Roar!

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Roar! is the newsletter of the Red Lion Group

CARING CLAIRE'S OUR NEW PATRON

Britain's number one health journalist and broadcaster Claire Rayner has agreed to be the Red Lion Group's new patron.

Having such an articulate and knowledgeable spokesman as our figurehead is quite a coup and will certainly help boost our steadily growing membership.

Claire is a Harrow-on-the-Hill resident and was a paediatric sister at the Whittington Hospital before opting for journalism, broadcasting and writing.

A non-executive director of Northwick Park Hospital Trust, Claire is frequently asked to sit on Government groups and committees on social and medical subjects. Last year she was awarded the OBE for "services to women's and health issues."

She is also the author of more than 90 books on health, welfare, and, under the pseudonym of Sheila Brandon, crime.

Her good sense and compassionate advice has helped many an anguished caller on TV and radio talk-shows and phone-ins and also on her many newspaper and magazine columns. For eight years, Claire was the Sunday Mirror's agony aunt, receiving 50,000 letters a year.

She has spent the last three weeks recovering from a knee operation at St. Mark's sister hospital, Northwick Park. We wish her a speedy recovery and a very happy new year as the mother-superior of our pride of Red Lions.

In this issue...

MARK THATCHER targets the Marksman appeal p.2.

SUSAN WALLS puts vanity before sanity p.4.

Ex-Red Lion secretary **MONICA MELLING** wants to look at life with a pouch p.6.

SYLVIA MIST gives us her group's view from Norfolk p.7.

JULIE LANIGAN and **HEIDI TANG** put our diets under the microscope p.17.

Please note the new address of your liaison officer, Morag Gaherty, on page 20.

MONICA'S MISSION: To find out what our former secretary is up to now turn to page 6.

St. Mark's Reaches the Parts other Hospitals Cannot Reach

MARK THATCHER (no relation) goes behind the screens to look at the vital pioneering work that goes on at St. Mark's Hospital and the support being given by The Marksman Appeal.

Since its foundation in 1835, St. Mark's Hospital has been as much a research institution as a treatment centre. The doctors at St. Mark's have always sought to learn more about colorectal diseases and to develop improved methods of detecting and conquering them.

Research at St. Mark's has been fruitful and the Hospital can lay claim to being the crucible of the speciality of coloproctology. Notable achievements and discoveries include:

the first hospital to follow up cancer patients. As a result the bowel cancer information bank at St. Mark's, dating back to the 1920's, is pre-eminent in the world;

the Dukes staging system formulated, to enable doctors to predict bowel cancer patients' prospects and to plan treatments accordingly;

the genetic component of some bowel cancers and familial adenomatous polyposis recorded and better understood;

the ileo-anal pouch operation devised to spare many patients undergoing proctocolectomies from having stomas;

the precise diets required by patients receiving parental nutrition continually refined;

the link between obstetric practice and anal sphincter damage established;

drug protocols for inflammatory bowel disease described; and

biofeedback developed and demonstrated to be an effective tool in overcoming some functional bowel disorders.

In recent times, research at St. Mark's has increased and progress has been aided by the Hospital's move to Harrow, where it has more space and improved facilities.

However, St. Mark's can only further expand its research work if funds are found for scientists, equipment and overheads. The surplus from the private Sainsbury Wing is an important source of revenue. Another source is The Marksman Appeal, a joint fund-raising campaign with the Imperial Cancer Research Fund, which has its Colorectal Cancer Unit within the Hospital.

If readers have any thoughts about fund-raising, or if they have contact with illustrious individuals who might be able to support research at St. Mark's, either financially or in other ways, please get in touch with:

Carol Cohen
The Marksman Appeal
St. Mark's Hospital
Northwick Park
Watford Road
Harrow
Middlesex
HA1 3UJ

Or tel/fax on 0181-235-4042

Going Insane with Pain

We've a lifetime going to the loo
But you can't discuss it - it's just too, too taboo
When the pain is crippling, the bleeding's appalling
You're absolutely desperate, but surgery's galling

What then can you possibly do?
Till the doctor suggests an op which sounds new
But you'll try anything once to get you through
Especially if they offer a room with a view

Doctors poke, but that just stokes
The furnace inside your guts
"Come along ducks, no ifs or buts -
It's just like having tummy tucks"

So you're left with one choice, and that's to choose -
You're so weak, you can't refuse
And though you're torn, you sign the form
Put up with queues for hospital loos
But nobody said, as you lay in your hospital bed

That the night nurse has loud shoes.

Sarah Myers

Editorial

Christmas is a time of good cheer, fellowship, faith and charity.

And for the past twelve months, Red Lion has been trying to achieve the last of these seasonal aims - charity status.

It would give us greater standing as a support group and enable us to organize substantial fund-raising events.

As you know, the committee, helped by a firm of Accountancy specialists, drafted a constitution that was approved at the April annual meeting.

Soon afterwards, we sent off our findings to the Charity Commissioners and waited for a positive response.

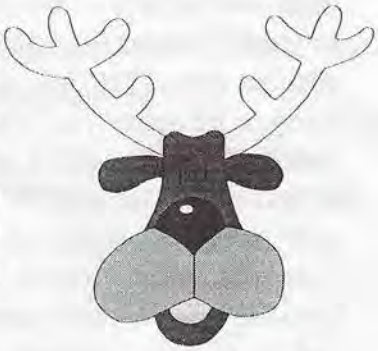
We had hoped to bring you the glad tidings in this issue of *Roar!* However, even the best laid plans can stray into unexpected waters.

The Commissioners told us there were seven other charities or trusts with a similar name - you would have thought other prides would have been delighted to be associated with us!

We have decided to persevere with our current name regardless. We have after all been using it for nigh on three years.

They also asked whether we were associated with illnesses of the bladder. We have been able to put them straight on that one too!

So, with a little fine-tuning, we hope to bring you the good news in the New Year.



Meanwhile, Happy Christmas and a healthy 1998 to all our readers!

Convalescence
After my main 'OP'

If you're feeling below par then come to Shangri La
It's called a convalescent home
The staff are all so friendly, so helpful, and so kind
There's not one gloomy face that anyone can find
Nice comfy beds, soft pillows too, a nurse at hand to take good care of you
No need to feel unhappy here, homesick, or even blue
There's always someone close at hand to have a chat with you
Soon it will be time to go, to face the world outside,
To leave some new found friends behind to travel far and wide
I hope you'll all feel better soon and home you soon will be
Maybe one day we'll meet again to share a cup of tea.

Audrey Ramsey

WHY GETTING BETTER CAN BE A SCARY EXPERIENCE

Coping with rude health can be just as tricky as fending off illness, discovers Susan Walls.

Getting better after a long chronic illness can be a very scary thing to do. When you're ill, you long to get your life back. But when you do get it back, you suddenly remember just how hard normal life is to cope with.

A friend of mine who has ulcerative colitis came round to see me the other day, for advice and comfort. She's waiting for a colectomy and pouch formation, and she's very scared indeed. But it's not just the long operation or the thought of an ileostomy that scares her. Once I soothed her fears and had shown my scar, she suddenly blurted out her biggest, deepest fear: "I'm not sure I'm ready to be better yet," she wept, "what on earth will I do with myself when I'm well?"

I can quite see her point. Pat has been ill for ten years now - she had a pituitary tumour before colitis struck - and she has built her life around her inability to function properly. She gave up a promising career in computer programming for a household existence. She gets regular letters from former colleagues who're now running multi-million dollar businesses in Australia or America, and she often wonders what her story would have been if the finger of fate hadn't singled her out for a double dose of ill-health. She has resigned herself to her lot, and when her health has allowed it she's been a great stay-at-home mother. This is now her life, and being well again just doesn't figure in her picture of herself.

Being ill is hellish, but at least you know your role. Getting well after you've been ill for so long gives you choices that you are unequipped to deal with. It's a bit like fighting a war: it's a terrible thing to do, but being in the army and following orders and living in pain and fear, and having absolutely no choice about how you live your life does have its upside. At least you know what to do, and you don't need to worry about whether you are doing the right thing, or making the right decisions. After the war is over, soldiers are at first hysterical with joy. Hurrah! - they're still alive, and they can have their lives back. But then what? A few weeks or months of real life, and suddenly it doesn't seem so great anymore.

Nobody warned me that after my own personal war was over, I'd go through periods of depression and fear. After being so ill, for so long, I had expected everything to be rosy and perfect once I was better, but of course it isn't - why should it be? My life is much like everyone else's except I lost five years somewhere along the line, and I tend to get more tired more quickly than other people. But Pat made me feel so much better by just saying the words out loud.

Other people feel this way too, these emotions are normal and okay. It's scary to get better. Just accept that fact, be scared, and then get on with the rest of your life.

SUSAN WALLS

When Beauty is in the Eye of the Beholden

Sometimes it's a good idea to put vanity before sanity, says Susan Walls.

One of my friends rang the other day. She had ulcerative colitis; and we met in hospital while I was waiting for my colectomy.

"How are you doing?" I asked.

"Fine," she said "I'm not too bad at the moment." Then, after a beat she added, "I'm still fat, though - not that it really matters."

But it does matter. I remember the steroid-fat: the puffy tummy, the bloated bits, and the great round waxy face shaped like a Halloween pumpkin. Ulcerative colitis is no beauty treatment. It's bad enough being ill without looking like hell, especially - and I hesitate to say this, but I think it's true - especially if you're a woman.

When I had colitis I looked like a blimp on steroids, and a skeletal freak if I didn't take them. My skin was thinning rapidly, thanks to the steroids, and stretch marks appeared everywhere, thanks to the thin skin and the dramatic weight changes. I had frizzy, fluffy flyaway hair, and a thick dark growth on my upper lip. My teeth suffered. My bones suffered. I got big black bags under my eyes from water retention. I looked like a beauty editor's nightmare; a candidate for an *Elle* makeover if ever there was one. I tried not to look in the mirror, because I really didn't want to think about it, and every day I chastised myself for caring about something so silly and shallow as my appearance. I knew it was better to look dreadful than be dead. I'm not a vain person - no more than anyone I know - but it did matter to me that I lost my looks. It seemed like the final insult.

Our culture puts so much pressure on women to look good, to look young and to look healthy, that it's truly hard work being ill. Even now, a year and a half after pouch surgery, I still have a hang-up about how I look, because I'm still dealing with the legacy of colitis. I get tired very easily, and I look pinched and drawn when I do. My skin is very fine now, so that fatigue shows quickly; it's dry too, because of the dehydration caused by the colectomy. And I'm slightly too thin, now that the steroids are gone, which doesn't do any woman approaching 40 any favours.

On a bad day (and I get quite a few) colleagues look at me sympathetically and say stupid things like: " are you all right, you look very tired today", or "you look awful - are you overdoing things?"

I have two fantasies to help me deal with this kind of thoughtless sympathy. In the first, I stand outside the office door and announce through a megaphone: "Do not be alarmed. I'm coming in, and I don't look well today. Please stand well back, and do not try to give me sympathy."

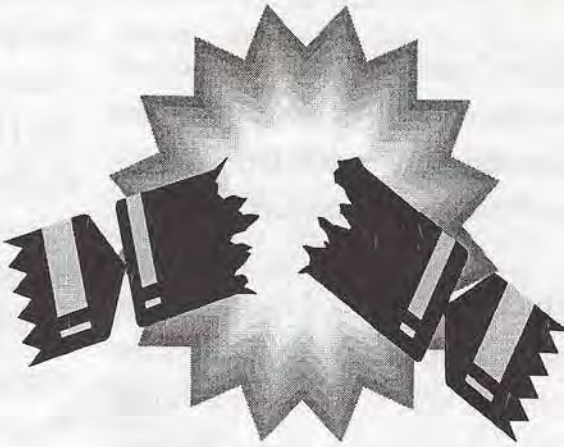
In the second scenario, I simply say to the sympathy-giver: "Hey,

you don't look so hot yourself."

I do not really recommend either of these strategies, but it cheers me up to imagine them.

On a more practical note, I do recommend a good light-diffusing make-up; some blusher; regular facials; loads of moisturizer; and lots of water to drink.

Oh, and a robust sense of humour.



MONICA'S MISSION

Your Group Needs

YOU!

Do the activities of your pouch interest, irritate, or even amuse you?

If so, former Red Lion Group secretary Monica Melling would like to know.

For Monica, who is currently taking a MSc in Health Education and Promotion at King's College London, is carrying out in-depth research into our inimitable private part.

If you would like to talk to her about your post-pouch lifestyle and experiences, please phone 0171-642-1664 or write to her at 48c Hackford Road, Stockwell, London, SW9 0RF.

All research will be carried out in the strictest confidence - a summary of her anonymous findings, due in Autumn 1998, will be published in a future issue of *Roar!*

Says Monica: "I hope the study will help inform experts and amateurs alike about the advantages and disadvantages of having a pouch."

MY DAUGHTER

(Written after my "op")

I have a lovely daughter, her friends all call her Sue
Without my lovely daughter I don't know what I'd do
She's generous, kind and helps me to unwind and sees me
Through my various 'OP's' and downs!
She never ever grumbles when I moan about my tumbles
She makes me laugh when sometimes I could cry
So here's to a super daughter, there's so very few
None of them are half as good as my own daughter Sue

Audrey Ramsey

The View from Norwich

I held the first meeting of the Red Lion Norfolk group at my house in November 1994. There were six people at that first meeting but we have since grown to a steady group of ten.

For the first six months we used to meet either at my house or one of the other member's about every six weeks. We were all very open and honest with each other and shared our "pouch" experiences. Through this, we were able to offer each other support, which we continue to do today.

In November 1995, our first Birthday, we were very privileged to have Mr W Stebbings (our local pouch surgeon) attend our meeting. Mr Stebbings gave us a talk on "The Pouch", complete with a slide show (not for the faint-hearted), followed by a question and answer session. Mr Stebbings gave us five hours of his Saturday afternoon, for which we were all very grateful.

During 1996, we continued to meet about every six weeks, holding some of our meetings over Sunday lunch at a local hotel. In the Summer of 1996, I held a barbecue at my house for all group members and their families; the weather was perfect and an enjoyable day was had by one and all. It was a great opportunity for us to meet each other's families.

In the last year, the group has come a long way. As well as supporting each other, we wanted to do something positive for others, so after much soul-searching we decided to volunteer our services as listeners at the colitis and pouch clinic (one Friday afternoon a month) at our local hospital, the Norwich and Norfolk. To prepare us all for this venture, we embarked on a day's training on listening skills, kindly paid for jointly by the Red Lion Group and Dansac. We followed up with several lengthy meetings discussing guidelines for ourselves, as well as producing our own booklet and posters for the whole project. Our first session was held on Friday, 7 February 1997.

In April 1997, our local stoma care nurses held an open day at a hotel and our group was invited along to provide a stand.

We are getting more enquiries for people to join our group. We have decided to keep group numbers at ten, so we can still meet in people's houses. We have also started another group, running the two separately but with a joint meeting over lunch in a hotel about every three months. At present I am co-ordinating both of these groups.

There is also a third Norfolk group headed by Sandy Hyams, to cover the Kings Lynn area, as Norfolk is a very big county.

As you can see, we are an active local group. I am always looking for ideas to keep the group alive and would be pleased to hear from other reps about their ideas and activities.

Sylvia Mist

Hospital Blockbusters

Please support the Red Lion Group

All donations, however small, are very gratefully received. If you have found this newsletter useful and wish to support the group and research into pouch matters, please send your donation to: **The Red Lion Group Treasurer, Mr. P B Johnson, 7 Chelston Approach, Ruislip Manor, Ruislip, Middlesex, HA4 9RY.**

(Cheques should be made payable to "Red Lion Group".)

A Colitis Christmas
Before my pouch op. In hospital 6 times on and off

Here I am in my hospital bed,
Feeling lousy and nearly half dead.
In my own little room and three concrete pillows
Suffering badly from Wind in the Willows!
Stomach aches and lots of pain
I'll have to send for the bedpan again!
Sleepless nights and fits of blues,
I wouldn't wish anyone else in my shoes
Lots of visitors coming in shifts, each one bringing
their own little gifts
The nurses are super, Sister is great too, but
I wonder just what they're planning to do
X-rays and blood tests, bedpans and pills
temperature taken, avoid sudden chills
Mustn't do anything just lie in bed,
my puzzles I've done, my books I've read
Nothing to eat, the Doctor says, and nothing
to drink for three whole days
Everything has to be tested and measured,
the memories of food a joy to be treasured
Can't leave the room cause I'm on a salt drip
Can't eat my grapes, fair gives you the PIP!
It's Christmas morning, the family's here
dispensing the shiny presents and cheer
The Doc has relented, he says I can eat
I shall get to have my Christmas treat
Turkey and sausage meat, pudding and jelly
sitting in front of my own little telly
Another day and I'm feeling much better
I might even feel like writing a letter
They have treated me royally and all been so kind
I almost feel sorry to be leaving them behind.

Audrey Ramsey

MY MUM

My mum had ulcerative colitis for many years before I was born. She was very self-conscious; she would never go our anywhere unless she knew there was a toilet nearby. She would not go on a train, a long bus journey or for walks on Mousehold Heath etc.

In 1992 when we were on holiday in Skegness, my mum became very ill. My dad called the doctor when we got home and my mum was rushed into hospital. She had an emergency operation and was given an ileostomy. She was in hospital for two weeks after the operation. I missed my mum a lot and would visit her every day. My dad worked away, so my nanny looked after my brother and me.

When my mum came home, I was really excited, but she had to rest for a couple of months. Once she was better, we would go out at the weekends to the beach or in the country where there were no toilets! In the summer holidays, my mum took my brother and me on a train to Lowestoft for the first time. It was strange at first to see my mum with her ileostomy, but I soon got used to it. My mum became more confident in herself and she started to worry less.

After having her ileostomy for one-and-a-half years, she was given the choice to have a pouch made. We all discussed it and agreed that she should have the operation. At first it was strange to see my mum worry about toilets again, but after a while she did not have to go so much as she did when she had colitis. She had a few small problems with her pouch at the beginning, but they were soon sorted out.

My mum's confidence continued to grow and in 1995 she passed her driving test. She would never have tried to learn to drive when she had colitis and her pouch has made a big difference in her life.

Sarah, Norwich

THE JOURNEY

It has taken me some time to write this piece. Like many writers the title has been one of the most difficult parts. There are times when I could have called it "The Nightmare" or "The Road From Hell" but today I am feeling more objective and positive.

This journey was unlike most in that it was not voluntary. I had no way of knowing how long it would take or where I would exactly end up. I was a new and naive traveller on my maiden voyage, alone.

At the time I did not understand that it was going to be a major and most significant part of my life. Nor did I know that along the way I would suffer enormous loss and great pain, but that eventually I would meet new people, go on to develop stronger relationships and gain greater knowledge of myself.

During my journey, the one person I hoped would be waiting there for me at the end, was not. He was as ill-prepared as I was.

I was mistaken that once the surgery was over, then so was this amazing journey. One year on, I made plans to rebuild my life but I had not taken account of how long it would take to recover fully (emotionally and physically). One more year and I finally began to live again. I retrained to forward my prospects in the caring profession, something I had wanted to do for some while. I used my experiences to get "in touch" with people, to feel real empathy.

At last my life has new meaning, I believe I appreciate people and things around me more, I try not to put off things that I want to do and most of all I want to live my life with no regrets. I make a point of spending time with the people I care about most and that by doing this I know that I am taking better care of myself.

However the journey never ends. I will always have a pouch and continue to find ways to integrate it and the experiences that went with it into the rest of my life. At times this will be a struggle but I also know there will be great joy.

Norwich Group Member.

WHY I JOINED THE RED LION GROUP....

I developed i.b.d. in 1986, it was chronic and severe and surgery was the only option. At the time I was one of the first people in the Anglia area to have pouch surgery.

I was desperate to speak to someone who had been through it, someone my own age and someone who was single but with a partner. While a national group for Colitis and Crohn's sufferers were helpful and supportive, no-one could supply me with all I needed to know.

My pouch was formed in 1988 but it was not until I moved back to Norfolk a few years ago that I learned about the Red Lion Group. Sitting in someone's house with people the same as me was totally liberating. So many people had had similar experiences, we shared ideas and tips, talked of our pain and later laughed about some of our tales.

Far from wallowing in our own self pity we have put our energy into positive changes for other people who are considering pouch surgery. We believe our listening at the Norfolk and Norwich Hospital is unique in this country.

It is my view that patients need help to heal from within - not just their bodies but their hearts and minds too. Self-support groups can offer so much in rebuilding self esteem and increasing confidence. I may not be the best example of a Parkes Pouch patient but, most importantly, I have come to terms with who I am and what I have to give to others.

Norwich Group Member

After 10 years of colitis and four operations, the question I kept asking myself over and over again was "Why me, what did I do to deserve all this?" For 10 years I felt that my life was in limbo, not knowing when I'd get a bad attack or even end up in hospital.

Then the day came when medical science went as far as it could and I was given a pouch. With limited information and the feeling of isolation, I knew that I wasn't the only person with a pouch but it sure felt that way to me.

I was pleasantly surprised when I asked to become a member of the Red Lion Group, a chance to meet people who've had similar experiences.

The growing membership of the group confirms the need for such a group. Our group has started expanding in areas to try to help people to come to terms with the changes that have been made to them, both physically and emotionally.

As pouch surgery is becoming more common, the need for associations like the Red Lion Group will continue to grow. It is up to the pouch owners to mould the groups in the way we want, after all they are formed for our benefit.

MA Norwich

I feel that since going to the meetings with the Red Lion Group, I have been able to talk about my problems concerning my illness and operations with people whom all understand. I wish the group had been around earlier as just after my operation my father died and I was having problems with my pouch. I felt I had nobody to talk to.

IBC Norwich

OUR GROUP

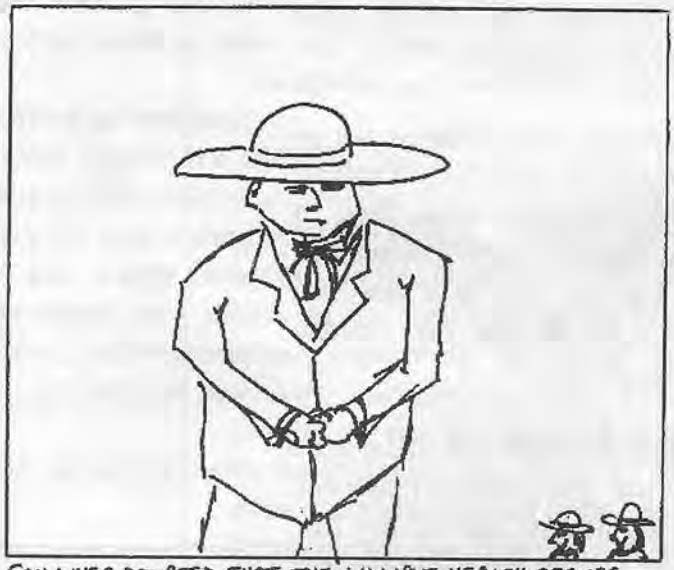
Our group had been meeting every six to eight weeks for the last two years. In this time we have become good friends.

The group has helped me in lots of ways, sharing common problems, tips on eating and drinking as well as just being there for each other.

We have had several social meetings which have been very enjoyable. Three or four times we have had Sunday lunch at a local hotel.

Then there was the barbecue that Sylvia held in her back garden on a lovely warm Sunday last July. We took our families with us on that day. Andy, one of our group, was in charge of the barbecue; Sylvia prepared most of the food, jacket potatoes, lots of tasty savoury bits and pieces, several different salads and a delicious gateau; we also had a huge bowl of fresh strawberries with lots of cream. It was a day we could all relax and enjoy ourselves.

PS Norwich



GULLIVER DOUBTED THAT THE LILLIPUT HEALTH SERVICE WAS UP TO THE CHALLENGE OF HIS POUCH OPERATION

The Norfolk Groups are planning to organize two events in the first half of next year.

The first will bring together all reps in Norfolk, Cambridgeshire, Northamptonshire, Bedfordshire and Hertfordshire, where they will be offered help and advice in how to set up and run a local Red Lion Support Group.

The second will be a support-cum-social event for all pouch and prospective patients in these counties, introducing them to their local rep. More details in due course.

This proposal was offered to and welcomed by the National Red Lion Committee at their meeting in November.

Letters

Roar! Letters Page

16 Hill Brow
Bearsted
Maidstone
Kent
ME14 4AW

Dear Sir

I read with great feeling Susan Walls' article in issue number 5 of *Roar!* I'm sure all of us suffering from ulcerative colitis has one special person in their lives who deserves a bouquet. Let me tell you my story.

I first became ill in 1968, whilst living in Germany 25 years old and pregnant with my second child. After countless visits to the doctor and health visitor, I was at last being examined by a surgeon, whose words were "No lumps or bumps, just a reaction to being pregnant. Everything will be fine once the baby is born". Things were a little better after my beautiful daughter was born and I somehow learned to live with the illness (still not knowing what it was.)

I had another lovely daughter in 1971, and then returned to England to live, still putting up with my all too frequent trips to the loo, sometimes not making it there in time. On my bad days the children just put it down to "Mummy's tummy playing up again". Suddenly, when my youngest child was barely a toddler, the illness came back with a vengeance - extreme bouts of diarrhoea, sickness, stomach cramps and loss of blood resulting in a feeling of great tiredness. My trips to the doctor became much more frequent and again "No lumps or bumps, with three young children under 5 years old, you're a neurotic mother". I was

I met Jonathan English, who is one of the regional reps for *Roar!*, a few months ago through work. I had never met anyone who had a pouch before and had never heard about pouches, let alone what it was all about. When Jon first told me about his pouch I wanted to find out some more information. As the weeks passed, Jon would describe situations and experiences but it still didn't make sense to me. Personally, I function better with diagrams than words and eventually Jon sat down with a pen and paper and drew the last few years of his life on paper for me. Finally it seemed to make sense.

Last month I went with Jon to St. Mark's Hospital for what he calls his yearly M.O.T; something he was not looking forward to. All went well, and Jon was told he did not have to go back until a year later. Whilst I was at the hospital, I tried to get hold of information regarding pouches for my personal reading, but found there was hardly any information readily available. I wanted leaflets with simple terminology and diagrams, something that gave me an insight on everyday situations, experience and advice.

I was so pleased when Jon showed me a copy of *Roar!* I read it from cover to cover and found the articles interesting. It made me feel a sense of security, that there was support out there if Jon or anyone else ever needed it. Issue number six - Autumn 1997 came along; with it was a "Healthy Eating for People with Pouches" guide which I found very interesting and helpful. The Red Lion Group is doing a wonderful job in supporting people with pouches and their partners.

In the last month I have been experiencing personal problems of my own. In these situations it's very easy to be selfish and to let your needs supersede everyone's around you. Jon has been totally supportive regardless of whether he has a good or bad pouch day. This I value and appreciate very much. I can't begin to imagine what Jon went through during the last years, and want to take away all the pain he suffered. I can only give him love and support. With Jon I get the full value of happiness.

Thank you for everything you have done at St. Marks to make it possible for Jon to be here.

Many thanks

prescribed gallons of kaolin and morphine, and dozens of valium tablets, which at first made me feel worse than ever, and did nothing to help my pain. It got to the stage where every visit to the doctor I was presented with another prescription for valium, which I ripped up on the way out. How could my poor family understand what was happening when the doctor just dismissed it as "Nerves". How could my dear children understand when I frequently had to leave them standing where they were to dash to the nearest toilet, very often not making it, only two minutes later to dash back to it again? I couldn't go anywhere without knowing where the nearest toilet was, and then positioning myself right beside it. I'm sure I knew every tree, bush or fence down our village road, as I frequently had to dash behind them.

Then in 1977, 9 years after I first became ill, I almost begged to be admitted to hospital. I was there for two weeks going through every test imaginable, and at long last I had a barium enema showing that I had ulcerative colitis. In a way it was a relief to find I had something definitely wrong, and that it wasn't all in the mind as I had been told so many times. Now it was just a case of giving me a tablet and all would be well.

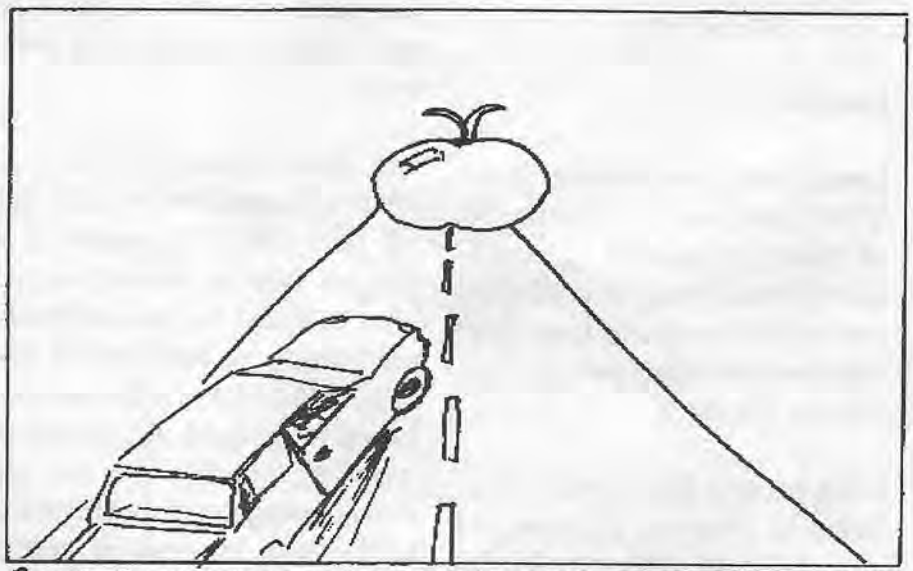
I was put on Salasopirine, and enemas twice a day. I began to feel even worse than I had in hospital, and after a routine blood test it was found that I was highly allergic to the tablets, so I carried on with the enemas. After a few months it was obvious that the enemas weren't doing any good at all, and back into hospital I went. More tests, and then the dreaded day when a doctor sat on my bed and told me the only thing he could do for me was to remove the whole of my colon and make an artificial opening in my side for the waste to go through. How horrifying! I had never heard of anything like that at all before. No I wouldn't have it done. I was so proud of my lovely flat tummy after having three babies, and how I loved to sunbathe in my bikini.

But it soon became more than apparent that I had to have it done, and very quickly too. However, after all my tears, my surgeon decided he would join the end of my small intestine to my anus making the ileostomy temporary. Although he didn't like to do this as there is still disease left in the body. I was in hospital four and half months leaving my dear husband with three tiny children to look after, as well as a very stressful job. It was at a time when children under 12 were not allowed to visit, which disturbed them as well as myself, the worst part being when all three got chicken pox, so David was not allowed to visit either for risk of infection.

The operation worked however, although I was not a new person. I began to put weight on my skinny frame of 5½ stones, and I was able to go out much more, but of course I still had to know the layout of every toilet in the area.

Sadly my husband died prematurely at 43 years old. Not only had I lost a good husband and devoted father, I had lost my support and encouragement in all my years of illness. Now I really did feel alone.

However I was very lucky and remarried four years later, a very fit and well man, the words 'doctor' or 'hospital' were alien to him. I told him nothing of my illness, using gallons of air freshner and perfume to mask the smell every time I went to the toilet. When he asked about the scars on my tummy, I just said I didn't want to talk about it.



Disaster struck again two years later, when the UC really returned with a vengeance. Much worse than before, as I had no bowel at all. I was backwards and forwards to the loo as many as eight times in an hour. I was very often sick, but in some strange way I wanted to hide my illness from him. Perhaps because it was my second marriage I wanted to appear perfect for my husband in every way. By this time I was practically incontinent, every day having one or two accidents, and I found every excuse in the book to hide them. I would dash upstairs, jump in the shower and come down with a fresh set of clothes on, only to say I was either too hot or too cold. If I went to a public loo, there was always water on the floor that my clothes had fallen into. Many nights I had to waken my husband from a lovely sleep to change the bed, my excuse being that I was on the "change" and my periods were very irregular. And the times I have been scrubbing the bedroom and bathroom carpets in the middle of the night. Looking back, I think I was kidding myself rather than him, but at all times I was assured of his total love and support. I often used to wonder why.

To cut this long story short, after we had been married 5 years, a new surgeon came to our hospital and I was straightaway offered the pouch operation. Neither of us had heard of this before, and naturally we were very apprehensive, me especially as I had had a very bad experience of an ileostomy in the past. But once again it became apparent that I had to have it done very quickly. With every care and reassurance from my surgeon I had the operation in 1993.

After several small setbacks, I am a new woman now, and I realize how ill I felt in the past. I have put on two stone in weight (which I badly needed), I eat and enjoy almost everything, and I can pass a public toilet without dashing inside. When other doctors or nurses have heard my history, there is always the same reaction "Oh you poor thing".

Poor ME? I have had not one, but two, fantastic husbands to love and care for me in all the dark and difficult days. I have always had the support of three beautiful children, and now I have four darling grandchildren, a constant source of pleasure and delight. I work full-time at a very demanding job, play golf two or three times every week, and of course I have one of the best surgeons in the country.

No, I have had one or two hiccups, but I have been extremely lucky, and certainly know that it isn't money that brings you happiness.

Diane Travell

Dear *Roar!*

Thank you very much for the Easter newsletter. Keep up the good work!

I was very interested in the front-page article by Dr. Martin Peters, about prescription charges. Unfortunately I have become very seriously ill again, even though I have a Colonic-J pouch, and paying for my tablets was taking a big chunk out of my sick-pay. Then my chemist said "Why don't you apply for an AG1, in fact here's a form, after all what have you got to lose." I filled out the form, and sent it to the following address:
PPA
(Prescription Pricing Authority)
Health Benefits Division
Sandyford House
Archbold Terrace
Jesmond
Newcastle-upon-Tyne
NE2 1DB

who rang me after about three weeks, to ask me some questions about my state, and illness. A week later I received my NHS certificate, which states that I can have:

Free NHS prescriptions
Free NHS dental treatment
Help towards buying new glasses
Help with going into hospital
Help if I need a wig, or support.

It has helped me but I think it's because I'm on sick leave, and also because I haven't got that much money in the bank, it may help other members, though from the number of new cars I saw at the last meeting, a lot of the members appeared to be better off than me, so they may not be able to get the benefit. Anyway it's something to think about.

Yours sincerely

John Draser
Redditch

Light at the end of the Tunnel

And there is light at the end of the tunnel
I see it shining there
Or is it just my imagination
Dressing up what's dark and bare?

If it's real, can I reach it?
What will it take to get me through?
It's been a long time since I saw the outside,
Felt the breeze, and you

If I sit quiet and concentrate my mind on that light
And how it makes me warm
Perhaps it will get bigger
And fill the room with dawn

Whose fingers drive the shadows
That flank my wasted soul
To leave a bleeding heart smiling
And a spirit distorted but whole

There *is* a light at the end of the tunnel
I see it still
It's not getting any bigger
I wonder when it will

Sarah Myers

By e-mail
Subject: Easter *Roar!*

Just a note to say that I thoroughly enjoyed the Easter Issue of *Roar!* Particularly the article by Virginia Ironside about the hazards of steroids, as it brought back memories of my own personal experience of these drugs. It was comforting to learn that someone of obvious intelligence was overcome by them to the extent of being removed from reality. Keep up the good work and let's have some more interesting articles that do not mention toilets.

"Delboy435@aol.com"

Editorial note: as explained in the Easter edition of Roar!, all pouch patients are eligible for free prescriptions in the same way as ileostomists. Copies of this article are available for sceptical doctors!

A VERY BIG THANK YOU ...

to Inez Malek's parents, Mr and Mrs Veglin, for their kind donation to the Red Lion Group of £500.

WRITE FOR ROAR!

Have you had any interesting or amusing experiences that you think other people with pouches might want to read about in the Red Lion Group's newsletter *Roar!*?

We are particularly looking for pouch-related articles, but we are happy to publish practically anything. Perhaps you've taken up a new hobby since having your pouch operation? Or are there any clever little tricks or diet tips you've picked up that you'd like to share? We'd even be willing to publish an article about why having a pouch was a bad idea.

Even if you've never been published before please send us something. You'll get the satisfaction of seeing your name in print and you may give hundreds of fellow pouch patients an insight into an aspect of their condition they hadn't noticed before. Most important of all you'll make the life of the newsletter editor a little bit easier.

If writing articles isn't your scene we are looking for other things too, including cartoons, crosswords and jokes. If you can't draw but have what might be a great idea for a cartoon please let us know. We'll get our resident artist on the case right away. (His work is scattered throughout this issue.)

With your contribution we can keep the newsletter bursting with life and make reading about pouch issues fun and stimulating.

In the next issue

The next issue due out in early 1998 will focus on the diseases that necessitate pouch surgery.

Please write in with any specific topics you would like to see covered.

Colonic Irrigation

Madam, I see from your list
That your symptoms are this:
Nerves, stomach cramps and constipation.
Well, our cure is ideal for stomach irritation
Caused by fibre build up and putrification.

The remedy is colonic irrigation.
Irrigation colonic
The very best tonic
As recommended by the Princess of Wales
Who, among others, swears it never fails

Well, lots of things are unnatural, that's no excuse
Look at cars, TV presenters and solvent abuse
It's only sixty litres of water
At pressure, pumped up your bottom
It makes you feel fresher

It's a one hundred percent safe solution
As recommended by all the world's media
I promise you, you won't regret it
And afterwards you'll feel so fit.
Comfortable? Good.

Excuse me, why is your head swelling?
What's that, smelling?
This is all going horribly wrong.
Well, why didn't you tell me you had no colon?

Sarah Myers

[Ed note: This poem, like the others in this issue, was performed by Sarah at our national meeting in 1997, some months before the tragic death of Diana, Princess of Wales.]

Decisions, decisions ....

One of our members who needed to make a decision about having a pouch operation was told by her surgeon that "50% of pouch owners who had ulcerative colitis revert back to an ileostomy within 20 years", and that the operation was not as successful as first thought.

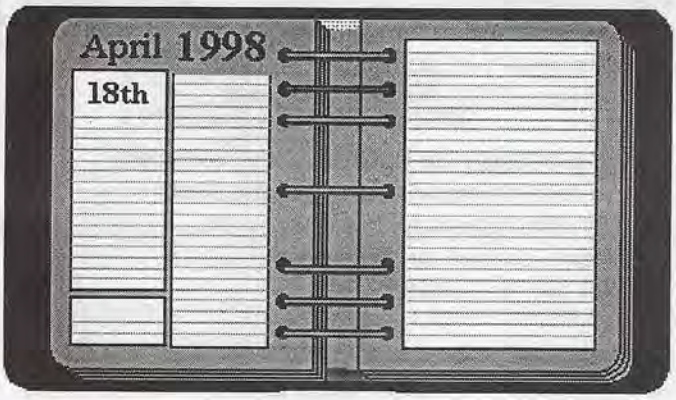
Our member asked us for more information on the latest statistics for failure rates.

While this is not the picture we get from our database, we thought that the query deserved a more complete answer so we passed this lady's letter on to Professor Nicholls for his comments.

This is his response....

The situation regarding the long-term outcome of pouches is, of course, an ongoing exercise. Our experiences here at St. Mark's are that at about a ten-year follow up, approximately 15% of patients will have had to revert to an ileostomy. Half of this failure occurs within the first few months after the initial pouch operation and closure of the ileostomy. There is thus a longer-term failure rate of about 7% or 8% over a ten-year period. Whether this will continue into the future is unknown. It may be that there will continue to be a small but significant failure rate, time only will tell.

I think the patients who have an ileostomy which they wish to get rid of, or those with ulcerative colitis requiring surgery who want to avoid an ileostomy, have only the option of a pouch procedure in most cases. I suspect that there is a surgeon-related variable in the failure rate. As you know there are various techniques carried out and they may not all be satisfactory.



One for the diary

Due to the success of the session in 1997, one event that we guarantee will be included is the question panel. If you have any issues you would like to be raised with the panel before the day please write to the editor with your question.

Thank you to all the people who returned their comment sheets on the format for the national meeting. The vast majority of people preferred the event to be held on one day.

The next annual general meeting will be on Saturday 18th April 1998 and will be followed by the Red Lion Group national meeting.

This year we will be joined by other pouch owners as we will be hosting the *ia* pouch owners' day.

More news about the event will be sent to you nearer the time, and we look forward to seeing you there.

Study Success Precedes Diet Booklet

JULIE LANGILAN AND HEIDI TANG report the findings of their study into diet and pouches.

Thank you all for your patience in awaiting the findings of our study. It was a great success, supporting previous research and highlighting specific areas for further investigation.

Ably assisted by Julia Williams, pouch support nurse, and dietician Morag Pearson, we produced a comprehensive dietary booklet for members of the Red Lion Group. *[Which came out with the last newsletter.]*

In brief, 157 responses were received altogether and we were able to analyse 143 of these. The majority (93%) of you reported experiencing some undesirable effects associated with certain foods.

Many of you highlighted some fruit and vegetable items as being problematic, but the severity of your symptoms varied widely and foods which caused problems for some people did not for others.

No firm trends were seen for symptoms or symptom severity with respect to the type or age of pouch. As expected, the most commonly reported symptoms were increased bowel frequency, passing undigested food, increased wind, peri-anal irritation and decreased stool thickness.

Many of you informed us of foods that you found beneficial in respect of pouch function, and it would be interesting to investigate these foods further.

There were many reports that eating later in the day caused greater bowel frequency at night, but interestingly more than half of you reported consuming a large evening meal.

One finding, which raised concern, was that more than half of you reported a low daily fluid intake. This is of particular concern in those individuals who have more than four to six bowel movements a day. It is possible that some of you underestimate the amount that you drink throughout the day, but it is always worth bearing in mind that you should aim to drink between six to eight cups of fluid and this should be increased if you have frequent bowel movements, especially in the early stages after surgery.

Once again thank you for your input. It has provided us with the information necessary to compile dietary guidelines and highlight further important areas for

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THEMES FOR FUTURE ISSUES OF ROAR

In some issues of *Roar!* we try to focus on a subject of special interest to pouch owners or those of you thinking of taking a test drive!

If there are any subject you would particularly like to see covered please let us know.

THE PUZZLE PAGE

This editions puzzle was submitted by Audrey Ramsey ....

BIRD WATCHING

Phil has recorded the following code words for birds he has seen while on holiday. What has he spotted?

1	**A naval bird**
2	**Coloured tool**
3	**Fuel for a car**
4	**A grumble**
5	**A smoothing cloth**
6	**Left or right?**
7	**Boot polish**
8	**Royal Sportsman**
9	**Twin Tin**
10	**Dockside Unit**
11	**Islands**
12	**A bad throat**
13	**West Country river**
14	**A dark wind**
15	**Golfing term**
16	**Greedy one**
17	**Xmas one**
18	**I shot Cock Robin**
19	**Unlucky for some**
20	**Heavenly object with a fish**

Answers on page 18

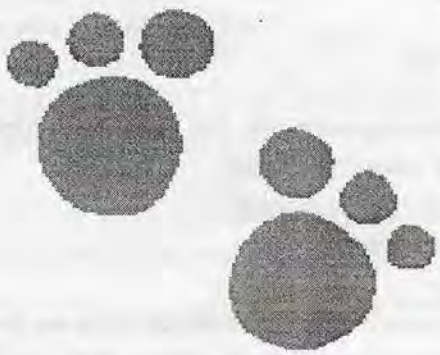
REGIONAL REPS

The Group's local reps are currently as shown below.

The number given is their home phone number. If you have not already done so, please feel free to contact your rep and get acquainted. Reps will be given updated membership lists for their area twice a year.

Bedfordshire		
Wendy Gunn	Luton	01582 423714
Berkshire		
Liz Davies	Langley	01753 586593
Cambshire		
Mike Hutton	Cambridge	01223 215264
Joyce Shotton	Peterborough	01733 706071
Cumbria		
Jonathan Caton	Kendal	01539 731985
Derbyshire		
John Roberts	Derby	01332 361234
Devon		
Gill Tomlin	Plymouth	01752 568643
Dyfed		
Briony Jones	Haverfordwest	01437 765359
Bruce Dibben	Haverfordwest	01437 731436
East Sussex		
Kate Bosworth	Brighton	01273 887102
Lisa Critchley	Brighton	01273 699286
Essex		
Peter Zammit	Benfleet	01268 752808
Gwent		
Robert Challenger	Cwmbran	01633 866820
Hampshire		
Phil Smith	Portsmouth	01705 426541
Les Willoughby	Winchester	01962 620012
Hertfordshire		
Carol George	Stevenage	01438 365707
Kent		
Beverley Dallen	Cranbrook	01580 850221
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 82529
David Smith	Northampton	01604 450305
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		
Bernadette Monks	Salisbury	01722 327388
Yorkshire		
Neil Anderton	Leeds	0113 258 2740
Sue Appleyard	Huddersfield	01484 311334

If you are interested in becoming a regional representative please contact Morag Gaherty at the address shown on the back page.



Join the Cubs ..... the Red Lion Cubs

We would like to produce an occasional insert for our younger pouch owners and the children of pouch owners containing articles, jokes and cartoons written for and by our younger friends. Chief Lioness will be Julia Williams, pouch support nurse.

If you would like to submit anything for publication please send it to the Newsletter Editor marked "Cubs".

Answers to Bird Watching

1. Wren 2. Yellow Hammer 3. Petrel (not acceptable if spelt Petrol!) 4. Grouse 5. Buffer 6. Tern 7. Kiwi 8. Kingfisher 9. Toucan 10. Crane 11. Canary 12. Thrush 13. Parrot 14. Nightingale 15. Eagle 16. Garnet 17. Robin 18. Sparrow 19. Magpie 20. Starling

JOIN THE RED LION GROUP

Why not join the freshest and fastest-growing pouch group around, for just £10. To receive newsletters and be kept informed of events you need to join the Red Lion Group. Anyone is welcome to join, especially people with pouches or people considering having the pouch operation.

The Red Lion Group is entirely funded by voluntary donations, and we need your help to get even bigger and better. The membership fee is £10 (£5 for the usual concessions and waived in cases of genuine hardship.) To obtain a membership form please write to the Liaison Officer (see below) including your name and address and ideally a stamped addressed envelope, giving details if you qualify for the reduced rate or waiver.

Don't forget to tell any other people you know with pouches about the Red Lion Group so that they too can join!

CONTACT THE RED LION GROUP

Chairman
Dr Martin Peters
16 Belvedere
Burnham-on-Crouch
Essex
CM0 8AW
Tel/Fax (home): 01621 783175
Tel (work): 01268 280585
Fax (work): 01268 534127

Press Officer and Newsletter Editor
Christopher Browne
3 Manor Court
Manor Road
Twickenham
TW2 5DL
Tel/Fax (home): 0181 894 1598

Social Secretary
The Red Lion Group is looking for a new Social Secretary. Please put yourself forward at the annual general meeting on Saturday 18 April 1998 if you are interested in sitting on the committee in this capacity.

Secretary
Inez Malek
33 Trevor Square
London
SW7 1DY
Tel (home): 0171 581 4107

Treasurer
Peter Johnson
7 Chelston Approach
Ruislip Manor
Ruislip
Middlesex
HA4 9RY
Tel (home): 01895 472955

Liaison Officer
Morag Gaherty
16 Hill Brow
Bearsted
Maidstone
Kent
ME14 4AW
Tel (home): 01622 739034
Tel (work): 01293 843150
Fax (work): 01293 843122

Pouch Support Nurse
Julia Williams
St. Mark's Hospital
Watford Road
Harrow
Middlesex
HA1 3UJ
Tel (work): 0181 235 4110

RED LION GROUP ON THE INTERNET

E-mail
You can e-mail the Red Lion Group on Moraggaherty@bakertilly.co.uk

Web site
Check out our site on the World Wide Web:
http://ourworld.compuserve.com/homepages/timrogers/Redlion.htm

Other newsgroups

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 the newsletter.