

# Roar!



Issue number 14 • Autumn 1999

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

## ***Finding the Cause***

Roar! editor Morag Gaherty brings news of a possible breakthrough in our understanding of the cause of ulcerative colitis

As everyone with ulcerative colitis knows, there are many theories on the causes of this illness, but none has as yet proved to be The Answer.

However, doctors in Leeds have been pursuing the theory that it may arise from an infection by a bug of escherichia coli group (you may know this group under its more common name of E. coli).

Based on a similar idea to that of vaccination, they tested their theory by wiping out the infection with antibiotics and then deliberately reintroducing a harmless form of the same bacterium. The idea was that the new colonisers (how appropriate for pouch owners!) might block the harmful ones when they tried to take hold again.

All the patients received antibiotics for one week to kill the bacteria in the colon. Then half received the harmless form of E. coli, while the others took mesalazine, a drug used for keeping ulcerative colitis in remission. Interestingly, the two treatments were equally effective.

At least one new member of the Red Lion Group can specifically date the onset of his ulcerative colitis to a bout of food poisoning, and remembers the event very clearly, even though it happened a long time ago. Perhaps other members could write in if they too have either had suspicions about such a link, or remember having had food poisoning just prior to UC striking for the first time. We would certainly like to hear any evidence, however anecdotal.

The question we now need to ask is: what steps are being taken to further this very important line of

research, to see whether the solution really is as simple as that? And if pouchitis is really a form of "mini uc", could this also be helped by



such a treatment, or does the removal of the colon to form the pouch render this approach impossible?

On behalf of the Red Lion Group, your Chairman, Brian Gaherty, will be contacting the researchers at Leeds General Infirmary to find out more. As ever, watch this space!

On a similar topic, I have also

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### **IDEAS FOR CHRISTMAS PRESENTS**

Why not treat friends and family to Red Lion Group clothing or other small items? See the order form enclosed with this newsletter for details of what is available.

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been reading a recent article in the magazine What Doctors Don't Tell You on the subject of parasites, about which they say "the most under-diagnosed health problem in the West, parasites may be responsible for a multitude of conditions - from joint pain and chronic fatigue, to many general disorders of the gut and immune system". Any of this sound familiar?

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# Quality of Life after Colorectal Surgery

By Annette Bisanz, BSN, MPH

Reproduced with kind permission from *Generation to Generation*, the newsletter of the University of Texas MD Anderson Cancer Centre.

Following colorectal surgery, there may be a change in bowel function due to the change in the anatomical structure of the colon or rectum, or both. This may necessitate a bowel management programme that is based on the same basic principles but needs to be individualized for each person. There is all the reason in the world to believe that your bowels can be managed after colorectal surgery.

These are the prerequisites for managing bowel control:

- Be committed to the programme and be willing to follow specific directions
- Seek guidance from a professional when you are not achieving the goals of your programme
- Keep your sense of humour

Following colorectal surgery, many people have several stools per day. The normal frequency of bowel movements in a healthy population varies from 3 bowel movements per day to 3 per week. The goal is to return to no more than 3 bowel movements per day.

## Transit Time of Food through the Gastrointestinal Tract

Eating a large meal or drinking a hot liquid will cause a normal peristaltic push down in the gastrointestinal (GI) tract. When frequent bowel movements occur, drink less fluid with your meals, drink more fluids between meals and avoid hot liquids.

## Medicinal Fibre to change the Transit Time

If you are having frequent stools, then introducing psyllium, a medicinal fibre also known (in the US) as Metamucil, can slow down transit through the GI tract. Most people take psyllium for constipation or to speed up transit time through the GI tract; however, after colorectal surgery, your goal will be to slow down the transit time. To do

this, take the prescribed amount of fibre right after a meal in very little fluid, approximately 2oz., and no more fluid for 1 hour immediately after a meal. This allows the fibre to act like a sponge in the GI tract, soaking up excess fluid in the digestive system and thus slowing things down. One teaspoon should be taken after the same meal each day for 3-5 consecutive days. Then increase to 1 teaspoon psyllium 2 times per day. Gradually increase the fibre by 1 teaspoon every 3-5 days until the GI tract transit time slows down a bit.

## Bowel Training

Once your stools become better formed and the transit time has been slowed down, the next step is bowel training, with the goal of emptying the colon fully at an expected time each day. Pick a meal of your choice around which you'll bowel train yourself. Bowel training is done around a meal since a big meal causes a push down the GI tract to make room for the food taken in.

Choose a time when you can consistently follow the programme. Then,

- Before that meal drink 1 oz of prune juice
- Eat the big meal
- Drink a hot liquid

If this does not produce results, you may try using a glycerin suppository after the hot liquid.

Do this for 3 straight days

If you don't empty as planned, substitute the glycerin suppository with ½ bisocodyl suppository.

If this is effective, stay with the programme for 2 weeks and then stop using the suppositories.

By this time, the stimulus for your bowel to empty will be the prune juice, big meal and hot liquid.

## Adjusting the Bowel Management Programme

Since each person's body reacts

a little differently, don't get discouraged if your programme doesn't immediately help. Problem solving is the key to success, and little changes made after trying something for 3 days will help you determine what will work for you. Overall bowel management involves a gradual balancing of food, fluid, fibre and medications.

## Food

If your bowel is stimulated by a big meal, eat 1 big meal per day and 4 smaller meals. Certain foods affect people adversely, and you need to be aware of what you eat that may cause increased bowel movements. (High fat and/or spicy foods seem to affect many people).

## Fluid

Fluid with meals tends to increase peristaltic push-down, so drink fluid in between meals instead of a large amount with meals, and avoid hot liquids.

## Fibre

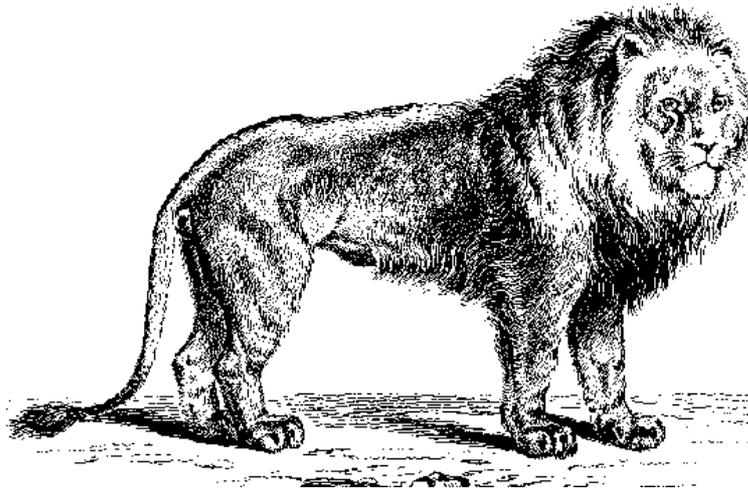
Adjust the amount of fibre gradually to see how much fibre is required to slow down or speed up transit time through your GI tract and maintain soft, formed stool.

## Medications

If you are taking antidiarrhoeal medications such as Lomotil or Imodium, as you gradually increase the amount of psyllium, try to decrease the amount of Lomotil/Imodium.

Most people get good bowel control just by the use of fibre. However, keep yourself comfortable during the process of defining your maintenance bowel management programme. Be patient with yourself.

Remember, there is hope for bowel management, the goal being a high quality of life after colorectal surgery.




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## Editorial

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It hardly seems five minutes since Tim and I put the last newsletter together, and here we are again, pushed up against our deadlines as usual.

We're so hi-tech here these days: I send all the material to Tim by e-mail, and he puts it all together then publishes the draft newsletter on the internet, for me to review and correct. It's all done by e-mail, and no paper is printed out until the master copy comes off the press. Welcome to the 21<sup>st</sup> century (nearly).

As those of you with ulcerative colitis know, theories abound on the causes of this illness, but the idea of some form of bug infection is an intriguing one. You can read more about this on page 1.

Our lead article was intended to be Annette Bisanz's article on bowel control (which you will now find on page 2), but somehow a news snippet from Sandy Hyams and an in depth article in *What Doctors Don't Tell You* seemed to be two sides of the same coin, and the timing was perfect. As ever, please do send in your own comments and experiences.

It was also Sandy who alerted us to the existence of the Toot Trapper mentioned on page 8, which should prove an amusing read, even if you decide that life can continue without one.

The internet is not everyone's cup of tea, but it is invaluable when searching out more information on those seductive little paragraph fill-

ers in the papers (in this case, the *Daily Telegraph*, which seems to be simply awash with bowel-related gems at present!).

The Tips from Members section on page 10 of this issue is devoted to dietary tips from the recent diet survey. I hope it gives you some ideas, if you are trying to find out what does and does not suit your pouch. Experimentation is the key.

There are many other great articles in the newsletter, which I will leave you to find for yourself. I know from your letters that *Roar!* is read avidly from cover to cover, and even our Patron seems to find time in her busy schedule to read it and also write some nice words of encouragement to us.

Sadly, we do not seem to have much interest in the Contacts page at present, but we will persevere with that, as and when you send me your details to put in. Remember, it is not obligatory to want to talk about pouch surgery - many members find the AGM a great day to make new friends who just happen to have a pouch, and I hope the Contacts page will develop in the same way. Why not try and find a badminton or bowling partner through the Red Lion Group?

The survey results in this issue are from the survey More About Your Surgery, which was included with the Spring newsletter. This quarter's survey is a little different: instead of asking you to fill in questionnaires, please take the time to

tell us about any aspect of your pouch experience. This will give us plenty of personal experience material for future issues of the newsletter, which is invaluable for new and prospective pouch owners. I look forward to hearing from you.

I know Christmas seems a long way away, but enclosed with this newsletter is an order form for the Red Lion Group merchandise available, to help simplify your Christmas shopping list.

All the logos are sewn not printed on, and the garments are of very high quality. You can even choose between a large Red Lion to cover your chest or a discreet one to nestle near your shoulder. And this year, we have added T shirts to the range for the first time. So go on, spoil yourself! You deserve it.

### Gala 2000

Sir Peter Maxwell Davies, Britain's foremost living composer, has written a short piece especially for us, entitled *In Osculum Leonis*, which - if my 'O'-level Latin holds up - translates as "In the Eye of the Lion".

We have also received signed pictures from former Prime Minister, Baroness Thatcher, a signed Red Lion from actress Joan Collins, a signed photograph and signed Red Lion from Russ Abbott and a signed Red Lion from astronomer Patrick Moore.

## Airbags and Seatbelts

Among other things, Bill Shepherd tells us how doing what you enjoy can help keep you off the toilet!

Having recently had my pouch operation, I applied for a Radar key so that I could use the disabled toilets if necessary. I should point out that the key is quite large, and I find it useful to wear it on a tape around the neck.

As of yet, I have not had to use it, but on behalf of our group checked out a number of disabled toilets both locally in Hertfordshire and in North Wales. Only one failed to meet a very high standard.

I am normally employed as a lorry driver, and returned to work ("light duties") in August. Between lorry and car, I cover in excess of 80,000 miles a year, so the Radar key will give me real peace of mind.

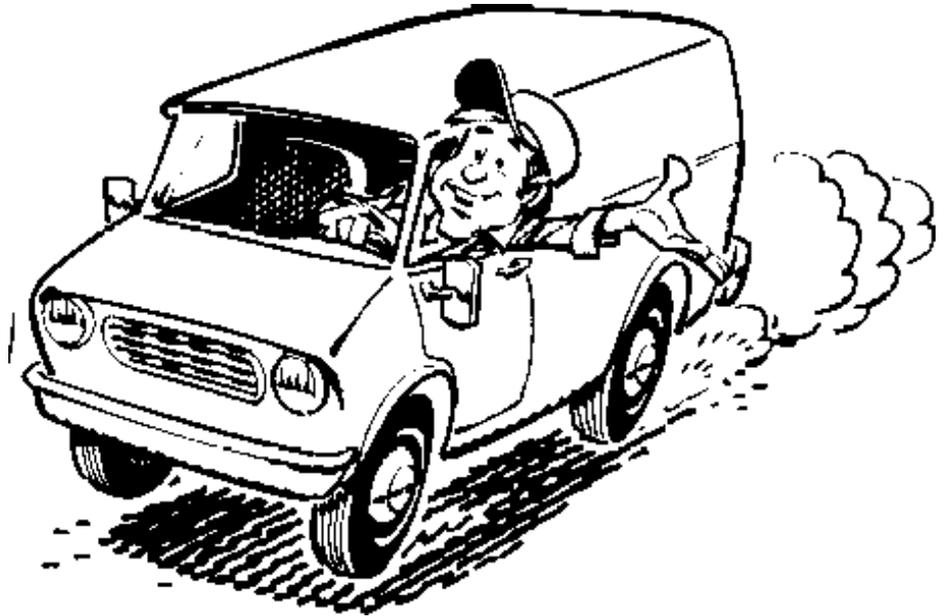
I am hoping it will be a bit like airbags and seatbelts: I don't want to test them for their purpose, but if I need them, I shall be really glad to have them!

I am of the opinion that if you are doing something you enjoy, your bowels, bag or pouch are not very active. In the 28 years that I have had ulcerative colitis, I have only had to stop three times in an unplanned, urgent, embarrassing way. I believe this is because I enjoy my job.

I also have another true story that illustrates my theory perfectly. Many years ago, I had an old school friend who commuted into London to work each morning to a job he did not enjoy.

He also had IBS. His journey each morning was about 18 miles on the train, but *every* morning he had to get off the train at three or four stops to use the toilets (any pouch owning commuter will tell you that the toilets on a commuter train are just not suitable for our needs!).

However, in his spare time, he was a tennis umpire at Wimbledon and other tournaments. Amazingly, he was never affected by urgency while on the court. I think it was because he enjoyed what he was doing, so he never gave his IBS a thought.



Perhaps there are Red Lion Group members who have problems controlling their bowels, and so have given up favourite hobbies because they are afraid of needing the toilet at an inappropriate time. I hope my friend's story will give you the confidence to go back to doing something you enjoy.

Finally, I do have one worry, which other members may share. I do not feel in control on public transport, with inadequate (or no) toilets on most trains or needing to get off and on buses then paying again to get on the next one. For this reason, I like the security of my car, holding my spare underwear, trousers, wipes and other toilet equipment (back to the airbags and seatbelts again).

My worry is toll roads, first tested in Leicester and now in Leeds and Edinburgh. I think we should look at this early on, while the tests are still going on, for some sort of help or exemption from payment. Maybe a disabled sticker with a "T" on it for parking near toilets, and only near toilets. After all, if Radar recognises incontinence as a disability, why not?

*Continued from page 1.*

You may think that parasitic infestation is a Third World problem, but in a recent study of over 400 patients with chronic fatigue immune deficiency syndrome in New York, an incredible 93 per cent had some form of parasitic infestation.

WDDTY is a fascinating publication, although it often goes over my head, because it is really geared at people with more medical knowledge than I can lay claim to. However, many pouch patients have acquired just as much knowledge about their condition (and often much more!) than their GPs.

For those who are interested in finding out more about parasitic infection as a possible cause of gut disorders, I am happy to send a copy of the 4 page article on request (please send a stamped addressed envelope).

The article contains advice about the best way to clean the body of parasites and to keep it clear. As ever, we would love to hear from any of you that try this advice out and what benefit - if any - it has brought you.

# Letters



## Roar! Letters Page

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*Dear Newsletter Editor*

Four and a half years ago, I was diagnosed with a malignant polyp in my back passage. Subsequently I had to have my colon removed and was given an ileo-anal pouch, a J design I think. This was done in a series of two operations. I was given an ileostomy for six weeks and then a reversal op was performed.

I woke up in the hospital bed and found I had soiled the bed. The wonderful nurses at Northampton General Hospital reassured me and made me comfortable again. For the duration of my week's stay in hospital I spent nearly all of it in the lavatory. I couldn't imagine how I was ever going to live a normal life again. Nobody said that things would improve in time. It seemed that every time food went in, it raced through and out the other end.

I also had 6 months of chemotherapy and this did not help things. Being alive and trying to function seemed an eternal nightmare. Friends and family visited me and sympathised with my plight, but of

course they could not really identify with my situation.

I returned to work as a Doctor's receptionist after 11 months. Being busy seemed the answer and gradually things started to improve. Trips to the toilet became less frequent and I slowly adjusted to my new bodily function.

I am now very happy to say that I only need to go to the toilet about 6 times in twenty four hours. Discomfort still happens but not nearly so often. I can now do all the things I did before my operation and am glad that I have a pouch and not an ileostomy

*R Tilley (Mrs)*

*Dear Newsletter Editor*

I had a one-stage pouch operation a year ago, expecting maybe to need iron tablets and Imodium if I was unlucky. I do indeed require iron tablets, and as the Imodium didn't work for me, codeine phosphate. I am totally dependent on codeine phosphate (without which I'm incontinent), with a liquid stool, no matter what I eat. The drawback of these tablets is a.) drowsiness and b.) not being able to drink alcohol.

*Yours sincerely  
Caroline Ingram*

*Dear Newsletter Editor*

Donna Swift's problems (*Roar!* issue 11) may be resolved by a change of diet. When I stick to plain food, ie toasted crispy bacon sandwich, meat and boiled/roasted/fried potatoes, my frequency and comfort are vastly improved. If I take vegetables, pastry, salads and spicy food, then my frequency and tail end discomfort increase.

Dry white wines, fruit juices, lager and beer cause considerable discomfort, whilst early and lunch-time tea is OK. I also find cold draught Guinness superb. It seems to absorb the enzymes and relieves discomfort. Although, consumed in quantities it will increase frequency! Don't eat or drink before bed, and make sure you are empty. Once you are in control, then you can experiment. Be positive.

I had my first op on 9 September 1996, followed by a second 10 days later due to peritonitis. In December I was joined, had a blockage and was opened up again on 23 December. It took me well over six months to regain my confidence. Even now I would not climb (unless there were strategically placed toilets). But now I can do most work, even physical, and can eat or drink nearly all foods (but I'm always aware of the consequences).

*Alfred Dickens*

**Ed's note:**

**Donna has since had a second opinion and has discovered that her pouch is kinked. Hopefully, further surgery will solve the terrible problems she has been having with her pouch. There is an important lesson for all pouch owners with problems here: if you have an unacceptable quality of life, and no-one can explain why, make sure you get a second opinion at a centre of excellence.**

## Can You Help?

I am a 32 year old female pouchie and am desperate to talk to fellow female pouchies who have become pregnant since having their pouch. When I had my final op September last year, I was advised by my consultant to wait a year before considering having a baby. I am very nervous of pregnancy and how it will affect me.

I would be very grateful if anyone could contact me with their experiences. I am grateful to everyone I spoke to before my operations, as it is so helpful to speak to someone who has experienced what you are about to go through. I was very reassured by this, and hopefully I can gain some further reassurance from this request. Thank you.

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Tel: 01454 261550

## A Friend in Need is a Friend Indeed

New member Jean writes about how the Red Lion Group helped her find out more about the pouch operation

In the month of June 1998 I had non-stop diarrhoea and bleeding from the rectum. After days of no appointment available at my doctor's, I asked my daughter to drive me to the local hospital, where the duty doctor admitted me saying I had ulcerative colitis.

"What happens now?" I asked. He told me they would give me a course of different kinds of medication to see if they could improve my situation and monitor my bowel movements.

What a humiliating business that was, having to inform the nurse each time I had a bowel movement, which was - I might add - duly inspected, discussed at length and details then entered on my medical notes.

The weeks went by, my weight dropped to 7 stone, I had three blood transfusions, I was losing my hair, the pain was unbelievable. And there was no improvement in my ulcerative colitis.

I then had a visit to my "bed space" by five men in white coats informing me that they had tried all possible ways of treating the condition with medication, but to no avail. My only option, they told me, to ultimately save my life and render me free of pain, was surgery. This involved fitting a "bag", until a reversal might be possible in a few months' time when my health was much improved. I signed the relevant forms and the ileostomy was performed in August 1998.

Out of hospital, months later, I was much better, and on my second visit to my surgeon, I discussed with him the possibility of me having a pouch operation.

His advice was very wise: "You realise you will never be the same. There could be leakage to deal with and other minor problems. Go away, make enquiries, read about it, do your homework and then come back to see me."

Help! I could not find anybody that had had the first op, let alone

the second. I badgered my friends, read everything I could lay my hands on relating to it, made lots of phone calls, and was a general pest to one and all.

My stoma nurse sent me a magazine called *Roar!* I rang the Chairman's number and spoke to him and his wife Morag, two extremely nice people (Ed: I promise I did not put this compliment in myself!), who were able to help with some of my questions. I have since joined the Red Lion Group as a member. My nurse also told me she had spoken to a Mr David Irving-James, also from the Red Lion Group, who would be willing to speak to me in connection with my operation.

I rang David, mentioned my nurse, and asked him if he knew of anyone who had had the pouch operation, as I was doing my homework prior to seeing my specialist. Well, David could not have been nicer. He sensed my unease, and by the time the conversation was almost at an end, I was made to feel like a long lost friend. He offered to visit me at my house, which he duly did 3 days later. He brought along with him a lady called Gill Hawkes, who had her pouch op in September last year.

Between them, they answered all my questions honestly, allayed my fears and provided some very relevant and useful information. David also advised me to get the best person for the operation if possible. I told him I was going to tell my consultant that I had done my homework and wanted to go to St Marks to have Professor Nicholls perform my operation. Both my visitors laughed because they too were under St Marks.

Before this article is published, I will have been to St Marks to see Professor Nicholls. I am not "out of the woods" yet. I may be rejected for the operation, but I do not wish to end on a negative note. If at the end of the day my stoma has to stay, then so be it. My stoma gave me

back my life, and wonderful people like David and Gill are on the end of the telephone willing you to enjoy every aspect of it.

*David Irving-James writes:*

*I am sure a number of you can relate to Jean's story and I hope that this article brings home to readers the importance of having capable and willing members who are available within the regions to help those who are considering pouch surgery.*

*It is a big leap into the unknown, especially for someone whose stoma works very well: exchanging a known acceptable quality of life for an unknown quantity is not an easy decision to take, as many of us know.*

*The advice, support and views from an existing pouch owner are so valuable to a person facing a decision that will affect the rest of their life. Of course, it is important to remember that everyone's experience is different, and no potential patient should be given the impression that what has happened to one pouch owner will happen to them. Nonetheless, the more people's experience they hear, the better able they will be to make an informed decision.*

*If you feel you could get involved in helping others prior to, during and after pouch surgery, let me strongly recommend that you attend the next listening skills course, to be held at St Marks in the Autumn. It could be just the opportunity you have been waiting for. If you are interested in this, please contact me on 01303 894614.*

*I am pleased to say that Jean has now heard that her pouch operation will be going ahead soon, hopefully before the end of the year.*

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In issue 13, Jessica Drewery's piece about her walk in the countryside was accompanied by a picture of a man with a gun. This image was simply intended to represent an idea of the countryside, and should in no way imply that Jessica supports any form of bloodsports. Apologies to Jessica and to anyone else who was offended.

## Polyposis People

Things have been quiet, the main happenings being the reception of the second edition of the new American Hereditary Colon Cancer Newsletter, now called *Generation to Generation* and the visit of my wife and myself to the St. Mark's Hospital Polyposis Registries.

*Generation to Generation* featured an article about post operative bowel control, which Morag has already hijacked for this issue. The important theme being that "overall bowel management involves a gradual balancing of food, fluid, fibre and medication". I have found the use of psyllium fibre quite beneficial in the recommended minimum amount of liquid. This has reduced the number of liquid stools I produce. I am going ahead slowly and being realistic about my goal, I should be quite happy at 6 per 24 hours and have already come down significantly thanks to this new approach.

Other articles are about methods of researching your family history and the second part of a basic introduction to genetics called *Genes and Cancer*. This article explains how normal cells can develop into cancer with accumulation of genetic changes but if you have an inherited mutation, one of the cells is one step ahead in the process. There is also Q & A section, and the main topic addressed is the tricky question of how to raise the subject of FAP in your family. As I discovered myself, the tendency is for some people to put their heads in the sand.

Our visit to St. Mark's did not quite go like clockwork. If it had a title it would be *A Comedy of Errors* (mainly John's). We had decided to incorporate it into a short holiday. On the Monday evening we arrived at the hotel in Oxford to find I had left my plastic card twenty miles away at a Garden Railway shop. Fran had a little panic over that and the next morning we had to divert to retrieve it. This meant we were going to be late at St. Mark's and after missing the Hanger Lane Interchange on the A40 (I was looking for an island) it took about half an hour to get back to it.

When we found the Northwick Park Hospital we orbited the one way system, found the St. Mark's

car park full and had to go around again to find somewhere to park. Only an hour late! This "seat of the pants navigation" in London is rather nerveracking for those of us not used to it.

We met Julia Landgrebe (The Thames Regions Polyposis Registrar) and Kay Neale (St. Mark's Polyposis Registrar) with a view to producing a UK polyposis newsletter. They will also contribute to the *Roar!* polyposis page. They have been considering a newsletter for some time but did not have the time to spare, so when my head went above the parapet (actually, Julia Williams told Julia Landgrebe about the *Roar!* polyposis page) they contacted me at the same time as I sent them a letter. So it was a case of synchronicity, or happy coincidence.

The plan so far appears to have a committee of editors: we will have to see who co-ordinates who! We hope to feature articles that will interest polyposis people, such subjects as genetics, treatment, personal stories and reports of the tests into chemoprevention. Publication will probably be twice a year. We are aiming for the first to be December 1999.

Afterwards, we drove down to Bognor Regis. I had thought that the M3 and the A3 went in the same direction, but at the first services on the M3, I found out how wrong I was. It was raining and the prospect of navigating across country seemed daunting. So, I took the simple route, straight down the M3 and turn left at Southampton! It's only about 50



miles further.

The next day at Bognor Regis was the normal mixture for a British summer of bright sun, high winds and rain. At times it seemed all of them simultaneously. We came back on the Thursday, straight up the middle of the country. When I got home, I thought at least I wouldn't have to drive on the M25 for a year.

Then I met my brother and he told me he was taking his daughter to Rickmansworth on the Saturday, as she will be living down there for a couple years. What could do I, I offered to ride shotgun. So back to the M25 sooner than planned.

I hope to have a bit more for the next issue. Contributions are welcome. If anybody would like a copy of the only issue of the JDR UK Polyposis Newsletter, I can print copies on demand. My contact details are: 21, Clinton Street, DERBY, DE21 6DH, Telephone 01332 361234

John D. Roberts

## Welcome to Emission Control

Tipped off by RLG member Sandy Hyams and her close reading of the *Daily Telegraph*, Morag Gaherty delves into parts only the bravest will venture...

Doctors in Minneapolis have taken the concept of the Odour-Eater and applied it to an area of more interest to pouch owners:

The Toot Trapper is a small charcoal-filled polyurethane cushion (at least, I assume it is small!) to be placed in the underwear, where it absorbs hydrogen sulphide gases. Apparently, the amount of gas released is reduced by 90 percent, and so the Toot Trap-



per is considered to have "therapeutic potential for those suffering from excessive offensive rectal gas". The therapeutic potential for those who work with sufferers is no doubt also significant!

I have found a medical website reviewing this product, so it must be more than a gimmick - unfortunately, I can't tell you much more, because the website was all in Dutch!

Want to get one? If you are on the internet, you can find out more at <http://www.flatulence-filter.com/page4.html>. Alternatively, phone 001 1 410 631 4776, or fax 001 1 281 933 2731, or write to: Ultra Tech Products Inc, 11191 Westheimer #133, Houston, TX 77042-3222, USA. The Toot Trapper costs \$39.95 plus \$14 airmail postage.

The manufacturers say the Toot Trapper will have the following effects, and marriages have even been claimed to have been saved:

- Reduce the side effects from diseases: Diabetes, Crohns, Colitis, Irritable Bowel Syndrome (IBS), etc.
- Relatives, co-workers, friends no longer complain.
- Reduce environmental pollution for others.
- Eat what you want without the ugly odour and embarrassment.

## Aga Do Do Do

The Greater London West branch of the ia are holding their Christmas "do" on 4 December 1999 at Northwick Park Hospital, Harrow, and members of the Red Lion Group are warmly invited to join forces for an afternoon of seasonal spirit.

Everyone is meeting up at 2pm in the newly-refurbished restaurant, and you are asked to bring along a small food contribution (a plate of sandwiches, cakes or nibbles etc). Tea and entertainment will be provided, and the afternoon will finish at around 5pm, or whenever people decide to stop talking!

There is no entry charge, but please phone Jan Woodhouse on 01753 859781 by 21 November if you are able to come, so that she can organise numbers. This would be a lovely way for the Red Lion Group and the ia to forge closer links, and I hope many of you will be able to go.



*In a bid to recycle waste, pouch surgeons turned their attention to the playground*

## Putting it in Writing

Press Officer Christopher Browne drops some handy hints about getting into print

Did any of you watch a recent BBC2 series called *Reckless*, about a colon surgeon and his management consultant wife? One scene showed him on a lecture tour of Finland, where he told his audience that the image of colorectal surgery was poor. "It is like going up a hill backwards," he said ruefully.

Thankfully, the patient work of gastroenterologists, health experts and support groups is slowly removing the Great British Public's smutty view of bottoms, lavatories and all things anatomical.

I recently asked Talk Radio (a London-based radio station) to run an item about the Red Lion Group seeking a fund raiser. My contact there was very enthusiastic and said he was sure they could put something in their Good Causes slot. He assured me I'd be hearing from one or two producers very soon.

Silence. No phone calls. As a jaundiced journalist, I am used to such disinterest. So I chased it up. They told me there had been a change of owner (the station was bought that week by former Sun editor Kelvin MacKenzie and Rupert Murdoch's News International) and good causes had lost their flavour (Gosh! We'll have to give them the sherbert lemon variety next time). This was an excuse, not a reason.

Though the item was a genuine and worthy plea, it needed a strong angle to succeed. News must be linked to an event (preferably a catastrophe) or an item of human interest. This had neither. If, for instance, I had said we raised £500,000 from a London-Birmingham Skateboard Marathon, it would have been used instantly.

The second lesson of PR is that it must be geared to its market. If you are writing a Guardian or Independent feature, you can afford to write in-depth and embellish it with some technical knowledge. Whereas the

Mirror just wants to know about the Bare Necessities.

Now, this leads to another thought. Has it struck you that as a Red Lion Group member, YOU may be able to get into the pages of your local newspaper? It could be a local Red Lion darts team challenging another charity (if the news pages



are not interested, try the sports editor) or a pub quiz based on health, sponsored by the local Red Lion Group branch. Then there's that old favourite, karaoke: you could have an evening of stand-up with a lion theme and songs featuring animals. Or a dinner with a well-known celebrity as a speaker. That is sure to get a mention in the people-hungry media. Why, pray, does the Red Lion Group AGM always get a write-up in the two local Harrow newspapers? It is because our patron is a noted broadcaster and commentator – and if we just happen to have an influential speaker on the agenda or feature a song-and-dance routine during the day, that always gets a line or two as well.

So, if by chance you are involved in a Red Lion event in your area or region, do contact your local newspaper and see if they will publish a news item about it. You could try to cultivate a rapport with the news editor anyway, by phoning and tell-

ing him/her about the Red Lion Group and our work. "New charity, local group, modern surgery, Claire Rayner as patron, and any local events" would be your key themes. For, as you know, any publicity item, whether 2 lines or 2,000 words, helps our cause. Many of you have already shown your true mettle with both moving and funny letters and articles in *Roar!*.

Writing a letter to your "local" is another good source of publicity – for it has your name and link with the Red Lion Group at the foot of the piece. You could choose one of a variety of subjects: a comment piece about Health Service bureaucracy, perhaps; your fears about the threatened closure of a gastroenterology unit at your local hospital; or your views on one of a large number of contemporary health issues. These are always being debated in Letters Pages – and we're all interested in our own health and well-being, and any ideas or cures that can enhance them.

If, however, you happen to come across a forty-five year old pouch owner who gives birth to quadruplets, or a Red Lion Group member who performs a strenuous feat like canoeing across a notorious stretch of rapids (we'll leave the Grand Canyon to the Kniewels), this may well have a national audience. So please contact me, and we can discuss suitable ways to highlight it in the dailies, Sundays and even on the box.

It just so happens that this month would be an ideal time to make a start to your Red Lion Group media career. Phil Smith, our assistant social secretary, is sending a specially written Letter to the Editor to reps, for them to send to their local newspapers. This will tell readers about what we do and how they can join us if they have a colon (or semi-colon) connection. It would be most timely for you, too, to make contact

with your local paper, and increase our chances of getting some useful coverage. If you too would like a copy of the letter being sent to the reps, please contact Phil, whose address is on the last page.

So brush out your manes and see what you can come up with. And just to give you another incentive, I have started a Red Lion Group cutting book which includes all items of publicity that appear about us in newspapers and magazines. I am also launching a competition with a prize for anyone who can get anything published anywhere (whether it's in your company newsletter, trade journal or local newspaper) in the next six months. So do send me anything you get into print for the cuttings book, and the best items will also be published in *Roar!*.

In the meantime, if you would like any advice about PR or wish to chat over publicity ideas, please contact me, your Red Lion Group Press Officer, on 0181-894 1598 or [chrisb@fdn.co.uk](mailto:chrisb@fdn.co.uk)

With the Millennium approaching, why not start laying a Red Lion media trail? You may be surprised at how many publications take up the scent.

## Poetry Corner

### I Don't Tell People That

My life goes on  
Without my colon.  
I miss it  
But I don't tell people that.  
So now I have a plastic bag  
Which has a tendency to sag.  
I miss my 5 foot colon  
But I don't tell people that.  
Of course, no-one really knows  
Because it's hidden by my clothes.  
I still miss my big intestine  
But I don't tell people that.  
How I wish I could poo again  
Even though, before, all I felt was pain.  
Do I really miss my bleeding colon?  
No, I don't tell people that.

*Written by Gillian Appleby before her recent pouch operation*

## Tips from Members

The following comments are taken from the responses to the recent diet survey.

It is important to appreciate that everyone's reaction to foods is highly individual. So what is suggested as a tip may not work for you, or may even have a detrimental effect.

However, these ideas should give you something to try if you are not happy with your pouch function at present.

"I always sit down at a table when eating, and concentrate on getting into a relaxed state of mind before starting. I try to eat slowly."

"For best pouch function, I try to eat a good mixture of food for each meal...this avoids a severe reaction to any one type of food."

"Eating 10 marshmallows before going to bed seems to help prevent/lessen leakage at night."

"I have a banana each day after lunch."

"Not eating regularly or going a long time between meals causes watery output and anal irritation [for me]."

"I've gone a whole week with no potato and I've found I'm much better. Gone from 6 - 7 to 3 - 4 times on the loo."

"[As I have to avoid lots of foods], I supplement my diet with Ensure!"

"[For me], too long between meals causes painful wind and cramps."

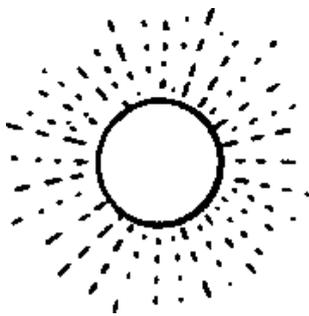
"Wind is increased the longer I delay going to the toilet."

"Since giving up smoking, pouchitis attacks have been very much less."

"Drinking vegetable juice is quite soothing on the digestive tract."

"Fish creates smelly stools."

"Routine, balanced meals (medium portions) with enough starchy foods and less protein works best [for me]."



"Onken bioyoghurt helps to settle my pouch and to decrease wind."

"Anything slightly off or out of date causes increased urgency and pouch irritation [for me]."

"I associate anal irritation more with a change of soap powder on underclothes."

"White wine settles my pouch - usually taken socially, so maybe relaxation helps."

"Physical activity using stomach muscles leads to increased frequency."

"I very rarely get anal irritation. I drink herbal alkalising teas."

"Globe artichoke is brilliant [for thickening

stool]."

"Aloe vera (from Forever Living) evens out consistency and is excellent."

"I have noticed if I eat cereal or toast for breakfast then use the toilet, I do not need the toilet until I eat again."

"[My pouch is settled if I drink] lots of fluids, especially water."

"Stress and tiredness have a detrimental effect on [my] pouch."

"I suffered from anal irritation for the first few years but now always use Hackle wipes and now it is no problem."

"I avoid fried foods. I would recommend a steamer!"

"More liquid output - seems to be caused by apprehension [for me]."

"Pouch function is slowed if I eat first and wait an hour or so before having a drink."

"Cold drinks or very hot drinks will speed [my] pouch function."

"Eating a lot of fruit with pips or seeds and skin will cause [my] pouch function to speed up."

"I find herbal tea helps to settle the digestion, especially after a main meal."

"Light but continuous activity eg gardening, walking [settles my pouch]."

## Pouch Surgery Survey Results

In the Spring issue of *Roar!*, we asked you to provide some factual details about your pouch surgery. We got 78 replies, and the results are analysed here.

### Q1. Were you admitted for emergency surgery?

A surprising 40% (31 replies) of you had the first stage of your operation as an emergency, and about half a dozen of the remaining 60% (47) noted that their surgery was "semi" emergency - that is, not rushed straight into hospital, but operated on within a matter of days or weeks.

### Q2. At what stage were you offered the pouch operation?

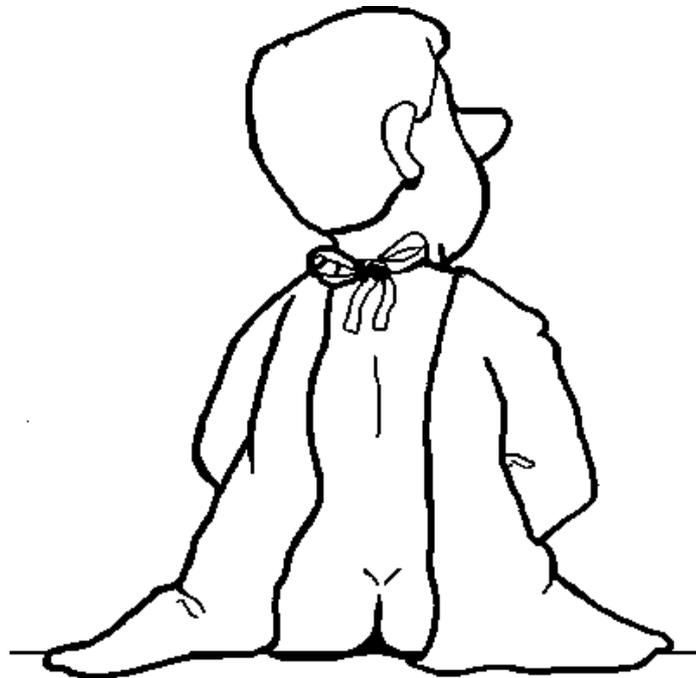
Despite the results to question one, most surgeons found time to discuss the operation before going ahead with any surgery. 55% (43) were offered the pouch operation by the consultant before any surgery took place, and a further 26% (20) were offered it by their consultant after the ileostomy was formed - as expected, the bulk of these were emergency cases where discussion beforehand was not possible.

One respondent wrote: "I was made aware enough to be as informed as possible. My husband was given more detail, although we were both unable to take much in. Options were laid open for me so an informed choice/decision could be made on recovery".

10% (8) were offered the pouch operation at a second opinion, 6 of them before any surgery was started and 2 after the ileostomy was in place. Of the remaining 9% (7) of respondents, 2 asked for the operation themselves, a further 2 had the pouch after many years with an ileo-rectal anastomosis (dating from before the availability of pouch surgery), 1 got put forward for a pouch after the "intervention of the stoma nurse" and 2 provided no details.

Overall, then, the picture is quite

positive, that surgeons are offering the pouch option at an early stage. However, of course, perhaps this question would be more interesting if put to current ileostomists, to find out why they do *not* have pouches. Obviously, in many cases, such as Crohn's, this will be because a pouch is not suitable, but there are likely to be a good number of surgeons out



there doing ileostomies because it is an operation they know, where a pouch would be entirely suitable.

### Q3. Did you ask for a second opinion?

We are certainly a trusting lot. Only 12% (9) respondents asked for a second opinion, 86% (67) said they did not, and a further 2 did not answer, which suggests they did not either.

Judging by the proportion of respondents under St Marks, it would seem that many GPs automatically refer their patients to a centre of excellence once surgery becomes inevitable. More than one person wrote that, given they were at St Marks anyway, a second opinion was therefore not necessary. A

handful of pouch owners were in fact offered a second opinion by their consultant, and so did not need to ask for it themselves.

### Q4. If yes, did you get similar advice at the second opinion?

The answers to this question, although the numbers are statistically small, are reassuring. 4 of the 9 people who answered this question (so 44%) received similar advice at their second opinion. A further 4 (44%) received more detail. Only one person received different advice, and that was practical rather than surgical: she was told to go and complete her family before any surgery.

### Q5. For how long did you wait for the first/only stage of your surgery?

For the vast majority of pouch owners, stage one was done within six months of the decision to operate being taken. Indeed, 38% (30) had it done within one month, a further 18% (14) in 1-3 months, and a further 17% (13) in 3-6 months. This does not even take account of the 12% (9) people who left this question blank because they were emergency admissions, and so they had no wait at all.

Only 12% (9) respondents waited between 6 and 12 months, and only 4% (3) waited for more than a year.

### Q6. If relevant, what was the gap between the first and second stages of your surgery?

St Marks usually suggest waiting at least 10 weeks between these two stages, and this is mirrored by the fact that 51% (40) waited between 1 and 6 months - 28% (22) were operated on between 1 and 3 months later, and 12% (18) between

3 and 6 months. Many of these will have been around the 3 or 4 month mark, which is in line with the St Marks guidelines.

26% (20) waited 6-12 months, 8% (10) waited for more than a year, and 9% (7) left this unanswered, presumably because they had a one stage procedure. For those who waited more than a year, 4 had their second stage within 15 months, a further 4 within 2 years, one had to wait 5 years, and another waited 30 years (because the operation had not existed when his ileo-rectal anastomosis was originally done, not because of a huge waiting list!).

**Q7. If relevant, what was the gap between the second and third stages of your surgery?**

For 67% (52) of you, this question was not relevant. Of the remaining 26, 54% (14) had their third stage 1-3 months after the second, 27% (7) had it within 3-6 months, 3 had it within 6-12 months and two waited for more than a year.

**Q8. If you waited more than 6 months between any stage, please say why**

The good news is that, of the 35 replies to this question, very few of these delays were caused by bureaucracy. 40% (14) were held up because they were not well enough for surgery earlier, 20% (7) were because of personal convenience (despite the fact that most people's surgery was on the NHS!), 14% (5) were because of lack of resources or a waiting list and 9 were for the following diverse reasons: pouch did not exist at the time (2), breastfeeding baby, not sure if suitable, making the decision (2), to put on weight, no details and one who was forgotten:

"A doctor returning from a period in South Africa was checking on patients he had seen before going but could not find any follow up on my notes. He telephoned my home but I was out shopping, so he telephoned my contact number, which was my husband at work. He delicately asked if I had passed away, as he could find nothing of my having had the reversal, and no checkups. After that, things moved

fast..." Well, thank heavens for conscientious doctors!

**Q9. Where did you have your surgery?**

Not surprisingly, as the Red Lion Group was originally a St Marks support group, 36% (28) of respondents had their pouch surgery there. 4% (3) respondents gave no details, and two each had their pouch surgery at: BUPA Bristol, Nuffield Plymouth, London Clinic, Norfolk & Norwich and Cambridge Addenbrookes.

37 other hospitals were each mentioned by one person, located all over the country. As many of the hospital names were unfamiliar (to me) as locations where pouch surgery is being performed, that would suggest that many surgeons are branching out into this field on small numbers of cases. Of course, this a good thing, but the risk of complications is usually expected to be higher than at a centre of excellence.

**Q10. Did you go NHS or private?**

The vast majority (83% or 65) of you had your pouch surgery on the NHS, with only 17% (13) going private. There was no significant difference in waiting times or complication rates between the two routes.

**Q11. Did you have any surgical complications?**

Although 35% (27) of you did report some level of surgical complication arising from your pouch surgery, this did not result in your pouch needing to be refashioned (question 13) for the most part.

Adhesions represented 26% (7 cases) of the complications reported, followed by abscesses (15% or 4), infection (7% or 2), fistulas (7% or 2) and excessive blood loss (7% or 2). Four pouch owners had a long list of complications including many of the above, and it is a sad fact that once one complication sets in, this increases the likelihood of others arising. Six respondents gave other details.

You should bear in mind that pouch surgery is often a multi-stage procedure, and so the risk of surgical complications may be higher than for other procedures simply because

the patient is being opened up so many times.

**Q12. Did you ask about your surgeon's previous pouch experience before surgery?**

More of you did *not* ask about your surgeon's pouch experience than did (53% or 41 to 47% or 37), although a few members pointed out that they already knew of their surgeon's reputation in this field, and so did not deem it necessary to ask.

It is perhaps a very British thing that we find it hard to question someone who is about to perform a relatively new and complex procedure on us about their experience. On the other hand, from the surgeons' point of view, this reticence probably allows the skill to develop outside the centres of excellence in a way that it would not in other parts of the world. Some surgeons made a point of offering details of their experience (or - in some cases - relative lack of experience) without needing to be asked, which is to be applauded.

**Q13. What was your illness?**

As usual, the vast majority of respondents had their pouch formed because of ulcerative colitis (91% or 71), which mirrors the makeup of our database. 8% or 6 respondents had polyposis, and one was diagnosed as Crohn's colitis.

**Q14. Have you had your pouch refashioned at any stage, and if so where was this done?**

Reassuringly, despite the high level of surgical complications arising (question 11), only 8% (6) patients had to have their pouch refashioned.

Four of these chose to go to St Marks as a recognised centre of excellence (three of these pouches had been originally done elsewhere), one returned to the Nuffield Plymouth where the original operations had been performed, and one gave no details.

**Q15 Did you speak to other pouch patients before deciding on pouch surgery?**

Clearly, those who had their pouch surgery a number of years ago were far less able to talk to other

pouch owners in order to come to a decision about whether to go ahead, simply because the procedure was so rare, and at the time pouch support groups did not exist.

Happily, however, 55% (43) of you were able to take advantage of the experience of other pouch owners in order to come to an informed decision. 45% (35) of you did not, but some of these were able to talk to other pouch owners after they had made their decision, in order to try and learn as much as possible about what to expect.

**Q16. Did you join any pouch support groups while considering surgery?**

Although 69% (54) of you did not, this is now changing as stoma nurses across the country have become more aware of the existence

and work of the Red Lion Group. Many of our new members do not yet have pouches but have been put in touch with us through their stoma nurse in order to help them decide whether to take this step. I would imagine, therefore, if we asked the same question in a year's time, the percentages would be quite different.

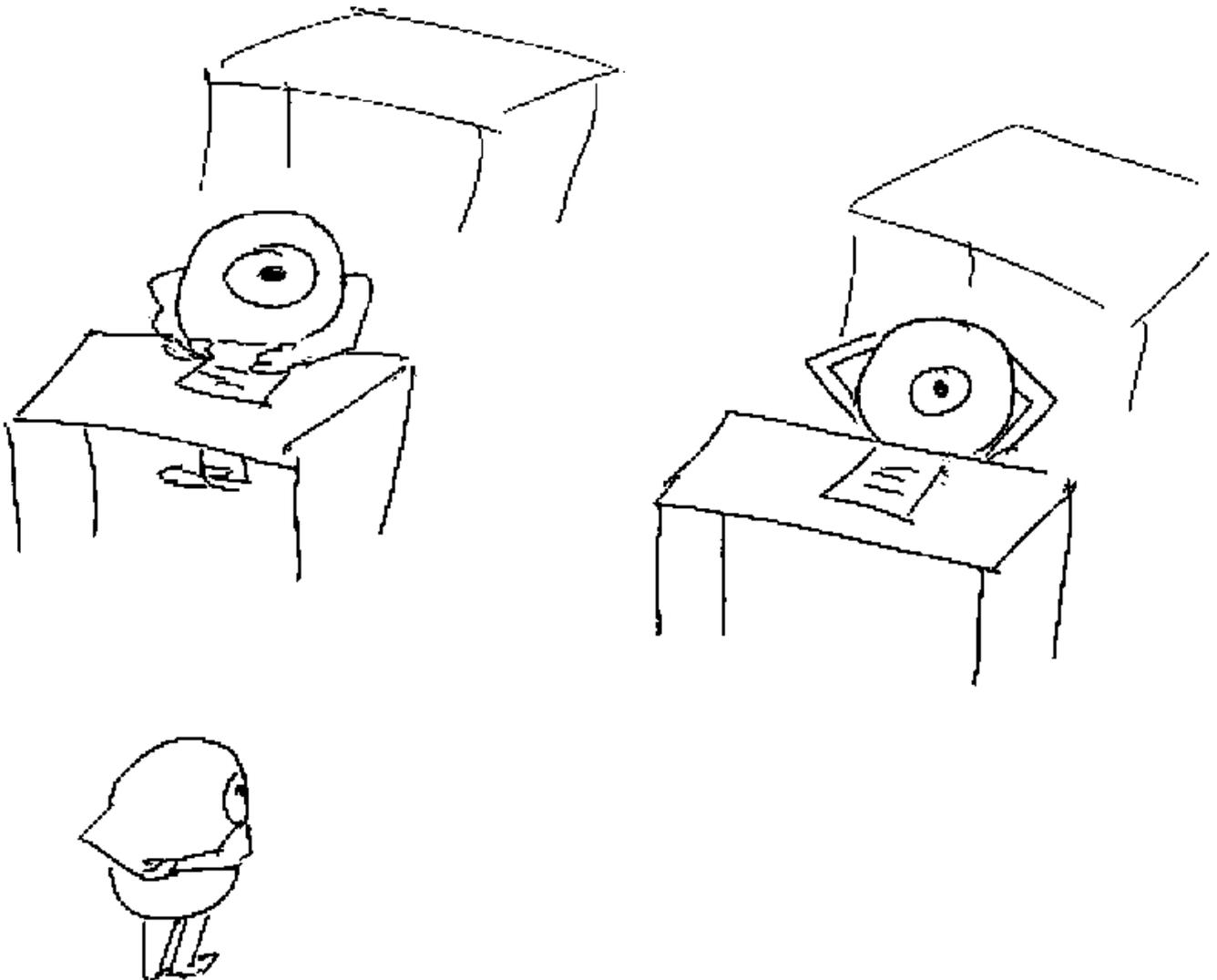
**Q17. How did you find out about the Red Lion Group?**

For the most part, potential and existing pouch owners discovered the Red Lion Group through their hospital: via their stoma nurse (38% or 31), their consultant (9% or 7) or a hospital noticeboard (10% or 8).

However, 8% (6) found out about the Red Lion Group from another pouch owner and a further 26% (20) from a variety of sources

including other pouch support groups: ia Journal (6), mailing from St Marks (3), "by post" (2), reading a magazine (2), Convatec (1), personal contact (1), Kangaroo Club (1), NACC (10), personal research (1). 6 could not remember how we came into their life, and 2 provided no details.

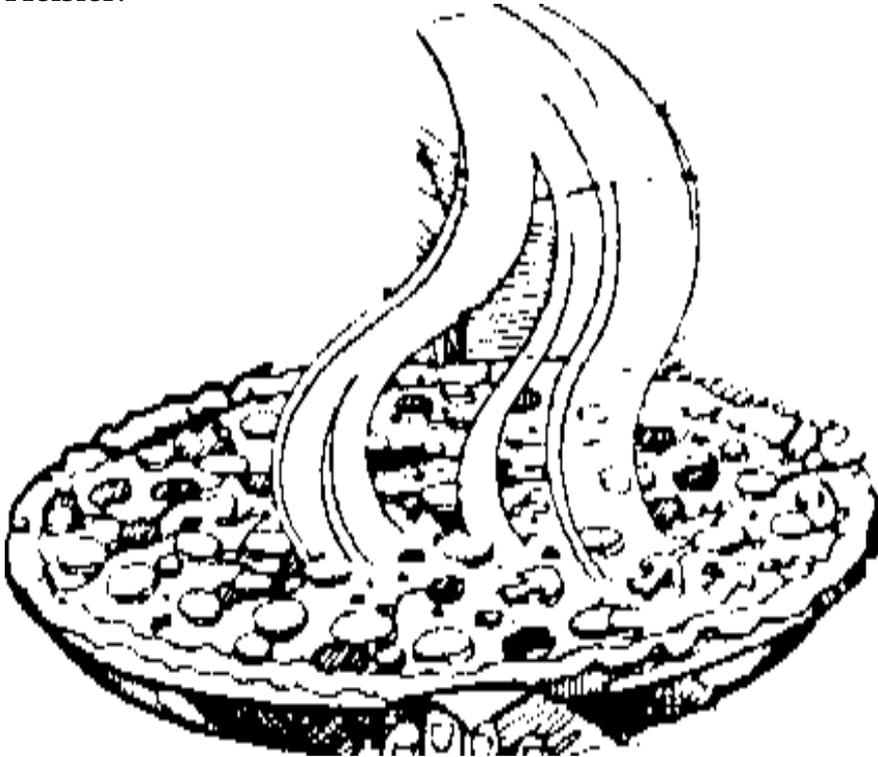
Stoma nurses are a key source of information for potential pouch owners, and we have had good links with some hospitals for some years now. However, it is only in 1999 that we have been able to make all stoma nurses aware of the Red Lion Group, and indeed some have joined as members in their own right, so as not to miss out on the newsletter. I hope this will gradually be reflected in a proportionate increase in non St Marks patients.



*Plans to make the eye test harder were scrapped due to logistical difficulties*

## More cookery for colitis sufferers!

In issue 12, we introduced you to the *Culinary Couple's Creative Colitis Cookbook*, and have reproduced another recipe from that cookbook in this issue. However, while surfing the Net, I discovered another website devoted to diet and ulcerative colitis, written by Hal Heisler.



In this case, Hal's wife found her illness greatly improved by applying a very restrictive oriental diet, and the two of them have since gone on to write a book of recipes using only foods permitted in that regime. Although the diet was used instead of surgery for her, it may well be that aspects of it may help pouchitis sufferers. As usual, please do write in with your experiences if you try it.

This is what Hal has to say:

"If you have colitis and go to a regular doctor who practices Western medicine, he will tell you in all honesty, he cannot cure your disease. If you are lucky, he can control it with drugs, but he cannot make it go away.

Two years ago, my wife's ulcerative proctitis turned into raging ulcerative colitis. After dealing with a gastroenterologist whose only solutions were steroids and surgery, neither of which were acceptable,

my wife and I went to a doctor of Oriental medicine.

He gave her a diet that was very restrictive. She could eat no meat or meat products including beef, chicken, fish, pork or turkey. No wheat or wheat products including breads, cake and pasta, no corn, no rice, no potatoes, no dairy, no fruit or fruit juices, no nuts, vinegar, tomatoes or tomato products including ketchup and spaghetti sauce, no peanuts or peanut butter, no alcohol, including wine and beer, no oats, no barley, no mushrooms, no sugar, no candy or chocolate, no caffeine including coffee and tea, no spices, no egg yolks, no canola oil, corn oil or palm oil.

What she could eat were all soy products (tofu, soy flour, tofu cheeses), all beans, all millet products, buckwheat, miso, olive oil, garlic, all vegetables, sweet potatoes, herbs, avocados, herbal teas, vegetable juices, Egg Beaters and egg

whites and sea salt.

From these limited ingredients I created recipes and fashioned a diet that not only tasted good, but, I believe, gave her control of her ulcerative colitis.

Today she looks great, feels terrific, takes no drugs and is totally asymptomatic as long as she stays on the diet.

We have since added rice, chicken, turkey, fish and some cheeses to what she can eat."

Here is a sample recipe:

### Soy, Millet and Buckwheat Kugel

One cup soy flour  
 ½ cup millet flour  
 ½ cup buckwheat flour  
 One and a third cup water  
 Five tablespoons olive oil  
 Seven garlic cloves  
 Two small to medium courgettes  
 ½ medium onion

Sea salt

Four sprigs rosemary

Grated tofu parmesan cheese

Whisk together soy, millet and buckwheat flour with water, salt and two tablespoons olive oil. Grate in garlic with coarse grater. Chop courgette and onions into small pieces. Add to batter. Chop rosemary very fine and add. Mix all together.

Coat 12" by 6" casserole dish with olive oil. Pour in batter. Bake in 350 degree oven for 45 minutes. Remove and sprinkle with tofu parmesan cheese. Let cool. Eat. Enjoy.

If you'd like a copy of *The Colitis Cookbook*, containing over 60 original recipes, send an international money order made out to The Colitis Cookbook to Hal Heisler

2044 Holmby Avenue, Los Angeles, CA 90025-5908, USA for the amount of \$15.95. (includes international postage).

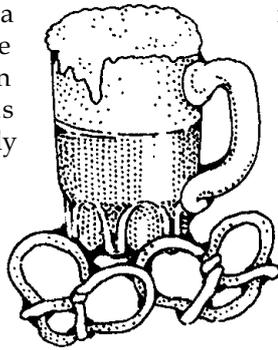
## Looney Prunes

Julia Williams offers a few thoughts on Annette Bisanz's bowel control article on page 2.

Although this article might prove useful in some cases it is primarily aimed at those following colorectal surgery but still have some large colon remaining.

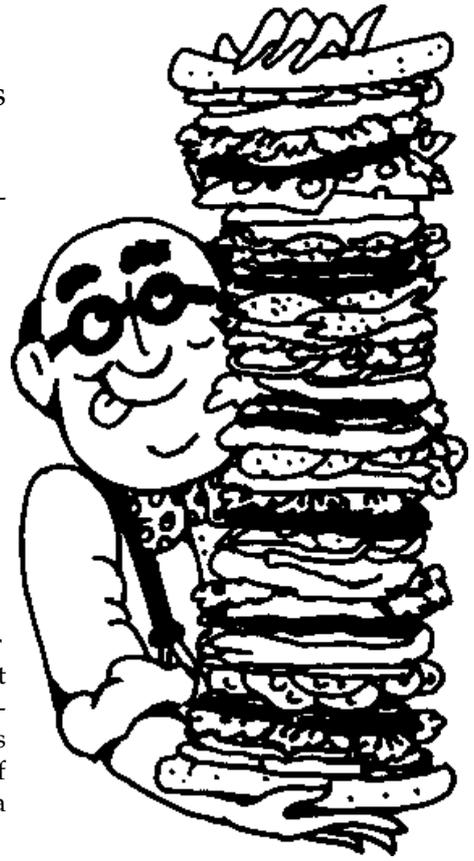
It is widely acknowledged that in the main most pouch owners will experience 3 - 7 bowel movements in a 24 hour period therefore the goal to return to no more than 3 bowel movements a day might seem a little unrealistic. Any increase in fibrous foods, such as prune juice, will ultimately increase pouch function.

It should also be noted that Metamucil is not available in the UK, however the equivalent medication would be



Fybogel or Normocol (both available on prescription).

If someone does have a high pouch frequency i.e., more than 12 bowel movements per 24 hours, bulking agents such as Imodium, Codeine Phosphate and Lomotil can be helpful if taken as prescribed. The article mentions how fluids increase the muscle movement of the gut (peristalsis) and it is for this reason that some pouch owners are advised to separate their solids and liquids at meal times, i.e. avoiding drinking with meals and drink either half hour prior to or after a meal.



## More on Scars

Pat Robson gives us some feedback on the subject of the Cica Care gel sheet to reduce scarring, mentioned in the last newsletter

On reading my copy of *Roar!* (issue 13), I felt I must respond to the article on page 15 entitled *Scar Tactics*.

Two years ago, I had my colon removed and a pouch constructed. I was in a great deal of pain after this procedure, and after a good deal of soul-searching and numerous hospital visits, I decided to have the pouch removed and my ileostomy made permanent. After the second operation, the scar on my abdomen was quite sore and red, especially from the navel upwards.

I had read about the CICA CARE gel sheet, so decided to try it. I found the sheet helped reduce the redness of the scar, from the navel upwards, and it also helped flatten the scar. One thing that I did notice was that the pulling sensation around my navel reduced greatly. Because I need to

wear an ileostomy bag, I couldn't treat all of my scar, but I was very



pleased with the part I did use the Cica Care on. Incidentally, a few weeks ago I had a mole surgically

removed, and the gel has helped reduce the scarring.

After my operation, I felt my body had been mutilated. I had never had surgery before and didn't know what to expect, certainly not staples in my abdomen! And to have that twice in a matter of eight months was just too much. So when I read about Cica Care, I thought "I'll try anything to help reduce the scarring". £35, although expensive, was money well spent.

We know our bodies will never be the same after major surgery, but every little helps us get our self-esteem back and makes us feel human again.

I'd say, if you can afford it, try it. By the way. I had no irritation to my skin. And the gel does not get rid of the scarring, but it definitely reduced it for me; I appreciate that it may not do so for everyone.

## Calling all Pouch Owning Parents



We have been approached by a stoma nurse for a leaflet designed to explain to children about their parent's pouch.

Before tackling this project, we would appreciate Red Lion Group members' thoughts on:

- would such a leaflet have been useful for you and your own family?
- what information should be included?
- even more importantly, what kind of things should be excluded?
- how should the information in the leaflet be pitched?
- is there anything else relevant to this topic?

We are also aware of the existence of a little booklet designed for children of ileostomists, explaining about the stoma.

We will need to investigate how to go about getting hold of a copy, but if anyone would find it helpful, please could they contact the Liaison Officer using the contact details shown on the back page of this newsletter.

## Internet News

<http://www.healthshop.com>

This website claims to be the most comprehensive natural health store in the world and it certainly seems to be a good place to research alternative treatments and to obtain almost any kind of health store product (although of course, it will be shipped from the US), with many special offer prices. There is also an Ask the Experts section (one item from which has been reproduced

on page 18 of this newsletter), a section to help you devise your personalized health planner and a section devoted to specific interest topics (such as Stress Management, Women's Health, Chronic Conditions etc).

The Community section contains bulletin boards for you to interact with other users of the healthshop.

<http://www.mdanderson.org/depts/hcc/>

This section of the M D Anderson Cancer Center's website deals specifically with hereditary colon cancer and related matters, which is highly relevant to families

in which polyposis exists.

John Roberts, the author of our Polyposis People section, first alerted us to the existence of this site.

<http://listserv.acor.org/archives/desmoid.html>

This is the website address for the Desmoid Tumor Online Support Group, which includes a chat room, a bulletin board and a very

detailed glossary of all the terms you are likely to come across during your treatment.

## Recipe Corner

### Rice Flour Pancakes (serves 4)

1 cup rice flour  
1 tbs. sugar  
2 tsp. baking powder  
1/2 tsp. salt  
1 cup rice or soy milk  
1 egg, lightly beaten  
2 tsp. olive oil or vegetable oil  
1 cup maple syrup

Sift the rice flour, sugar, baking powder and salt together in a bowl. Beat in the rice milk or soy milk until the mixture has a smooth consistency. Add the beaten egg and olive oil or vegetable oil and mix until just blended.

Heat a non-stick griddle to 375 degrees or until it is hot enough that drops of water splashed on the griddle bounce and sizzle.

Lightly oil the pan. Ladle the pancake mixture onto the griddle to form 4 inch cakes.

Turn the cakes once the bottom has browned and bubbles appear on the tops. Cook the cakes for an additional two minutes.

Serve the pancakes with



warmed maple syrup. Recipe will yield 12 pancakes.

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

## Deeds of Covenant

John White explains how the Treasury can also support the Red Lion Group financially – with a little bit of help from our friends!

As your new Honorary Treasurer I have been asked to explain a few details of deeds of covenant. It always seems to me that people get worried about these, consider them complicated and think they have to pay over more money. Well they aren't complicated, cost you nothing and the only person who need worry at all is your treasurer as he or she has all the book work to do.

A deed of covenant is an agreement that you sign, stating that you will pay a certain sum of money to a registered charity for a minimum of four years. It can be for any length of time over four years but the usual is from four years to ten years. It can only be signed by a person who pays income tax.

The reason for this is that the charity is allowed to claim back tax

the donor has made on the amount given grossed up at the moment at 23%. This will go down next year to



22% due to the proposed reduction in the income tax rate. At present what this means is that for every £1 given we can claim back 30p. So if you covenant for £10 per year the tax reclaimed is £2.99, so in effect

you have given £12.99 as we have claimed from tax paid by you to the Inland Revenue. Don't ask me where the other 1p goes: in the Treasury I suppose!!

There is also the gift aid scheme, whereby if a person who pays income tax wishes to donate £250 or more to a charity in one lump sum, they can complete the special form obtainable from me, and we can then obtain the appropriate amount from the Inland Revenue. I understand that the amount is to be reduced to £100 shortly which will yield a further £29.88.

As I said at the beginning it doesn't cost the donor any more cash and it is a very worthwhile way to pay your subscription. If you have any queries I shall be pleased to try to answer them.

## Articles you may have Missed

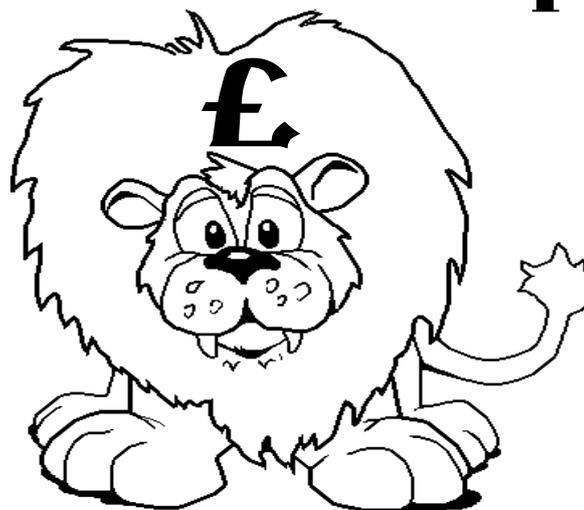
For the benefit of newer members, this little section mentions the most important articles for pouch owners that have appeared in previous issues. Earlier issues can be obtained on request from the Liaison Officer. Please enclose a large SAE (31p stamp for 1 issue, 60p for 2 or more).

- Prescription exemptions (and update) – issues 4 and 10
- Family planning – issue 5
- Electrolyte Mix, St Marks Formula – issue 8
- Keys for disabled toilets – issue 13

### Bowels for Sale

No doubt colorectal surgeons up and down the country have been queuing up to get hold of this very special offer, originally printed in the Nottingham Evening Post: "Bowels, size 5 Taylors, with grips, set of 4, still boxed, £50".

## 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**

## Dietary, Herbal and Nutritional Strategies for coping with UC

The following question on ulcerative colitis was posed to the experts at <http://www.healthshop.com>, which bills itself as the world's most complete natural health store. Naturally, all of the items mentioned can be bought via the website!

**Q.** I was diagnosed with ulcerative colitis. For about a year, I used the medication called (in the US) Azulfadine to control my diarrhoea. This drug comes with strong warnings about liver damage and some mild irregularities have appeared with my liver already. Do you know of an alternative?

**K. Mathai** replies:

Azulfadine is used as an anti-inflammatory for ulcerative colitis. There are some dietary strategies as well as some nutritional and herbal strategies that may help to control the inflammation and diarrhoea. Inflammatory bowel disease can be aggravated by trigger foods, and common trigger foods include dairy, wheat (including barley, rye and oats) corn, citrus, coffee and tea. In fact, any food which you eat regularly may be contributing to your condition.

If you suspect that a certain food or foods are trigger foods, you can test whether these foods are "feeding" your inflammation by eliminating the suspect foods from your diet for 10 to 14 days.

"Challenge" the foods at the end of this period by eating servings of the suspect foods at each meal. Monitor your body's response; if you have symptoms, you will know to avoid those foods.

Here are some general guidelines for a dietary approach to managing ulcerative colitis.

Eat a diet which is high in whole grains (brown rice, millet, quinoa, kasha, buckwheat and spelt). You can puree cooked grains and add to soups or make into cereals as you introduce them into your diet. Eat soy foods, which are nutrient-dense and easy to digest.

Try tofu smoothies (tofu, banana or frozen or fresh fruit or berries,

vanilla extract, honey and water), and substitute soy milk in place of cow's milk.

Include generous amounts of cooked vegetables in your meal plans, puree them if necessary and add to soups.

Use flaxseed and other foods high in the omega-3 fatty acids — these are anti-inflammatory foods



that send out chemical messengers which quell inflammation. Grind 2 to 4 tablespoons of flax seed daily and sprinkle on cereal or add to soups or sauces, or use 1 to 2 tablespoon of flax seed oil daily. Fresh salmon, tuna (or canned albacore tuna), mackerel or sardines are also excellent sources of these omega 3 fatty acids, so try to have servings at least three times per week.

Limit processed foods with additives, preservatives and chemicals and eat organic foods when

possible.

Keep your intake of simple sugars and white-flour processed products (e.g., cakes, candies, pastries, white bread) to a minimum.

Carminative herbs have volatile oils which aid in improving the tone of the intestinal muscles, reducing the occurrence of spasms and may be helpful to control your symptoms. Peppermint is one of these carminative herbs, and can be taken as enteric coated capsules. The recommended dosages are two to six 0.2 ml capsules daily in liquid form and 2 to 4 grams per day as a powder.

Ginger is another anti-inflammatory herb which may be used for ulcerative colitis. The recommended dosage of dried ginger is 0.25 to 1 gram per day.

The herb turmeric contains the volatile oil curcumin, which supports anti-inflammatory pathways in the body.

A recommended dose of curcumin is 400 to 600 mg three times per day.

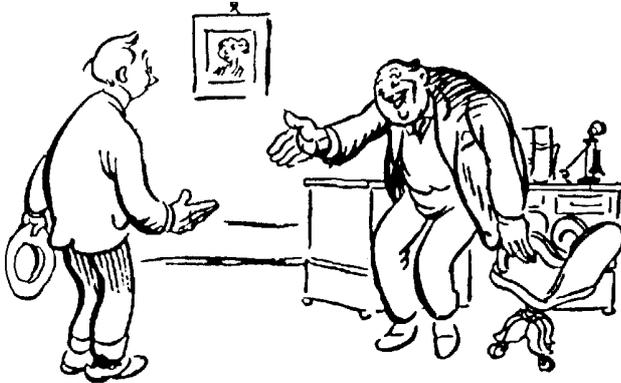
Due to your ulcerative colitis you may have general nutrient deficiencies, particularly of the nutrients magnesium, vitamins K, E and C, zinc and copper. Supplement daily with a general multi vitamin/mineral supplement, and use a supplement to ensure a healthy population of bacteria in the intestines, including lactobacillus acidophilus and fructo-oligosaccharide (FOS).

Stress is a significant factor in ulcerative colitis and other forms of irritable bowel disease, so consider integrating some forms of stress reduction techniques in your daily routine, such as exercise, meditation, biofeedback or hypnosis, or counseling.

## 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).



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## What does a "normal lower GI scope" mean?

The information below is reproduced from Dr Minocha's section in <http://www.mdanderson.org/depts/hcc/>.

The term normal, although it appears definitive, is a relative term in relation to colonoscopy and depends on a variety of factors. As many as one in twenty cancers are missed on colonoscopy.

If polyps have been found, a repeat exam may reveal more polyps

in as many as twenty to thirty percent of cases.

Missing of important abnormalities occurs due to a variety of factors.

These include poorly cleaned colon or increased movements of colon during the examination.

Polyps may be hidden behind the large colon folds and not easily visible.

This happens especially where the colon makes sharp turns (just like it is easy to miss seeing an object on a winding road than on a straight road).

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### 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 lit-

tle 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.

Don't forget to look at the Red Lion Group website on the internet:

[WWW.RED-LION-GROUP.MCMAIL.COM/](http://WWW.RED-LION-GROUP.MCMAIL.COM/)