

Roar!



Issue number 17 • Summer 2000

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

High Flier!

On the weekend of 29 July 2000, pouch owner Katrina Marshall is going to leap out of a plane to further research into bowel surgery. She also hopes to have a very good time, and will be writing a piece for our next issue of *Roar!*, to tell us how it all went. This will be her first attempt at parachuting, but she is no stranger to mastering physical feats that are beyond most of us, pouch or no pouch. Perhaps being a sports instructor has something to



suitable copy for your sponsored event, to go to your local newspaper. It doesn't have to be as physically demanding as a parachute jump to gain interest: the more unusual the better, to get people's attention.

do with it!

As Katrina says, "having a pouch changed my life, but the main thing is that it has allowed me to get back to the kind of life I had before UC struck". Since having pouch surgery in 1986, Katrina has swum the Channel and been involved in many other such challenges, for which she has raised sponsorship money in aid of bowel research.

This is the first time that one of her activities has raised money for the Red Lion Group, and we are proud to support her in this venture. We wish her fine weather and a good jump on the day, and we look forward to hearing how much she has raised.

Katrina is currently looking for

sponsors for her jump, and I am sure many of you will want to support her. Please contact her on 01303 279774 to give her details of how much you would like to pledge, and to find out how to get it to her.

Every penny you give will go to the Red Lion Group, and we have earmarked this sponsorship specifically for research into bowel surgery, in accordance with Katrina's wishes.

If any other Red Lion Group member would like to consider some kind of sponsored activity to raise funds for the group, we would be happy to provide you with sponsorship forms and a mention in *Roar!* Our PR officer, Chris Browne, may well be able to provide you with

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AGM and Study Day 2000

David Irving-James gives us his own summary of how it all went.

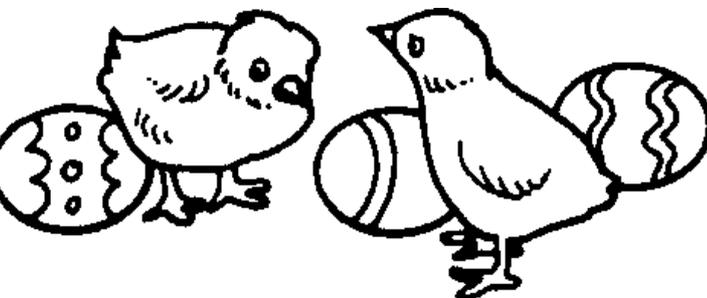
I would like to start by giving my personal thanks to those who made it a great day.

Firstly, thanks to all those who attended on 14 April – I must say, you were all a friendly and fun group of people.

Secondly, many thanks to all those generous people who donated their reservation deposit (£12.50 per head) to the group rather than receiving it back on booking in. We do very much appreciate it.

Thirdly, a very big thank you to two lovely ladies, Lorraine Howells and Lucille Zahl, who (wo)manned the reception area in a very professional manner.

A total of 60 people attended the day, which was rather fewer than the 80 who attended in 1999. My records show that the majority of these came from London, Middlesex and Kent. To those who travelled from as far afield as Bristol, Bath and North Wales, it was lovely to see you, and thank you for your kind comments that it was well worth the distance

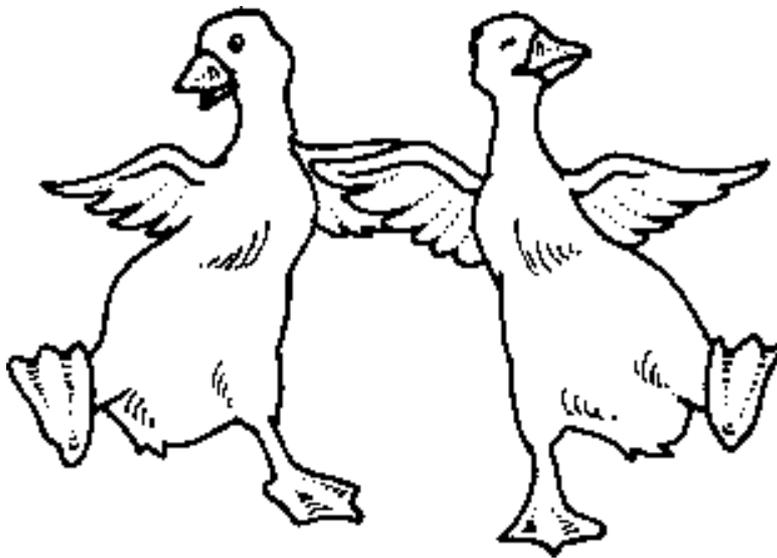


travelled for a lovely day.

I have made a note of the comments made regarding improving the day so as to make it even more helpful to those attending. I will as always endeavour to improve the day according to the wishes of our

members.

The House of Colour (colour co-ordination demonstration) was a great hit, and very well received and appreciated by those who watched it. It may not have seemed an obvious choice in the context of a pouch support group meeting, but I know that the theme of “looking good, feeling good” struck a chord with many. Now everyone knows



why I co-ordinate my socks, tie and pocket handkerchief!

Sadly Claire was unable to be with us to do her talk on reflexology, because of her knee problems, but her handouts were eagerly snapped up.

If you would like to receive one, please let Morag know.

If any reader has any ideas for a similar demonstration

or theme for next year, please contact me with your ideas.

Tombola ticket sales came to £49, and many of the prizes were very worthwhile – no cans of beans this year! Thanks to those who donated tombola prizes.

For the first year, we sold raffle tickets in aid of the Alexandra Rose Day (ARD) charity. The ARD charity is an umbrella charity working to help smaller charities by running two raffles a year and the Alexandra Rose Day house to house collection in June. Money is collected in their recognised name, and they provide very generous raffle prize (top prize in the May raffle was £2,000). Each

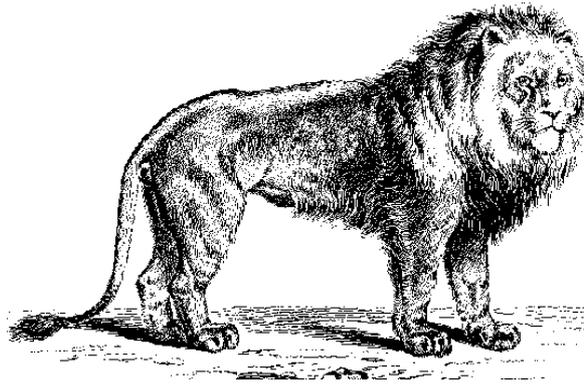
small charity retains 80% of the proceeds they have collected, forwarding only 20% to the ARD to cover the cost of prizes and of administration. I am pleased to say that we collected almost exactly £100 at the AGM, of which the Red Lion Group retains £80 and £20 has been sent to the ARD charity.

We have decided to stick with the raffles for the present, and not to branch out to the house to house

collections until such time as we have someone to organise this as a project.

I look forward to our next meeting in 2001. I hope that you will all be able to attend again, plus many new faces, and I promise different subjects on our afternoon presentations, to ring the changes.





Editorial

Our front page story is about Katrina Marshall, and her sponsored parachute jump, and I hope that you will be able to sponsor her for this event. You will see that all the funds will come to the Red Lion Group, and have been earmarked for research into bowel surgery. Even if you are too late (depending on when we go to press) to sponsor Katrina beforehand, there is nothing to stop you making a donation to this worthwhile cause after the event. I hope she raises lots of money as well as having a good time.

Although numbers were down for this year's AGM in comparison with last year's, it was lovely to see all those who attended. Many of you also told us how much you enjoyed it, and I hope that David's write up of the day, elsewhere in this issue, will tempt you to book next year's date (provisionally booked for 7 April 2001) into your diary now. As usual, we have avoided Easter, which falls in the following week.

The location of the 2001 AGM and information day is not yet fixed, and you will see that the survey enclosed with this issue of *Roar!* is specifically on the subject of our annual day. Please do take the time to complete and return this, as your comments will shape the final arrangements.

As a point of order, the minutes of the 1999 AGM should have been read out and signed at this year's AGM, but unfortunately the only copy was held by Inez, our secretary, who was away on holiday. As

agreed at the AGM, therefore, these minutes have been included in this issue of *Roar!* instead. We have also included the minutes of this year's AGM, for the benefit of those who could not attend.

The only resolution to be voted on was the question of accepting advertising, and this was carried unanimously. There will be a higher rate for relevant trade advertising



and a nominal rate for members' advertising. If you would like to advertise YOUR business in the next issue of *Roar!*, please contact me as soon as possible. The rates have yet to be ratified by the committee, but I imagine that £10 for a quarter page members' advert is around the right mark. There will be a maximum of 16 quarter page adverts in the centre of the next issue, ie over four sides.

You will see elsewhere in this issue that we continue to have made no headway with the Auction/Book Sale plans. Without someone to take on this project, the committee has effectively agreed to cancel it. Instead, the various items we have so far received will probably be auctioned via the internet. I am very sorry that this has not worked out, after such a hopeful and promising

start, but we believe it is better to do this than to half-arrange a complete flop. Full details about how to bid for items will be contained in the next issue of *Roar!*, including arrangements for people who have no access to the internet but would like to bid at the auction.

Please do not let this put you off suggesting ideas for Red Lion Group fund raising in the future. Having said that, the next time we will ensure that someone takes on responsibility for running the project *before* launching it! The best idea in the world will not work without someone being prepared to project manage it, and both David and I are unfortunately unable to take on extra responsibilities of this kind.

As I write this editorial, we are running a couple of weeks late for going to press, for which I must bear the blame. As most of you are aware, I have also been treasurer of the NAPG for the last year, and I am unable to keep up responsibilities to both groups as well as running my own business (you'll see my advert next issue!) and looking after our toddler, Bob. When we discovered that we were to become parents again at the end of the year, we were very pleased, but clearly something will have to give. For this reason, I have resigned as NAPG treasurer. My responsibilities to the Red Lion Group continue, and I hope that this quarter's slightly late issue is a one-off. I also hope that it has not arrived too late for you to take on holiday!

Talking of which, let me close by wishing you a very warm and relaxing summer.

Unconventional Remedies

As many Red Lion Group members who have had a hard time post operatively have already discovered, complementary or alternative therapies of various sorts can do wonders. Sometimes this is after many years of failed drug therapy.

Many of these treatments lack formal scientific proof (mostly because the drug companies have no vested interest in running expensive trials, in my personal opinion), but anecdotal evidence often suggests impressive results.

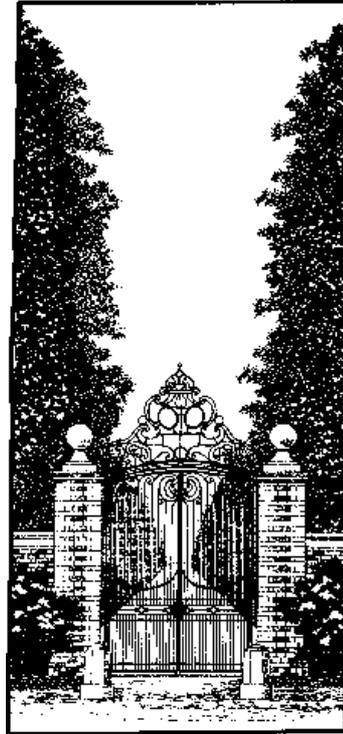
One thing is clear, however, and that is that not everyone responds well to the same thing. This is exactly the same as we have discovered for dietary guidelines: what is a miracle cure for one may be a disaster for another. It is a question of finding what it is that suits your own body.

It is for this reason that we at the Red Lion Group are keen to hear from anyone who has tried homeopathy, nutrition, osteopathy, reflexology, yoga, herbal medicine, meditation etc etc to control their symptoms. We are as keen to hear about failures as about successes, because the more balanced information our readers have, the better. We have no axe to grind in pushing any particular viewpoint, simply an

interest in sharing experiences and information for everyone to benefit.

There is one final point I would like to make. It is always sensible when trying out any kind of therapy that involves taking something internally to visit a suitably qualified practitioner for advice, and to be clear with them about your medical history and your existing drug regime.

This is particularly important when looking into any kind of herbal remedies. Just because herbal remedies are natural rather than synthetic does not change the fact that they are drugs, which can react both



with each other and with synthetic drugs.

It is far better to visit a properly qualified medical herbalist and obtain advice (even if you choose only to do so at the dispensary rather than in an appointment) than to make your own selection at the local health food store. At the best, self-selection is only a hit and miss approach, which may involve wasted money.

At the worst, it could even be dangerous. Your nearest medical herbalist should be listed

in the Yellow Pages, and will often offer some level of telephone advice.

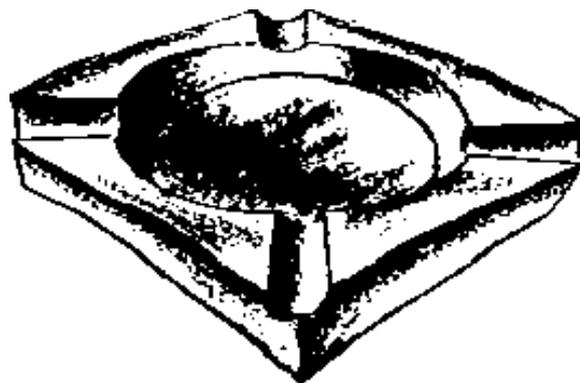
UC in the News

On Tuesday 18 April, the Daily Telegraph ran a full page article about the baritone John Rawnsley, who has had ulcerative colitis for many years.

The article was interesting and well researched, and included information about the Red Lion Group, although Mr Rawnsley is not himself a pouch owner. Around 20 people have since contacted Julia Williams for membership forms and copies of *Roar!*

According to the article, the "bloody flux" which caused Bonnie Prince Charlie to abandon battles may in fact have been ulcerative colitis, according to some

historians. The ever-resourceful Flora MacDonald advised him to control this by giving up milk, so



even at that time diet was recognised as an important factor, at least by some.

The article also mentioned the nicotine patch trials being done by Prof John Rhodes and Dr Gareth Thomas in Cardiff, based on the evidence that non-smokers are more likely to be affected by UC than smokers are. However, before you rush all out to buy your nicotine patches, the results so far indicate that, while they do ease acute flare ups, they do not prevent relapses. Nonetheless, it might be something worth considering as a stop gap until you can get to the doctor!

My Story...by Audra Maitland

I had my first symptoms of UC at the end of May 1998, with the usual diarrhoea with a slight bit of blood through it. My GP sent away a sample and told me to phone for the results the following week, whereupon the receptionist told me that my sample had come back negative and then put the phone down on me! I thought 'Oh that's good but why am I still running to the toilet about 5 times a day?'

The symptoms seemed to settle for a couple of weeks until the day after my 30th birthday party, but I just put that down to the amount I had to drink! The following week the stomach spasms started and my GP then told me I had a bug and that was causing the diarrhoea also. But when I went back the following week with no change, he decided to get me seen at a hospital clinic that same week. I was told I was suffering from severe, acute UC and was admitted to Aberdeen Royal Infirmary the next day.

I was put on steroids and was told that they normally start working within 5 days. When the 7th day came and went and my condition was getting worse I knew I was in trouble. I was introduced to the Stoma nurse, who put an X on my stomach (just in case), that didn't really bother me, as I thought 'I'm not that ill?' Then my consultant came to talk to me and told me he was going to introduce me to a surgeon, Mr T O'Kelly. Anyway on the 19 July, 11 days after being admitted to hospital I went to theatre to have my large bowel removed and was discharged a week later with my bag attached.

I am an aerobics instructor and a personal trainer, and went back to work 14 weeks later. After a couple of check ups and discussions of the pros and cons with Mr O'Kelly I was readmitted in April 1999 for pouch construction. I went home 2 weeks later due to the fact that my stoma output was quite high, which I found was the case during the 10 months that I had my loop ileostomy. I had a couple of blips after this with some pelvic pain and

spasms down at my tail end, but was back teaching my classes 10 weeks after this procedure and feeling well.



I had my closure done on the 20 January this year and was horrified when my bowel started to work. When my friend, who is going into

hospital in March 2000 for closure, came to see me, I asked if she would like to change places! My bottom was on fire and there was a track appearing on the floor from my bed to the toilet! I would advise anyone who is having their stoma closed to go into hospital with Johnson baby wipes, because as soon as I started to use them the fire went out! I went home the following week, but had really bad trapped wind and phoned Mr O'Kelly who told me to go to the ward the following day. He admitted me to ward 49 and, after an investigation, they found a slight narrowing of the bowel so put me on a drip and full fluids for a few days, which cured the problem.

Four weeks after my surgery my output dropped below 8 times in 24 hours and I was managing to sleep until about 6am before having to get up to the toilet. I started light exercise in early March and managed a 45-minute low impact class without having to go to the loo.

Unfortunately, on Tuesday of the same week I was readmitted again with a wound infection and had to go back to theatre to have it investigated, which turned out to be an infected haematoma. Four days later, I was back home with clips intact and feeling wonderful again. I was a wee bit annoyed that I had to wait 6 weeks again before I could do any exercise. I also feel that doing the exercise between operations helped to keep my pelvic floor muscles tight and maybe that's why I can sleep all night?

I would like to express my thanks to all the staff in ward 49 ARI who are brilliant. Also to Christine, Alison and Marion, the stoma nurses who have an immense area to cover in the North East of Scotland, but mainly to Mr T O'Kelly for without his expertise I wouldn't be feeling so well today. You say St Marks is a centre of excellence and I'm not sure what qualities you need to have to be specified as this, but Mr O'Kelly and Mr Keenan and the surgical teams in Aberdeen are definitely that as far as myself and others are concerned.

My Story...By Sharon Hendron

Sharon Hendron tells her story. She is 30 years old, married and has two children aged six and four.

I had my colon urgently removed in December 1997 due to ulcerative colitis. Soon after, I developed a lot of joint pain – mostly my knees but also my shoulders, elbows, hands and lower back. I was given anti-inflammatory tablets and painkillers (and of course anti-sickness tablets), but after a few weeks decided they were doing more harm than good, so I stopped taking them. I went to a Chinese Medical Centre and started a course of acupuncture and herbal medicine. In no time at all, I was back on my feet and feeling great. I now use a TENS machine for any joint pain that occurs.

I had the pouch-forming op in March 1999. It was going so well that the surgeon connected it all up. I was thrilled when I woke up and had no bag! But a few days later I got very sick. I was in absolute agony and was vomiting constantly. I was taken back to surgery on the 6th day and given a temporary ileostomy to let the pouch settle. I had a lot of problems with the temporary stoma. It leaked constantly, and the bags just kept falling off; my skin was burnt raw. This lasted three days, until the stomatherapist came back after the weekend and almost magically fixed the problem by putting on a 2-piece appliance. A few days later, my skin was healed and I was happy.

A couple of weeks later, I developed psoriasis all over my body: on my head and even around the stoma. I was driven frantic with itching in that area, because if I used the psoriasis cream around the stoma, then the bag would not stick! Which was worse?! So I had another four months of hell until the psoriasis left me.

During that time, I had gone from 9 stone down to 6 stone 10, and also had problems in my chest, including pleurisy and a partially collapsed lung.

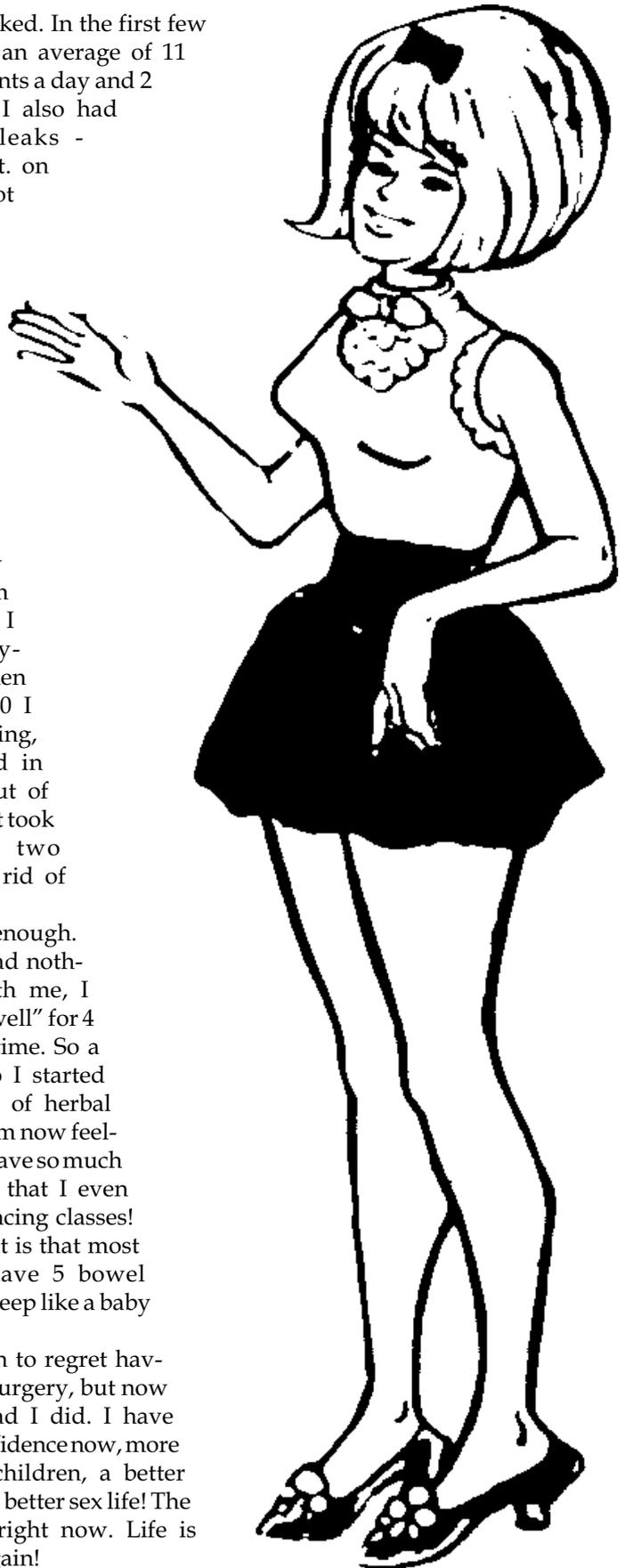
In August 1999, I had the pouch reconnected and, much to my relief,

this time it worked. In the first few months, I had an average of 11 bowel movements a day and 2 or 3 at night. I also had quite a few leaks – mostly at night. On immodium, I got down to an average of 8 a day and 1 or 2 a night. It wasn't long before I had my first experience of pouchitis.

Generally, I was always tired and my immune system was very weak. I caught everything going! Then in January 2000 I got food poisoning, which resulted in my second bout of pouchitis, and it took me almost two months to get rid of this.

I had had enough. Even when I had nothing wrong with me, I only ever felt "well" for 4 or 5 days at a time. So a few weeks ago I started another course of herbal medicine and am now feeling fantastic. I have so much energy in fact, that I even started line dancing classes! And the best bit is that most days I only have 5 bowel movements. I sleep like a baby at night.

I had begun to regret having the pouch surgery, but now I am really glad I did. I have much more confidence now, more fun with my children, a better social life, and a better sex life! The future looks bright now. Life is worth living again!



Letters



Roar! Letters Page

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Dear Newsletter Editor

I have just read "My Story" by Buddug James in issue 16 of *Roar!* It is obvious that she underwent a terrible ordeal whilst having a colonoscopy.

I find it hard to believe that she had to ensure such a procedure without sedation.

I realise that time and resources are at a premium within the NHS, but for a few pounds and an extra ten minutes this patient could have been spared the discomfort and indignity she endured.

As a long time sufferer from UC and now an ulcerated pouch I find that an intravenous dose of 4 ml midazolam works very well. One would have to be very needle-phobic to prefer the alternative.

If any medics are reading this, please offer patients sedation for any procedure where introduction of an instrument through the anal sphincter is necessary.

Ray Farley
Peterborough

Dear Newsletter Editor

I would like to refer to issue 15 of the newsletter, which I have unfortunately misplaced. In it was an article from a lady stating how happy she was that she no longer had an ileostomy bag, and how she no longer felt a freak.

Having the experience of an ileostomy reversed for a J pouch (a disaster) over a two year period, I now have - for a better quality of life - an ileostomy. Not desirable, but a very positive move to a better life-style. And, I must add, I don't feel a freak.

I think the writer of this article could perhaps have used less offensive language to express her joy at no longer having a bag.

Since becoming a member of *Roar!*, I have passed your newsletters to friends with bags with a view that some day a pouch could become a possibility for them. Issue 15 wasn't one which I felt I could pass on, as I am sensitive to people's feelings, and I wouldn't want them to consider themselves freaks.

I would be happy for you to publish this in your next newsletter as a response to the lady who made the remark I found offensive.

Patricia Hezelgrave
Bridlington

Ed comment: In the article in question, Gillian Appleby commented that she felt a freak when she had an ileostomy bag, and was relieved to have her pouch formed. It was clearly stated that these were her personal feelings about her own situation, and I am sure Gillian and any other Red Lion Group member would not wish it to be inferred that they consider anyone with an ileostomy bag in this way. Sadly, the feelings Gillian referred to are all too common, especially for our younger members, who are constantly bombarded with images of physical perfection from the media.

I would like to make it clear that the remark in question was not intended to be offensive, and I hope that other readers were not offended by it. Roar! is used as a medium by which our members can express their feelings about

their illness and surgery, and views are sometimes published which other members may not agree with, or which may be misinterpreted. Where an editorial comment is required to make that clear, then I will include it in future, to avoid these kinds of misunderstandings.

Dear Newsletter Editor

I read with interest your article in *Roar!* issue no. 14 about the possible link of food poisoning with ulcerative colitis I am a member of the Red Lion Group on behalf of my son Daniel. I would like to ask whether any other members can identify with the following link and draw a similar conclusion?

This is Daniel's story - at the age of eighteen he had ulcerative colitis diagnosed in the summer of 1991 by the colo-rectal surgeon in Bath, Mr. David Britton. In spite of increasing doses of various medication, his condition deteriorated to such an extent that he was admitted to hospital with acute dilatation of the colon. Intravenous steroid therapy failed and at the beginning of December 1991, he had a total colectomy. His rectum was also severely diseased but wasn't removed because of his perilous state - during this time he lost three and a half stone in weight.

After initial recovery, he contracted septicaemia during which time he developed multi-system failure. He was admitted to the Intensive Care unit at Bath RUH where we were warned that his life 'hung in the balance'. As a last resort, organisms were found growing in his blood, revealing yeasts - this was treated and from then on a slow, gradual process of recovery took place. Daniel spent further periods in hospital with toxemia. Due to the deterioration of the colitis in his rectum, we asked for a referral to St. Marks for advice on further treatment.

Daniel continued with an ileostomy and systemic steroids until 1994, in order that he could continue with his education. In October

of that year John Nicholls operated on Daniel in order to remove his rectum and create an ileal pouch. The removal of the ileostomy followed in February 1995 and Daniel was now able to embark on the road to 'normality' except in the summer of 1996, hypertension was diagnosed and tests revealed kidney malfunction, for which life-long medication is required. The kidney consultant indicated that this is a direct result of the septicaemia.

The significance of the aforementioned account is to say that, previous to this sequence of events, in 1989 Daniel was prescribed Roaccutane by a dermatologist for the treatment of severe acne and this continued for a period of three months. It was very successful. *We have gathered substantial evidence (from the UK and abroad) that this drug is linked to bowel disease, particularly UC and Crohn's disease.* In fact, the company who manufacture the drug, Roche Pharmaceutical, have gone some way towards acknowledging a link with 'temporary bowel disease' but not a direct link with UC.

Although a solicitor in Swansea is investigating a possible link between Roaccutane and suicidal tendencies, she is unable to pursue any possible link with bowel disease because after significant interest was registered with a previous solicitor, only a handful of people have now come forward.

IS THERE ANYONE 'OUT THERE' WHO CAN IDENTIFY WITH THIS POSSIBLE LINK?

Judy Pix.

Ed note: Rather than give out Judy's number for you to contact her direct, I would ask anyone who has any experience of this possible link to contact me, so that the Red Lion Group can keep track of how widespread an issue this might be.

Dear Newsletter Editor

My name is Debbie. I am 35 years old, married with two children. I had my surgery in three stages at Huddersfield Royal Infirmary, Yorkshire 1997-1999.

I had suffered from ulcerative

colitis for several years, and although it made life pretty miserable at times, I always felt I had the upper hand until I had an uncontrollable attack in 1997. This meant I had to have my colon removed by a wonderful surgeon at Huddersfield.

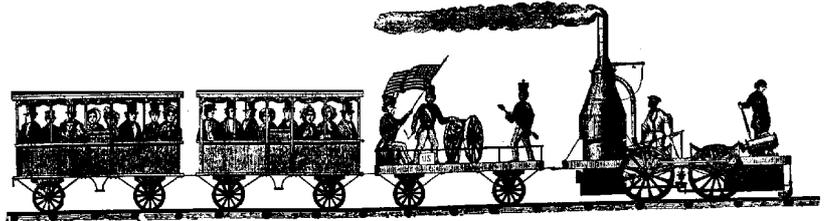
I had marvellous support from my stoma care nurse, and went on to have my pouch formed by another brilliant surgeon at HRI. I had some dreadful complications after the pouch formation which resulted in further surgery and a six week stay in hospital. At this point, I really wondered what I had done. I thought it was the biggest mistake of my life, but as I recovered I realised that the complications could have happened even if I had had a

permanent ileostomy formed, which was the other option open to me.

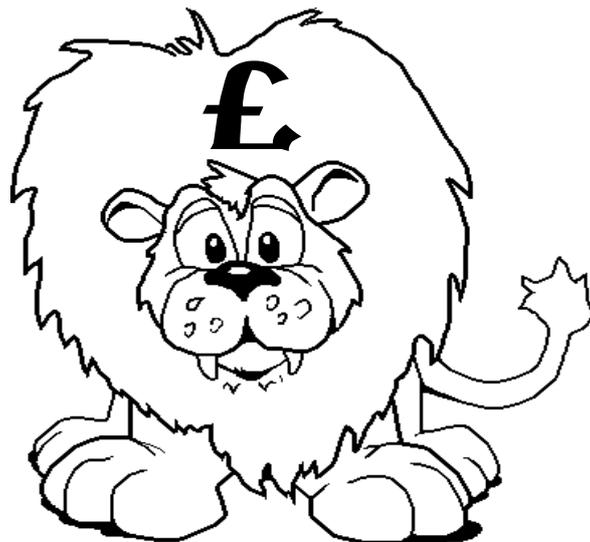
In August 1999, I had the closure of the temporary ileostomy, it was not easy at the start, with the frequent trips to the toilet, and the soreness that I cannot possibly describe. But with the advice of my stoma care nurse and equally patient consultant, the support of my family and the information I gathered from *Roar!*, I can now honestly say it was worth all the hardship.

I know I am still learning, and my pouch will probably get even better as the months go by. In the meantime, I have started a job as an auxiliary nurse, and I would not part with my pouch for anything.

*Deborah Armitage
Huddersfield*



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

Making Babies - the colon-free way!

Susan Walls gives a "pouch eye view" of having a baby

This is a picture of my baby son Sam, taken the day after he was born.

Now he's just over two months old; a perfect peach of a baby, endlessly entertaining and full of daily surprises. But the biggest surprise of all is that he's here at all.

By the time I became pregnant last summer I had completely given up hope of ever having children. I'd been colon-free for four years, and we'd started trying to conceive as soon as the steroids were out of my system. But every month it was the same story - no baby - and soon I began to get embarrassingly weepy during nappy adverts.

Maybe it eventually happened for us simply because we gave up the quest. Or perhaps my regular bouts of pouchitis had been taking too much out of me. Or maybe my body just took four years to get over all that surgery. Most likely, it was a bit of everything. Whatever, I feel incredibly lucky. So, for what it's worth, here are my top tips for a healthy, happy pregnancy, from conception through to delivery.

Don't Worry, Be Happy!

I honestly believe this the best advice you can give to anyone who wants to get pregnant - colon-ed, or colon-free. Try to forget that you're trying; becoming obsessed with ovulation dates is boring, counter-productive, and a real passion killer. Go for pleasure, not babies: eat, drink, have great holidays and really enjoy each other.

Rest Regularly.

Rushing about like a mad thing, trying to prove to everyone that you're NOT an ill person is just too exhausting, and exhausted, stressed-out people don't get pregnant. And when you do conceive, make sure you have lots of restful time: you're allowed - you're not ill, you're pregnant!

Learn to Make a Fuss!

If something does go wrong with

your body while you're expecting, kick up a fuss and demand the very best medical attention straight away. You're probably so used to self-medicating and just getting on with your condition that you don't like to cause any trouble. I ended up in hospital six months into my pregnancy with a kinky bowel, which isn't as amusing as it sounds. It started as a colicky pain just after



lunchtime, and I put it down to a spot of indigestion. By nine o'clock that night I was rolling around the floor in agony, and by the time I made it to hospital I was vomiting and severely dehydrated, and the baby was in distress. It turned out that I had some adhesions on my intestines from surgery, which had never caused any problem before I got pregnant. But as the baby grew he re-arranged my innards to make more space, and a bit of bowel got blocked. I was only allowed home from hospital once I had promised the doctors that I would seek medical help RIGHT AWAY if I had any more unexplained pain.

Make the Most of Your Pregnancy.

You'll be the envy of every other mum-to-be: you probably won't get fluid retention or piles, and you certainly won't get constipation! And, if you suffer from pouchitis, chances are that your symptoms

will improve dramatically. Some doctors who specialise in pouch surgery are coming round to the idea that pouchitis, like ulcerative colitis, may be an auto-immune problem. And many auto-immune diseases improve during pregnancy (apparently, a pregnant woman's immune system becomes less active during gestation so that the fetus isn't attacked by the immune system defenders).

Certainly, in my experience, pouchitis has tended to strike when colitis would have - when I'm tired, stressed and run-down - and I suffer the same flu-like symptoms and swollen joints when my pouch is inflamed as I did when my colon was having a flare-up.

But I sailed through pregnancy - hardly a murmur from my pouch, and not a swollen joint for the whole nine months.

Have a C-section.

They're recommended if you've had pouch surgery - you risk irreversible anal incontinence if you try to give birth naturally. Personally, I think it was a brilliant way to give birth: quick, painless, and Sam came out looking picture-perfect and not a bit squashed-up. And a C-section is nothing compared to the surgery you've already had. This is great because the midwives and obstetricians think you're incredibly brave - most normal women make a great fuss about cesarean surgery, but to you it's a tiny scratch compared to a colectomy and pouch construction. I am still basking in the glow of medical admiration!

And finally, the answer to the question you've been dying to ask: how's my health since the birth? Well, of course I'm exhausted, but what new mother isn't? And it's a different kind of exhaustion - it's a warm, delicious and bursting-with-happiness-sort-of-tired. And as an extra bonus, my pouchitis seems to have improved - or maybe I'm just too awash with love to notice it anymore.

Probiotics and Prebiotics

At this year's study day, Dr Alistair Forbes talked about the importance of probiotics for keeping the gut in healthy balance.

Probiotics is the name given to "friendly" bacteria in foods, such as the lactobacillus organism in some yoghurts, and the newer probiotic drinks such as Yakult.

Shortly after the study day, an article by Susan Clark, "health journalist of the year", addressed very much the same topic in an article for the *Times* (25 April). This provided additional information which will be of interest to all ulcerative colitis sufferers, and indeed to anyone with

foods and highly processed foods become ever more prevalent in our diets, cases of irritable bowel syndrome, ulcerative colitis, food allergies, chronic fatigue and depression and the like are soaring. Many natural health practitioners believe that dysbiosis is behind the rise in these illnesses and consultants like Alastair Forbes can see the logic behind this.

Probiotics were the first to be identified as the way to reverse this trend, by effectively reintroducing friendly bacteria into the gut to restore the bacterial balance. This aids digestion and prevents the

ucts such as yoghurts or the new health "drinks" such as Yakult, or to freeze-dried preparations that you keep in the fridge.

Going on from this, the *Times* article talks about the latest method of introducing healthy flora into the gut: prebiotics.

The difference is significant: with prebiotics, you do not add live bacteria to the gut environment. Instead, you feed the existing population, in order to build it up and redress the balance of the harmful flora.

The technical definition of a prebiotic is: "a non-digestible food



symptoms of a run-down immune system.

Everyone's digestive tract contains a substantial level of bacteria, some beneficial to the body, and some not. In a healthy person, the "friendly" bacteria keeps pathogenic bacteria under control. However, it is easy for a body to get the balance between the good and the bad guys wrong, especially after prolonged use of antibiotics or years of a diet that is too high in refined foods and sugar.

Sometimes the good bacteria can virtually disappear, a condition known as dysbiosis. As convenience

overgrowth of harmful organisms.

However, there are problems associated with successful use of probiotics. Firstly, the replacement bacteria have to be live, and this is difficult to control as they make their way through the digestive system, a particularly acidic and hostile environment.

Secondly, these bacteria need an oxygen-free environment in which to survive prior to ingestion, and are very sensitive to temperature change.

In order to minimise these problems, probiotics have so far been restricted to fermented milk prod-

ingredient that beneficially affects the host by selectively stimulating the growth and/or activity of one or a limited number of bacteria in the colon that can improve the host health".

The active ingredient is usually a sugar derived from plants, and is not affected either by storage temperature or travel through the digestive system, as it is not "live". This gives prebiotics an important advantage over probiotics.

Finally, it is already easy to identify and eat prebiotics simply by choosing foods which naturally contain fructooligosaccharides (FOS).

Let's Talk Salads

In this country, we do tend to be a bit unadventurous about salads, thinking that lettuce, tomato and cucumber are the only options.

However, as I was a chef for over 24 years, I like to try something a little more interesting, and would like to offer this simple recipe suggestion.

The quantities given are for one person, but they are obviously adjustable according to personal preference.

Salad

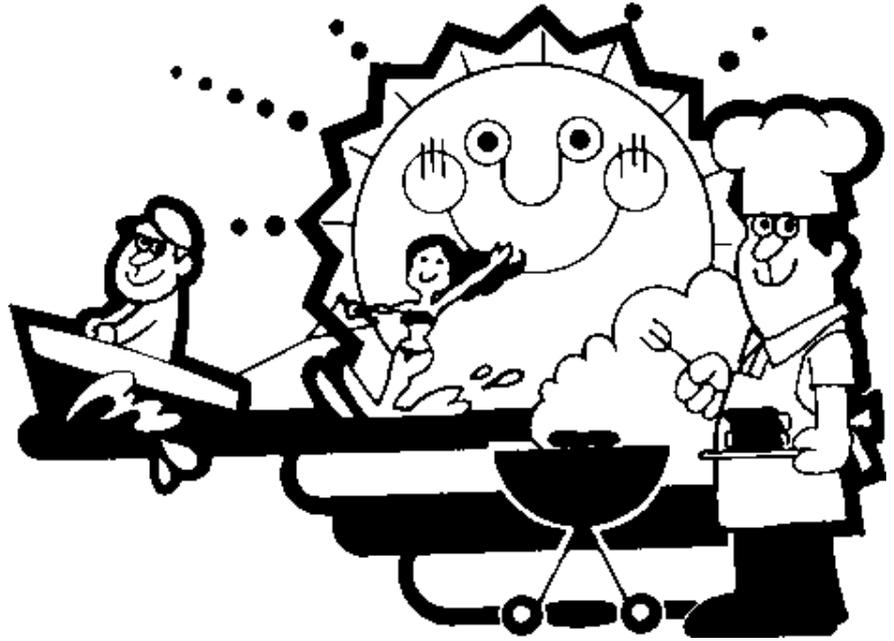
4 ripe dessert apples
1 ripe avocado pear
½ iceberg lettuce
¼ cooked ham or skinless and boneless chicken

Dressing

½ pint milk
2 tbs malt vinegar
Salt and pepper to taste

Peel and core the apples, then slice, dice or grate them according to what your pouch can manage. Put in a bowl.

Cut the avocado in half, remove the stone and skin carefully. Dice and add to the apple.



Dice the meat to whatever size suits your pouch or preference.

Break up the lettuce and wash in *salty* water so that it is completely free of grit etc. When clean, drain and shake the lettuce in a kitchen cloth to remove all water. Chop or break up the leaves and add to the other food in the bowl.

Whisk all the dressing ingredients together and pour over the salad. If you prefer to use mayonnaise, you may want to add a little water and whisk it, to make it a little

less thick. Alternatively, you could use salad dressing, whatever takes your fancy.

One thing I have learned from personal experience is that it is important to find your own levels, and not to overload the system. In the early days, your stitches and cuts have to heal, so fibre may be better in smaller quantities.

As regards meals, little and often is a good way to start after hospital, as are regular eating patterns.

John Drasar

FOS are not damaged in the upper intestinal tract, and so make the journey to the gut intact, which is why foods high in these were first tested. However, these will not usually provide sufficient prebiotic effect in a normal diet and supplementation is recommended.

Items high in FOS include leeks, asparagus, Jerusalem artichokes, garlic, onions, wheat, oat and soya beans.

The beneficial prebiotic effect of FOS has already been proven in clinical trials on people conducted by Glenn Gibson, Professor of Food Microbiology and head of the Food Microbial Sciences Unit at the University of Reading. More advanced trials continue, and research is being extended to other foods which reach as far as the gut and are me-

tabolised only by beneficial bacteria, such as carbohydrates. Who knows, perhaps a protective role may be found for the humble biscuit?

An extension of the whole idea is likely to prove rather more contentious: the implication that genetic modification could be used to incorporate some kind of a receptor site into the prebiotic so that the harmful bacteria will bind to this rather than to the gut wall. This would prevent the condition known as leaky gut.

Whether or not this stage is developed is not clear. In the meantime, however, you can do yourself a favour by eating more of those foods that are naturally high in FOS, to give your healthy bacteria a fighting chance.



Minutes of the Red Lion Group AGM

The AGM was held on 16 April 2000 in the Jonathan Levi Theatre, Northwick Park Hospital. Christopher Browne provides the minutes.

A total of 61 members and associates came to the sixth Red Lion Group AGM and Information Day at St Mark's Hospital, Harrow on Saturday April 16.

Chairman Brian Gaherty introduced the AGM. He said the group's millennium aim was to build up local group activity and to continue the high standards established by the newsletter. The meeting also voted unanimously on the only resolution, to introduce paid-for advertising in *Roar!*.

John White, the treasurer, said that the Group's expenditure included a one off £2,000 donation to the Marksman Appeal for research into bowel cancer, as agreed at the last AGM. The newsletter was also self-supporting for the first time, and we now pay both printing and postage, as our initial sponsors Dansac have gradually withdrawn

funding as the Group became self-financing.

Press officer Christopher Browne said that an article would

and newsletter co-editor, said around ten new members were joining the group each month, although some obviously did not renew each year, for various reasons. Total membership of paid up subscribers now stood at around 400. Morag said that the Red Lion auction on November 9 would include an original musical score by the leading UK composer, Sir Peter Maxwell Davies, and the auction of celebrity Red Lion drawings and other items would be combined with a book sale at St Marks. She appealed for help from the members to find someone who could manage this project on

behalf of the committee, and also asked for book contributions. She added that the Group was investigating the production of a charity Christmas card for the first time this year.



appear that week in the national press about a famous opera singer's experiences of ulcerative colitis, and the Red Lion Group would also be mentioned.

Morag Gaherty, liaison officer

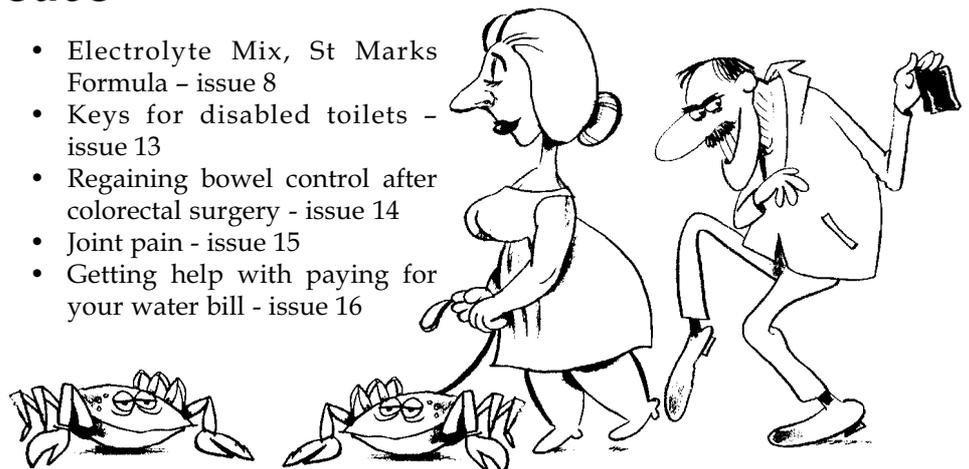
Articles from back issues

For the benefit of newer members, this 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 stamped addressed envelope with a 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
- Regaining bowel control after colorectal surgery - issue 14
- Joint pain - issue 15
- Getting help with paying for your water bill - issue 16



National Association of Pouch Groups News

The NAPG held their annual AGM and information day at the University of Central England on a very hot and sunny 17 June 2000.

Just under 90 attended, which was somewhat down on last year's numbers, but everyone found the day enjoyable and interesting. A wide range of workshops were offered and the day included a series of informative talks by various specialists in the field. Dick O'Grady was pleased to note the relatively high level of interest being shown by younger pouch owners, and also by the response level to his request for database information about pouch owners within the NAPG.

However, just like the Red Lion Group, the NAPG desperately needs people prepared to become committee members and to

put in some effort to share the workload among more than the "usual suspects". One innovation this year was the introduction of telephone conferencing for committee meetings. Whilst this cannot replace face to face meetings entirely, it provides a very cost effective method for committee members to get together, given their geographical spread from Cornwall to Scotland. Also, it is believed that more people may be prepared to get involved with committee work if they know that their weekend will not be entirely disrupted by meetings.

(In-

centally, following the success of the first NAPG conference call, the Red Lion Group will be trialling telephone conferencing as well, for one of our committee meetings later on this year.)

There has been a change around of posts within the NAPG, with effect from 17 June. The key positions are now filled as follows:

Julia Williams, Chairperson

Dick O'Grady, Deputy Chairperson/Chair Elect

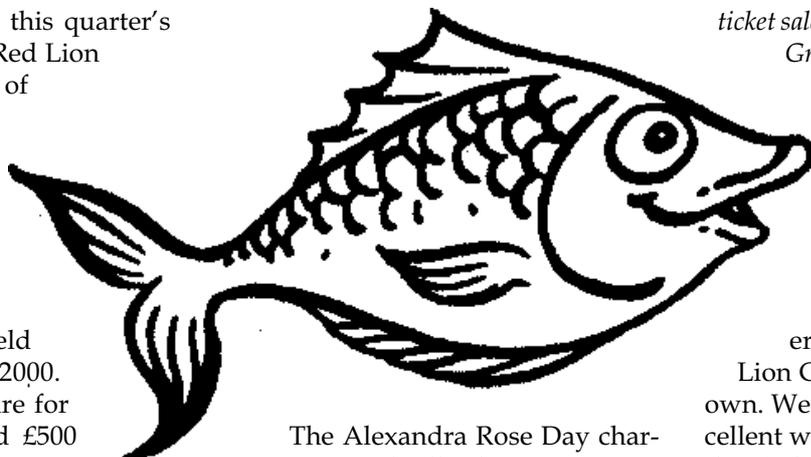
Marica Pilkington, Secretary

John Noble, Treasurer, following my own resignation from this post.



Support the Red Lion Group and you Might Win a Prize

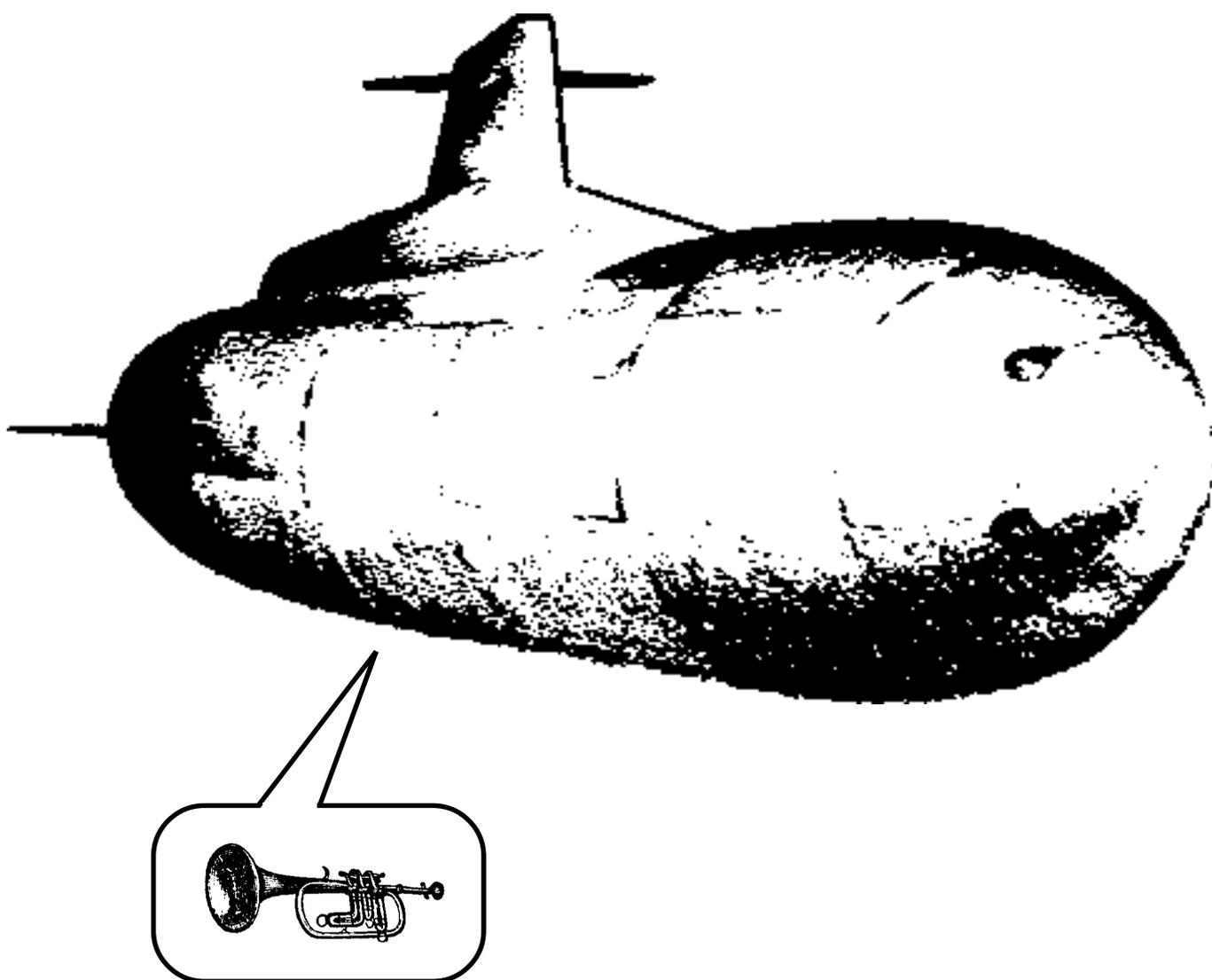
Enclosed with this quarter's mailing from the Red Lion Group is a book of five raffle tickets (50p each or £2.50 for the book) in aid of the Alexandra Rose Day Guy Fawkes 2000 raffle. This is being held on 2 November 2000. The main prizes are for £2,000, £1,000 and £500 respectively, and there are other smaller prizes as well.



The Alexandra Rose Day charity is an umbrella charity supporting small charities like the Red Lion Group. 80% of the proceeds from raffle

ticket sales come direct to the Red Lion Group, while the remaining 20% goes to the ARD charity to pay for prizes and administration.

From the point of view of the people buying raffle tickets, the prizes are far more generous than we at the Red Lion Group could afford on our own. We recommend this as an excellent way to support the work of the Red Lion Group whilst at the same time offering the opportunity to win a substantial cash prize.



As the destroyers above listened grimly so that they could drop their deadly load of depth charges, pouch-owner Rating Smith emptied his pouch, thus consigning the crew of the M571 to its doom.

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).



AVON		
David Mair	Bristol	0117 922 1906
BEDFORDSHIRE		
Wendy Gunn	Luton	01582 423714
BERKSHIRE		
Liz Davies	Langley	01753 586593
CAMBRIDGESHIRE		
Joyce Shotton	Peterborough	01733 706071
CLEVELAND & NORTH YORKSHIRE		
Christine Jackson	Saltburn	01947 840836
CUMBRIA		
Jonathan Caton	Kendal	01539 731985
DERBYSHIRE		
John Roberts	Derby	01332 361234
DEVON		
Gill Tomlin	Kingsbridge	01548 810028
DYFED		
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Bruce Dibben	Haverfordwest	01437 731436
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ESSEX		
Peter Zammit	Benfleet	01268 752808
Clare Shanahan	Ilford	020 8591 2936
GWENT		
Robert Challenger	Cwmbran	01633 866820
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Les Willoughby	Winchester	01962 620012
HERTFORDSHIRE		
Carol George	Stevenage	01438 365707
KENT		
David Irving-James	Folkestone	01303 894614
Phil Elliment	Barnehurst	01322 558467
LANCASHIRE		
Joan Whiteley	Clitheroe	01200 422093
MERSEYSIDE		
Blanche Farley	Liverpool	0151 286 2020
NORFOLK		
Sandy Hyams	King's Lynn	01485 542380
Sylvia Mist	Norwich	01692 580095
NORTH LONDON		
Susan Burrows		020 8882 5318
NORTHAMPTONSHIRE		
Cynthia Gunthorpe	Kettering	01536 482529
David Smith	Northampton	01604 450305
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Clive Brown	Chard	01460 234439
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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/