Roar!

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Issue Number 10 • Autumn 1998

Roar! is the newsletter of the Red Lion Group

EXCLUSIVE
One of Britain's first pouch patients writes for ROAR! Pages13-14

WHERE WILL THE RED LIONS TREAD NEXT?
A Progress Report by MoragGaherty
pps 5-6

The ABC of pouches
Julia Williams' valuable guide
pps 15-16

Why one Red Lion member feels on top of the world

Read all about it on pps 11-12

A prescription for success

To claim, or not to claim? That is the question put by new chairman Brian Gaherty

NORTHANTS health authority has banned all free prescription claims by Red Lion pouch owners.

The move came after an RLG member went to his GP with an exemption form and, to his surprise, was turned down.

When the GP told Northamptonshire health authority why he had refused the claim, they sought guidance from the Department of Health. The DoH wrote back, supporting the GP.

The ruling means that any RLG member who falls under Northamptonshire health authority will automatically have their claim turned down. However members can continue to approach other health authorities that are not not bound by DoH guidelines.

So far, a large number of RLG members have successfully gained exemptions from different health authorities. Several have also been turned down.

The first successful claim was made nearly two years ago by former RLG chairman Dr Martin Peters.

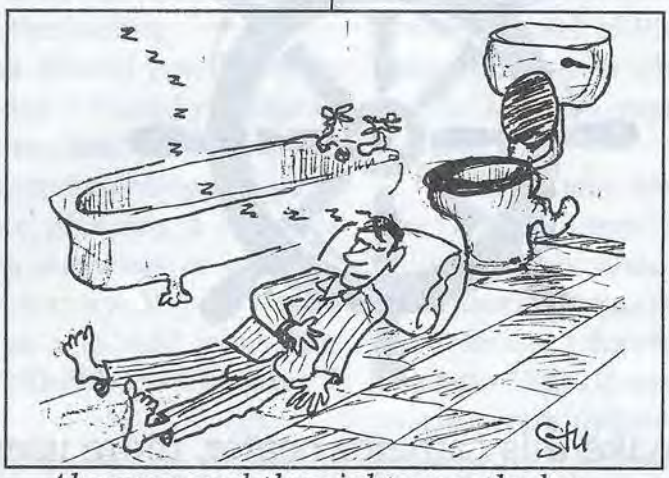
He argued that if ileostomy patients could claim free prescriptions for medication to cope with stoma problems, so too should pouch owners.

His local authority accepted his claim without question.

In the fourth issue of ROAR!, Dr Peters explained that the only difference between the two groups was that pouch owners had internal stomas, while ileostomy patients had external ones. Both needed medication and creams to prevent irritation.

We believe it is worth claiming, especially if you spend a sizeable sum on medication.

To do so, you should first write to your local health authority (you can get details from your GP's surgery) giving a full description of your medical condition and the basis of your claim (the argument used by Dr Peters).



Always spend the night near the loo....

ATTENTION ALL MEDINA CATHETER USERS!

We would like to modify this catheter

CAN YOU HELP?

We want to make this catheter neater, more user-friendly comfortable, and easy-to-handle

We would welcome your bright ideas. So please tell us on one side of a sheet of A4 paper the good and not-so-good features of the medina catheter

Please send your ideas to Julia Williams, Clinical Nurse Specialist, St Mark's Hospital, Watford Road, Harrow, Middlesex HA1 3UJ

Editorial

It's time to pool our talents

The growing number of pouch support groups is a sign of health, wealth and hopefulness.
Colon illnesses are isolating experiences and the operations taxing and time-consuming.
Support and after-care are essential, St Mark's pioneering the way by appointing a full-time pouch support nurse in 1996.
There is no reason why there shouldn't be scores of support groups, though a few with national links and resources might be a preferred option.
The reason for the current trend is easy to spot.
The NHS has an uncommunicative streak. Hospitals rarely cooperate with one another (unless under the auspices of an NHS trust), surgeons talk sparingly, and patients' notes are sometimes coveted like top-secret dossiers.
Such a climate tends to encourage multiplicity – different support groups springing up linked to different hospitals and favoured consultants.
But is this such a bad thing? It means individual patients' interests and needs are being catered for.
It's up to us to show our true Red Lion grit and cooperate. A Pouch Support Groups Federation would be an excellent way for us to pool our mutual resources.

A Message from the Editor

WELCOME to the Autumn issue of ROAR! I hope you enjoy it. It is, after all, your newsletter and you do most of the writing.

Now, here's an idea. Would you like to be a ROAR! reporter for a day!? Would you like to interview your own consultant or one of the others in your local gastroenterology department? The reason? I am planning a series of ROAR! interviews with surgeons or medical consultants round the country. If you would like to try your hand as a ROAR! journalist, give me a phone on 0181-894-1598 and we'll talk deadlines!

Summer is the traditional silly season of the year. However the Red Lions haven't exactly gone into hibernation. One idea that has evolved is a possible Symposium of Pouch Support Groups. This would enable us to liaise with fellow groups and maybe feed off each other's strengths. We will carry a full report on the first meeting in the next ROAR!. (See **Progress Report** page 5 and **Comment** above).

Back to current business. There was a higher-than-ever response to Morag Gaherty's market research survey into Working With A Pouch. A total of 95 questionnaires were sent back with some choice and amusing comments. Morag's report is included with this issue.

Your letters have continued to flow in. The "Letters Pages" are your personal property, so don't hesitate to reply to any that interest or inspire you. You'll notice that in the last three issues I have been trying to launch a Contacts Page. It seems, however, that most of us are pretty upfront about our illnesses – so perhaps we don't need one after all!

Articles about your experiences are always welcome, as are comments or criticisms of the newsletter. It's your baby and, like all growing offspring, needs to be nurtured. The December issue's theme is Sport and Exercise, so any energetic offerings will be welcome.

For now, I wish you a busy and healthy autumn and an invigorating ROAR!.

CHRISTOPHER BROWNE

Continued from page one

So long as your facts and argument are clearly stated, the health authority has the discretion to send you an exemption claim form. The next stage is to get this signed by your GP or consultant. Remember that as an independent contractor, your GP may not sign, if he or she disagrees with the basis of the claim.

It is always worth trying - even though success cannot always be guaranteed.

Because of the Northamptonshire ruling, the Red Lion Group have not written to the Department of Health for guidelines - our experience shows the response would almost certainly be "no".

Instead, we have decided to leave this to local authority discretion for as long as possible.

If any of you receive a negative ruling from your health authority, please let us know, so that we can publish a list of "no-go" authorities. We would also like to hear about any of your claiming experiences - successful or otherwise - so we can monitor the situation.

● An effective way to support your claim for exemption is to send with it a copy of the article about Dr Peters (ROAR!, Issue Four). Copies are obtainable from the Liaison Officer.

A CHUCKLE BREAK

Anagram of Irritable Bowel Syndrome:

O, my terrible drains below

A ST MARK'S HOSPITAL version of the television show This Is Your Life marked the retirement of surgeon Peter Hawley at the Medawar Centre, St Mark's, on September 14. A copy of the big red book with photographs of Mr Hawley and his patients, plus comments and anecdotes, was presented to him by staff and patients. One of those patients was Red Lion social secretary David Irving-James, who presented a poem to Mr Hawley as a personal tribute. ROAR! has pleasure in publishing David's poem:

GOOD OLD ST MARK'S

The nights seemed so long between the loo and the bed,
The constant shuffle down the landing ahead.
The cramps and the soreness, the tablets and cream,
Was this for real or was it a dream?

The doctors had seen me, they'd all had a look
The diagnosis is simple, it's all in the book.
"Go on, please tell me", I said with politeness,
"OK, my lad, it's Ulcerative Colitis".

My tail end's on fire, my tum is upset.
Will these steroids work? I hope and expect.
The enemas' are soothing, the Colifoam's a help,
It's passing that motion that makes me sit up and yelp.

For two long years I struggled in vain,
The cramps and diaorrhea, the exhaustion and pain.
The doctors keep looking, they 'um' and they 'ah'.
Finally, the decision, "you'll be left with a scar".

So off to St Mark's in the old City Road,
Where I meet Sister Driscoll, who lightens my load.
"Come on my dear, everything's alright!"
"We're the tops in bottoms," she says with delight.

Then Mr Hawley, so tall and polite,
Came and looked up me with his little bright light.
"I'll make you a pouch, tailored to fit.....
"No more pain for you, you'll have a good sh...".

True to his word, the plumbing went well,
It was all fitted in there, where no-one can tell.
A few minor itches, "oh" nothing to speak.
From the depths of despair to the world's highest peak.

Thanks Mr Hawley, I hear the time's come,
To hang up your white coat, you've seen enough of my bum.
I'm "internally" grateful to your talent and skill,
You gave me back life, when I was so ill.

When I look back over the years of despair,
I remember those who helped me with their tender care.
My Hawley and Sister Driscoll, they all played their parts
Thank heavens for them and good old St Mark's.

A PROGRESS REPORT

Every now and then we need to take stock and work out where we are going. At the last committee meeting we did just that. Here are the points that we believe have a major bearing on the group's progress over the coming year. **MORAG GAHERTY** gives her fly-on-the-wall assessment

- What kind of support should the group aim to provide?
- How can we fund this support?
- How do the answers to the above fit in with the work being done by other pouch support groups in the country?

SUPPORT

The question of support came up at the 1997 AGM when the constitution was voted on. The wording of the constitution is deliberately neutral, so that we are not bound to an exclusive definition of what we can or can't do, nor does it exclude us from new ideas as and when they occur.

At the June committee meeting (see report on next page), we decided that the purpose of the Red Lion Group's fund-raising is to provide money for *practical* support to pouch owners, rather than funds for research. If members specifically want to raise funds for research, the money should be channelled directly to the Marksman Appeal, a joint fundraising venture between St Mark's and the Imperial Cancer Research Fund (see ROAR!, Issue 7). The Red Lion Group may also decide to make periodic contributions to the Appeal. This will be voted on at the AGM each year.

So far, we believe we are the only pouch support group to provide quarterly newsletters, giving a point-of-contact for pouch owners and a source of information about the latest hot topics in the pouch world. To date, this has been our main form of practical support to members. In addition, there are local groups, although many of these are not very active because of lack of members in those areas.

As well as trying to boost the numbers of members across the country, so increasing the size of the local groups, the committee agreed that we want to provide other forms of practical support. One topic under enthusiastic review is some form of post-operative help for patients, such as someone to take over the chores at home for a week or two or arranging a delivery of shopping essentials. These ideas are still in their early stages- and we need to make contact with possible suppliers (eg. a supermarket chain) to sponsor the latter.

We also need to set up a register of volunteers in the regions to help with domestic chores - could <u>you</u> offer an hour or two on a fairly regular basis? You would probably have your travel expenses refunded and maybe paid on an hourly rate. We will be addressing this topic in more detail in later issues of ROAR!, once we have worked out the practicalities in greater detail. If you think you can help in any way, we would love to hear from you, without any commitment at this stage.

FUNDRAISING

The good news is that Ann Foley came to the June committee meeting with some excellent ideas for national fundraising activities, for which we could obtain good publicity. These would provide funds for the practical support initiatives suggested above.

Continued on next page

Continued from page five

However since then, Ann has unfortunately had to resign from the role of Fundraising Officer due to other commitments. The post is therefore vacant once more and we would be delighted to hear from anyone prepared to take it on and progress some of the existing ideas, or else to develop alternatives.

We need someone who has the enthusiasm and patience to organise one major event per year (the first one being in 1999 or even 2000 – these things take time to arrange) and offer advice and assistance (perhaps by way of a tip sheet of ideas) to regional reps on fundraising activities in their area. Could this be you?

OTHER POUCH SUPPORT GROUPS

The Red Lion Group is not the only pouch support group in the country, although of course we pride ourselves on being the best. There are other groups local to specific hospitals and surgeons. Our overall concern is that the pouch owner should obtain the form of support most compatible with their needs. The Red Lion Group's newsletters are the best source of regular information available, but other groups have a stronger network of social support at present.

Therefore, we need to find a way whereby all the support groups complement each other's work and the patient is able to choose which is the most appropriate one for their needs. Many people may want to join two or more groups, but are put off because of having to pay more than one subscription fee.

Overall, the Red Lion Group is in favour of closer liaison with other support groups, but we need to work out practical ways of achieving this for everyone's benefit. Of course, we all have different ideas about the best way forward.

This is why a Pouch Group Symposium was held on September 9. Two representatives from each group discussed a number of topics including the forming of a possible Federation of Support Groups. Brian and I attended in our capacity as chairman and liaison officer respectively. **We will carry a full report of this meeting in the next newsletter. In the meantime, we would like to hear any thoughts you might have about this.**

RED LION GROUP COMMITTEE

Venue: St Mark's Hospital, Sainsbury's Wing

Date: Saturday, June 13

Present::

BRIAN GAHERTY, chairman
MORAG GAHERTY, liaison officer
CHRISTOPHER BROWNE, press officer and ROAR! editor
INEZ MALEK, secretary
DAVID IRVING-JAMES, social secretary
STUART PORTER, vice chairman
ANN FOLEY, fund-raising officer
PETER JOHNSON, outgoing treasurer

Apologies:

BOB NYE, Dansac
JULIA WILLIAMS, Clinical Nurse Specialist

A GRAND alliance of pouch support groups may get the go-ahead, members of the Red Lion committee heard at the June meeting.

Brian and Morag Gaherty, chairman and liaison officer, are to attend a meeting to discuss the possibility of setting up a Federation of Pouch Support Groups (see **Progress Report** above).

Another key point raised was the absence of any ia (Ileostomy Association) members at the April AGM. This was due to the allure of lectures held at the same time! Future AGMs would be held before or after the lectures, members decided.

The new social secretary, David Irving-James, is to explore several sites for next year's AGM on April 17. A different venue will help RLG to be more independent of St Mark's, the meeting agreed.

Ann Foley, who was elected fund-raising officer at the AGM, told members about her plan to ask celebrities to sign Red Lion cards. She is also looking into the possibility of a Red Lion Pubs Day.

There was encouraging news from three regions. Brian and Morag reported that the Eastern Region Pouch Support Day on May 17 had been a great success, David said Mid and East Kent group had held a lively and informative Sunday Lunch, while North Kent group is to hold its first meeting in September. David is also planning to help organise a Listening Skills course in October for RLG members wishing to give counselling support to patients in hospital or at home.

Future themes for the newsletter are: Relationships (this issue), Sport and Exercise (December). The Gahertys agreed to edit Paw, a junior version of ROAR! for young pouch patients and children of RLG members.

Stuart Porter was welcomed as the new vice-chairman, while retiring committee members Martin Peters and Peter Johnson were thanked for their work as chairman and treasurer, respectively.

Letters

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A leaning question

Dear Sir,

It was in 1996 that I read the article From Rome To Raphael (ROAR! Issue Three) – until then I was afraid that I might not be able to have children because of the pouch.

However my operations were not as successful as Rachel Nicholson-Abedi's and the pouch tipped slightly after the third operation, I now have to use a catheter to release any stool or wind.

My question is – has anyone else had a similar condition and, if so, do they have any tips or advice they might like to share? My second question is about pregnancy. My husband and I wish very much to have a baby but feel there might be difficulties because of my condition.

Any help, advice or information on how to seek some professional expertise would be most welcome.

Alison Lawford
London SE5

Two stars in the East

Dear Editor,

My husband and I went to the Pouch Support Day in Norfolk on May 17. I wasn't keen on going because I thought it would mainly cater for stoma people.

When we arrived we received a really nice, warm welcome and found everyone mixing together. Then when Suzanne Wood, the dietitian, started to explain how things actually work and what we could do to improve our health, it made a lot of sense. I realised then that living with a pouch can be made better.

Finally, when Susan Myers performed her cabaret, she hit the nail on the head. I thought she was very brave to stand up there and say such wise things - because it was all true.

By the end of the day, I felt these two ladies had given me so much help, one by improving my condition and the other by giving me the courage to do something worthwhile.

I just want to say thank-you - it was the best meeting my husband and I have attended since my operation.

Mrs L.D. Cooper
Baham Toney

The ROAR! Letters Page has had two replies to Rosemary Tilley's letter "A Burning Issue". We are pleased to carry both of these. This is what Rosemary Tilley originally wr ote:

"I get a lot of discomfort and burning when I empty my pouch. This does not always happen however. I have also tried to monitor what I eat, but have not reached any conclusions whether diet is the direct cause or not.

"I would also like to know if any pouch-owners know of a cream that might ease this condition. I look forward to hearing from anyone who can enlighten me further."

Bob Gordon from Uxbridge, Middlesex, replies:

I HAVE had a Nicholls W-pouch since 1984 and also suffered from burning, soreness and bleeding of the skin when emptying my pouch.

Fortunately I was referred to the St Mark's skin specialist some years ago and she recommended washing the area

twice daily with a mild soap and warm water. I do this every morning and night and am lucky that my wife bought me a bidet which makes it quick and easy.

If you don't have access to one, I believe Boots The Chemist sell a portable version. I haven't actually seen it, so you must check if it is suitable for you.

She also prescribed a barrier ointment called ORABASE which I use night and morning after my wash. If you still get a problem, or when it is painful, she prescribed an ointment called METASYN, but this is for occasional use and must be used sparingly as it can thin the skin, if used excessively. The problem is caused not so much by food, although curry gives me a problem, as by the liquid composition of the faeces and the enzymes which digest your food in the bowel.

Normally they are taken care of in the large bowel and the skin is able to cope with normal, drier, firmer faeces. Foods which help to firm up faeces from a pouch were listed in a booklet sent out with ROAR!, but I found bread, potatoes, bananas, porridge and biscuits helpful.

It is important <u>not</u> to cut down your liquid intake in an effort to combat the liquidity of the faeces, as to do so can lead to problems with the kidneys.

Many issues like this are the subject of workshops at the Red Lion Open Day and AGM and I would recommend that you attend these if at all possible.

Helen Bradshaw of Swanscombe, Kent, replies as follows:

I must report a similar problem. In my case, however, the burning and prickling lasts for hours and seems to be associated with a lot of wind.

I have only had my pouch for eight weeks, but have spent many evenings so far in a heap of misery, and I am beginning to regret even having had this operation.

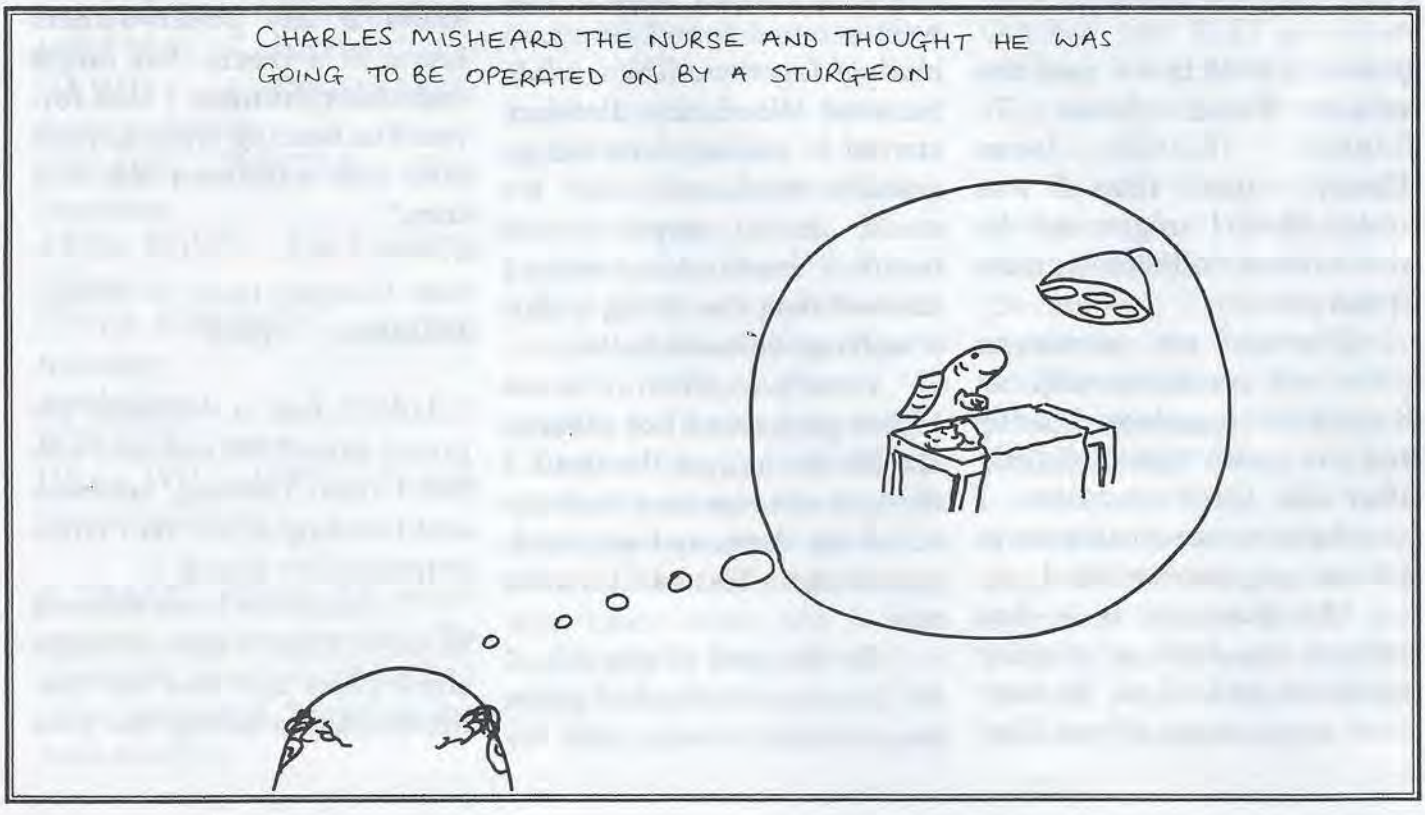
In the last few days however I have had some relief by taking charcoal tablets after every meal, and ASILONE suspension in between. Keeping the wind under control also seems to control the constant leakage.

The doctors say I have to give it time to heal etc., but I have encountered no other patient who remembers being as uncomfortable as I have been in the first few months.

Rosemary Tilley might also like to try PROCTOSEDYL ointment, which is available on prescrption.

Is there anyone else out there who also suffers from severe anal irritation?

<u>IF YOU HAVE A VIEW OR PROBLEM YOU WOULD LIKE AIRED, PLEASE SEND IT TO THE EDITOR C/O THE LETTERS PAGES (ADDRESS AT THE TOP OF THE PREVIOUS PAGE)</u>



THE MISSING LINK

MR C. R. CREEK of Sheffield wrote a moving letter in Summer's Roar. He said that in 1994 he had a J-pouch fitted after a spell of uc, only to discover while having five fistulas removed in hospital recently, that he might have Crohn's Disease, too. In his letter, he asked if there were any pouch-holders who suffered from both conditions.

MRS JILL HARE from Norwich replied to Mr Creek. She has kindly given ROAR! permission to publish the letter:

Dear Mr Creek,

IN JUNE, 1994, I had the first part of a two-stage pouch operation and was told afterwards by my consultant that I had also got Crohn's Disease and we would have to 'see how things went'.

I was still on the ward at the time and feeling slightly bemused, as you can imagine. I was then asked to go to London to see Mr Nicholls at St Mark's, who was to decide whether I could have the third and final stage of the operation.

I was still feeling pretty weak and was very pleased when Mr Nicholls decided I could carry on to have the second part, which as I'm sure you found, was relatively straightforward compared to the first one. It took me a long while to get my strength back, but on the whole I feel I have done quite well.

Although I belong to the Red Lion group, ia and NACC, I still wanted to chat to someone about my condition and asked St Mark's and the other groups if there was anyone else in the same situation.

Most people just stated that they don't do pouches for people with Crohn's, so that left me feeling rather isolated.

I have tried to be sensible with monitoring my diet, accepting my physical stamina limitations, and although I work part-time and took early retirement from my job (as I worked extremely long and unsociable hours) I feel that I am still improving each year.

I also had some trouble with my oesophagus during the period after my first colectomy operation, but this seems to have cleared up and, as mentioned before, I feel fine for most of the time. Occasionally I have a few off days and feel tired, but so do most of the people who have just had ulcerative colitis.

Irritation and soreness was quite a problem at first (again people with just ulcerative colitis seem to get his). I was told that I had some skin-tears, but nothing was mentioned about doing anything.

Recently I have heard that another person with ulcerative colitis and Crohn's disease has just had the pouch, but that she has had to go back into hospital for bed-rest as she hasn't felt at all well.

I have put my name forward as a contact if she wants to speak to me. It seems ironical that I have almost felt that I was the only person in this situation and now there seem to be at least two others - maybe you have had other contacts. If so, perhaps we can form a contact support group!

I have also occasionally had the comment made to me by a nurse or hospital doctor that it is probably "indeterminate colitis", but I know from both consultants' diagnosis that this is not the case.

Therefore, I was pleased to know that someone else has the same condition (although you may not be!) as I was intending to write a letter myself to ROAR!; it's just that everyone said "nobody with a pouch has Crohn's".

The England football team's signature tune "The Lions Roar" certainly reverberated round several French football stadia during the World Cup. Perhaps the England supporters should have shouted it from the rooftops. Then we might have won the coveted trophy

CARTOONS by ROAR's resident artist Brian Gaherty

Please support the Red Lion Group

All donations, however small, towards our ever-increasing administration costs will be gratefully received. If you would like to send a donation please make your cheque payable to The Red Lion Group, and send to: **The Chairman (Address and Telephone Number on Back Page)**

A PEEK THROUGH THE REAR VIEW MIRROR

A new column featuring stories and events that directly affect us as a group

A recent Guardian article asked: Is Channel 4's The Drop Dead Show, with its photos of used toilet bowls and on-stage bowel movement competitions, breaking taboos in the interest of public health or just deeply offensive?

Probably both. Though, in the interests of our group, the more publicity that is given to such sublime goings-on the better. After all, these activities are pretty commonplace to us, even if we sometimes have to adopt a shocked exterior – just to be sociable! – Ed

Three recent Government and industry measures give new hope to bowel cancer sufferers:

● **The government recently announced that an extra £10m is to be given to the NHS to help treat the disease which affects 31,000 people in Britain, of whom 19,000 die every year.**

● **A drug to help prevent polyps growing in the large intestine is due to come on the market at the end of 1999. The drug, known as Exisulind, has been successfully tried on patients with Familial Adenomatous Polyposis (FAP) - a hereditary disease that leads to colon cancer and possible death.**

● **A national screening programme is being considered by the Government for sufferers. If caught early, the cure rate is higher than 85 per cent. But many, hoping their symptoms will disappear, fail to contact their doctor early enough.**

Lisa reaches her peak

Mrs Lisa Pouncey is a 41-year-old mother-of-two. She suffered from ulcerative colitis for several years before finally having a W-pouch fitted in 1994 by Mr A. Berry at Northampton General Hospital. Earlier this year Lisa embarked on the journey of a lifetime to Mount Everest's base camp. Here is her account

MY FRIEND Penny Wake and I started our fifteen-day trek at Lukla, a comparatively 'small' mountain of 2,880 metres in the Himalayas.

We had spent a month touring Nepal ending up at Katmandu and the Chitwan jungle. At Mt Lukla, we were met by our sherpas, a team of ten dedicated to making our journey as painless as possible. The first day was fairly easy as our walk began by descending to Mt Phakding (2,640m), where we spent our first night.

Somehow I managed to get a blister on each heel! Thank goodness for modern plasters. We ate a hearty supper and were tucked up inside our cosy two-man tent by early evening.

Action Woman: Lisa flanked by Himalayan peaks

Day two was one of the hardest for me. The way to Namche (3,445m), the main sherpa village, seemed almost vertical and it took me approximately two-and-a-half hours of non-stop knee to chin leg action to make it there. In all I must have walked about five hours this day. It was from here that we got our first glimpse of Everest. Namched consists of about 100 lodges built in a horseshoe formation into the side of the mountain. Edmund Hillary (the man who first conquered the 29,002 ft or 8,848m mountain) funded a museum here where hundreds of photographs and newspaper cuttings of previous expeditions to Everest are on display. Our tent was pitched next to a lodge where thirty monks were staying. That night we went to sleep with the strange and eerie sounds of monks chanting and playing high-pitched pipes, then blowing deeps mournful sounds into their horns.

One the seventh day we left Dingboche (4,412m) at 8.30am. It had been snowing and our route was completely white. This was the nearest we came to the very steep mountain of Ama Dablam (6,812m). The sherpas thought Everest was easy to climb. Ama Dablam was for real men! It was a difficult start as the path was steep and it was not long before the village was far below us. We reached a plateau and the mountains levelled out into a plain.

We arrived at our lunch-time stop, Duglha, three hours later. As I sipped my hot lemon drink, I looked up at this black vertical wall of rocks and boulders. I was glad that I did not have to climb that! Little did I know that this was the route we had to take to Lobuche! It didn't look that far but one hour later we were still only half way up.

On reaching the summit of this pile of rocks, the mountain levelled out again and we traversed the side of the mountain, climbing all the time for another hour to Lobuche. I fell into my tent

Continued from previous page

where I remained static for the next half hour. I had the most horrendous headache and I felt so sick I couldn't move. Pssang my Sherpa was worried because I had classic altitude sickness symptoms and he wanted to get me to move around and drink something, but I felt too ill. He told me it might be dangerous for me to attempt the climb to Kala Pattar the next day. I decided to wait and see how I felt in the morning. I went to bed at 6.30pm. It must have been at least -10°C. Freezing, I slept in all my clothes.

It was a full moon and the view of the illuminated mountain was stunning, I was on top of my world and my summit was to be Lobuche (4,931m). I was just thrilled to have reached as far as I did and as a good friend said to me: "it's the journey, not the destination, that counts."

Before I left England, I had a telephone call from a man who was suffering from ulcerative colitis. He was critically ill and about to face the same operation that I had - a total colectomy. He thanked me for being so brave and giving him the courage to face his ordeal. I carried his words to my summit..

During the journey, my diet was anything from curried cauliflower to Yak stew. I tried the local rice wine and drank boiled water from the previous night's hot water bottle. I was not ill at all and feel now that I can do anything I want to, whereas four years ago all I wanted to do was die. I feel extremely proud of myself for finding the courage to make this trip.

I took all sorts of precautions with me (my medicine chest was larger than my suitcase) as well as having excellent insurance cover. I learnt so much about myself , my pouch and my toilet habits! At home I used to do all sorts of things to myself in order to try and empty my pouch completely. I had the idea that if I was empty, I wouldn't need to go to the toilet as often! I used to wipe incessantly and always used a barrier cream. I often used a bidet and couldn't resist the temptation to have a go at myself. I have learnt since that this only aggravated my rectum and made me incredibly sore.

In Nepal I went to the toilet in a hole in the ground. My privacy was ensured because there was a small canvas tent erected for this purpose. I found the crouching position so much easier to empty myself (I think it is called the 'Alexander position') and, because there was no running water, I could only wipe with soft toilet paper followed by a wet wipe and no messing around with my back passage.

Since returning to the UK, I have stopped all interference with myself and my backside has improved dramatically. I no longer bleed or get sore and I have been able to stop taking my painkillers.

I would be happy to give anyone advice or encouragement and more information should anyone be interested.

Lisa raised more than £3,500 for NACC (National Association for Chron's and Colitis). If anyone would like a copy of Lisa's journal ie. a full-blown account of her journey, she will be very happy to send them a copy. Her address is: Lisa Pouncey The New House, Little Horton Drive, Horton Northants NN7 2BB Tel: 01604 870399

NEWS IN BRIEF

****

ANI-MATION

With a top speed of 50mph, the lion is the third fastest animal (equal with the wildebeest). The fastest is the cheetah (70mph) followed by the antelope (61mph). The fifth fastest is the horse which can travel at a speed of 47mph.

TIME & MOTION

If you happen to be temporarily immobile and travelling by train, London's mainline stations have their own electric buggies – together with personal driver – to take you and your luggage from the train to the nearest taxi-rank. The buggies, which can carry 4-5 people, need to be booked in advance.

WALEY'S COMET

One day Simon Waley was shown an article in the British Medical Journal about a revolutionary 'pelvic device'.....suddenly his life went into orbit

MY CLAIM to fame is that I was one of the first guinea pigs to be given a pouch operation. Eighteen years later I am fortunate enough to be able to say that I have been perfectly healthy ever since.

In fact it is only on occasions like this that I give the matter any thought - although this is not to understate my gratitude for the new, normal life that I have been granted.

Back in 1979, I was 27-years-old, married for two years, and starting out in my chosen profession of town planner. However I had ulcerative colitis which cast a nasty shadow over my life and that of my wife.

Of course this meant I was never "well", but it was the frequency and severity of the attacks which made an operation inevitable.

It's the care that counts not the buildings

If you are then faced with wearing a colostomy bag for the rest of your life or getting more and more ill, it's not really a choice. However, just at that time the consultant dealing with me in Cambridge where we lived told me he had just read an article in the British Medical Journal about a new 'pelvic pouch' operation being pioneered by his old friend Sir Alan Parks. I remember that I went to the library and photo-copied the article so I could find out what it was all about.

So, off for my first appointment at the illustrious St Mark's Hospital in City Road, London. Well, it's the care that counts, not the buildings! Yes, they said, we will take you on as one of the guinea pigs for the new pouch operation.

I was also introduced to a lady who had already had the operation and who was able to give me some of the lowdown on what to expect. Not that anything quite prepares one for major surgery when you've previously spent only one night in hospital.

After my own pouch operation I was able to offer the same 'service' to someone considering whether to have pouch surgery, as well as being paraded before a lecture being given by Sir Alan Parks to a large audience of doctors.

The risk, although small, of damage to vital tubes in the operation meant that they advised that it might be appropriate to start a family, which we were considering anyway, rather than to wait.....So, by the time I had the operation a few months later, my wife was in fact pregnant. Fortunately, no such complications occurred and we now have three children.

I don't know when I first became ill with ulcerative colitis. In my memory it wasn't something that suddenly happened. I think it started at the end of my time at university. It was more than a year until I went to my GP when even I had to recognise I had a problem.

After the usual routine examinations, I spent a day and a night in hospital in Nottingham undergoing tests. That I do still remember! Water was dripped through a tube down my nose into my stomach over several hours to clean me out

The consultant swept through with his gaggle of students

before an examination under anaesthetic. The whole experience was pretty unpleasant, not least because I had no idea what was going on or what they were looking for.

At one stage, however, the consultant swept through with his gaggle of students, one of whom actually spoke a few words to me as they departed. It was he who mentioned the words 'ulcerative colitis' - a condition which I had never heard of before. I was then into the routine of 'ulcerative colitis' sufferer: always try to keep within reach of a toilet, wake up to go to the toilet once or twice a night and so on. Still, I was in the university hockey team, so my general state of health obviously wasn't that bad and only my closest family and friends knew there was anything wrong with me. Ulcerative colitis is not the

sort of illness one readily wishes to discuss with one and all. However my condition did not improve and I was put on the 'wonder drug' prednisolone.

In the spring of 1976 I began a course of treatment, the first time I had had any drugs prescribed as far as I can remember. Great big tablets they were - salazapyrene or something like that.

What I do know is that shortly afterwards I became more ill than I had ever been, could retain nothing and lost a lot of weight. I was taken into the university medical centre where

I went in the day after the dramatic Cup Final

I was very well looked after, but I simply became more and more ill.

Eventually in desparation my parents came and transported me home. I hardly had the strength to get out of bed and every joint in my body hurt. I later discovered I had had an allergic reaction to the pills.

At that stage, I was put on a low dose of the 'wonder drug' prednisolone. Whenever my condition got worse, I simply stepped up the dosage until things got better again.

On this relatively low dose, I didn't have any real problems with side-effects either. Nevertheless, I still had ulcerative colitis and all that entailed. The prednisolone enabled me to have a pretty manageable life, socially and at work, and I was playing hockey, cycling to work every day and generally leading a fairly active life.

Despite the steroids, it became clear that it was getting worse rather than better and I had my pouch operation early in May, 1979. I remember because I went in the day after the dramatic FA Cup Final between Arsenal and Manchester United.

I had a temporary colostomy and was then 'joined up' to my pouch in the second operation some eight weeks later. At that time they still weren't sure whether it would be possible for the patient to empty the pouch without a catheter and I was 'trained' to use it.

However, it soon wasn't necessary and, to my own surprise, within a couple of weeks I was out walking on holiday and then back to work, free of illness and medication. Apart from the initial check-ups and a couple of days when I was in for tests for possible vitamin deficiency, that's basically been it.

My close family often refer to my pouch as Waley's Comet!

I now live in the Netherlands and neither employers nor even insurance companies are much concerned when you have been completely well for a number of years, although I still have to write it on forms and they do raise queries about an operation they have generally never heard of.

What do I recall about the whole experience of my time then in St Mark's? The care of the doctors and nurses was excellent, the conditions Victorian, the food also, while I found the companionship between patients a valuable support.

I was the only pouch patient in residence at the time but one learned an awful lot from other patients about other diseases affecting that part of the body - even at meal times!

The tests and the anxiety prior to the operation were worse than anything which then followed and I probably benefited from a particular interest among the doctors themselves in the results of such a new operation. The same cannot always be said of GPs, who often have a pretty limited knowledge about our insides when they are not functioning as they should.

So, what do I have to tell from all this?

First, I have been extremely fortunate in being around when the pouch operation was just becoming available and the lack of any complications which I have had following my operation.

Second, I hope that after such a long period I can demonstrate that there is real hope for a long and healthy life following a pouch operation.

Third, I know that I and many other fellow pouch patients owe a lifelong debt of gratitude to Sir Alan Parks, who sadly died quite soon after those earliest operations, as well as to the other doctors and nurses

I was the only patient in residence at the time

throughout the country who are so professional and dedicated.

Finally, like most people who get ill I suppose, I do sometimes wonder why. This is particularly relevant if there is a genetic factor. For example, do my children have an increased risk of ulcerative colitis?

There do seem to have been other cases of it within my family. And could there be some link to cow's milk, as I once read somewhere?

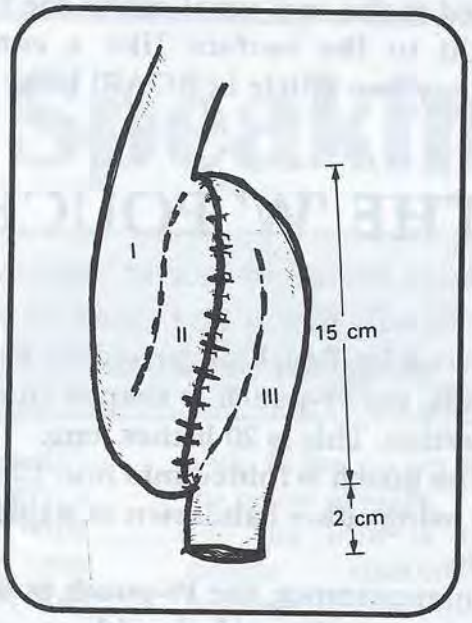
Because of an infection my mother got, I was bottle-fed, while my brother and sister were breast-fed. Our eldest child had an allergy to cow's milk.

What about links to stress? Could this trigger an illness which might otherwise lie dormant? I have no particular medical knowledge, but it would be nice to know, specially if it could help early detection and treatment in the future.

THE ABC OF POUCHES

Do you know what make or model you have? No, we are not talking cars here – we are referring to pouches. Believe it or not there are five different versions of this unique piece of surgery and a surprising number of us don't know which one we've got. Here St Mark's clinical nurse specialist **Julia Williams** gives a step-by-step guide to our much-prized private part. So, if you haven't already found out, next time you speak to your consultant ask him to tell you your make or model.

THE 'S' POUCH

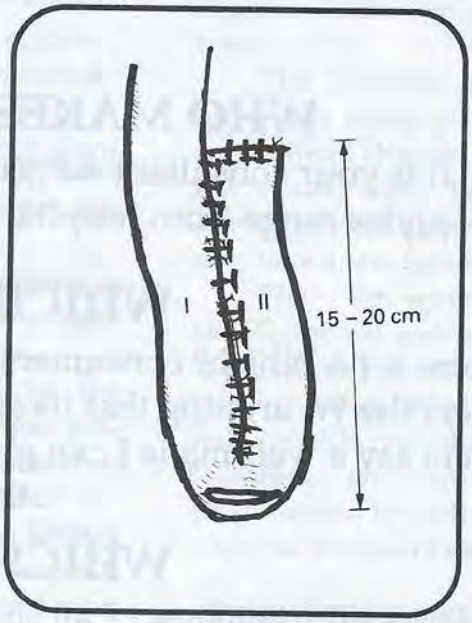


The story begins in 1976 when Sir Alan Parks began developing the first ileo-anal pouch. Two years later Sir Alan, with the help of his then registrar Professor John Nicholls, produced the S-pouch.

The name stems from the pouch's distinctive 'S' shape. It consists of three loops made from 40cm (approximately 16 inches) of the patient's small intestine. This is then handsewn or stapled from side to side to produce a self-contained pouch.

Read about Simon Waley, one of the first S-pouch patients, on page 6.

THE 'J' POUCH



Taking its cue from the first one, each pouch developed since 1978 has been named after a letter of the alpahabet.

The second, a modified version of the S, was named the J-pouch. Created in 1980, it was made from 30 cm of small intestine. This is approximately a foot in length.

The pouch was then folded into two 15cm-long segments or loops. An H-pouch, a lateral version of the S, was also developed in 1980, and is rarely used today.

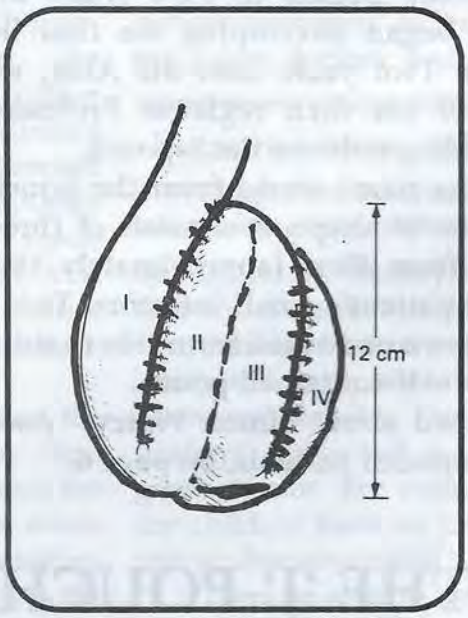
THE 'K' POUCH

The K-shaped pouch was introduced in 1984. Like its J predecessor, the K-pouch is made from 30cm (approximately a foot) of small intestine and folded into two 15cm-long loops.

This is either hand-sewn or stapled from top to bottom (see diagram).

The K-pouch is not to be confused with the KOCK POUCH. Though they are made the same way, the K, like the others, is attached to the anal canal, while the Kock is brought to the surface like a continent ileostomy (see article in ROAR! Issue 8).

THE 'W' POUCH



Pioneered by Red Lion president Professor Nicholls, the W-pouch is shaped from 50cm of intestine. This is 20 inches long.

The pouch is folded into four 12cm-long loops using either handsewn or stapled techniques.

In appearance, the W-pouch is like two J-pouches standing side by side.

WHO MAKES THE FINAL DECISION?

It is your consultant surgeon who decides which pouch to fit. Preferred styles range from hospital to hospital, though most opt for the J-pouch

WHICH POUCH IS BEST?

There is no Which? consumers' guide to the best ileo-anal pouch. St Mark's prefers the W, arguing that its spherical shape provides a better daily function. Others say a well-made J can give as good a function as the W and uses less of the small intestine

WHICH BEHAVES BEST?

The expected frequency of all shapes of pouch is 3-7 times in twenty-four hours. Frequencies vary from individual to individual.

the contacts page.....

I know we have mentioned this in previous issues, but here is a reminder of a NEW SERVICE ROAR! is offering readers. Many of us go through experiences that are private and personal. A helping hand from someone who has been in a similar situation can be invaluable. If you have had such an experience and don't wish to include it in the LETTERS PAGE, you can make contact with someone via a BOX NUMBER on the ROAR! CONTACTS PAGE. Just send us your name and address (not for publication, of course) and message and we will print it over a Box Number. All replies we receive will then be sent to you in strict confidence. ANOTHER IDEA: You might wish to make contact with someone you met while you were in hospital or at a Red Lion meeting or function. Simply send us your name, address, phone (or e-mail) number. We will then publish this together with your message. You never know, it might just be the start of a beautiful friendship!

Alternatively Speaking

In each issue of ROAR! we like to give space to news and views about complementary medicine. If you have any experiences or ideas you would like to be included please send them in. Meanwhile, here's a piece from the editor.....

IF YOU haven't already joined Cherie Blair's select group of crystal-wearers, all is not lost. For a similar device is now on the market

Just in case you think I'm talking gobbledeegook, recent newspaper articles have been musing over a six-sided crystal pendant said to be worn by the prime minister's wife to help "ward off evil spirits". Opposition parties have a lot to answer for these days!

Well I have just been sent a small pendant that also claims to have healing powers. It is called the Em-wave electronic tonic. Around 11/2 inches square, this slim cream-coloured box can be worn round the neck, in the pocket or under the pillow at night.

The idea is to send minute electro-magnetic impulses round the body, tuning up your energy levels and "removing extreme anguish, suffering and distress".

The Norfolk manufacturers say some people will notice small changes in just a few hours, while for others any significant improvement may take a few weeks.

The Em-wave costs £69.95 (inc vat and p&p) For the more ambitious, there is a bigger version called the Em-pulse which, say the manufacturers, is "individually programmed to each client at a special treatment centre".

IF YOU WOULD LIKE MORE DETAILS OF EITHER PLEASE CONTACT THE EDITOR

WELL, WELL, WELL, JUST FANCY THAT!

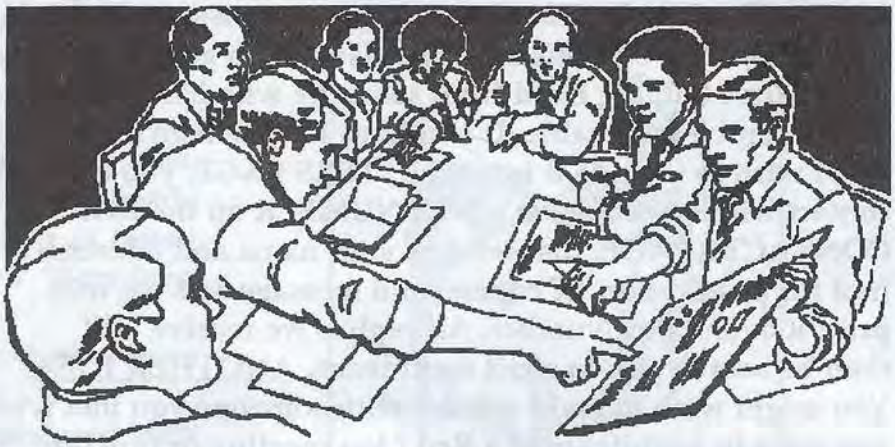
A REPORT by the Centre for Complementary Health Studies reveals that there are more alternative therapists than GPs.

Researchers found that more than 40,000 people are working as acupuncturists, healers and complementary practitioners – compared with 36,300 GPs.

Roger Hill, author of the report commissioned by the Department of Health, said: "Some therapists undergo proper programmes of education and are governed by thorough standards of competence, others are not. We need to tidy up the second lot."

Eric Rose, a Milton Keynes GP and a member of the BMA's GPs committee, said: "At one end are the respectable therapists, such as osteopaths and chiropractors, who most doctors would refer patients to, while at the other end there are people who have done a three-month correspondence course....."

NEWS FROM AROUND THE REGIONS



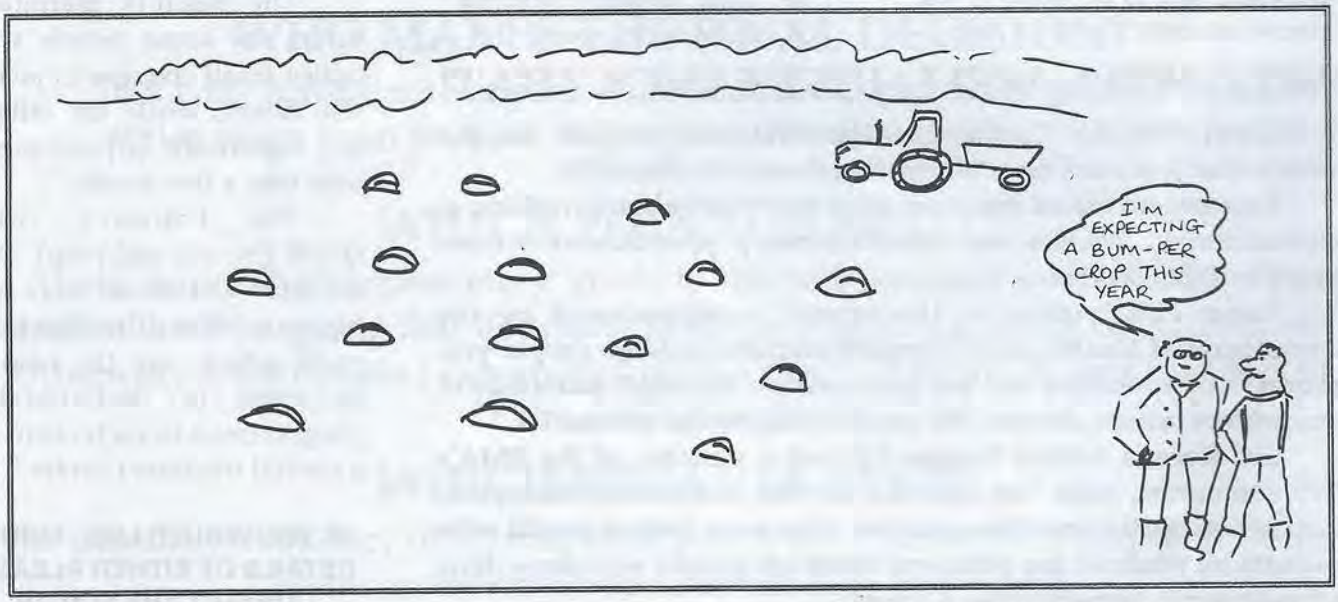
After their successful launch meeting at Sturry, near Canterbury, on May 17, **MID AND EAST KENT REGIONAL** group had a second get-together at the Beefeater Restaurant in Ashford, Kent. A total of eight pouch owners, most of whom were with their partners - and two very well-behaved little boys- met for a Sunday Lunch social meeting on July 5 and had a light-hearted, informative and enjoyable afternoon.

The group agreed to meet three times a year for social functions with friends and families.

Kent region's next event is a one-day **COUNSELLING SKILLS COURSE** on October 24. Run by members of the ia and internal pouch support group, the course's aim is to train pouch members how to help people considering pouch surgery - either face-to-face or by phone. Although the course is fully subscribed, there may be a few cancellations. If you are interested, please contact Kent co-organiser and RLG social secretary David Irving-James (details on the back page).

.....

A leaflet drop of former pouch patients from Kettering and Northampton General Hospitals is being organised by the **NORTHAMPTONSHIRE** group. The idea is to attract new members to the group's second meeting on September 27 (the first was held on June 7). The venue is Northampton General Hospital (2-4pm).



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

BEDFORDSHIRE
Wendy Gunn — Luton — 01582 423714

BERKSHIRE
Liz Davies — Langley — 01753 586593

CAMBRIDGESHIRE
Rita Deans — St Neots — 01480 403148
Joyce Shotton — P'borough — 01733 706071

CLEVELAND & NORTH YORKSHIRE
Christine Jackson — Saltburn — 01947 840836

CUMBRIA
Jonathan Caton — Kendal — 01539 731985

DEVON
Gill Tomlin — Plymouth — 01752 568643

DYFED
Briony Jones — H'fordwest — 01437 765359
Bruce Dibben — " — 01437 731436

EAST SUSSEX
Kate Bosworth — Brighton — 01273 887102
Lisa Critchley — " — 01273 699286

ESSEX
Peter Zammit — Benfleet — 01268 752808

GWENT
Robert Challenger — Cwbran — 01633 866320

HAMPSHIRE
Phil Smith — Portsmouth — 01705 426541
Les Willoughby — Winchester — 01962 620012

HERTFORDSHIRE
Carol George — Stevenage — 01438 365707

KENT
David Irving-James — Folkestone — 01303 277819

LANCASHIRE
Joan Whiteley — Clitheroe — 01200 422093

MERSEYSIDE
Blanche Farley — Liverpool — 0151 924 4282

NORFOLK
Sandy Hyams — King's Lynn — 01485 542380
Sylvia Mist — Norwich — 01692 580095

NORTHAMPTONSHIRE
Cynthia Gunthorpe — Kettering — 01536 482529
David Smith — Northampton — 01604 450305

SOMERSET
Clive Brown — Chard — 01460 234439

SOUTH LONDON
Andy Jones — SE6 — 0181-690 1360
Jonathan English — SW12 — 0181-673 2518

WEST LONDON
Dee O'Dell-Athill — W10 — 0181-960 6726

WEST SUSSEX
Amanda Metcalf — Arundel — 01243 554257

WILTSHIRE & DORSET
Bernadette Monks — Salisbury — 01722 327388

YORKSHIRE
Neil Anderton — Leeds — 0113 258 2740
Sue Appleyard — Huddersfield — 01484 311334

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- **Free quarterly newsletter with all the latest news, views and events**
- **Membership is £10 (conc £5, free for hardship cases)**
- **Write to Liaison Officer (address on back page)**

If you would like to be a Red Lion Rep, please contact Liaison Officer Morag Gaherty (phone numbers on back page)

ROAR! Issue Number 10 • Autumn 1998

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FUNDRAISING OFFICER
The position is now vacant – anyone interested in applying should contact the secretary Inez Malek (address and telephone number on this page)

SOCIAL SECRETARY
David Irving-James
51 Langdon Road
Cheriton
Folkestone
Kent
CT19 4HY
Tel: 01303 277819

TREASURER vacant

Patron: Claire Rayner

THE RED LION GROUP WEB-SITE ADDRESS IS:

www.red-lion-group. mcmail.com

. Tim r. dircon. co. uk/pouch.