# Roar!

**Issue number 21 • Summer 2001**

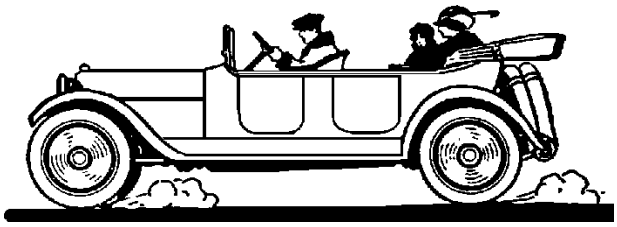
*Roar!* is the newsletter of the Red Lion Group • St. Mark's Hospital • Watford Road • Harrow • Middlesex • HA1 3UJ

## Take Cover!

Newly-elected vice chairman, Michael Dean, has been busy since the Information Day and now has good news on the travel insurance front…

Following the seminar on travel problems at the AGM I was somewhat dismayed to hear of the problems many of the members have faced in obtaining travel insurance, and I felt particularly aggrieved that the insurance industry was getting a bad name through the ineptness of travel agents. You will, of course, appreciate that travel agents don't particularly care what problems a person may have, their only interest is selling a very lucrative travel policy with every holiday they sell, which is at a very high cost.

I spoke with the CEO of my company, JLT Risk Solutions (a broker), who in turn had discussions with our specialist travel division. I am pleased to advise you that, following discussions with underwriters, JLT Travel Services will be only too happy to assist where possible in obtaining suitable travel insurance, whether it be for a short period or an annual policy. They have also had much experience in obtaining cover for people with medical problems and disabilities.



Although I cannot promise that we will be able to provide full cover on every occasion, they will certainly look at each person with empathy, giving the best cover available. In most cases provided there has been no surgery within the previous 12 months a yearly policy is fairly easily obtainable. In most questionnaires insurers will ask 'are you seeking medical assistance', however, JTL Travel Services are aware of the fact that our members have frequent medical check-ups. I give below 2 contacts who have been made aware of our organisation and they will be able to help with any queries that our members may have:

Mr Brian Birch and Miss Sam Linley

JLT Travel Services
1 St James's Square
Manchester M2 6DN
Tel. No. 0161 957 8000

I trust that the above may be of use to the group and I am more than happy for members to contact me if they have a problem.

Michael's contact details are on the back page of *Roar!*, if needed.

## Losing a Pouch Nurse Specialist, But Not a Friend

Red Lion Group committee members were saddened to receive confirmation from Julia Williams recently that she has decided to move on from St Marks.

We warmly congratulate Julia on her new position as full time lecturer in colo-rectal nursing at City University London. We will all greatly miss the warmth and expertise that she brought to the Red Lion Group.

Although Julia will be on secondment to St Marks at least one day a week for some time, it is appropriate that the pouch nurse specialist co-opted to the Red Lion Group committee should be filled by a member of the St Marks pouch care team.

At the time of going to press, it was not known who this would be, as Julia's colleague Alison is also shortly leaving St Marks for a different reason, more associated with sleepless nights and the patter of tiny feet! As soon as we know more, we will let you know.

We wish Julia all the best, and hope that she will stay in touch: six years of talking bottoms with somebody does confer a degree of familiarity which it would be a shame to lose.

Maybe once she has left St Marks, she might even consider giving me her home phone number!!!

Morag Gaherty

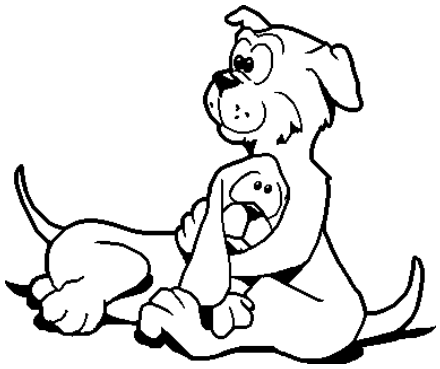
## In This Issue...

# The Most Informative Day of the Year

Chris Browne gives a brief review of our annual information day and AGM which was held on 7 April 2001 at St Mark's Hospital.

A Gaherty-free Red Lion AGM and Information Day is unthinkable. But it nearly happened. This year only Brian, RLG chairman, was in harness. Morag, liaison officer and *Roar!* co-editor, was at home nursing a sick child and looking after his very young brother.

Organised by St Mark's Hospital clinical nurse specialist Julia Williams, the day went with a flourish, with almost 100 members attending. There was a surge of raffle-ticket buying (most of the prizes being donated by RLG secretary Inez Malek) - if any more had been sold the next day's newspaper headlines might have read: "Raffle black market at Red Lion AGM". There were also some rousing speakers to broaden the mind and stir the senses. And all this came before the AGM itself.



After a preliminary welcome by Brian in the John Squire medical wing at St Mark's, Nicky Horton from the hospital's physiology unit discussed Biofeedback, a technique that helps pouchees use mind over matter to cope with mini-loo crises, while Christine Norton, an incontinence specialist, showed us how to deal with what laymen like to describe as "being caught short". Computers were now showing patients how to use their muscles to reduce some of those embarrassing moments, she said.

How often do we hear the phrase: "You are what you eat."? Often enough. Michelle Alley, a dietitian from John Radcliffe Hospital, Oxford, had some useful variations on this theme, highlighting the importance of isotonic drinks -mixing salt and glucose with diluted orange, lemon or grapefruit and water - a process that replaces vital minerals lost through the pouch's comparatively low absorption level. Eating live bio yoghurt was another of her useful dietary tips. Michelle also advised members not to overdose on coffee, tea and water and to eat regular, smallish meals to aid pouch control.

At the AGM, Brian emphasised the importance of *Roar!* as a focal point and information-provider for members. The group is now funding many of its activities such as producing *Roar!* every quarter and paying for the AGM and Information day, he said. John White, the treasurer, said the year had shown a healthy surplus of income over expenditure of £1,664. A sum of £500 would be put aside annually to help members in need of genuine assistance, with a maximum of £100 per individual, John added. All RLG officers were re-elected and Michael Dean was elected as the group's vice-chairman.

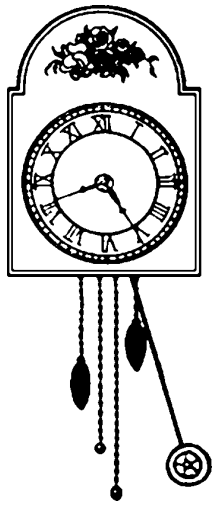
Some lively workshops followed a sit-down buffet lunch and more furious raffle-ticket selling. The first two - on how to recognise signs of FAP and UC - were led by Kay Neale, of St Mark's polyposis registry, and Julia Williams, St Mark's clinical nurse specialist, respectively.

Ex-pouch patient, nurse and counsellor Gill Tomlin headed an entertaining session on her experiences of life with a pouch, while Julia (again!) talked about family planning, pregnancy and fertility as well as helping to lead a discussion with Gill Tomlin and RLG press officer Chris Browne on pouch problems; and Wendy Osborne, a stomacare specialist at Oxford's John Radcliffe hospital, explained how to cope with travel and exercise.

# Looking Forward to 2002

The next Information Day and Annual General Meeting for the Red Lion Group looks likely to be held either on 13 or 20 April 2002. Confirmation of the final date and venue will be in next quarter's newsletter.

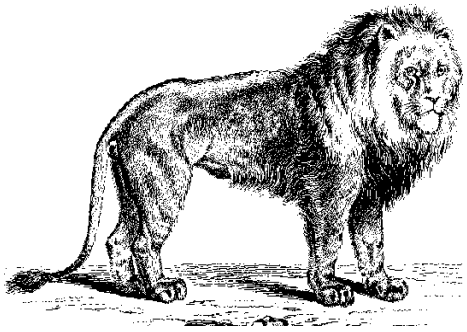
As in previous years, the venue will probably be St Marks, although Ashford is still a contender. This is as accessible as St Marks for everyone except maybe those from the north west. Unlike getting to St Marks, it is motorway almost to the entrance of the hospital, and so the extra distance is offset by substantially easier access.



One of the suggested topics to be covered at the information day, either as a talk or in a workshop, is "Coping at Work". If you have any information to offer about this subject, or would like to suggest other topics for inclusion, please contact the newsletter editor, Morag Gaherty.

We are also considering a pouch from a younger person's perspective, so if any of our junior pouchies would like to contribute their experiences, or let us know what information they would have found helpful (eg what, if anything, to tell close friends), we would be very pleased to hear from you. And if you'd like to talk at the information day, please do let us know - surgeons can't in the limelight all the time!!!

# Editorial



I'm thinking about renaming this the "Apologies for the Late Newsletter" page, given that this is how I usually start the Editorial. And this issue is no exception - if it seems even later than usual, it's because the last issue (by something which can only be termed a minor miracle) actually came out early. Which just made the gap between the two seem even longer. If I'm going to be late, therefore, I should at least be consistent about it.

Anyway, you obviously look forward to your *Roar!* magazines each quarter, judging by the number of you who have contacted me in a panic to see if your subscription had somehow lapsed without you knowing it!

You already know that you are in the hands of two co-editors who can't quite believe how civilisation survived before the advent of the internet, and I apologise to those of you who feel that the rest of the world has turned "virtual". I promise you, we will always have a paper copy of the newsletter, because it is not easy to take your PC onto the train just to read *Roar!*. However, we do like to embrace the possibilities that the internet offers.

One of these is the Yahoo! Groups service, which provides a way for people to meet other people who share their interests and experiences, just like a real life club. They really do work. Let me give you an example from my "other" life: on the internet, there is a thriving market for the buying and selling of real nappies. One of my friends who is not on the internet asked me to place an advert for her, selling some items her baby had outgrown. I placed the ad at 10.37 am. At 11.30 am, she phoned me to say they had been sold. She was gobsmacked - I had to stop her from rushing out to buy a PC there and then.

So if you are on-line, please do join the new redliongroup Yahoo Group, and make some friends, chat about how you cope and anything else you want to talk about. You don't have to be on-line for ages, as all the messages come through the e-mail system. You just download them in a matter of seconds, log off, reply at leisure and then go on-line to send them. But the beauty is that all of the messages are archived, and this archive can be searched for key terms - so members joining later can find out if their topic has been discussed before.

Even if you don't have a computer, you can get e-mails through your TV now, which is ideal for this sort of thing. Even my parents, the ultimate Luddites, have succumbed to e-mail through the TV as a cheap and fast way to stay in touch with their friends! It needn't cost much, but it offers so many possibilities.

There is an article in the newsletter about how to find the redliongroup in Yahoo Groups.

You will see in this issue that Julia Williams has now sadly left St Marks, and so is unable to continue being our pouch nurse specialist. At the time of going to print, the St Marks post had not been filled, but we hope that whoever does fill it will become the pouch nurse specialist for the Red Lion Group as well. We will all miss Julia, but hopefully we will bump into her from time to time, as she will still be on secondment to St Marks one day a week for the foreseeable future.

Many of you will also have seen in the papers that our beloved patron Claire Rayner had emergency cancer surgery in recent months. I have been in touch with Claire, who - as you might imagine - is brooking no nonsense, has had the necessary surgery and is getting on with her life. I passed on our warmest wishes (as did our treasurer John) to Claire and assured her that you are all thinking of her. I also cheekily reminded her that here at the Red Lion Group, surgery is most definitely NOT an excuse for getting out of writing deadlines, otherwise I would never hear from any of you. Don't forget, Claire - if you get bored, we'll be happy for a newsletter article on any topic which grabs your fancy!

Anyway, if all goes well, there should still be some Summer left by the time you get this newsletter, so I hope you will continue to enjoy it. Otherwise, maybe I should be wishing you a Merry Christmas?!

# Going Down the E-pub

The following information comes from the National Digestive Diseases Clearinghouse website, and is a useful introduction to ulcerative colitis. It is not copyrighted, and the clearinghouse encourages users of this e-pub to duplicate and distribute as many copies as desired. Publications produced by the clearinghouse are reviewed carefully for scientific accuracy, content, and readability.

Ulcerative colitis is a disease that causes inflammation and sores, called ulcers, in the top layers of the lining of the large intestine. The inflammation usually occurs in the rectum and lower part of the colon, but it may affect the entire colon. Ulcerative colitis rarely affects the small intestine except for the lower section, called the ileum. Ulcerative colitis may also be called colitis, ileitis, or proctitis.

The inflammation makes the colon empty frequently, causing diarrhoea. Ulcers form in places where the inflammation has killed colon lining cells; the ulcers bleed and produce pus and mucus.

Ulcerative colitis is an inflammatory bowel disease (IBD), the general name for diseases that cause inflammation in the intestines. Ulcerative colitis can be difficult to diagnose because its symptoms are similar to other intestinal disorders such as irritable bowel syndrome and to another type of IBD called Crohn's disease. Crohn's disease differs from ulcerative colitis because it causes inflammation deeper within the intestinal wall. Crohn's disease usually occurs in the small intestine, but it can also occur in the mouth, oesophagus, stomach, duodenum, large intestine, appendix, and anus.

Ulcerative colitis occurs most often in people ages 15 to 40, although children and older people sometimes develop the disease. Ulcerative colitis affects men and women equally and appears to run in some families.

**What Causes Ulcerative Colitis?**

Theories about what causes ulcerative colitis abound, but none have been proven. The most popular theory is that the body's immune system reacts to a virus or a bacterium by causing ongoing inflammation in the intestinal wall.

People with ulcerative colitis have abnormalities of the immune system, but doctors do not know whether these abnormalities are a cause or a result of the disease. Ulcerative colitis is not caused by emotional distress or sensitivity to certain foods or food products, but these factors may trigger symptoms in some people.

**What Are the Symptoms of Ulcerative Colitis?**

The most common symptoms of ulcerative colitis are abdominal pain and bloody diarrhoea. Patients also may experience

- Fatigue
- Weight loss
- Loss of appetite
- Rectal bleeding
- Loss of body fluids and nutrients

About half of patients have mild symptoms. Others suffer frequent fever, bloody diarrhoea, nausea, and severe abdominal cramps. Ulcerative colitis may also cause problems such as arthritis, inflammation of the eye, liver disease (fatty liver, hepatitis, cirrhosis, and primary sclerosing cholangitis), osteoporosis, skin rashes, anaemia, and kidney stones. No one knows for sure why problems occur outside the colon. Scientists think these complications may occur when the immune system triggers inflammation in other parts of the body. These problems are usually mild and go away when the colitis is treated.

**How Is Ulcerative Colitis Diagnosed?**

A thorough physical exam and a series of tests may be required to diagnose ulcerative colitis.

Blood tests may be done to check for anaemia, which could indicate bleeding in the colon or rectum. Blood tests may also uncover a high white blood cell count, which is a sign of inflammation somewhere in the body. By testing a stool sample, the doctor can tell if there is bleeding or infection in the colon or rectum.

The doctor may do a colonoscopy. For this test, the doctor inserts an endoscope—a long, flexible, lighted tube connected to a computer and TV monitor—into the anus to see the inside of the colon and rectum. The doctor will be able to see any inflammation, bleeding, or ulcers on the colon wall. During the exam, the doctor may do a biopsy, which involves taking a sample of tissue from the lining of the colon to view with a microscope. A barium enema x-ray of the colon may also be required. This procedure involves filling the colon with barium, a chalky white solution. The barium shows up white on x-ray film, allowing the doctor a clear view of the colon, including any ulcers or other abnormalities that might be there.

**What Is the Treatment for Ulcerative Colitis?**

Treatment for ulcerative colitis depends on the seriousness of the disease. Most people are treated with medication. In severe cases, a patient may need surgery to remove the diseased colon. Surgery is the only cure for ulcerative colitis.

Some people whose symptoms are triggered by certain foods are able to control the symptoms by avoiding foods that upset their intestines, like highly seasoned foods or milk sugar (lactose). Each person may experience ulcerative colitis differently, so treatment is adjusted

for each individual. Emotional and psychological support is important.

Some people have remissions—periods when the symptoms go away—that last for months or even years. However, most patients' symptoms eventually return. This changing pattern of the disease means one cannot always tell when a treatment has helped.

Someone with ulcerative colitis may need medical care for some time, with regular doctor visits to monitor the condition.

**Drug Therapy**

Most patients with mild or moderate disease are first treated with 5-ASA agents, a combination of the drugs sulphonamide, sulphapyridine, and salicylate that helps control inflammation. Sulfasalazine is the most commonly used of these drugs. Sulfasalazine can be used for as long as needed and can be given along with other drugs. Patients who do not do well on sulfasalazine may respond to newer 5-ASA agents. Possible side effects of 5-ASA preparations include nausea, vomiting, heartburn, diarrhoea, and headache.

People with severe disease and those who do not respond to mesalamine preparations may be treated with corticosteroids.

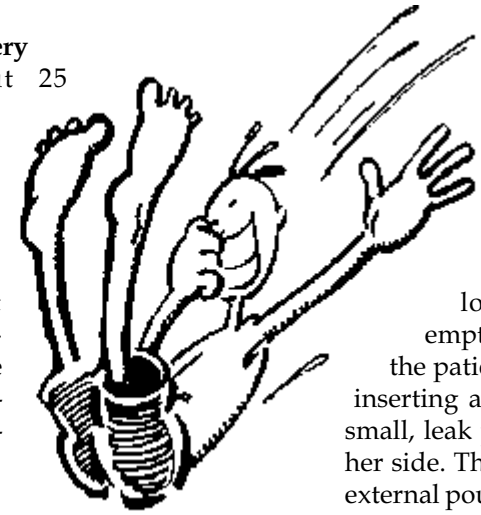
Prednisone and hydrocortisone are two corticosteroids used to reduce inflammation. They can be given orally, intravenously, through an enema, or in a suppository, depending on the location of the inflammation. Corticosteroids can cause side effects such as weight gain, acne, facial hair, hypertension, mood swings, and increased risk of infection, so doctors carefully watch patients taking these drugs.

Other drugs may be given to relax the patient or to relieve pain, diarrhoea, or infection.

Occasionally, symptoms are severe enough that the person must be hospitalized. For example, a person may have severe bleeding or severe diarrhoea that causes dehydration. In such cases the doctor will try to stop diarrhoea and loss of blood, fluids, and mineral salts. The patient may need a special diet, feeding through a vein, medications, or sometimes surgery.

**Surgery**

About 25 percent to 40 percent of ulcerative colitis patients must eventually have their colons removed because of massive bleeding, severe illness, rupture of the colon, or risk of cancer. Sometimes the doctor will recommend removing the colon if medical treatment fails or if the side effects of corticosteroids or other drugs threaten the patient's health.



One of several surgeries may be done. The most common surgery is a proctocolectomy with ileostomy, which is done in two stages. In the proctocolectomy, the surgeon removes the colon and rectum. In the ileostomy, the surgeon creates a small opening in the abdomen, called a stoma, and attaches the end of the small intestine, called the ileum, to it. This type of ileostomy is called a Brooke ileostomy. Waste will travel through the small intestine and exit the body through the stoma. The stoma is about the size of a quarter and is usually located in the lower right part of the abdomen near the belt line. A pouch is worn over the opening to collect waste, and the patient empties the pouch as needed.

An alternative to the Brooke ileostomy is the continent ileostomy. In this operation, the surgeon uses the ileum to create a pouch inside the lower abdomen. Waste empties into this pouch, and the patient drains the pouch by inserting a tube into it through a small, leak proof opening in his or her side. The patient must wear an external pouch for only the first few months after the operation. Possible complications of the continent ileostomy include malfunction of the leak proof opening, which requires surgical repair, and inflammation of the pouch (pouchitis), which is treated with antibiotics.

An ileo-anal anastomosis, or pull-through operation, allows the patient to have normal bowel movements because it preserves part of the rectum. This procedure is becoming increasingly common for ulcerative colitis. In this operation, the surgeon removes the diseased part of the colon and the inside of the rectum, leaving the outer muscles of the rectum. The surgeon then attaches the ileum to the inside of the rectum and the anus, creating a pouch. Waste is stored in the pouch and passed through the anus in the usual manner. Bowel movements may be more frequent and watery than usual. Pouchitis is a possible complication of this procedure.

Not every operation is appro-

priate for every person. Which surgery to have depends on the severity of the disease and the patient's needs, expectations, and lifestyle. People faced with this decision should get as much information as possible by talking to their doctors, to nurses who work with colon surgery patients (enterostomal therapists), and to other colon surgery patients. Patient advocacy organizations can direct people to support groups and other information resources.

Most people with ulcerative colitis will never need to have surgery. If surgery ever does become necessary, however, some people find comfort in knowing that after the surgery, the colitis is cured and most people go on to live normal, active lives.

**Research**

Researchers are always looking for new treatments for ulcerative colitis. Several drugs are being tested to see whether they might be useful in treating the disease:

**Budesonide.** A corticosteroid called budesonide may be nearly as effective as prednisone in treating mild ulcerative colitis, and it has fewer side effects.

**Cyclosporine.** Cyclosporine, a drug that suppresses the immune system, may be a promising treatment for people who do not respond to 5-ASA preparations or corticosteroids.

**Nicotine.** In an early study, symptoms improved in some patients who were given nicotine through a patch or an enema. (Using nicotine as treatment is still experimental—the findings do not mean that people should go out and buy nicotine patches or start smoking.)

**Heparin.** Researchers overseas are examining whether the anticoagulant heparin can help control colitis by preventing blood clots.

**Is Colon Cancer a Concern?**

About 5 percent of people with ulcerative colitis develop colon cancer. The risk of cancer increases with the duration and the extent of involvement of the colon. For example, if only the lower colon and rectum are involved, the risk of cancer is not higher than normal. However, if the entire colon is involved, the risk of cancer may be as great as 32 times the normal rate.

Sometimes precancerous changes occur in the cells lining the colon. These changes are called "dysplasia." People who have dysplasia are more likely to develop cancer than those who do not. (Doctors look for signs of dysplasia when doing a colonoscopy and when examining tissue removed during the test.)

According to 1997 guidelines on screening for colon cancer, people who have had IBD throughout their colon for at least 8 years and those who have had IBD in only the left colon for at least 15 years should have a colonoscopy every 1 to 2 years to check for dysplasia. Such screening has not been proven to reduce the risk of colon cancer, but it may help identify cancer early should it develop. (These guidelines were produced by an independent expert panel and endorsed by numerous organizations, including the American Cancer Society, American College of Gastroenterology, American Society of Colon and Rectal Surgeons, and the Crohn's & Colitis Foundation of America Inc., among others.)

http://www.niddk.nih.gov/health/digest/pubs/colitis/colitis.htm

The National Digestive Diseases Information Clearinghouse (NDDIC) is a service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The NIDDK is part of the National Institutes of Health under the U.S. Department of Health and Human Services.

Established in 1980, the clearinghouse provides information about digestive diseases to people with digestive disorders and to their families, health care professionals, and the public. NDDIC answers inquiries; develops, reviews, and distributes publications; and works closely with professional and patient organizations and Government agencies to coordinate resources about digestive diseases.

# Letters

**_Roar!_ Letters Page**
**"Arcady"**
**16 Hill Brow**
**Bearsted**
**Maidstone**
**Kent**
**ME14 4AW**

**gaherty@bigfoot.com**

*Dear Newsletter Editor*

Many thanks for your article in *Roar!* issue 18, Getting Help with Water Bills. I applied to my local water authority, Anglian Water, and was successful. I have now been placed on the Aquacare tariff, had my monthly payment reduced from £29 to £21 and got a £120 cheque back.

Once again, many thanks for bringing to my attention something I did not know existed.

*Carol Rippon*
*Lincoln*

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*Dear Newsletter Editor*

I wonder whether the following may be of interest to any other "pouch people".

I had my pouch surgery during 1992-93. Since then I've had various ups and downs, as most people seem to. When I wasn't very well and felt I could not eat properly, I used to indulge myself with things like marshmallows, popcorn and jelly babies, all of which I had read, or had been told, would really help to thicken pouch output. It took me some time and lots of worry to discover that the more I did this the more ill I felt.

Frequently I had no energy, had bad night sweats and generally felt terrible. My GP put this down to various causes ranging from reaction to certain medication to depression. I was prescribed Prozac, which did not make me feel any better but did give me violent diarrhoea. I suffered these bouts of feeling dreadful, on and off, for at least two years, believing it must be all part and parcel of not having a colon. It was not until we moved house and I had to have a medical overhaul before signing on with a new surgery, that I was sent for tests before being told that I had developed diabetes.

I was somewhat stunned, as I have never been overweight and there is no known diabetes in the family. This condition is now controlled with tablets.

It has been suggested to me that either steroids taken when I had ulcerative colitis or trauma to my body during various stages of surgery could be the cause of this onset of diabetes.

I have read that Steve Redgrave suffers from UC and is also diabetic, and would be interested to know whether any other pouch owners out there have had similar experiences. Or is there a recognised link between ulcerative colitis, Crohns, the pouch and diabetes?

*Sandra Allen*
*Tel: 0114 251 0577*
*E-mail:*
*dallen@ridgeway.skynet.co.uk*

# Christmas Cards

Our lovely Christmas cards with the Red Lion mascot on the front are available as from now. We have decided to tell you about them in plenty of time, for a change!

We will also be posting them on the redliongroup internet forum (see elsewhere in this newsletter), so that those of you with internet access can see them in their full glory.

The message inside the card reads: Best Wishes for the Festive Season. This makes them suitable for a range of celebrations and religions.

There is no reference to the work of the Red Lion Group, so you can give them to anyone without fear of them reading the dreadful "bowel" word!

Actually, I'll let you into a secret: due to an administrative oversight by me (as I shall call it!), the cards don't even mention the Red Lion Group or charity details - that will be rectified when they are reprinted.

In line with other charity cards, they cost £3 for 6 including P&P. Contact Christine Lawton, Fundraising and Merchandise Officer (details on back page) to place your order.

Every pack of cards you buy benefits the Red Lion Group, so do consider supporting us in this way when you come to buy your Christmas cards.

# Contact Needed

Tony Barnard has just come out of hospital after having his closure operation.

After 2½ years with an ileostomy, he is finding it hard to cope with the frequency of output and would very much like to speak to other pouch owners (particularly those who had UC) about how they found what foods did and did not work for them.

You can call him on 01622 204298. In the meantime, he'll be eating sandwiches!

# Travel Tips

The following information was provided for the Information Day workshop by Wendy Osborne, Clinical Nurse Specialist in stoma/colorectal surgery at John Radcliffe Hospital, Oxford.

A change of water, climate or food can upset anyone's bowels. In general, as with anyone taking a holiday, be sensible and prepared. But best of all, relax and have a really enjoyable holiday.

Ensure your travel insurance is from a reputable company and does not exclude "pre-existing conditions".

Telephone numbers of professionals who have a knowledge of pouches abroad can be obtained from your local support group, NAPG or your stoma care nurse.

Plan your journey

Use a checklist before you travel to avoid forgetting things like:

barrier cream, wet wipes, soft toilet roll, air freshener, mirror and water sprayer

anti diarrhoeals (loperamide/ imodium or codeine phosphate)

antibiotics (metronidazole, ciprofloxacin or augmentin)

electrolyte replacement (dioralyte, WHO)

Carry medications and essentials in hand luggage.

If you are flying, request an aisle seat for easier access to the toilet. Flying is not recommended less than 6-8 weeks after major surgery without obtaining your surgeon's approval.

Avoid fizzy drinks, alcohol, high fibre food and large meals before going on a journey, to minimise the amount of wind you may produce.

Drink bottled water, avoid ice cubes and foods washed in local water if the water is suspect.

Ensure you drink extra fluids in hot climates; always have a bottle of water with you.

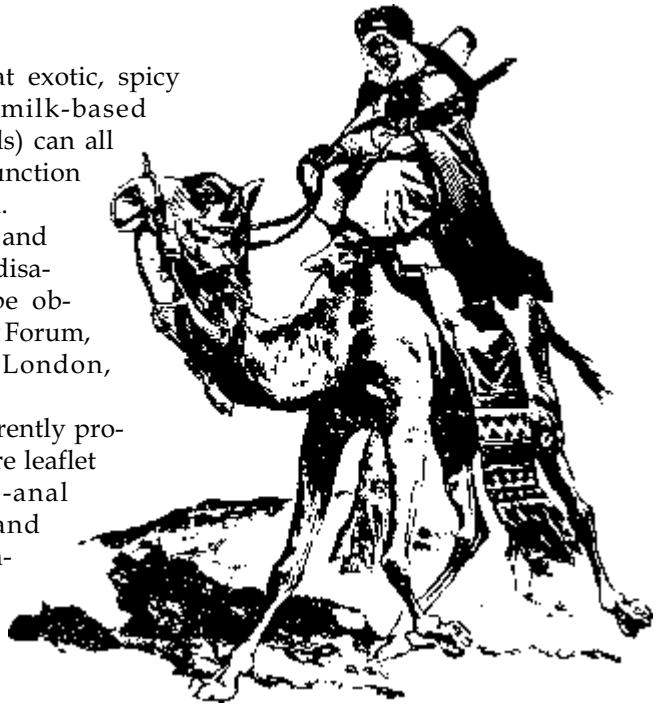
The use of an electrolyte replacement is recommended if you are in a hot climate or if you experience "holiday tummy", as you will be losing excess fluid and salts.

If you need to take an antidiarrhoeal, remember to take it 1-½ hour before meals, to promote effectiveness of the tablet.

Remember that exotic, spicy foods, alcohol, milk-based drinks (eg cocktails) can all increase pouch function and produce wind.

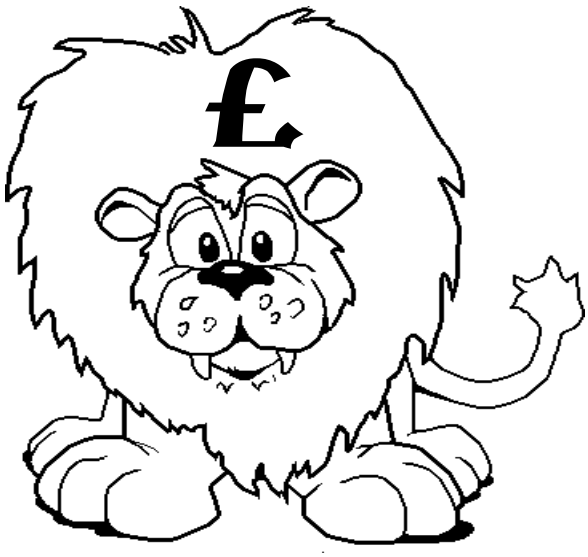
A RADAR key and card for access to disabled toilets can be obtained from 12 City Forum, 250 City Road, London, EV1V 8AF.

NAPG are currently producing a travel care leaflet explaining ileo-anal pouch surgery and other vital information in foreign languages - it should be available for summer 2001.



## Please support the Red Lion Group

Registered Charity number 1068124




All donations, however small, towards expanding the work of the group will be gratefully received. If you would like to send a donation please make your cheque payable to The Red Lion Group. And send it to: **The Red Lion Group Treasurer, Mr John White, 44 France Hill Drive, Camberley, Surrey GU15 3QE**

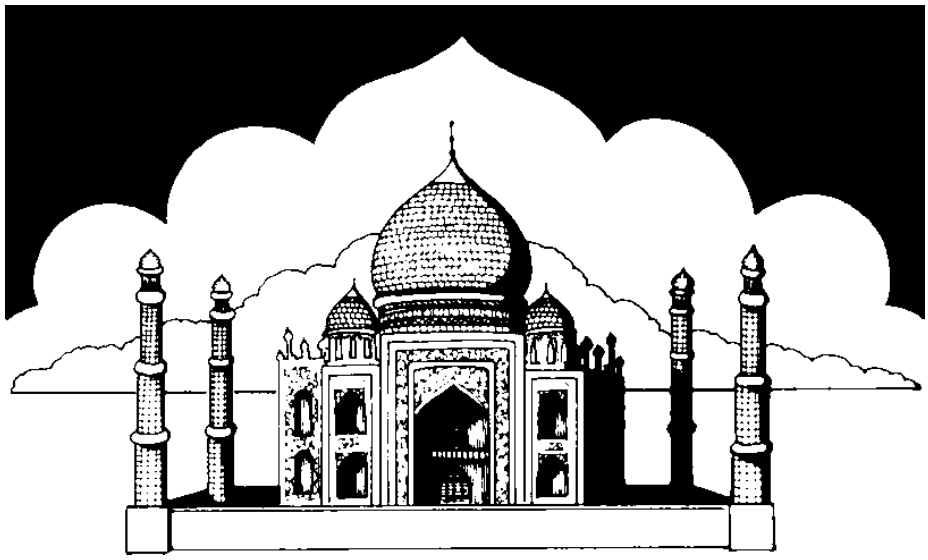
# My Story - by Kanta Patel

In June 1996 polyps were discovered in my large colon. Because of this, two-thirds of my large colon were removed.

It was major surgery and after a few days I became very ill and was in a lot of pain. Strong painkillers didn't help. My consultant thought the join in the colon may have become undone and further surgery would be necessary, which I was dreading.

An X-Ray was done and all was fine, but the cause of the pain could not be found. I was prescribed strong painkillers and gradually the pain became less. I took three months to recover.

Six months after my first surgery, I was advised to have the remainder of my colon out. After careful consideration, I decided to have the colon removed and was told that an ilea-anal pouch would be constructed. I was warned that the operation was not always successful, and that if it was a failure I would end up with a permanent ileostomy.



I was asked to contact a pouch support nurse and the Red Lion Group. I became a member and was informed about the annual general meeting which was due to take place in April 1997. This was before my operation, which was due in July 1997.

I went to the meeting and found it very helpful. I read previous *Roar!* newsletters and found that a lot of people were happy with their pouches. The impression I got was that if a consultant managed to construct a pouch then all pouches are successful. To me it was either a successful pouch or a permanent ileostomy.

I was asked whether I wanted a one-stage operation or a two-stage operation. After reading newsletters, speaking to several people, I decided to opt for a two-stage operation.

On the day of the surgery, the consultant informed me that they tried to construct four pouches and they couldn't be done, the patients ended up with permanent ileostomy. I was very nervous and was praying that mine would be a success.

The day after the surgery, my consultant came to see me and told me that an ileo-anal pouch had been constructed and I had a temporary ileostomy. This would be reversed in about eight weeks. I was so pleased with the news.

A few days after the surgery I became very ill, was feeling sick, couldn't breathe and was in terrible pain. Tests were carried out. I had become anaemic and needed a blood transfusion.

Two weeks later I went home and I started having problems with the stoma bag. It started leaking. I tried different bags but w was frightened to go out because of the leakages. Eventually the fifth bag was suitable.

In November 1997, my temporary ileostomy was closed. At first I was emptying my pouch every hour, but this slowed down after a few days. I went home and a few days later the problems started. At first I was emptying six times an hour, lasting for a few days. I got worried so I contacted the hospital. I went to see my consultant, who decided that dilation of the pouch was necessary.

I was emptying my pouch three times a day for a few weeks and then suddenly I got worse. I was in constant twisting pain and my consultant couldn't understand why. I had barium but nothing showed up. My consultant thought I had ulcers so an endoscopy was done, but again nothing showed up.

I was in so much pain. Painkillers were prescribed by my GP but they didn't work. I wasn't eating or sleeping and was helpless. The pain was unbearable. My GP contacted my consultant and I was admitted to hospital in December 1997.

Further tests were carried out. I had a full CT Scan but nothing showed up. I had a pouchogram but nothing showed up again. I was hoping there might be something. In the end I asked the consultant to open me up.

There were a few adhesions. I was sent home two weeks later. The pain started again. I was re-admitted again.

The pouch was dilated again. I was fine for a few weeks and then back to the pain. I asked for an ileostomy but my consultant was reluctant, as he didn't know the

cause of the pain.

By this time I had lost three and half stone in weight. I asked to be referred for a second opinion. In the meantime I was taking laxatives to empty my pouch. This drained me out but I was pain free for a few hours. The only problem was I couldn't take laxatives every day.

On the day of the second opinion I was in so much pain but I wanted to see the consultant so I took a laxative and emptied my pouch.

I explained everything to the consultant who listened carefully and then examined my pouch. He informed me that the pouch was full and that was the cause of pain. He emptied my pouch with a catheter. Straight away I felt much better, I hadn't felt like this since the closure of my temporary ileostomy. He told me to try a catheter for two weeks and go and see him again. That evening I slept properly for the first time since the closure of the ileostomy.

After couple of days, the catheter was getting stuck inside and I couldn't get it out. Sometimes after pulling hard it did come out. On occasions I had to go to the hospital to remove it. It was difficult to get to the hospital with a catheter dangling. My mum drove me to the hospital. I wanted to use the catheter to relieve the pain but was scared in case the catheter got stuck.

The hospital gave me an adult proctoscope to use and then insert the catheter. The proctoscope was too big to insert and I refused to use it. I was supplied with a dilator. Using the dilator didn't help, the catheter was still getting stuck.

Eventually I was given a child proctoscope which I am currently using with a catheter.

Sometimes I empty the pouch well, some days I can't empty at all, and then I am in constant pain. I have been using the equipment since June 1998.

Since January 1999, I have drinking PRUNE JUICE, which loosens the output. I feel better since taking the prune juice. I only take it after the evening meal as the prune juice works as a laxative.

It is such a hassle using the equipment. I mainly tend to use it at home. I am therefore very restricted in going out. If I go out, I go locally so I can then rush back home. If I have to go far then I fast or prepare myself for journey. I drive only when I fill fine.

I have been abroad three times, twice to India, the last trip was cut short due to the earthquake. I don't know what I would have done if I had lost my equipment in the earthquake. I was lucky to be alive.

I fasted for 24 hours to travel there and 24 hours to get back. It is difficult to use the equipment on the plane.

My last resort is to carry on doing what I am or have a permanent ileostomy. I have never had pouchitis and I have been told that my pouch is healthy but not emptying naturally.

It would be nice to hear from somebody who may be experiencing a similar situation.

Also I would like to hear from someone who had a pouch and now has an ileostomy.

You can send a letter to me c/o Morag Gaherty, Liaison Officer, Arcady, 16 Hill Brow, Bearsted, Maidstone, Kent ME14 4AW.

Or you can call me on 020 8951 5403.

# Red Lion Group Internet News: the 21st Century is very Definitely Here!

## Morag Gaherty gets all e-technical…

First of all, let me confirm that the website is currently in the process of being rewritten. As a number of past issues are already available on-line (as that's how we newsletter co-editors communicate), the website will contain links to these, as well as other containing lots of other information.

There will be a new website address too, and all will be revealed in due course.

Also, effective immediately, I have set up a Yahoo Group called (no spaces) redliongroup, which is open to anyone to join. Effectively, this will become an on-line support group, without all the limitations of paper and phones. Every member will be able to e-mail messages freely to other members, finding new friends and information about common experiences. Also, we will be able to conduct on-line polls, which is a very effective and immediate way to gather information.

We will also post documents for you to be able to view on-line. The very first one, which has already gone up, is the Red Lion Group Christmas card: find it in the Files section of the website.

At the time of writing, the Yahoo Groups directory is not showing the group because it is so recent, although it does exist. If a search for redliongroup does not bring it up, feel free to send me your e-mail address and I will directly subscribe you. If you want to look at the archive of messages and posted documents on the website, you will need to have a Yahoo ID and password - go to www.yahoogroups.com and follow the instructions at the left hand side for getting yourself set up with these.

I know from experience that there can sometimes be difficulties in getting access to a group initially, but equally I know how to solve that, so do get in touch if you have any problems. Once you're in, it's plain sailing. You can even post photos of yourselves if you want!

In fact, I can't think why we didn't do this a year ago….

# *Sister Annie's Special Day in Kent*

David Irving-James, South East Kent regional rep, tells us about a lovely special occasion recently.

Sunday 13th May was a special day in the calendar of the East Kent Red Lion Group. A Sunday lunch at a rather attractive restaurant perched high upon the white cliffs between Dover and Folkestone was the venue for the Group's annual social get-together. We were truly blessed with fine sunny weather (the best day so far this year). An attendance of some 30 pouch owners, families and friends made the party a real group gathering.

The icing on the cake was that our very own Sister Annie Driscoll from St Mark's outpatients department was our guest of honour.

I had heard several months ago that there might be a probability that Sister Driscoll might be leaving St Mark's to work at St Barts in Central London and closer to her home.

In anticipation of a possible move the East Kent Group decided to hold an early retirement party (a dress rehearsal, if you like!) for Annie, coinciding with our summer social function.

Pauline and Jim Garety from Maidstone kindly volunteered to act as chauffeurs, collecting Sister Annie from her home in London on the day and returning her to it later on.

As we all know, Sister Annie is a much loved member of the St mark's staff. Within minutes of her arrival, the bar of the restaurant was alive with smiles, big hugs and laughter. As she sipped her first drink, she declared she felt very much at home amongst all her friends.

The photocall was taken outside on the cliff top, and we all willed Sister Annie not to step back too far! The photos are excellent and will I hope be reproduced in this newsletter.

My wife Tina will, or has by now, produced a photo album of the day which will be given to Sister Annie to remind her of the special day.

Prior to lunch, Sister Driscoll was presented with 2 pieces of cut glass crystal. A bouquet of flowers was also presented to Morag Gaherty for all her hard work behind the scenes for the Red Lion Group.

For several weeks I had been toying with the idea of penning a poem especially for this occasion. I finished it with only hours to spare. The poem was read out by Tina, who then presented it to Sister Annie. It was attached to a rather suitable print of Doctors, Sisters and Nurses, in the old fashioned 1930s uniforms, enjoying a cup of tea and a gossip.

Without labouring what was said in the speech, I will simply reproduce a paragraph from a letter received from Mrs Sally Thelen who unfortunately could not be there, as she was in Southern Ireland. Sally's words echo the thoughts and feelings of our group and, dare I say, all who know Sister Annie Driscoll:

"She really is a lovely person and always so cheery that I am sure she puts everyone at ease straight away. Hospitals can be daunting

places, so to have someone like Sister Driscoll was a real Godsend. I have never once seen her lose her temper or be impatient in any way. She always used my name and made me feel special, which I am sure she did to all her patients. I think it is a case of St Mark's loss being St Barts' gain…"

I will close by saying it was an honour to host Sister Annie and it was wonderful to see so many of our local group with their families and friends.

**Farewell**
The clinic is full to the brim
Some faces are sad and some have a grin
Then she appears in her normal sweet way
"Hello everybody, how are we today?"
St Marks has been trading for a very long while
But there is one wee person who makes the place smile
She's lovely and kind and as bright as crystal
It's someone we know, it's our own Sister Driscoll
The time has come for her to leave good old St Marks
There will be some tears and a few broken hearts
For she is the centre of what we all know
She lifts up your spirits when you're feeling low
No-one can replace her, how try hard they might
For she is the star that shines a bright light
With her genuine smile and her own loving ways
We will remember her for the past happy days

David Irving-James
May 2001

# Diet Tips For Your Ileo-Anal Pouch

A summary of the dietary considerations outlined at the Information Day by Michelle Alley, Gastroenterology Dietitian, John Radcliffe Hospital, Oxford.

The Function of the Colon: re-absorbs salt (Na), re-absorbs water, forms stool, fermentation, synthesizes vitamins (vitamin B12 and vitamin K).

Post-Operative Guidelines: light, soft and low fibre food, adequate fluid and salt intake, regular eating pattern and re-introduce fibrous foods after 4 weeks, in small quantities and well chewed.

The Dysfunctional Pouch is usually attributable to: erratic eating habits (including skipped meals), high caffeine intake, high fibre intake, food intolerances (eg wheat or lactose), high fat intake, poor fluid intake, irritable bowel syndrome or pouchitis.

Special Dietary Considerations include: calcium intake, vitamins and minerals, hydration, food safety and high energy.

What should you eat to maintain a healthy body? In most cases, just a healthy balanced diet. This means 55-60% carbohydrates, 30% fat, 15% protein, food which contains calcium, and fruit and vegetables to your own tolerance.

Fluid Intake: very important (rehydrate well). Thirst is not a good indicator of your hydration status (too late). High pouch output results in the loss of a lot of water, salt and potassium. You should aim to drink 8-10 cups of fluid per day.

Types of Fluid: isotonic (sports drinks with added salt, dioralyte, WHO). Keep tea, coffee and water to a minimum as these are a diuretic. Limit fruit juice and sugary drinks.

Probiotics: these are "good bugs" in the digestive tract. Gionchetti et al 2000 showed that 85% of patients with chronic pouchitis remained in remission after taking high doses of probiotics. Pouchitis is associated with a lack of "good bugs" (lactobacilli and bifidobacteria). Probiotic foods include yoghurt, Yakult, Actimel and capsules.

Foods that Thicken Output: rice and rice cakes, pasta and white bread (fresh), mashed potato, apple sauce, smooth peanut butter, marshmallows and jelly cubes and ripe banana.

Foods that Increase Wind and Odour: broccoli, sprouts, cabbage, onion, garlic, leeks, asparagus, beans, spicy foods, carbonated drinks, beer, eggs.

Foods that Increase Pouch Output: pulses and leafy vegetables, raw fruit and vegetables, wholegrain cereals, nuts and sweetcorn, alcohol, fruit juice and caffeinated beverages, chocolate, fatty foods and any food intolerance.

Optimising Pouch Function (1): don't skip meals; eat small meals regularly. Eat foods that thicken output. Avoid eating and drinking at the same time.

Optimising Pouch Function (2): healthy eating, freshly cooked. Fruit and veg to tolerance. Consisitnet fluid intake throughout the day. Live yoghurt. Limit foods that cause irritation (eg spicy).

Optimising Pouch Function (3): limit food that increases output and that cause gas. Chew food well. If active overnight, aim to finish eating early in the evening. Get a formal assessment from the dietitian: in exceptional cases, an exclusion diet may be advised.

There is no reason why you cannot follow a normal healthy balanced diet and remain in good health.

# Mr Windsor's Top Bottom Tip!

If you get a sore bottom, this may well be caused by minute amounts of leakage causing what is effectively nappy rash right at the anus.

Apart from pain (no doubt called "discomfort" by those medical professionals who don't suffer from it!), this also exacerbates feelings of urgency.

Wash the bottom carefully, and use a cotton bud to clean the cracks of skin as thoroughly as possible. Then apply a barrier cream, to protect the skin.

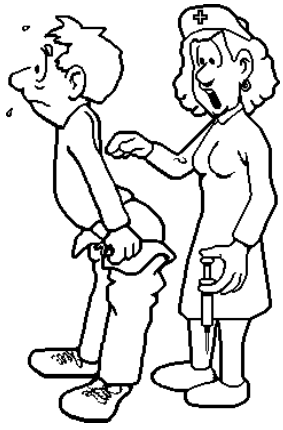
Then pop a small amount of absorbent gauze or cotton wool at the entrance to the anus. This will absorb any tiny leakages and stop them from getting to your skin. Obviously you should change the padding occasionally throughout the day!

This should ease discomfort and cause a significant improvement in how you feel in as little as 24 hours.

Christine Lawton followed Mr Windsor's tip and reports that it is miraculous.

Not only is she now feeling better than she did when her colon was first removed back in 1978, but her toilet visits have reduced dramatically as a result.

Three times a day is acceptable in anyone's book, let alone a pouch owner's.



Why not try it and let us know how you get on?!

# A Retired Pouch

Former Red Lion Group Chairman and current expatriate in Spain, Dr Martin Peters, tells us what it is like to move abroad with his constant companions: wife and pouch.

By the 31st December 1998, I had reached a sufficient level of decay to be retired early on medical grounds. A pouch and two total hip replacements seemed to do the trick. My pensions came into effect, Amanda gave up work, I had a retirement party at Basildon Hospital and by the early hours of 25th January 1999 we were in our car and on our way to Spain. We had been dreaming of this moment for ten years, and now that it had arrived we were a little nervous of what we had let ourselves in for. We would be a long way from St Mark's and familiar medical care, as well as our families and friends.

Two days later, we were in the Sierra Nevada, deserted roads, lots of snow and night falling. We then encountered a road block. Three large men in camouflage gear wearing black balaclavas and waving submachine guns ensured that we stopped. They checked inside and outside the car and then waved us on. They were the Guardia Civil looking for illegal immigrants. Not a word had been spoken. What a welcome to Andalucia, our new home! Later that evening, we arrived in Alhuarin de la Torre, the town in which our urbanisation was located, still somewhat shaken but ready to start our new lives.

The first few months were spent painting, plastering, cementing and then more painting. One hundred and thirty litres of paint and some weeks later, the job was finished.

Toilets are very important to pouch owners, and in February disaster struck both of ours. After flushing one of the toilets, we noticed the contents reappearing in the bidets and baths. Years of medical training made me conscious of the fact that this was not a good thing. Attempts to fix the problem only made matters worse, and when six inches of you-know-what entered the bedroom, we decided it was time to call for expert help.

This arrived the next morning and after much digging up of beautiful marble floor tiles and passing of strange whirring machinery along exposed pipes, everything cleared. We were told that the cause of the problem was too much toilet paper being flushed down the loo, and that in future it must be collected in plastic bags hidden in pretty pedal bins. This we and all our visitors now do religiously, and we have had no further problems.

So all you pouch owners who by nature use large quantities of toilet paper: be warned! Disaster may await you on your next holiday abroad, where the drains don't seem to be ready for the pouch invasion.

When March arrived, we thought about getting the swimming pool in working order, ready for us and a horde of visitors we had been warned to expect. For eight and a half years it had contained nothing but four feet of green slime and layers of limescale. This all had to be removed by hand.

Using hydrochloric acid to remove the limescale worked well, but dodging the clouds of chlorine gas formed in the chemical reaction that followed was no easy matter. If my colleagues in the field of Occupational Medicine could have seen me, some very unkind things would have been said.

Amanda and I returned to England at this point to attend to family matters (the arrival of a new granddaughter), leaving our Spanish friend Antonio to tell us that the water he had put in the pool had disappeared overnight by running through the concrete of the walls and flooding the surrounding garden. Six weeks and "mucho dinero" later, we had a functioning pool.

The end of May was the beginning of our visitors' season, and from then until the end of October we enjoyed a constant stream of family and friends, and a chance to catch up on all the latest gossip from the UK.

All had gone too well so far, but the next dramatic episode was not far away. I woke up with a yell one night because of a severe pain in my left big toe. I rushed to switch on the light and to my horror I saw and eight-inch long centipede on the end of the bed. My foot swelled alarmingly, and Amanda was unsure whether to rush for the adrenaline injection we keep for emergencies, or to get the bug killer spray and deal with the menace.

Getting rid of the centipede won the argument and once that was disposed of, treatment with copious amounts of ice and steroid cream reduced the pain and swelling. We did not get much sleep for the rest of that night, and it was some time before confidence was restored to the marital bed. Two more of these creatures have since appeared in the house and (although I don't think we are getting used to the experience of nasties) we did react very calmly when we discovered a scorpion in our dining room.

With the approach of the cooler weather, our thoughts turned once

# 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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| Liz Davies | Langley | 01753 586593 |
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again to jobs in the garden. This is going to occupy us for a considerable amount of our time, as there is so much to do and an acre of garden to do it in.

Christmas came and we enjoyed Christmas Andalucian style as guests of the family of our friend Antonio and his wife Ines. Very, very different, but great fun with vast amounts of seafood and lots of drink, but no turkey.

We spent a very quiet New Year's Eve watching the worldwide celebrations on Sky. Our second year was far less eventful and we completed a lot of jobs that needed doing in the house and garden. We gradually acquired furniture to replace all the plastic stuff that had to suffice while we used the place as a holiday home. We now live here for eleven months of the year and are very happy with our decision to make the big move. If anyone is thinking of doing the same, please get in touch. Our e-mail address is martingpeters@eresmas.com.

Now that we are well into our third year here, I can assure all you pouch owners that there is nothing to be afraid of in trying out new things and going for that big dream. I am thankful for the treatment I received at St Mark's and from Mr Hawley, which has made it possible for me to be a happy retiree, fit enough to enjoy all the new experiences of food, drink and fun that are to be found in foreign parts, where the sun shines most of the time and the aches and pains seem far away.

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* 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

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

**WWW.RED-LION-GROUP.MCMAIL.COM/**

# 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.