serious, 5 (8%) thought it was too lighthearted, and the vast majority of you (55 or a whopping 90%) thought we had the balance about right. That was very gratifying to hear.

Similarly, two (3%) of you thought it was too positive, 6 (10%) thought it was too negative, but 53 (87%) thought we had it about right. We certainly try to present both the positive and the negative, so that members who are considering pouch surgery can make an informed decision. Our only constraint is that not enough people with good pouches contribute to the newsletter, and so sometimes it can present too one-sided a view.

In the last newsletter, I asked in the editorial for survey responses from members who do not usually reply, as theirs are the views that I am least familiar with. Sadly, I am not much better informed, because only 11 (18%) of the responses came from such members. The other 50 (82%) came from what might be called The Usual Suspects! However, that is better than nothing, and so we know we are at least hearing from some of you who don't normally make your views known.

We then moved on to the questions about the detailed sections of the newsletter, the results of which I have put in tabular form (see Table 2). I have put it all in percentage terms, to avoid complication on the figures, but every 5% equates to 3

people or thereabouts, if you want to work out the maths.

A number of respondents made the point that they have used the "no view" column to indicate where they are happy with the quantity devoted to a particular area. Others may have used this column to indicate no interest plus or minus in the topic in question.

On the whole, as I have said, the results of these questions are very encouraging. Looking at the items in the "less" column which are in double figures, a few points are worth mentioning:

We reproduce recipes for ulcerative colitis sufferers from the Creative Couples Culinary Cookbook for Colitis sufferers. Given that more than a quarter of respondents would like to see more of these recipes, I assume that this means at least some of you are trying them out! This is another way we can provide more information about dietary advice for pouch owners, which the vast majority of you would like to see. Sadly, our budget is not up to supplying lovely colour pictures, which is a shame because it's for the pictures rather than the recipes themselves that most of us end up with so many cookbooks on our shelves (or is that just me?). Those in the "less" camp may soon win anyway, because we are running out of recipes available on the website and will either have to stop or buy the book.

Or perhaps readers would like to supply us with some of their most successful recipes for keeping their pouch happy? I look forward to hearing more.

Most people are either interested in relevant internet news or have no view about it, and the 15% that are not probably do not have access to the internet. That being the case, we try to summarise useful information from the internet, rather than providing a long list of websites for people to look at themselves. I plead guilty to making substantial use of this technology as a reference tool, because it's just so darn useful. How would we have found out more about the wonderful Toot Trapper without the internet search facil-

ity?! (Anyone bought one of these? We'd love a review if you have).

As for Polyposis People, the vast majority of people replying had no view on the inclusion or otherwise of this section, as most of our members have a pouch because of ulcerative colitis. 13%, presumably UC sufferers, would like less of this section. Although we only have around 30 polyposis members, I know from some of them that they get a bit tired of seeing everything from the UC pouch owner's point of view, and one page a quarter does not seem excessive to most of our respondents, which is a view I share. Of course, having a spouse with FAP may colour my view slightly!

Onto the hotly debated bit: cartoons. As Brian is inordinately (and misguidedly, in my opinion!) proud of

his cartoons, he is gunning for the person who wrote that we should get ourselves a better cartoonist. It's a good job replies were anonymous,



is all I can say! I am not sure whether the comment was about the quality of the drawing - which I think is not bad. Or whether it was about the jokes themselves, some of which I agree are very corny.

We don't always put in bottom jokes, although that does provide a

useful function for many members in allowing them to laugh about a sensitive area (haha, some of our jokes are even literary rather than visual). Certainly, the number of cartoons per issue will tend to give a good indication of how much material we have got for that newsletter. The clipart which breaks up the text of the newsletter is sourced by Tim, who I think is very talented at finding just the right picture to illustrate a piece (it pays dividends to stay

	More	Less	No view
Interviews with healthcare professionals	75%	0%	25%
Recent advances in surgery or illness management	92%	0%	8%
Readers' experience and articles	67%	8%	25%
Survey results	39%	8%	53%
Relevant alternative/complementary health	62%	7%	31%
Dietary advice for pouch owners	64%	5%	31%
Recipes for ulcerative colitis sufferers	26%	20%	54%
Relevant internet news	36%	15%	49%
Readers' letters	74%	3%	23%
Polyposis People	8%	13%	79%
Editorial	25%	5%	70%
Cartoons	16%	28%	56%
Snippets	43%	11%	46%
Poetry	10%	36%	54%

Table 2

on the right side of the guy who puts it all together, I find), and these images often convey just the right impression.

A lot of you want to read more snippets, presumably because they are concise and easy to read, and also because they are often very amusing. We are very grateful to Sandy Hyams in particular who scours the Telegraph for interesting items, and I would ask everyone to keep their eyes peeled in their own choice of paper or magazine for something that other Roar! readers would enjoy. Just send the snippet to me and I will do the necessary. It doesn't need to be about pouches, or even about anything to do with the nether regions. The main criteria is whether or not it makes you

Poetry is the one area where a substantial minority of you would like to see less. You are either a poetry reader or you are not, I think, and if you are not, then I understand that a poem takes up space which you consider could be better spent on something else. Also, there is a question of taste. Let me explain why I as an editor put poetry into Roar, regardless of its artistic merits:

For many people, poetry is a way of expressing their feelings about their illness and their surgery which others might put into a letter, or keep to themselves. It is an outlet for very significant feelings.

For others, it is an entertainment provide by others at a time when they were down - Debbie's Story, in a recent issue is a good example of this. I think Debbie herself would agree that it was not the world's greatest poem, but it was written by a friend for her while she was in hospital, recovering from what was an extremely fright-

what was an extremely frightening situation. We British are so reserved, it can be difficult for a visitor who comes to see you in hospital to broach the subject of why you are there and humour is a way of overcoming this obstacle. So, another form of release, but maybe for others as much as for the patient.

Nothing we put into *Roar!* is there for artistic reasons. It is there because it may help somebody, either because it is factual information, an opportunity for people to get their feelings off their chest, or to ask a question, or to make them smile. All of these things help different people, and your replies show that we have generally got the balance about right.

Turning now to other questions, 39 (64%) of you felt that we should accept advertising of some form, on the basis that this would bring in extra revenue to the Red Lion Group. Concerns were expressed by a few that we should not turn into a magazine full of advertising like the ia journal has done. Content is far more important that a glossy look. Some felt that advertisements should be for relevant products only like barrier creams. We also had a couple of suggestions to accept advertising from members' own businesses at a lower rate. Having my own little business, I thought that was an excellent idea! Finally, concerns were expressed by some about readers interpreting some kind of Red Lion Group approval for products appearing in the newsletter.

As you will see from the proposed AGM resolution elsewhere in this issue, I am suggesting accepting limited advertising on the centre two pages of the newsletter only. This will take account of the ideas and concerns expressed above. I hope that this solution finds favour even with the 12 (20%)

of you who were against advertising.
The final ques-

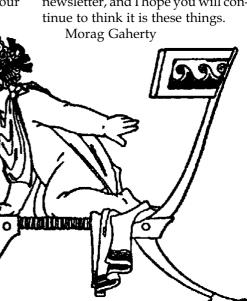
tion related to
whether or not you
felt too much
prominence is
given to St Marks
personnel by the
Red Lion Group. I

am glad to say that more of you felt it is not (39 or

64%) than feel it is (22 or 26%). However, these percentages are not as clear cut as we would like, especially as many of our members are St Marks patients, and therefore would probably have said no anyway! We are interested in other surgeons and hospitals, and I would urge you to interview your local surgeon for Roar! if you feel they do not get enough of a mention for what they do.

The banner on the front page of *Roar!* gives the address of the Red Lion Group as St Marks Hospital. Some interpret this as meaning it is a support group for St Marks, which it most certainly is not. Our most far flung members are in the Bahamas and in Singapore. The only reason we have this address on page one, is because it is important that if someone picks up an old copy of the newsletter, they will be able to find the Red Lion Group - having moved once in recent years, St Marks is unlikely to do so again!

In summary, I can promise you that *Roar!* will not be turning into a poetry newsletter, or a selection of cartoons and jokes, or a magazine full of advertisements. Each of these things in moderation may help someone, and so we will print them. But moderation and balance are the key, and I rely on you to tell me when either of those appear to be missing. I am very grateful to those of you who have congratulated us over the years on providing an intelligent, readable and interesting newsletter, and I hope you will continue to think it is these things.



Auction Plans have Changed

Despite our impassioned plea in the last newsletter for a project manager to take on the Gala Auction, we have got no further with this

In the meantime, we have also found out that it costs a fortune to stage any kind of event to which celebrities are invited, because the usual arrangement is that they will come if you make a donation to their own favourite charity, and that donation is usually required to be in four or even five figures. As we do not have anything like the funds to do this, we have had to change tack.

Instead, we hope to have the auction items on display for a few days at St Marks, and to invite written bids. At the same time, we will hold a book sale, to encourage people in to the area to buy books and to look at the auction items.

I am very sad we have had to do this, but with the lack of any help

and any funds, we are otherwise stuck. I am sure we can make this alternative arrangement work very well. We have some good items to auction, a

Red Lion Group Christmas cards

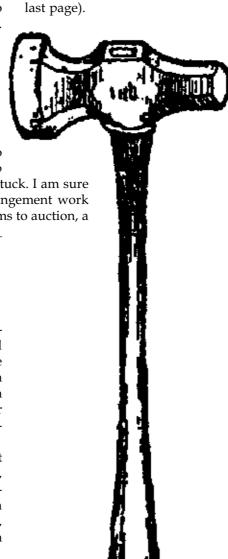
At our recent committee meeting, we decided to start selling Red Lion Group Christmas cards. We will be producing only one design this year: a copy of the friendly lion vibrantly coloured in by our 7 year old joint colouring competition winner, Stuart.

Unfortunately, as we do not have colour printing inside *Roar!*, we cannot show you this lovely design. However, as Stuart has won a T shirt with his design printed on it, I hope he will let us have it on display on 15 April 2000.

Christmas cards will be on sale when the Autumn newsletter comes out, but we can take provisional orders at the AGM and information Day, subject to the prices being finalised.

I hope you will buy your cards from us this year, and support the Red Lion Group. large "passing population" and we know that book sales always do well.

Please can I appeal to any of you that can provide any books to bring them to the Information Day on 15 April if you are coming. Otherwise, we will be able to arrange for them to be accepted at the NAPG open day on 17 June 2000 in Birmingham. Or you could post us a few paperbacks at very little cost. If you do this, please send them to Julia Williams at St Marks (address on last page).



Relevant Internet News

Next time you head out to surf the web, we recommend checking out www.gastrohealth.com. This site is relatively new to the web and they have done a great job of putting together an attractive and very informative site. Once there, you can access lots of stuff like a bulletin board, information about how to get books about your disease and plenty of useful reading.

For those of you interested in a homeopathic approach to your health, http://elixirs.com/newsletter.htm is an excellent archive of newsletters from very basic principles.

Thanks from the Treasurer

A word of thanks to all those members who have renewed their subscriptions and especially those members who have completed a standing order of a deed of covenant (or both!).

At the time of writing, we have 79 standing orders and 66 covenants. That is excellent.

The extra amount received from the Inland Reveue in the last financial year was £73.77. Since most of the covenants commenced in January 2000, I would expect this year's amount to be much higher.

Thank you again. If you have not yet completed either of these forms, they are available from me on request.

John White

Blankety Pouch

As usual, Red Lion Group Merchandise will be available for sale at the AGM and Information Day. The range has been slightly expanded, so do bring your cheque book and pen.

If you would like an order form to prebook items to pick up on the day, please contact the newsletter editor as soon as possible.

My Story by Buddug James

I have just finished reading Issue 15 of *Roar!* from cover to cover (as usual) and decided to respond to your request for contributions to "our" newsletter.

I did not suffer for very long with ulcerative colitis before being operated on. I became ill on the 8th August 1997. I had diarrhoea within half an hour of eating some gammon. This always stuck in the back of my mind and I was amazed when I read your article on food poisoning in Issue 14. However, I was diagvery nosed quickly as having UC by my G.P. (within 3 weeks).



Iwas given steroids to take (both ends) for several months and did recover quite well *until* I had a horrific colonoscopy (if someone offered me a million pounds I seriously would not contemplate having it done to me again) .Then the UC returned immediately with a vengeance I was back on the steroids and numerous other tablets and creams.

To cut a long story short, by the beginning of January 1998, I was getting worse, totally depressed, in severe pain and desperate. I *begged* for an appointment at the hospital and tipped a carrier bag of tablets on the doctor's desk and informed him that I was not going to take another tablet (I was on about 27 tablets a day). In the end, I do not think they knew what and how many tablets they were prescribing to me.

That afternoon I was admitted for the first time into hospital. They observed me for a week and gave me intravenous steroid by drip . It did not work. My colon was well and truly 'cream-crackered'. I was told that it would have to be re-

moved and that I would have a bag instead.

I had such mixed emotions - the main ones being fright and relief. Relief, that I would be better and fright of the unknown future - a bag of 'poo' stuck to my tummy. I felt as if was going to become deformed, and felt I was too young at 32 to be disfigured. I had my whole life ahead of me. But I had to be realistic in the thick of it all and realised sensibly that I could not carry on as I was (house-bound) and that this was my only option.

I was scared, very scared, and had so many questions. My surgeon was brilliant and answered all my questions and I owe him so much. I also owe a great deal to my family, especially my boyfriend (now my fiancé) and my mum. I do not think I could have come through this as well as I did without their tremendous support.

It all happened so quickly that I did not have time to speak to a fellow patient before my first op which was a great shame. One of the worst times however was having to wait a whole week after the op to see

if I could have my stoma reversed. When the surgeon told me I would be able to have the reversal and have the pouch, I kissed him - I was that relieved. I was crying with joy.

I recovered really well and went back to work part-time in May and June. I was ready for op number 2 (pouch formation) on the 8th July (boyfriend's birthday). I had an additional surgeon at this op. So this time I had two brilliant surgeons looking after me. It went well and I was out of hospital after 10 days.

I had managed to speak to a fellow pouchie before this op and he told me to be prepared for a difficult time between op 2 and 3. Boy was he right or was he right? For $3\frac{1}{2}$ weeks I was constantly sick, could not eat and lost over a stone. I went down to $6\frac{1}{2}$ stone and was so weak I could not get out of bed. Needless to say my recent scar was hurting like hell!

I was in and out of hospital trying to find out what was wrong. Eventually, it was discovered that my potassium levels were too low and this was cured by placing me on a drip. Whilst all this was going on I also became paralysed in the

mouth. This was very frightening as I thought I had had a mini - stroke on top of everything else. The cause of this was eventually traced to the 'Stematol' injection to stop sickness. If this was not enough I also had major problems at this time with leaks.

This was my lowest point. I was supposed to have my 3rd and final op at the end of August but had to wait until the end of September because of this hiccup.

Since the 26th of September (date of op) my pouch and I have not looked back! No more incontinence and soiled knickers. No more pain. No more being house-bound. No more being frightened of what to eat/drink. No more depression. Instead, plenty of happiness and joy at being alive and living and living and living some more!

I went back to work last January (1999) part-time and have been full-time since March (1999). I have been seriously making up for lost time recently.

At this moment in time, looking back, it does not feel as if I have been through all of this. I knew what I had to go through, dealt with it and just went from one op to the next and eventually came out the other side. I do not know how I did it to be honest, but one thing I do know - I am glad I did.

One very important thing to remember is that even at your worst: "There is *always* someone else worse off than yourself".

Another point I would like to add is that the help of a herbalist and reflexologist were an enormous boost to my recovery. The herbalist did wonders throughout helping me with my diet. I had two excellent surgeons, great family and friends supporting me. So anyone who is considering a pouch - GO FOR IT you only live once. I would only be too willing to speak to anyone who wants advice/reassurance on the pouch op.

Finally, thanks to those ladies who responded to my request for advice on pregnancy recently. And let me wish everyone in the Red Lion Group a Happy New Millennium!

Food Intolerance

As pouch owners are all too aware, what we eat has a direct bearing on our overall health. In the UK, there is a charity called the Society for the Promotion of Nutritional Therapy, who promote the use of nutritional principles to improve our health.

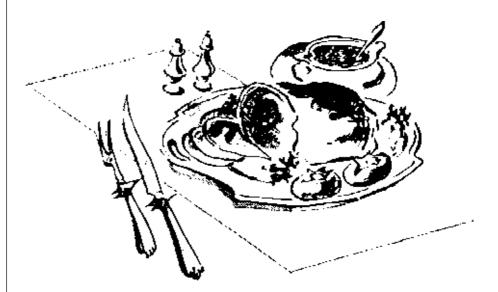
The following extract on the topic of food intolerance comes from their website. I have highlighted in italics one sentence which is of particular interest to pouch owners, as this may explain the enormously different reactions to foods noted in our recent diet survey.

Food Intolerance

One type of allergy is known as a 'food intolerance'. Reactions are often delayed, intermittent or chronic, and although they may involve the release of histamine by the and stock cubes). Alternatively histamine may be released through effects which occur to cell membranes and prostaglandins as a result of the body's response to a problem food.

Causes of Food Reactions

Food intolerances may be due to enzyme deficiencies, which may be inherited or induced by a toxic overload or by nutritional deficiencies. Any of us can react to any substance if the enzymes responsible for its metabolism are inefficient or absent.



mast cells of the immune system, they are not generally considered to be immune system mediated. Examples of these reactions include

- Chronic fatigue
- Eczema
- Intermittent migraine
- Irritable bowel syndrome
- Joint pains
- Sinusitis

Foods which cause reactions may be rich in tyramine, which releases histamine from mast cells (e.g. chocolate, alcoholic beverages, mature cheese, salami, bean pods, bananas, yeast concentrates, soy sauce Symptoms are not related to the substance itself, but to our reaction to it. Thus one individual may develop migraine after eating bread; another may experience diarrhoea.

Adverse reactions to the consumption of high-protein foods may occur if the individual lacks the nutrients (such as magnesium) needed for the conversion of ammonia - a breakdown product of protein - to urea, which is excreted via the kidneys. The symptoms of ammonia overload may include fatigue, headache, lethargy, irritability and allergy-type reactions.

What is Reflexology?

In view of the fact that we are going to have a reflexology workshop on 15 April 2000, I have reprinted below (from Reflexology for Every Body's website at http://www.footloosepress.com/benefits.htm) some information

about what this alternative therapy is and how it can help. I hope it whets your appetite to learn more about an ancient therapy which, like homeopathy, is steadily gaining in popularity.

Every body from the body of a newborn baby to the body of a centenarian can benefit from the relaxing and healing effects of reflexology. Reflexology applied to the feet or hands can help remove excess body tension, improve circulation, and normalize body function. When properly applied, reflexology feels great and leaves a body feeling relaxed, renewed and full of vitality. Your body! Every body!

Reflexology not only positively affects our physical bodies, but has a positive balancing effect on the mental, emotional and spiritual parts of ourselves. Reflexology is easy to learn and can be applied by virtually any person eager enough to learn.

How does reflexology work? It's really quite simple. We press a reflex point on the foot or hand. A message is sent to a body part. That body part begins to let go of excess stress, tension and congestion. Blood flows in, waste products are removed, circulation is normalized. The body begins to heal itself.

Reflexology is a powerful and effective twentieth century healing art based on century old principles. The term "reflexology" has been around since the beginning of its practice in North America in the 1930's. The technique has probably been with us since the beginning of man. Most primitive societies practised some form of reflexology. Records show the practice being used in 2500 BC in Egypt. The principle of "zone therapy", used for 4000 years in China, contributed to the development of modern reflexology.

An ancient technique has been rediscovered for the benefit of mod-



Go For It!

After her experience of colitis and then surgery, Yvonne Wright decided it was about time to take a gamble.

I have been writing poetry for over 20 years, and when faced with ulcerative colitis 7 years ago, I found writing to be a great solace. Whilst recovering from surgery, it was also a tonic to be able to put pen to paper and write about how I felt.

I have set up a small business called "Presence in Poetry" writing personalized poems for all occasions eg Weddings, Birthdays, Anniversaries, Graduation, New Home. In fact, I can write for any occasion. The emphasis being that the poem is unique to that person/couple/event, as it is tailor made. The poems are presented in a framed or card format.

My business has been running for just a year, and at present it is a part time venture, as I work in the NHS as a Training Officer. I am



hoping that it will grow and become more established. One of my aims is to donate a percentage of the profits to research into ulcerative colitis.

One thing that the experience of colitis and surgery has taught me is to take a gamble in life and to "Go

for it". Be positive and believe in yourself.

If you would like to talk to Yvonne about commissioning a poem for a special event, or as an unusual gift, you can contact her by phone or fax on 0181-402 1374 or by e-mail on yvonnemarie@princesrd.freeserve.co.uk.

KEEP SMILING

Keep smiling tho' its raining, keep smiling tho' you're sad, keep smiling & soon you'll see, that things can't be that bad. Keep hoping and you'll make it, keep praying and you'll see, that if you just keep positive, the rain will clear and you will be... ... ready to face another challenge, ready to stand up and fight, keep smiling and you'll make it, everything will be alright. ymw 1999

Water Good Idea!

Red Lion Group member Gill Tomlin has been investigating what help pouch owners can get from their water board, given their need to use more water than an average person. This is what she has found out.

South West Water have now set up a system for people on meters with an average bill of £310 p.a. to receive help with payment. In order to qualify, you need to be in receipt of one of the following benefits:

- Income Support
- Income based JSA
- Working families tax credit
- Disabled persons tax credit
- Housing Benefit
- Council tax Benefit

In addition, you must have 3 or more children living with you, or someone in the household diagnosed/receiving treatment for:

- Desquamation (flaky skin loss)
- Weeping skin disease (eczema,psoriasis, varicose ulceration)
- Incontinence
- Abdominal stomas
- Kidney failure requiring home

dialysis.

The contact phone number is 0800 169 1133

Ihave contacted them and asked for an application form but as this is all so very new I haven't received it as yet. Any application will be checked with the Benefits Agency and/or your GP.

Some pouch owners may qualify through incontinence or an application might succeed under the "abdominal stoma" heading, if you explain that the ileo-anal pouch is simply an alternative procedure to arrive at effectively the same net result.

A chat with your GP about your needs and how he/she could best explain this when your application is checked would seem to be the best way to start. They may be able to advise you on how best to com-

plete the application form.

For metered water customers in other areas, it is quite likely that other water boards run similar schemes, and so you should try to find out more if you appear to qualify.

In addition, any pouch owner or ileostomist is recommended to find out about what procedures are in place to ensure your water supply is not interrupted in the event of an emergency.

There will be a scheme of some sort for people for whom it would be impossible to manage if water supplies are cut off. It is worth finding out if you could qualify for one of these.

We would love to hear more from any of our members who investigate these issues further for their own situation.

Recipe Corner

Here's a nice non dairy recipe for someone with a sweet tooth. A bit late for Valentine's

Day this year, but who needs an excuse to indulge?

Raspberry Souvaroffs

13/4 cups all purpose flour
1/2 cup confectioners' sugar
3/4 cup solid vegetable shortening
1 large egg yolk
2 tbs. ice water
1/2 tsp. vanilla extract
2/3 cup seedless raspberry jam

In a food processor or in a bowl with a pastry blender, sift flour and confectioners' sugar together. Add the solid vegetable shortening and pulse chop in a food processor or mix with the pastry blender until a coarse meal consistency is achieved. In a separate bowl combine the egg yolk, ice water and vanilla extract and mix well. Add the egg yolk mixture to the flour mixture and either pulse chop in a food processor or continue to mix until a dough begins to form. Remove the dough from the bowl, form a ball, place in a plastic bag and refrigerate for half an hour.

Halve the dough, on a floured surface roll out one of the halves 1/8 thick and cut it with either 2½"

round or heart shaped cookie cutters.

Gather the scraps together, reroll them, and cut more shapes. Roll out the remaining half of the dough 1/8 thick and cut more shapes in the same manner.

Cut out the center of the shapes with a smaller similarly shaped cutter. Bake the shapes in batches on greased baking sheets in the middle of a 325 degree F oven for 12 minutes or until light golden in color. Transfer the cookies to a rack to let them cool.

Spread the bottom of each solid shape with 1 tsp. of jam and top them with the cookies with the holes in them.

Press the together lightly and allow to set for 1 hour and dust with additional confectioners' sugar prior to serving. Makes about 18 to 20 cookies.

From the Culinary Couple's Creative Colitis Cookbook \$12.75 including P&P from the UK. Order via their website at www.colitiscookbook.com or call free on 00 1 877-423-3438.

Please support the Red Lion Group



All donations, however small, towards expanding the work of the group will be gratefully received. If you would like to send a donation please make your cheque payable to The Red Lion Group. And send it to: The Red Lion Group Treasurer, Mr John White, 44 France Hill Drive,

Camberley, Surrey GU15 3QE

Income and Expenditure for the Year to 31 December 1999

Income: Subscriptions Donations Merchandise and AGM tombola sales Bank interest Tax refund on covenanted payments Miscellaneous TOTAL INCOME	£	£ 3,485.00 1,001.20 624.60 67.56 73.77
Expenditure: Postage, phone and stationery Merchandise cost Printing and postage for <i>Roar!</i>	543.78 1,974.15 2,593.44	
Travel expenses Reps expenses Purchase of merchandise trolley Donation to Marksman Appeal as agreed at 1999 AGM	293.55 40.00 180.87 2,000.00	
Other donations made TOTAL EXPENDITURE	360.00	(7,985.79)

Note that the bulk of the excess expenditure related to the one-off donation to the Marksman Appeal agreed at the previous AGM, and for which surplus funds were available at the beginning of the financial year. Our financial statements also take no account of stock adjustments, and so the apparent loss on the sale of merchandise is not a true figure, as merchandise stocks are held but not valued. Had the stocks been valued, this would have reduced the remaining deficit for the year.

£2,713.66

As at 31 December 1999, the Red Lion Group had cash reserves of £1,838.51.

Excess of expenditure over income



Pet Passports prove to be a success with owners and pets alike

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 Red Lion Group rep, please contact Morag Gaherty (phone number on back page).



	1 -1	1110
AVON		
David Mair	Bristol	0117 922 1906
BEDFORDSHIRE		
Wendy Gunn	Luton	01582 423714
BERKSHIRE		
Liz Davies	Langley	01753 586593
CAMBRIDGESHIR	E	
Joyce Shotton	Peterborough	01733 706071
CLEVELAND & NO	RTH YORKSHIR	ĽΕ
Christine Jackson	Saltburn	01947 840836
CUMBRIA		
Jonathan Caton	Kendal	01539 731985
DERBYSHIRE		
John Roberts	Derby	01332 361234
DEVON		
Gill Tomlin	Kingsbridge	01548 810028
DYFED		
Briony Jones	Haverfordwest	01437 765359
Bruce Dibben	Haverfordwest	01437 731436
EAST SUSSEX		
Lisa Critchley	Brighton	01273 699286
ESSEX		
Peter Zammit	Benfleet	01268 752808
Clare Shanahan	Ilford	0181 591 2936

GWENT						
Robert Challenger	Cwmbran	01633 866820				
HAMPSHIRE						
Phil Smith	Portsmouth	01705 426541				
Les Willoughby	Winchester	01962 620012				
HERTFORDSHIRE						
Carol George	Stevenage	01438 365707				
KENT	O					
David Irving-James	Folkestone	01303 894614				
Phil Elliment	Barnehurst	01322 558467				
LANCASHIRE						
Joan Whiteley	Clitheroe	01200 422093				
MERSEYSIDE						
Blanche Farley	Liverpool	0151 924 4282				
NORFOLK						
Sandy Hyams	King's Lynn	01485 542380				
Sylvia Mist	Norwich	01692 580095				
NORTH LONDON						
Susan Burrows		0181 882 5318				
NORTHAMPTONS						
Cynthia Gunthorpe	Kettering	01536 482529				
David Smith	Northampton	01604 450305				
SOMERSET						
Clive Brown	Chard	01460 234439				
SOUTH LONDON						
Andy Jones	SE6	0181 690 1360				
Jonathan English	SW12	0181 673 0704				
SUFFOLK						
Anna Morling	Leiston	01728 830574				
WEST LONDON						
Dee O'Dell-Athill	W10	0181 960 6726				
	colin@odell-ath	ill.demon.co.uk				
WEST MIDLANDS						
Linda Bowman	Birmingham					
0121 766 6611 ext 4332 or pager 0027						
WEST SUSSEX		04000 005/00				
Amanda Metcalf	Arundel	01903 885682				
WILTSHIRE & DOI		04.500 005000				
Bernadette Monks	Salisbury	01722 327388				
YORKSHIRE	T J .	0110 050 0540				
Neil Anderton	Leeds	0113 258 2740				
Sue Appleyard	Huddersfield	01484 311334				

Go for the Burn!

And finally, one interesting dietary titbit Morag learned this week concerns the effect of avocados on a dodgy stomach or bowel.

A friend of her and Brian used to live in Columbia, and had a serious stomach upset. Her husband called the doctor who asked what she had eaten: just a bit of avocado on toast. "Ah well", said the doctor, "there's your problem.

Everyone knows that avocados tend to exacerbate any kind of acid-

ity in the stomach."

Apparently, in those countries round the world where avocados are eaten regularly, this is something most doctors are aware of. It is supposed to be something to do with the fat content, which is very high in avocados.

The reason this conversation took place was because Morag's young son Bob had eaten avocado at lunch (which is something he enjoys a great deal) and when he came to do the necessary a few hours later, he literally screamed as he filled his nappy. Had Morag not whipped it off there and then, he would have had a severe nappy rash, as welts were already developing.

Although he would not normally have any effect from eating avocado, because he is teething at the moment, his stomach was sufficiently off balance to have a great deal of trouble processing it.

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ME14 4AW

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Tel: 0181 661 7778

E-mail: timr@dircon.co.uk

FUNDRAISING OFFICER

This position is currently vacant. Anyone interested in applying should contact the secretary, Inez Malek (address and telephone number on this page).

* contributions to the newsletter should be sent to Morag Gaherty

PRESIDENT Professor John Nicholls

PATRON Claire Rayner

Join the Red Lion Group

- Quarterly newsletter with all the latest news, views and events
- Membership is £10 (free for hardship cases and under 16s) per annum
- Write to Liaison Officer at the address above for a membership form

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.