Roar!

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Roar! is the newsletter of the Red Lion Group

A message from our new (m)patron

In her first Roar! article, writer, broadcaster and RLG mother superior Claire Rayner looks forward to a long and happy association with her new pride of Red Lions

Let me introduce myself: I am your new Patron (I suspect that ought to be Matron, for real accuracy; but let that go) and you're fully entitled to know something about me.

I trained as a nurse, back in the 1950s, at the Royal Northern Hospital in Holloway, London, and it is this, rather than any later experience as a health educator and journalist that, I believe, makes me suitable for the honour of this new appointment.

One of the surgeons with whom I worked closely in those days was a remarkable man called William Bashall Gabriel. He was a famous colorectal surgeon and I suppose it was inevitable that his nickname

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LIONS WIN THEIR STRIPES

The message in the brown envelope was dry, to-the-point and without frills.

It said: "The Red Lion Group has been entered in the Central Register of Charities." The news may have been brief, but it was greeted with joy and relief by the committee.

After more than a year of trying, our efforts to become a health charity had finally received the Charity Commissioners' blessing.

The surge of fact-checking, medical inquiries and correspondence that flowed between committee and Commissioners had borne fruit.

However the date of the Charity Commissioner's letter - Friday, February 13 - could have been an unlucky omen!

On this occasion, Lady Luck won the day.

Red Lion chairman, Dr Martin Peters, said: "We have achieved what we set out to do - a steadily growing membership, some impressive merchandise and charity status. Achieving it proved a tougher task than we had expected and many technical details had to be thrashed out, but in the end persistence won the day.

"We could have continued as a support group, but this gives us credibility in the eyes of the public, particularly over fund-raising."

The theme of this quarter's Roar! is ILLNESS - ranging from conditions associated with having a pouch and progress in the ileo-anal field, to disease in general. It is such a wide-ranging subject, that we will carry a second section in the next issue. If there is anything you would like to be included, please send it to the Roar! Editor by June 1.

In This Issue...

Sandy Hyams discovers an unlikely slimming aid P.4

Elaine Escott finds a new lease of life.....P.10

Dr Paul Thomas has an inside view of pouchitis... P.7

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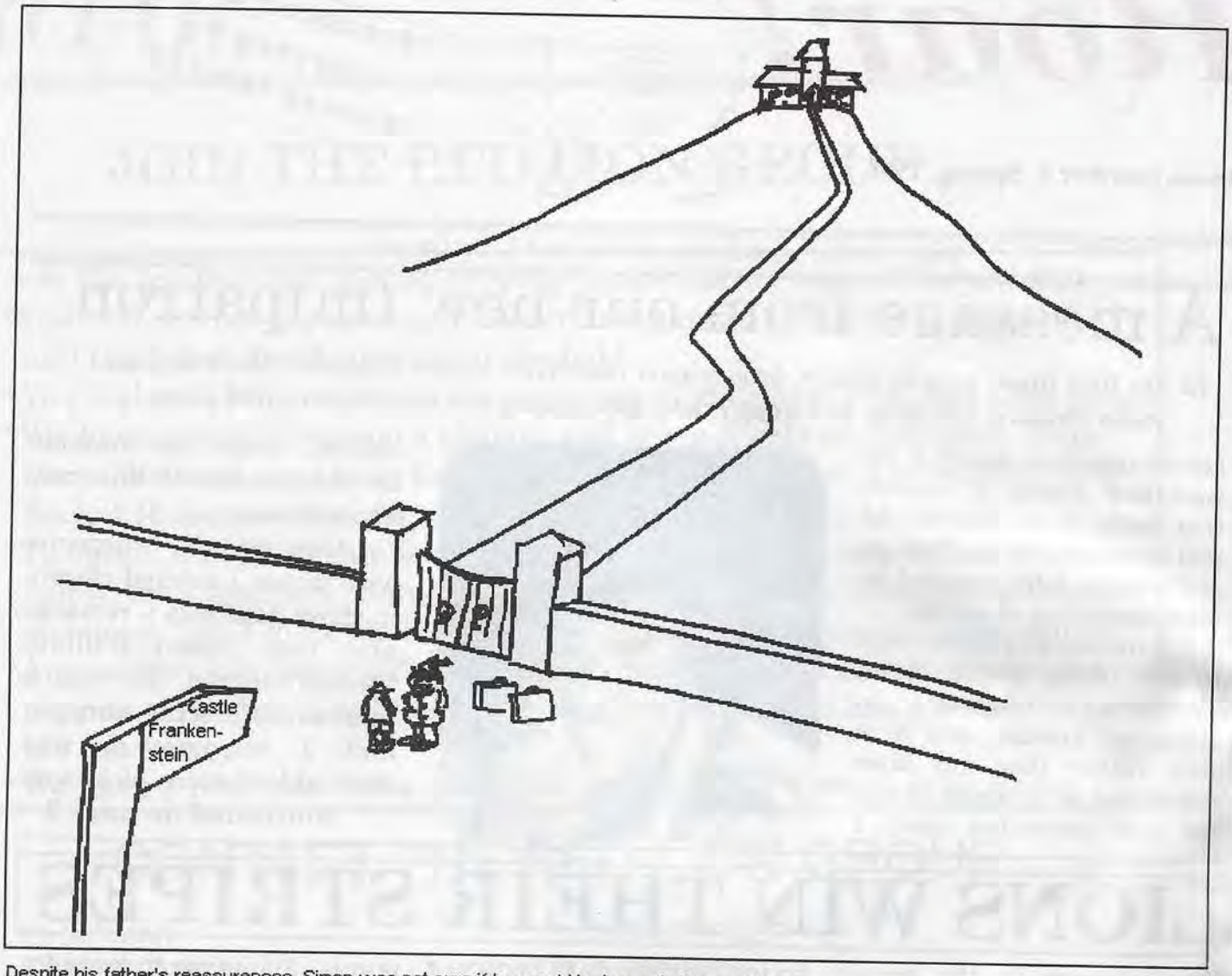


Despite his father's reassurances, Simon was not sure if he would be happy in his new job

A MESSAGE FROM OUR PATRON (CONTINUED)

give the medical vulgarity) was the Arse Angel. Anyway, whatever we called him, he did some fine work - for the 1950s.

But it wasn't easy to be one of his patients. I remember some very young people having to cope with ileostomies and colostomies with what today would be regarded as positively primitive dressings, bags and belts.

We had none of the modern materials and systems that make life so much more comfortable for the patients of the 1990s, and there were certainly no specialist nurses with extra training to help patients learn to live with their new body images.

We did our best - and I have some happy memories of patients who went home and on to get married, have babies and and live perfectly normal lives, even though they had only us to look after them!

I grew very fond of Mr Gabriel's patients and I hope Ican say some of them grew fond of us. This is why I'm so happy to be involved with the Red Lion Group now. St Mark's is a great hospital with a great past as well as a splendid present.

Above all, it is a place where people matter and patients come first. Just as they did when I was a scatty young nurse back in the 1950s.

Now I look forward to a long and, I hope, useful association with you all.

Thankyou for having me.

Editorial

We've got two former patients Rachel Nicholson Abedi and Tim Rogers to blame for all this.
It was their idea to set up a small, but perfectly-informed, network for pouch-owners, their families and friends.
Shortly afterwards, a meeting of 80 po's and medical staff met in the exotic setting of Sion Park, SW London.
As a result, a support group was born, the first edition of Roar! appeared and a tiny pride of Red Lions met for the first time. Today, three-and-a-half years on, we are a fully-fledged charity with a famous broadcaster as patron.
Though we are still relatively small - albeit growing - we have a little more standing than we did before. When people hear or read about us, they know we are serious and sincere. In short, we mean business.
Anyone can set up a support group and then close it six months later.
A small minority like ours go on to become charities. The main difference is that a charity is bound by law. A support group is not.
As a charity we have our own articles of association and must keep annual accounts. We can also raise money by covenants, giving donors the benefit of tax relief on their contributions.
Finally we can hold national fund-raising events.
It is an important step. Our new status will give us greater scope to help each other and to keep up with the latest ideas in surgery, medicine and health.

Peters to hand over baton

Charity status brought late Christmas cheer to the committee - it also marked the end of Dr Martin Peters' chairmanship

A slightly delayed Star in the East brought late Christmas cheer to the Red Lion Group committee.

For members heard at their January meeting that our efforts to become a charity were about to bear fruit. All we had to do was answer a couple of technical points - and we were there.

This late Christmas present follows a year of correspondence as the committee sought to fulfil the Charity Commissioners' strict criteria.

One of the pioneers of this work was chairman Dr Martin Peters, who announced at the meeting that he is to hand over to someone else. Peter Johnson, the treasurer, is also leaving the committee due to prior commitments. Both were thanked for their hard unstinting work in helping to set up the Red Lion Group.

Tribute was paid to Norwich rep Sylvia Mist for

Peter Johnson

organising such a thriving group membership in her area. Two Eastern region-events - for reps, stoma nurses and new members - are being held during the first half of 1998, members heard.

Red Lion member David Irving-Jones was co-opted on to the committee as social secretary. His role will be rat ified at the AGM. Members agreed his job would include organising national social events and creating ideas for local and national fund-raising.

Liaison officer Morag Gaherty said membership stood at 375 - a steady growth on the 250 members reported at last year's AGM. St Mark's pouch support nurse Julia Williams said orders for Red Lion merchandise were brisk - with a new range of sweat-shirts for Red Lion cubs (see picture on page 9).

A new Red Lion leaflet, prepared by press officer Christopher Browne and acting vice-chairman Brian Gaherty, was adopted by members. Brian Gaherty is continuing Tim Rogers's good work in designing an exclusive Red Lion web-site.

GOODBYE TO A DIETER'S DREAM

Friends and acquaintances kept asking Sandy Hyams the secret of her slimming success - if only they knew the real truth

"It's just a bloody nuisance," the consultant told me condescendingly. This was not what I wanted to hear. I just wanted it to go away. Little did I know how much would be taken away just a few months later.

'It' was constant bleeding every time I went to the loo. For two years I had suffered from piles - a comi-tragic condition that, like dandruff, one-in-five people seem to have. An unmentionable in polite company; an unquenchable at home.

Eventually my surgeon, a lovely man, suggested he operate. "Yes please," I gasped. "The sooner, the better." I went to theatre on April Fool's Day, feeling nervous and perhaps a little foolish!

That might have been the end of my story, except I didn't stop bleeding after the haemorrhoids were removed: and it got worse. So my kind surgeon sent me to another consultant, a specialist in matters down below.

He diagnosed distal proctitis, inflammation of the lower region of the rectum - "a bloody nuisance", but evidently treatable.

There followed months of trying various pills and potions - Asacol, Colifoam enemas, Celevac tablets (which were as large as horse pills), and finally Pentasa enemas. A week's supply of t the size of a shoe-box; using them involved some minor contortions of which I didn't know I was capable!

In between times I underwent two colonoscopies, both of which were clear. But still I bled. How could it be that I was into my fourth year of wearing panty-liners, five years after a hysterectomy? Another doctor tried me on

steroids for a while (which had no effect at all) then wondered if I had food intolerance. An appointment was duly made and I shuffled off to see yet another specialist. I still don't know what sent me over the edge, what turned distil proctitis into ulcerative colitis. The colonoscopy in January showed nothing, but from Easter to May my condition escalated. Suddenly, I was running with some urgency up to 20 times a day.

Day-to-day life became a logistical exercise in finding the nearest loo. Even my hands suffered, roughened by all the extra washing!

By the end of the month my temperature was behaving like a yo-yo. I couldn't face food and I burst into tears at the slightest provocation. We cancelled our Bank Holiday trip to Madrid and I stayed in bed over the weekend. So, on the Tuesday, my husband's birthday, instead of enjoying a Spanish meal washed down with Rioja, he found himself rushing me into hospital.

I was re-admitted under the care of Dr Hunter, the specialist in food tolerance whom I had seen a few weeks previously. The next 12 days were among the longest in my life. I was given only special liquids to drink (no food) and pumped full of steroids. I soon assumed the typical 'moon face' and my ankles swelled to keep it company.

Crohn's disease was mentioned to me - a new phrase, as were ulcerative colitis and ileostomy. I was able to dress each day and wandered about in a daze, unable to concentrate on anything. My days were punctuated with a battery of tests: X-rays, a leucocyte scan, a barium meal. Everything going in and out had to be measured.

How many times did I walk along the corridor, carrying the 'top hat' to be weighed? Every morning I was weighed and I watched as the pounds dropped off daily. It was a dieter's dream - in another life I would have been pleased at the weight-loss!

It seemed the more tests I had, the weaker I became. My temperature soared as my blood count dropped.

continued on page 6

Letters

3 Manor Court
Manor Road
Twickenham
Middlesex
TW2 5DL

Winds of change

Dear Sir

As a pouch owner since 1994, I would be glad if you could share this important observation with our members.

Owners and operators of the pouch share one technical weakness which could, with thought and planning, be engineered out of the present design. This improvement is, of course, the "Fart Facility Mode".

All one's specialist really wishes to known post-implant is "How many times do you visit the lavatory?" The answer is invariably "As many times as it needs to have a good fart", which seems to be most of the time.

It is common knowledge among the pouch fraternity that to fart without a "follow-on" can only be achieved by adopting a recovery position or visiting the quiet place which we have all come to love and cherish. Though lying on the floor at a synod chaired by the Archbishop of Canterbury and farting for England, or similar acrobatics while being interviewed for a key job with the European Parliament, might be carrying the spirit of tolerance too far!

Bruce Dibben
Dyfed Area Rep

Any ideas (ed)?

One of the in-crowd

Dear Sir,

After having the pouch at 17, eight years ago, I've felt quite alone with my condition. Now, with the Red Lion Group and Roar!, I feel as though I'm understood and very much a part of something precious.

The recent booklet on a balanced diet was very helpful too - it's very difficult to find healthy food that's kind to your pouch.

Recently I've been thinking about having a baby, but I am worried my body will be unable to take the strain. Does anyone have any information they can pass on?

Alison Lawford,
London SE5

Putting it in writing

Dear Sir,

I have a very long and complicated medical history and I also have asthma. Do you produce a card giving an explanation of our op, ie like the membership card NACC produces? If not, I think this is really needed. As a post-script, I would like to thank the Red Lion Group for your prescription campaign. I no longer have to pay for my drugs after I took the Roar! article about pouchholders being exempted from prescription charges to my GP.

Mrs S.E. Allen,
Norwich.

There are two "No Waiting" cards in eye-catching orange and turquoise, produced by Dansac Freephone 0800 581117 and Convatec Freephone 0800 282254 (ed)

What a little mover

Dear Sir,

As an older member of the Red Lion Group, I thought readers might like to know that at 74, I have joined a line dancing group! It's great fun and I'm told excellent for keeping the old bones moving and the memory active - you have to memorise hundreds of steps. It is also good for mental and physical coordination.

I feel a bit ancient among the younger members, but manage to hold my own. I could never have considered doing this 10 years ago, before I had my pouch operation.

Good luck, and a healthy 1998 to all Roar! readers

Audrey Rumsey,
Bristol.

The Contacts Page

Many of us go through experiences that are private.and/or painful. A helping hand from someone who has been through a similar experience can be invaluable. In future issues of Roar! we will be publishing a Contacts Page for readers who wish to contact other readers over matters both personal and medical. If you would like to make contact with someone, please send us your message with your name, address and, if necessary, phone number, and we will publish it on the Roar! Contacts Page. If you prefer complete confidentiality, then send your name and address and we will give you a box number that will appear in the next issue of Roar!

Continued from page 4

Eventually I was put on a saline drip alternated with a blood transfusion. And finally Dr Hunter admitted defeat and brought in Mr Miller, the consultant who was to save my life.

As this was at the weekend and my condition deteriorating rapidly, the operation was scheduled for the Sunday morning. Consequently I did not see a stoma-nurse until it was all over. Pre-op I was beyond caring and doubt if I would have taken in anything she said. I remember one nursing sister telling me that I would feel like I had been kicked by a mule afterwards - an understatement, I thought later.

I think it was not knowing what the outcome of surgery was going to be that proved such a shock to the system. I had no time to prepare myself for my altered body image and what it entailed.

The first three days post-op passed as in a dream-world, floating in and out of consciousness and continually pressing the morphine pump when I was awake. By the Thursday I had come round, more or less, and received my first visit from the stoma-care nurse. Now I had an opportunity to examine my new appendage for the first time. I was not impressed.

The stoma-care nurse showed me how to empty and change the ileostomy bag, which I attempted, successfully, that afternoon. After a week I was becoming quite proficient - when my stoma behaved itself. I decided then to call it Stromboli, after the Italian volcano, as it was always erupting. As the days passed and I had the various tubes and attachments removed, I began to look forward to going home.

For some unaccountable reason I thought this was something to be endured only while I was in hospital. It's OK, I told myself, it'll be gone once I return home. I would be back to normal again. It still hadn't sunk into my addled brain that this was something I would have to learn to live with.

Coping with the practicalities of an ileostomy proved relatively easy - so long as Stromboli was well-behaved. Problems only started when the inevitable accidents happened and I tried to do 13 things at once, often reducing me to tears in the process.

It was a year of tears. Every time I packed for a holiday, I cried when I saw my redundant bikinis in the drawer. With some uncanny prescience I was loath to throw them away (and of course I can now wear them again). I alternated between feelings of awe for the medical profession that had saved my life and incredulity and despair that this had happened to me.

It was this mental incapacity to come to terms with sharing my life with a stoma that led me to investigate pouch surgery. I spent hours on the telephone talking to pouch patients and researching all the available literature on the subject. Unfortunately, I didn't discover the existence of the Red Lion Group until a few weeks after my pouch operation.

By March, 1996, I had definitely made up my mind to proceed. And at the end of July 1996, the reign of Stromboli was ended..The era of Rita the Reservoir was just beginning.

AGM....APRIL 18

THE BIG DAY IS NEARLY UPON US AND WE'VE GIVEN IT A SPECIAL TITLE TO CELEBRATE OUR NEW STATUS

THE RED LION GROUP POUCH INFORMATION DAY

THE VENUE IS: THE HIMSWORTH HALL, NORTHWICK PARK HOSPITAL

HERE IS THE RUNNING ORDER:

10.00am.....	Registration and Coffee
11.00-12.30..	RED LION AGM - members only
	The following are open to non-Red Lion members
11.30.....	RESTORATIVE PROCTOLECTOMY - THE OPERATION **(speaker to be confirmed)**
12.00.....	THE FUTURE OF THE KOCH POUCH **(Mr Matthew Morgan**
12.30	Registration, lunch and viewing of exhibition
1.45pm.....	CURRENT RESEARCH IN ULCERATIVE COLITIS **(Dr Chris Probert)** or CURRENT RESEARCH IN FAMILIAL ADENOMALOUS POLYPOSIS **(Mr Robin Phillips)**
2.15.....	NURSE-LED WORKSHOPS. inc MANAGEMENT OF POUCHITIS **(Angie Perrin)**, TAKING CONTROL - MANAGEMENT OF INCON TINENCE **(Christine Norton)**, ANAL SKIN CARE **(Julia Williams)** FAMILY PLANNING, SEX AND PREGNANCY **(Di Jones)**, HAVE POUCH, WILL TRAVEL **(Carolyn Bond)**
2.45.	Tea
3.15.....	QUESTION TIME **(Dr Martin Peters, Mr Phillips, Mr Stebbings, Julia Williams, Morag Pearson)**

If you are a Red Lion Group member and wish to propose someone for election to one of the executive committee posts, please fill in the Nomination Form enclosed with this newsletter.

Please see overleaf for a JOB DESCRIPTION of the EXECUTIVE COMMITTEE posts

NOTE: The following committee members are standing down at the AGM: Dr Martin Peters (chair) and Peter Johnson (treasurer). We are also seeking a Fund-raising Officer

ROLES OF THE RED LION GROUP COMMITTEE

CHAIR:..... Chair and coordinate RLG committee meetings (three-monthly)
Chair the annual RLG meeting
Sign and confirm previous minutes of committees and annual meetings
Organise all meeting agendas
Update Red Lion members on the Group's progress at the AGM
Liaise with committee members over current and future RLG activities
Act as spokesman over key committee business or negotiations

VICE-CHAIR: As above in the absence of the Chair

SECRETARY: Take notes of committee and annual meetings
Send minutes and agendas of meetings to committee members
Arrange outside speakers as suggested by other committee members
Liaise with all committee members
Keep a central file of all minutes and correspondence sent out by other committee members
Provide summary of annual meetings for the newsletter

VICE-SECRETARY: As above in the Secretary's absence

TREASURER: Keep and maintain an accurate record of RLG finances
Provide RLG members with an up-to-date expenditure of the group at AGMs
Ensure "Thankyou" letters are sent to all RLG donors
Liaise with all members of the committee
NOTE: This role may be slightly extended with our new charity status

LIAISON OFFICER: Maintain RLG database, send out information to new members, input database details when they join
Liaise with regional reps
Correspond with members and potential members regarding surgery and arrange contact with others
Write and provide analysis of newsletter questionnaire
Monitor and report back to the committee on membership matters

PRESS OFFICER/NEWSLETTER EDITOR:
Handle press inquiriesand article requests
Organise RLG marketing literature
Publicise RLG events in the newspapers/radio/television
Edit, cordinate and commission articles for the quarterly Roar!
Report back to committee on all publicity and marketing matters

SOCIAL SECRETARY: Coordinate the AGM
Help arrange outside speakers
Suggest ideas for local and national functions/fund-raising
Keep RLG committee informed of social function plans

FUND-RAISING OFFICER:..... Organise and coordinate fund-raising activities
Suggest fund-raising ideas

JOIN THE RED LION CUBS AND BROWNIES TODAY

Holly Enser
& T-Shirt

If you're under-16, why not join the RED LION CUBS
the liveliest, most fun-filled group around

All you've got to do is send your name to

Morag Gaherty
Red Lion Liaison Officer
16 Hill Brow
Bearsted
Maidstone
Kent ME14 4AW

And you'll become a Red Lion Cub or Brownie FREE

You'll also receive your own wild, wacky and wonderful
copy of PAW, your own special newsletter, completely FREE

It'll be full of fun, games, puzzles, stories and cartoons

And we'd love to receive your own stories, puzzles and pictures

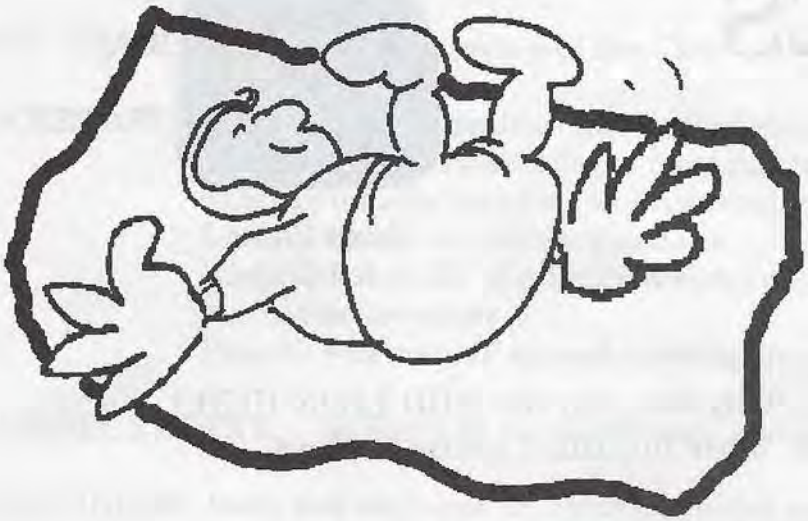
We're giving a £10 PRIZE for the best entry

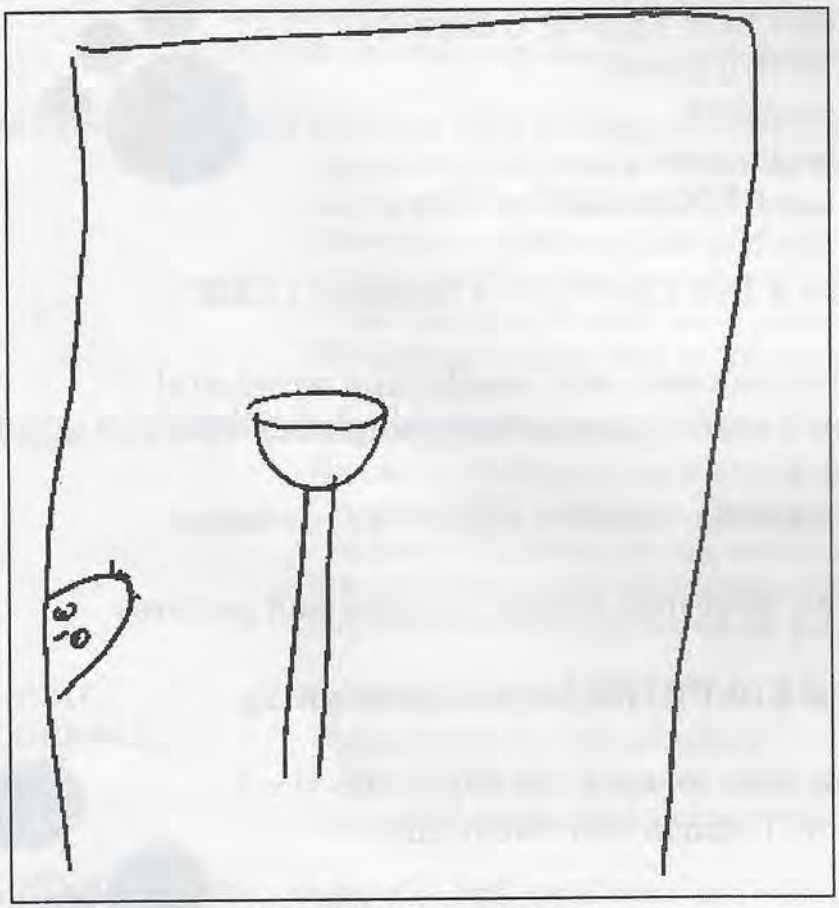
Finally you'll be able to wear our super cub-sized
Red Lion T-shirts and sweatshirts

WHAT ARE YOU WAITING FOR?

CARTOON CAPERS

The soccer coach had his eye on Jeff from an early age as a potential goalkeeper ...





The Shy Coconut found it difficult to fit in to fairground life

DOES ANYONE HAVE THE ANSWER TO JULIA'S DILEMMA

My name is Julia Morgan. I am a J-pouch patient and I have a problem with losing faeces during the night while I am asleep.

I had my J-pouch fitted in 1996 after having ulcerative colitis. At first, everything was fine and I had no problem with losing faeces during the day or night. Then in March last year I developed a fistula.

I had to have a temporary ileostomy while the fistula healed. This was reversed in July, 1997, since when I have not gone through a night without having to get up and find myself soiled.

I was wondering if any Roar! readers have, or have had, a similar problem to mine and know of any possible solutions to it.

Julie Morgan
The Birches
Almeley
Herefordshire
HR3 6LQ.

Can you shed any light on Julia's problem? If you can, perhaps you would be good enough to write to her at the above address

THE POUCH FILE

Over the next four pages we aim to answer many key points about internal pouches, including the Koch method, progress on Pouchitis, and the recipe for Electrolyte Mix

Taking the ouch out of the pouch

By Dr Paul Thomas
Research Fellow of the
St Mark's Institute

"Yes, I'm afraid you have pouchitis" are words many patients with ileal pouches dread.

Yet, though the condition has some similarities with ulcerative colitis, many of the worries patients have about a return to the misery of life with colitis or fears about losing the pouch are, in the majority of cases, misplaced.

Pouchitis is a much less severe condition than colitis. Symptoms are often shortlived, either resolving of their own accord or responding to anti-biotic therapy. Furthermore, most patients will suffer only one or two episodes before normal pouch function returns.

Pouchitis only seems to occur in those patients who have had the procedure performed for ulcerative colitis, and only then in about one-third of cases.

Symptoms may include increased pouch frequency, blood in the stool, abdominal pain and flu-like symptoms. Diagnosis is made by examining the pouch lining with an endoscope where ulcers or other evidence of inflammation may be seen. A biopsy is usually taken to confirm that the pouch is inflamed.

Though the underlying cause of pouchitis is not known, at St Mark's we have a major research interest in this condition.. Understanding pouchitis may not only enable us to devise better treatments, but also help us to better understand the processes that lead to ulcerative colitis.

There is now increasing evidence that some underlying abnormality of the immune system may predispose to ulcerative colitis, possibly through an abnormal response to the bugs that normally live in the gut.

We are examining the possibility that this subtle change in the way the immune system works may persist in certain patients after colectomy, leading to a recurrence of inflammation in the 'new colon' ie. the ileal pouch. The successful use of anti-biotics such as Metronidazole which alter the type of bacteria in the gut is in keeping with this theory.

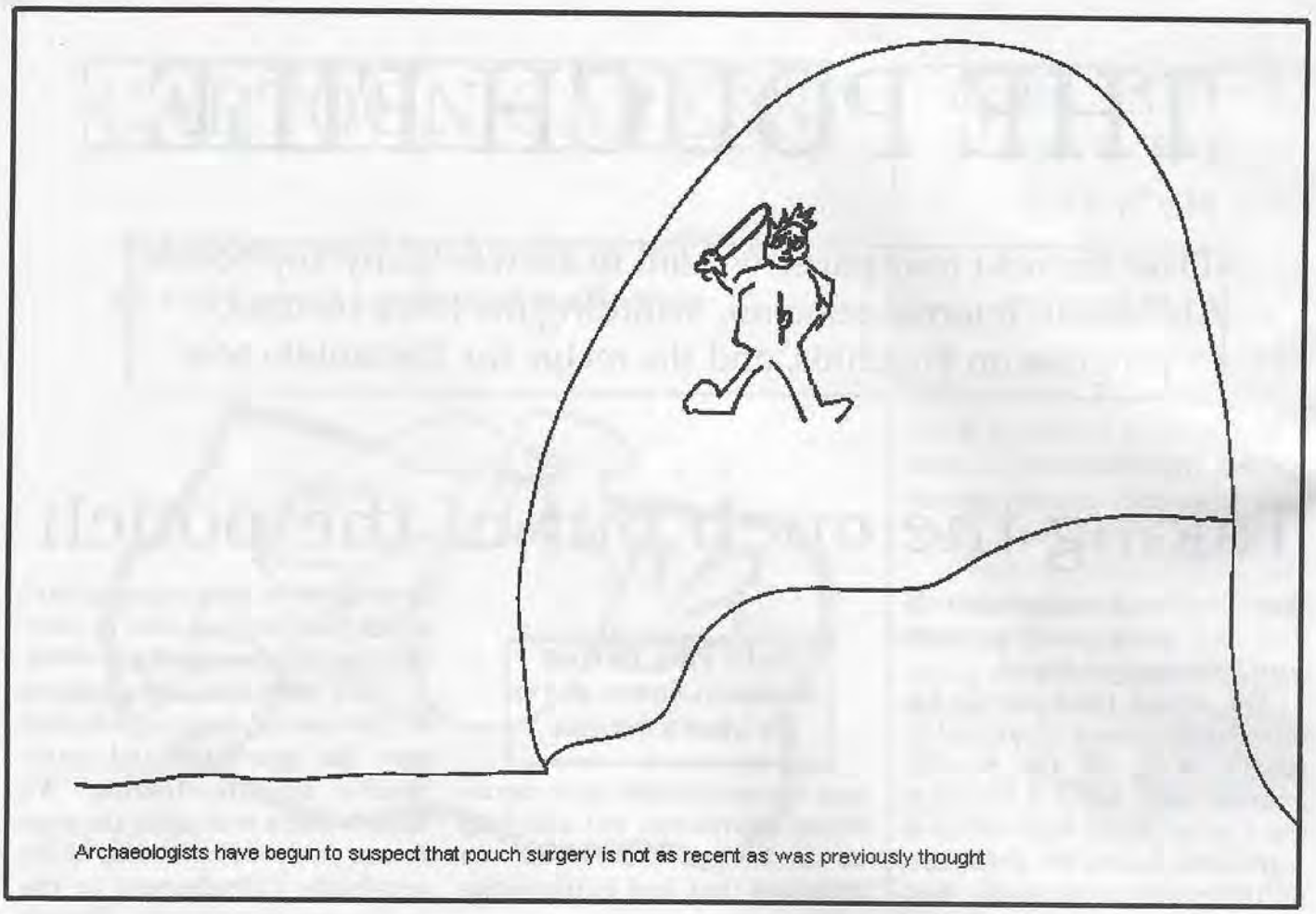
Several studies on the causes and associations of pouchitis are being carried. out at St Mark's.

Many pouch patients seem to experience joint symptoms. Our study on this has shown that nearly 30% of patients have mild aching or swelling of hand or knee joints in particular. Though this can be troubling, it does not seem to be causing any direct joint damage and is unrelated to the presence of pouchitis.

We have also been looking at the use of a potential stool test for pouchitis and early results are encouraging. We hope to begin a study in the near future on the effectiveness of the anti-biotic Ciprofloxacin in the treatment of pouchitis. Though this is sometimes prescribed, there is no evidence to demonstrate how, or indeed if, it works.

As ever, for all of these studies, we are indebted to pouch patients who have taken part in research work. Without their help little progress can be made into the causes of this condition.

If anyone would like to take part in pouch or pouchitis research, or even discuss projects that have been carried out so far, we would be very glad to hear from you. Please contact Dr Paul Thomas, Inflammatory Bowel Disease Research, St Mark's, Tel: *0181-235 4000 extension 2770.*



Archaeologists have begun to suspect that pouch surgery is not as recent as was previously thought

COPING WITH A KOCK POUCH

Most of us are familiar with W and J pouches, but not many of us - apart from those who have them - know anything about the Kock pouch. Here St Mark's Clinical Director Professor John Nicholls and Pouch Care Nurse Julia Williams give us the full facts

What is it?
The Kock pouch aims to produce an ileostomy that is continent until the owner wishes to empty it. It is not necessary, therefore, to wear an appliance.

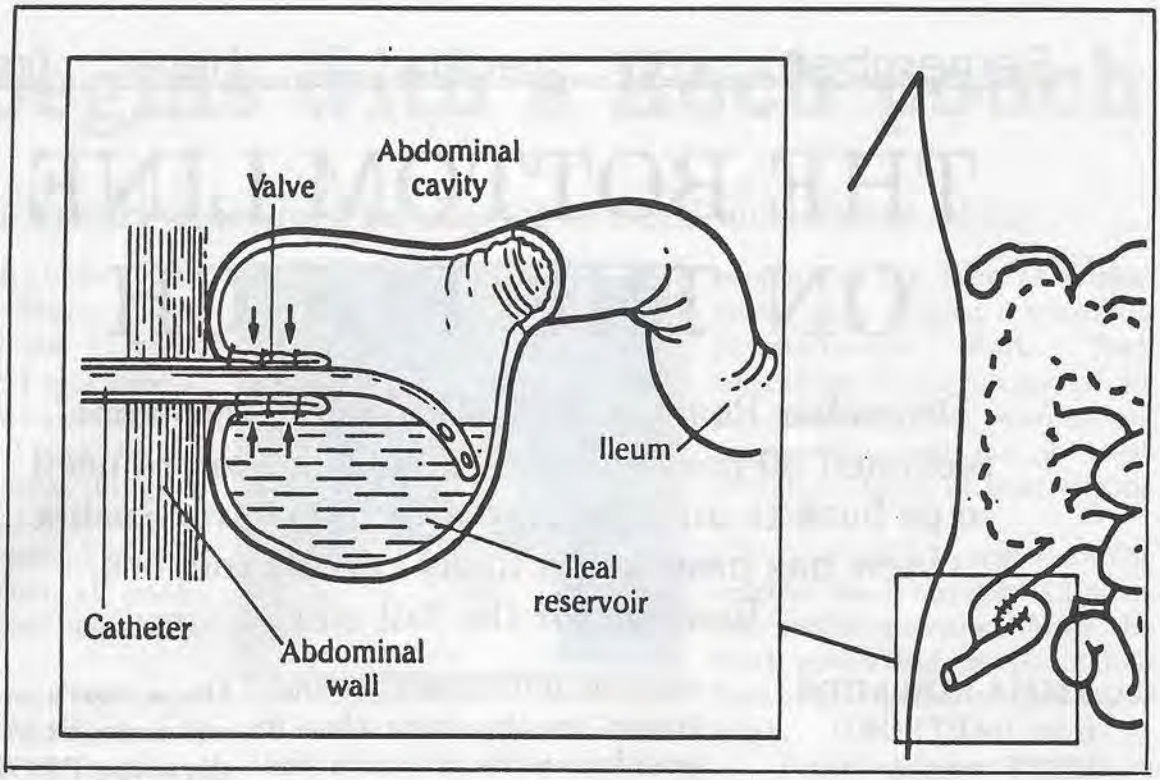
When is it needed?
It is an alternative to an ileostomy or external bag for patients whose muscle tone is too weak for an ileal pouch or who have had their sphincters removed.

Technique
The large bowel is removed. Then the last 45cm of small intestine is used to construct a reservoir. The end-piece of the intestine is pulled back into the reservoir to make a valve. As it fills with faeces, pressure in the reservoir builds up, the valve is squeezed shut and faeces cannot escape. A catheter is inserted into the pouch and sometimes secured to the skin with a stitch.

Post-operative period
When the bowels start working (the patient starts passing wind and producing faeces), he/she can start eating and drinking again. Once bowel activity returns, the faeces drain out of the pouch via the catheter inserted during the operation. The catheter remains in the pouch for four to six weeks from the operation to allow the valve to heal.

.....see diagram overleaf

Here is a diagram of the Kock ileostomy. We will give you more details about coping with the Kock in the next issue of Roar!



AND NOW FOR SOMETHING COMPLETELY DIFFERENT.....TWO RECIPES FOR SUCCESS!

ELECTROLYTE MIX
ST MARK'S FORMULA

If you have been prescribed Electrolyte Mix, you will need to make up the solution fresh each day. The ingredients are:

Glucose powder
Sodium Chloride powder
Sodium Bicarbonate powder

Measure out SIX level 5ml spoonfuls of glucose, ONE heaped 2.5ml spoonful of sodium bicarbonate and ONE level 5ml spoonful of sodium cloride, dissolved in ONE LITRE OF TAP WATER.

PS: You can buy the three ingredients from any pharmacy and most supermarkets. By the way, Sodium Chloride is table salt which you will have in your home anyway. Sodium Bicarbonate is also known as Bicarbonate of Soda. If you still pay prescription charges (ie you may not have read recent issues of Roar! sic ed!) they are cheaper to buy than obtain under prescription. If you have any queries Tel St Mark's Pharmacy on 0181-235 4100

Here's a cheerful ditty by Audrey Rumsey

IN FAVOUR OF A POUCH.....

Ulcerative colitis, oh please don't remind me.
I'm happy to say that it's now all behind me.
So many visits all day and all night
It left me incredibly sore
But now, since my Pouch, I no longer say Ouch
I don't need to run anymore

It took quite a while before I could smile,
Move a few yards from the loo.
Now I'm OK, and just want to say -
Have a Pouch, don't say 'Ouch'
Just smile when you go to the Loo.

Remember .... you .... read .... it .... here .... first!

THE BOTTOM LINE ON THE POUCH

December Roar's article "Decisions, Decisions" reckoned 50 per cent of ex-uc pouch owners need to go back to an ileostomy after 20 years. Such a view has provoked a lively correspondence. Read on for the full story

First **EMMA EDWARDS** from DARTFORD KENT writes:

I recently saw my surgeon Mr Parker at Joyce Green Hospital and we discussed the reversal. I told Mr Parker that I read that 20% of previous uc sufferers with pouches can develop pouchitis (Roar! Issue No 2).

I now read that 50% of pouch owners who had uc revert back to the bag within twenty years and that the operation is not as successful as first thought

Then a letter arrives from **CLIVE BROWN** of CHARD SOMERSET who says:

I was stopped dead in my tracks by the quote in Roar! that "fifty per cent of pouch owners who had ulcerative colitis revert back to an ileostomy within 20 years".

I had to read it again to check whether I had taken it in correctly. I then started wondering about the criteria for "pouch longevity". Now suppose, for argument's sake, increased bowel frequency resulted in the pouch lasting longer, on the basis that it wouldn't have to store the food for so long, then we would have to devise menus that would send us rushing to the loo.

What about about something like:

THE TOP THREE MOST TANTALISING TANDOORIS

for example - guaranteed to pass through the digestive system in record time? Perhaps we could also have the bottom three!

It would be interesting to see how this evolves in future issues of Roar!.

Let me begin with:

VEGETABLE VINDALOO
(without rice)
* served on a bed of salad,
* lashings of oil and vinegar
* washed down with lager and red wine.

Send Roar! your own Top (or Bottom) Three Digestive Delights to give readers some food for thought (ed)!

On a more serious, surgical note, St Mark's clinical director PROFESSOR JOHN NICHOLLS replies:

Assessing the long-term outcome of pouches is, of course, an ongoing exercise. Our experience at St Mark's is that at about a 10-year follow-up, approximately 15% of patients will have had to revert to an ileostomy. Half of this failure occurs in the first few months of the initial pouch operation and closure of the temporary ileostomy.

There is thus a longer-term failure rate of about 7-8% over a 10-year period. Whether this will continue in the future is unknown. There may be a small, but significant, failure rate. Only time will tell.

I think patients who have had an ileostomy they wish to get rid of, or those with uc needing surgery who wish to avoid an ileostomy, only have the option of pouch procedure in most cases. I suspect there is a surgeon-related variable in the failure rate. Various techniques are used and they may not all be satisfactory.

Life begins with a Koch pouch

Elaine Escott remembers the day she received some timely advice

Hi, I'm Elaine and I have a Koch Pouch. My story began a long time ago when I was 11 years old. Every month I was very ill with diarrhoea and sickness.

Then when I was 14 the doctors at my local hospital diagnosed ulcerative colitis. As the illness progressed, I became housebound. I lost all confidence in myself and my ability to tackle tasks.

After ten years' of treatment and four pregnancies, from which I had two beautiful children, Katie and Jason, I finally had no alternative but to agree to surgery.

At the time I was thrilled to think my illness would finally be over. I went ahead and had a total ileostomy at my local hospital in 1984. After the operation I felt great, happy and confident that I could lead a normal life. I would be able to go out without fear. Those feelings did not last long. I found it extremely difficult to adjust to the enormous changes to my body. I found I was always in the bath trying to get clean, as I was convinced I was dirty. Within a year I had been referred to what I considered my 'life-saver', St Mark's Hospital and consultant surgen Mr Peter Hawley.

He was extremely kind and completely understood how I felt. He asked me to consider having a Kock pouch. He explained the operation in great detail and by the end of 1985 I was settled into St Mark's awaiting my operation.

I spent a whole month in hospital, initially recovering from the operation and then trying to adjust once again to my

new appearance and, what I didn't realise, a new way-of-life. St Mark's staff and stoma-care nurses were amazing. They spent so much time with me and gave me so much understanding.

It was a very difficult time. In the space of just over a year, I went from a conventional ileostomy, which I totally disliked and which made me feel very unhappy and dirty, to basically nothing. The stoma, now reduced, only needed to be covered by a stoma cap. I could control how many times I went to the toilet. I didn't have to worry about the stoma-bag filling up and not being able to empty it.

I finally had no alternative but to agree to surgery

This change in appearance and habit brought a whole new set of problems. I found I still hated myself, I was convinced I was huge. I think this was due to my stomach swelling as the pouch filled during the day. Once again, St Mark's staff offered support in the form of professional help. I spent a year in a psychotherapy unit. They taught me to accept myself for what and who I am, to accept my appearance, and not to treat myself as different from anyone else.

It is now 13 years since the original ileostomy and 12 since the pouch operation. After the Kock pouch and treatment had finished, I decided to go back to work.

I worked for six years as a phlebotomist (you know the person who takes your blood in hospital). I really enjoyed the job, but felt I needed to pursue a career. I went back to college in the evenings to study human biology and chemistry A levels. Three years ago I changed jobs again.. I landed a job training to be a pharmacy technician. I passed the examinations last year.

I thoroughly enjoy my job and the challenge it gives me. I always felt that the pouch could not interfere with what I wanted to do. I wanted to be able to live with the pouch and not live for it. I now feel, finally, that I have achieved that goal and become my old self again.

I am sure anyone who has a pouch or a conventional ileostomy would agree that it changes yourlife drastically, but if you can learn to live with it and not let it lead your life, you will achieve great heights.

That is not to say the road is easy, but you can certainly follow it. Positive thinking, dear readers, is a must.

STOP PRESS INTERNATIONAL NEWS STOP PRESS INTERNATIONAL NEWS STOP PRESS

"GOSH IT'S ALL HAPPENING AT ONCE," SAID ALICE.

"WHAT DO YOU MEAN? WHAT DO YOU MEAN?" ASKED THE MAD HATTER.

"WELL, YOU KNOW THAT GROUP THE PRIDE OF RED LIONS OR SOMETHING.....IT'S BECOME A CHARITY, AND ITS'S GOT A FAMOUS PATRON AND IT'S GOT MEMBERS FROM ALL OVER THE WORLD," GASPED ALICE, SCARCELY ABLE TO CATCH HER BREATH.
"STEADY ON. STEADY ON. DON'T LET IT GO TO YOUR HEAD, DEAR GIRL. I'VE JUST CAUGHT YOUR BREATH - I WON'T BE ABLE TO CATCH YOUR HEAD AS WELL.
"CLIMB ON TO THE WEB-SITE NEXT TO THE LILY POND AND WE'LL E-MAIL THEM FOR A MEMBERSHIP FORM."

Did you know that you can e-mail the Red Lion Group on mag1@bakertilly.co.uk

Why not check out our web-site on the World Wide Web
http://ourworld.compuserve.com/homepages/timrogers/Redlion.htm

There are two newsgroups on the Usenet which cover discussions about pouches

* alt.support.crohns-colitis
* alt.support.ostomy

If you know of any other pouch-related sites on the World Wide Web, please let us know and we'll include them in Roar!

MEANWHILE BACK IN THE OUTBACK.....

Morag Gaherty has just had a letter from Michele Grumont in Hillarys, Western Australia. Michele has joined the Lions and will be writing an article about her experiences in the Summer issue of Roar!

So watch this space!!!!!!

Another contribution has just landed in the Red Lions' den from Simon Waley. He joined us last year and is writing an article about his experiences as one of the original guinea pigs for the pouch operation in 1979!

Watch these spaces!!!!!!!!!!!!!!!!

And as if that isn't enough for one Spring Roar!, here's another foreign item.....this time our source is the "PELVIC POUCH NEWSLETTER" in Toronto, Canada. In their recent newsletter, they ask readers to check us out on the World Wide Website (see above). They also tell their gentle readers that we have a newsletter called Roar!!!!!!! Fame at last!!!!!!

REGIONAL REPS

Here is our current list of reps with home telephone numbers - please feel free to contact your local rep and get acquainted

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Luton: Wendy Gunn
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Sue Appleyard
(01484 311334)

IF YOU ARE INTERESTED IN BECOMING A RED LION CONTACT MORAG GAHERTY

ROAR! Issue number 8 Spring 1998

JOIN THE RED LION GROUP....

Join the freshest and fastest-growing pouch charity around for just £10

*You will receive our newsletter Roar!, with news of events, local groups and the latest developments in the field

*You'll also be able to join in the activities of your own local Red Lion group

*We have recently become a charity and rely entirely on voluntary donations. We need your help to get even bigger and better. The membership fee is £10 (concessions £5 and free for cases of genuine hardship).

*To obtain a membership form, please write to the Liaison Officer (see below) enclosing your name and address and ideally a stamped addressed envelope. Don't forget to tell us if you qualify for the special concessions.

*Anyone can join, especially people with pouches or those considering having one Don't forget to tell anyone else you know who has a pouch, so they too can join.

*We have a Red Lion Cubs and Brownies group for anyone aged under 16.

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