

Roar!



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Roar! is the newsletter of the Red Lion Group

Exclusive: How Fleet Street columnist Virginia Ironside got out of jury service P 7

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THE REGIONS

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- revealing evidence of how Red Lion members cope at work.....P 11-17

Gaherty goes for it

NEW RED LION GROUP chairman Brian Gaherty is calling for a bigger, better and more dynamic network of local groups.

In a letter to committee members he says: "My aim is to consolidate our success as a charity by getting more local groups off the ground."

The spearhead of his campaign is the recent appointment of David Irving-James as social secretary and Ann Foley as fund-raising officer.

"They will be the twin lynchpins of our local group successes," he says. Their roles will be to rally local membership with regular social functions and fund-raising events.

At present only Norfolk, Essex, Kent, and recently Northamptonshire, can lay claim to a dynamic set-up.

And at this year's annual meeting, Norfolk rep Sylvia Mist encouraged her fellow regional reps when she offered them copies of a special information pack she had devised to help them get off the ground. So no excuses, please!

Meanwhile, the chairman's other main ambition is to put the RLG on a more national footing, making it less dependant on St Mark's Hospital, Harrow.

The first step, he says, will be to hold the 1999 annual meeting at an alternative venue to St Mark's.

This year's AGM at Himsworth Hall, St Mark's made an imaginative break with tradition. During the members-only meeting, workshops on various topics of interest were held in other parts of the building.

So while Red Lion members handled the charity business and election of officers, non-Red Lion members and Ileostomy Association (ia) supporters could listen to talks on new findings and research in the colon field.

The two highlights of the year, retiring chairman Martin Peters told the AGM, were RLG's new charity status and the appointment of health commentator and broadcaster Claire Rayner as patron.

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Yvonne Wright: A Woman Of Letters... Page 11

POET'S CORNER

*"You are old Father William," the young surgeon said,
And you colon from polyps is free
Yet most of your siblings are known to be dead
A really bad family tree.*

*"In my youth," Father William replied with a grin,
"I was told that a gene had mutated,
That all who carried this dominant gene
To polyps and cancer were fated."*

*"I sought some advice from a surgical friend,
Who sighed and said without doubt
Your only escape from untimely end
Is to have your intestine right out."*

*"It seemed rather back luck - I was only nineteen -
So I went and consulted a quack,
Who took a firm hold on my dominant gene
And promptly mutated it back."*

*"This," said the surgeon, "is something quite new
And before we can ascribe any merit
We must see if the claims of this fellow are true,
And observe what your children inherit!"*

From: FAP and other Polypsis
Syndromes C.E. Dukes (1952)



Editorial

FAMOUS cures and famous diseases are often linked with famous people.

But why, oh why, is no one associated with the discovery of uc.

The man who first referred to it as a specific illness was Sir Samuel Wilks, of Guy's Hospital, in 1859.

But hardly anyone has heard of him.

The only Wilkes whose name resounds through history is Sir John Wilkes, the revolutionary Whig MP.

As Professor John Nicholls said in his inaugural lecture this month, no one credits the other Wilks for explaining one of today's most important illnesses and one

that is linked to that other Big C.

We have all heard of Parkinson's and Alzheimer's disease and Huntington's chorea - all named after people.

We have also heard of the pasteurization of milk and other products - after the Frenchman Louis Pasteur.

But Wilks' colitis? Not one for the history books, sadly.

We can take heart that in our own circle we refer to the Parks Pouch - created by Sir Alan Parks in 1976.

Parks of St Mark's in fact.

Sir Alan's last senior registrar was Red Lion president John Nicholls, who developed the W-pouch.

So let's call it the Nicholls Pouch, and repeat the phrase at least three times a day to make up for this historical oversight!

Note to Readers

You will see that two new pages have been included in this issue: A Regional Review and an Alternative Medicine page. From now on these will be regular ROAR! features. If you have any ideas or articles for these or any other pages, please send them in.

Happy Reading
Editor

Continued from Page One

Morag Gaherty, liaison officer said membership had risen by almost 200 during the year. We had also added to our growing band of overseas members.

The new RLG web-site set up by the chairman will certainly help us reach a wider audience and provide key information on colonic matters.

RLG member Jon Keeley, meanwhile, is to carry out a one-man leaflet drive at Red Lion pubs in the Norwich area. A pleasanter summer occupation would be hard to find!

After announcing his and treasurer Peter Johnson's retirements, Martin said the committee had reached the goals he set when elected chairman two years ago - ie. increased membership, charity status, a Red Lion leaflet and *Experts: Pearson, Williams, Phillips and Stebbings* a regular newsletter. Morag

paid tribute to both officers for their hard work and dedication. After an appetising lunch provided by our sponsors Dansac, talks

on research into ulcerative colitis and polyposis were given by Dr Chris Probert and Mr Robin Phillips respectively.

A popular nurse-led workshop session included such topics as travelling with a pouch, anal skin-care and family planning, and was followed by what has turned into a Red Lion AGM favourite - Question Time.

This year's Experts - Dr Peters, Mr Phillips, Mr William



Stebbins, Julia Williams and Morag Pearson - answered questions from an enthusiastic, if slightly less expert, audience of

RLG and ia members, their friends and families.

It was a day to remember. Nothing could disturb its harmony - even the cries of "fix" echoing round the hall when Martin won six prizes in the raffle. There was a very simple explanation, however. He had bought twice as many tickets as everyone else!

We owe St Mark's clinical pouch specialist Julia Williams and Bob Nye from Dansac our sincere thanks for organising such an enjoyable, good-humoured and smooth-running event.

The new committee is as follows: Brian Gaherty (chairman), Stuart Porter (vice-chairman), Inez Malek (secretary), Morag Gaherty (liaison officer), Christopher Browne (newsletter editor and press officer), David Irving-James (social secretary), Ann Foley (fund-raising officer). Brian and Morag agreed to share the work of the treasurer until a new one is found.

Why I never wear the trousers

Well-known journalist Virginia Ironside's uc has led to numerous accidents, dinner party upsets and even caused her to miss one of Britain's most revered rituals

I NEVER tell people the real reason I never wear trousers. I say it's because I've got a droopy bottom or that I think they look unfeminine.

But the truth is that, as an ulcerative colitis sufferer, when I do have an accident it's more easily concealed under a skirt.

I can't think what it's like if you're a man. I can carry a spare pair of pants and tights in my handbag, but a man presumably has to carry a spare pair of trousers around with him everywhere in a large plastic bag.

I've got so used to accidents now that I can't even count how many I've had. But I'm determined that they will never stop me living a normal life.

I've had them in Marks and Spencer, in the street, at Brixton Market, on walks in the country with friends, in other people's immaculately carpeted lavatories - oh yes, I know the agony of try-

The lavatory was like the cell of an angry Maze prisoner

ing to mop up huge stains with a handtowel, and just hoping no one will notice later.

Perhaps two of the worst accidents I've ever had were at Skipol Airport and in a tanning parlour.

The tanning parlour was horrendous. I was standing browning myself with no clothes on when suddenly the attack occurred. I panicked, hurled on my dress and, pantless and tightless, raced for the lavatory.

Too late, I left a trail of horri-



ble tracks, and the lavatory and my dress were ruined. There wasn't enough lavatory paper to clean up, and I had to hobble upstairs to the reception and blushing explain the situation.

I was handed a large and rather useless bottle of bleach and a new toilet roll, and had to proceed to wash the entire floor, seat and bowl until every trace of my accident was removed. But there was still the problem of the dress, as I was miles from the car.

I crawled up again to reception in a towel, where I was kindly given a nylon shift with orange lapels to go home in. I carried my stinking dress in a carrier bag and just hoped I wouldn't meet anyone I knew as they would have been astonished at my get-up. I looked like a manicurist or a nurse.

Skipol Airport was just as bad, but I got to the loo in time. At least in time to shut the door. The entire lavatory turned into the state of how I imagine the cells of angry prisoners in the Maze might look - smeared with shit, deep in slime, blood and strange clots.

What's amazing about the stuff is how it gets around. One drop on the floor and you step in it, blobs on tights fly off onto the walls as you remove them, your

hands are covered with the stuff, then your legs and knees, and the whole of the seat, and within seconds a thoroughly decent clean lavatory had turned into a hell-hole of smeared faeces.

I tried desperately to flush the toilet to get new water to clear up, only to discover the airport is so high-powered that the lavatory flushes itself - but only as you open the door and leave the toilet.

Clasping my skirt gingerly round me, I had to creep to the door, open it, hope no one saw what was inside, and slam it again very quickly before the next person in the ever-increasing queue barged in. I have no idea what

I have been relieved of jury service twice

they thought of me because it took about six door openings and shuttings to achieve enough flushings to clean up completely.

Due to regular doses of imodium and remission from uc, I have luckily been accident-free for the past nine months. The only benefit I can find out of the whole caper is that I have been relieved of jury service twice.

It doesn't seem to compensate for the horror of having uc, or the accidents, or the haring out of dinner parties time after time to go to the loo.

And I have just learned that as a result of a colonoscopy I have pre-pre-cancerous cells, so it looks as if at some time in the future I may be a candidate for a pouch.

But then I guess if one can survive the horrible, smelly, embarrassing accidents, one can survive anything.



ROAR! LETTERS

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A burning issue

Dear Sir,

I LOVE getting ROAR! and always enjoy the letters and comments from fellow pouch-owners.

I have a problem, which I wonder if other pouch-owners have, and if so, whether they know how to cope with it.

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

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

Rosemary Tilley
Wellingtonborough

Come On, You Reps!

Dear Sir,

IT WAS VERY evident at the AGM and pouch information day that very few regions or counties have an effective support group operating in their area.

Those that have such as the Norfolk and Kent groups are really ahead and reaping the benefits of a close-knit support group with a social scene.

Having myself now experienced what a regional group has to offer, I urge all representatives or willing group members to give it a try to put your county on the map by organising members in your area into a local support group.

For those who are interested, if you would care to contact me, either in writing, or by telephone, I will gladly send you an *aide memoire* (guide) for organising such a group.

The Red Lion Group will only function and prosper as an effective organisation if regional groups play their part in promoting enthusiastic support groups, with social and fund-raising activities at their regional level.

PLEASE, PLEASE, PLEASE give it a try and organise your own group. It does work and can be fun and very rewarding.

DAVID IRVING-JAMES

Kent rep and Red Lion social secretary

Double trouble

Dear Sir,

IN SEPTEMBER 1993, I was diagnosed as having ulcerative colitis and in January, 1994, had my colon removed and a J-pouch fitted.

I have just five fistulas removed from my rectum in hospital and have been told that the cause of these is probably Crohn's Disease. I

am now totally confused with the situation and would like to know if this has happened to any other ROAR! readers?

I would also like to know if it is advisable for Crohn's Disease sufferers to have a pouch, and whether after having ulcerative colitis, I have now been unlucky enough to have both illnesses?

R.Creek
Sheffield

Letter From Australia

Dear Sir,

I AM THE mother of two children aged 18 and 20 and am 48-years-old. I got married for the second time three years ago.

I emigrated to Australia in 1980 and I work full time as a secretary for a government department, and so lead a very full life.

When I first became ill, I had never before been troubled with eating problems or weight loss (I have been around eight-and-a-half stone for the past ten years or so) and it came as a complete surprise when I first became ill.

I was diagnosed with uc in 1987 when I was 37. It is very hard to remember exactly what my symptoms were at the time. I had always been troubled with constipation, so when the reverse started happening I sought expert help.

After numerous tests, I was given Salasopirine which I must admit seemed to take away the problem. I thought no more about my illness as I presumed I was cured.

It was not until 1995 that it reared its ugly head again with a vengeance.

The previous year had been a pretty rough one. I was diagnosed with breast cancer and had a lumpectomy followed by radiation treatment. I had put that behind me and was well on the way to getting on with my life again.

I was in the middle of arranging our wedding when I noticed things were not as they should be. At first I put it down to stress and tiredness. I had been very busy at work and was trying to make arrangements for

the wedding. Things got progressively worse very quickly and I suddenly found I could not stray very far from a lavatory. I stepped up the tablets and that seemed to give some relief and I managed to get through the wedding with no mishaps.

This was followed by a period of not going to the toilet at all,

doctors soon realised this prognosis was wrong. I underwent unimaginable kinds of x-ray, was constantly on a drip, and was given all sorts of drugs until I was hallucinating and thought I had gone to heaven. Five weeks later and three-stone lighter the doctors decided the only course open to me was an operation.

I was horrified when it was explained to me, devastated would be more exact. How could this happen to me, especially when I had just got married? I had always been so healthy. Panic took over very quickly and by the time my husband visited me that evening all I could do was cry.

At this stage, I should say, that I could not have got through this if I had not had such a caring, understanding and thoughtful husband.

I was told I could have the reversal operation right from the start, but it would be in three stages as I was too ill to undergo it in two.

In July, 1995, I had the first operation. It took me three months to recover, and I went back to work in September. All was well. I had put on the weight I had lost. They decided to do the second operation in February, 1996, so back I went, knowing this time what I would be in for and dreading it. I do not take kindly to operations and suffer terribly with nausea afterwards.

Four weeks later I was back at work, waiting for the final stage of this saga. Late in April I went back for what I thought was the last stage and hopefully some return to normal bowel

Continued on next page



or so I thought, for everything was coming out as water.

A few more weeks went by and I began to feel really ill, I kept eating but nothing seemed to come out. I was suffering with terrible stomach pains and cramps and my stomach became so bloated. I remember coming home from work early one day and just getting into bed and wishing I was dead.

My specialist sent me to see a dietician and I had one of those dreaded endoscopies. Not much showed. Another few weeks passed with me just lying around at home feeling awful. Then my doctor told me to go to hospital.

I was admitted and told I needed complete bed rest. Along with a spell on steroids, all would be well, they said. The

Continued from Page Five

movements. This was not to be. I came home from hospital and within a few days I was vomiting. This would last the whole day until I was drained and exhausted. I was told it was just me reacting to the operation again, but I had never had the vomiting before, just nausea.

I returned to work again four weeks later, only to take a day off every fourth or fifth day with vomiting. I changed my diet. I thought maybe I should eat more mushy-type food. I lived off soups, but to no avail. I went backwards and forwards to the doctors, more tests.

I was convinced I had a blockage. Finally, in September 1986 I just turned up at the hospital one day, feeling very ill again. This time, after more x-rays, they agreed I did have a blockage.

So I went through it all again. After an operation they told me the join made during the last op had closed right over to the size of a pin-head. It was no wonder nothing could pass though. The only way out had to be up!

It had been a long eighteen months. The first few months after the operation I had a lot of teething trouble, a lot of wind pains, mostly due to eating the wrong things.

The next six months was trial and error. Then a friend gave me your magazine and I read what other people found upsetting in their diet and, lo and behold, I have been a different person since.

I still get the occasional bad day, but I don't drink red wine any more, much to my dismay, and I find green

salads upsetting which makes life a little difficult in a hot climate, but I manage with pasta or rice-type salad dishes now.

I feel so much better now. The next six months was trial and error. Then a friend gave me your magazine and I read what other people found upsetting in their diet and, lo and behold, I have been a different person since.

I still get the occasional bad day, but I don't drink red wine any more, much to my dismay, and I find green salads upsetting which makes life a little difficult in a hot climate, but I manage with pasta or rice-type salad dishes now.

I feel so much better now, knowing that there are other people out there who have suffered all this and are willing to put pen to paper and pass on their experiences.

I would like to say a big 'thankyou' to you all for making my life so much better. Keep up the good work with ROAR!. I just wish I had time to start something similar here in Australia.

*Michele Grumont
Hillarys
Western Australia*

COULD THEY BE ON TO A WINNER?!

*England's signature tune
at this year's World Cup
in France is THE LIONS
ROAR!*

NICHOLLS DAZZLES AUDIENCE

RED LION President Professor John Nicholls's inaugural lecture was a sell-out!

An extra lecture theatre was opened at St Mark's to cope with the spillover of experts and former patients who came to celebrate his professorship.

It meant another 100 or so were able to watch the June inauguration at the Charles Clore lecture theatre on video.

Among some of Prof Nicholls' his gems of wisdom were that Herod, King of the Jews at the time of Christ, died of ulcerative colitis.

However the illness was not officially registered until 1859, by surgeon Sir Samuel Wilks at Guy's Hospital.

Diets were used to try to combat UC at the start of the 20th century, a time when the mortality rate was comparatively high, said Prof Nicholls.

The first ileostomy was carried out at St Bartholomew's Hospital, London, in 1936.

The lecture was an absorbing hour of facts, figures and anecdotes on the history and progress of surgery ranging from pouchitis to pouch salvage.

Alternatively Speaking

Complementary medicine is as popular as ever. Love it or hate it, take it or leave it, you cannot ignore it. Many swear by it; others use it together with more orthodox treatments. Here are some intriguing examples

A recent Daily Telegraph article tells of a doctor who's spicy Indian curry is said to have 'cured' hundreds of patients.

The article says the doctor received many letters from grateful individuals claiming to have been given relief from Crohn's Disease, uc, constipation and diarrhoea.

The remedy? A special tablet made from a compound of curry spices and exotic fruits.

The doctor has been reported to the General Medical Council for failing to tell patients' GPs that he has been prescribing the tablets.

Talk about getting rapid results, eh!

A COVER STORY

Larger branches of Boots The Chemist are currently selling a new gel for the "effective treatment" of scars.

The gel is sold in sheets which you simply put over the offending wound.

Called Cica-Care, the gel can be used on both new and older scars. If you are worried about your post-operative marks, why not give it a try?

The scar gel is no snip though - it costs around £35 a packet!

If you decide to try it, perhaps you could let ROAR! know how you got on.

I once had what I can only describe as a psychic experience.

When I had uc, I went to see an Essex healer. He told me to lie down on a couch and, suddenly, before my astonished eyes, turned into a German surgeon of the 1920s.

He put his hands on my lower abdomen and, in a deep guttural accent, asked me to relax.

The surgeon then performed a spiritual operation, cutting what appeared to be an incision and removing the troubled part.

I felt nothing. However I had a slight problem with my eye. When I told the

tall, stern surgeon, he poked it sharply with his forefinger.

When he returned to his more familiar role as a High Street carpenter, I told him I was a journalist. He said he didn't mind, adding that he welcomed the publicity.

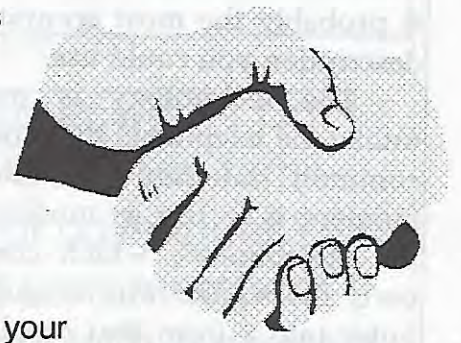
I also spoke to two of his patients. One was convinced she had been cured of stomach cramps and the other of a badly sprained arm.

My eye took an hour to recover from the blow - and was in no better shape than before. Neither did I notice any change in the severity of my uc.

EDITOR

the contacts page

Many of us go through experiences that are private. Sometimes 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!



Confessions of a secret surfer

Red Lion Chairman BRIAN GAHERTY has come out at last and revealed his private obsession as an Internet user. It is good news for us however. He has developed a gleaming new Red Lion Website.....We persuaded him to come right out into the open and tell all in this article on Surfing For Beginners

IN THIS INTRODUCTION to the Internet, I promise to avoid using jargon wherever possible, basically because it confuses the heck out of me!

When, in 1995, I was first diagnosed as suffering from Familial Adenomatous Polyposis (FAP), my wife and I spent some time trying to find out information about the disease from various sources.

Finding out at the age of 34 that you have a potentially fatal disease which you had never heard about, and being told that, even though you were healthy, the only cure was major surgery wasn't easy to deal with, so one of the first things we did was to try to find out more.

Trying to get useful information proved quite a task and included a trip to the British

Library's database. We all deal with databases all the time, and in the simplest terms, it means an organised collection of similar pieces of information.

For example, your address book is a "database", it just so happens that it uses less expensive equipment to run!

This was time-consuming and the information we obtained was not always relevant - although the highlight was finding an article about using digital examinations in the rectum called "Putting your thumb on the problem"!

One thing we didn't try was the Internet, partly because we knew little about it at the time and partly, even as recently as 1995, it was not the phenomenon that it is now. It's estimated that the number of

people using the Internet in 1998 will be more than 100 million.

So what is the Internet?

It all started in the late 1960s as a set of links between the computers of universities, defence companies and the US defence department to help researchers share information and develop systems.

The idea of being able to link computers together in order to communicate caught on in a number of places and several such "networks" started to develop. The key development was a method of letting these networks communicate with each other.

These networks grew like topsy with no one person or company being responsible for development into what we

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now know as the world-wide web or Internet. The term web is probably the most accurate description you could use.

The technology is not unlike the telephone; the most common method at the moment is to use a modem, the "telephone", which converts the signal from a computer into a form that can be sent down the telephone line to the computer of the person who gives you access to the Internet, known as the Internet service provider or ISP.

Each ISP has permanent links to other ISPs, so that they can pass the call from one to another to connect you to the location you want.

People who want to publish information on the Internet need to either set up their own "site" or give it to someone to include on their site. Each "site" has a unique address so that you can find it and see what is there. When you are "telephoning the Internet" you have a unique identifying number which is

used in all the information flowing around the network to identify where it is going to, and where it has come from. Just like your phone number.

You can use the Internet for a number of purposes, from sending electronic letters called "e-mails", connecting into chat rooms to discuss any subject under the sun and to access "web pages" which are like the pages of a book, with text and pictures.

They also include other things people think you might find useful such as computer programmes including games which you can copy on to your computer. In addition the ISPs may set up chat rooms and web pages themselves. So with some of them you may not always need to go any further on to the Internet.

With the rate of change on the Internet, there is no single Yellow Pages telling you where to find things. So some companies have set themselves up to provide an index, with tools you can use to search their indexes and find

whatever you are interested in. Which is where we came in!

Even if you don't have a computer, you can still get access to the Internet through places like Cyber Cafes where you can use their computers for a reasonable charge. In time you

may see your local library providing Internet facilities. Meanwhile, back to pouches. I thought it would be interesting to search for information on colonic diseases and pouches, just to see what is out there.

It might be of interest to you, especially if, like me, you are looking for information on your condition.

So here are my findings:

In a brief search of one index I found

- 73 places mentioning pouch surgery

- 794 for FAP

- 1028 mentions of bowel cancer

- while there were only 21 references to ulcerative colitis and 7 to just colitis (which surprised me), Crohn's Disease got 27 hits. Compare that to 21 references to "Red Lion", including hospital radio at Guildford, Surrey.

Most of the pages I visited were in Europe and the USA, and were mainly technical references to research that were not directly of interest, but one included the Ileostomy Association (ia) web-site.

Perhaps readers could let us know of sites they have found useful.

If you want to get up-to-date information on the Red Lion Group, you can visit our own web-site, developed by Brian Gaherty over the past few months. See back page for our web-site address

Please support the Red Lion Group



All donations, however small, towards our administration costs are gratefully received. If you have found this newsletter useful and would like to ensure we have funds to produce future issues please send a donation to either the Chairman or Liaison Officer (see back page)

The Jobbing Pouch

Does your pouch behave itself when you are at work? Do you have to interrupt tasks to go to the loo? Do those familiar rumbling noises embarrass you in front of colleagues? Do you sometimes get over-tired? Five Red Lion members describe their personal experiences of working with a pouch

A dose of the write stuff

Training officer Yvonne Wright says she finds words speak louder than actions. The Editor went to find out exactly what she meant

HOW DID you celebrate your end-of-term operations (!) - a family get-together, perhaps, a fun holiday or simply a huge sigh of relief?

Training officer Yvonne Wright found a particularly novel way of getting back to full health - writing a book.

Its title *Sunshine After Rain* reflects the joy most patients experience after they have been through a period of trauma and pain.

Yvonne is quite lucid about her motives. "I am writing it to clear my head. I have always written a lot of poetry, and I find writing a book helps me see some light at the end of a long tunnel," she says.

Yvonne is also writing the book to give fellow patients a clear and human guide to one of the twentieth century's medical mysteries.

"I scoured libraries, colleges and hospitals and found the books and pamphlets were mainly couched in technical language. There was very little straightforward information about uc."

Yvonne was working as a 29-year-old health visitor

when her problems began. She found her employers refreshingly helpful.

When she visited patients, she took a secret weapon with her - a flask of predigested food which she sipped instead of meals.

Yvonne decided not to tell her patients about her condition, believing it would interfere with her professional approach to their problems.

The uc got worse. She took six weeks off work, relying on high steroid doses to try to keep things under control.

She also kept quiet about her problems when going out with friends lest tea and sympathy got in the way of fun and games!

The flare-ups persisted and Yvonne had several spells off work. Her employers arranged for Yvonne to attend an occupational health clinic.

Then, after ten weeks in Queen Mary's Hospital, Roehampton, she started working a three-day week.

She lost two stone and was admitted to Chelsea and Westminster Hospital before being transferred to St Mark's

in Harrow where she had the first of a three-stage pouch operation. It was just after the final closure, in April, 1997, that Yvonne started writing her book.

In November she felt fit enough to go back to work as a health visitor. Working two and then three days a week.

Then in March this year, Yvonne applied for a job as a training officer at Lambeth Health Care Trust, south-east London. She was accepted.

To preserve her current state of health, Yvonne is keeping to a balanced daily diet. "My pouch has been wonderful, apart from two small spells of pouchitis," she says.

"Writing the book has made me much more focused. I feel I can now reap the benefits of being well."

One such benefit has been her decision to move from her Putney flat to a house in Penge, Kent.

Yvonne's next ambition is to train students to be health visitors. This time, though, she won't have to disappear to an oh, so familiar place in between teaching sessions!

Gliding over troubled waters

A bout of serious illness did not blunt yachtsman **SIMON ROGERS'** competitive edge, it simply made him win in a different way, discovers ROAR!'s editor

ROUND BRITAIN Yacht Race winner Simon Rogers has charm, good looks and a lively sense of humour.

Not long ago, a question-mark hung over his life.

A crisis you would never suspect on meeting this swarthy, 6'2" 31-year-old.

One minute he is enthusing over his successful yacht design business, the next discussing the prospects of a British win in the famous America's Cup yacht race.

Simon was an international skier at the age of 18, travelling and competing all over the world. He was also an accomplished yachtsman.

Little did any of his rivals suspect that since the age of 14, he had been suffering from bouts of ulcerative colitis. Then a month after taking his A levels, Simon had a chronic ulcer attack and was rushed to hospital where they discovered he had a perforated colon.

He was put on a life-support machine, fed internally and, literally, given 24 hours

to live. Simon, a patient at St Mark's, City Road, recovered and had the first stage of a pouch operation.

With an athlete's tenacity, he was back on his feet within days. "I was used to being competition fit and bounced back. Nobody could believe I had been ill," he says.

Fate intervened again. Simon's weight dived from 79 kilos to 44. He was rushed back to St Mark's and, once again, put on an internal drip.

Then something extraordinary occurred. Simon had not seen his brother for several years. Just after his second attack, he arrived at Heathrow Airport. Suddenly, Simon's health yo-yo'd back - and he was fit enough to have the main pouch fitted.

Simon was still a very youthful 19, and an eminently suitable film material, the hospital decided.

A video of his operation, performed by Red Lion president Professor John Nicholls, is now used nationwide for students training to be pouch surgeons and nurses.

Simon had the third stage - or closure - a year later at the age of 20. The celebrations for his 21st birthday party soon afterwards were unashamedly raucous.

But the young yachts-

man emerged from his trials with a new outlook. "I had been used to a strenuous daily weight-training regime. Now, having cut out the weights, I took a more mental view to competing in yachting races.

"I remained fit, but not in a superhuman, macho way. I also began to see the value of planning and strategy in my sailing technique.

"Instead of being a winchman in the middle of the boat, I was now shrewd enough to be the skipper. Also I no longer had any fear of needing to go to the loo mid-race."

Like his father before him, Simon started a yacht design business near his home in Lymington, Hampshire, in partnership with his wife Rebeca.

Four years ago he both designed and skippered the boat that won the Round Britain Yacht Race, beating the course record by 46 hours.

"The pouch behaved impeccably. I now have to go to the loo about four to five times in 24 hours, and it certainly didn't affect me during the race," says Simon.

The pouch operation has also enabled him to "forget about being superman and to take life as it comes. This three-year period of my life really shook me up, but instead of hampering my competing ability I think it has improved it.

"I would never have made the top ten as an international skier, but I have been able to combine two careers as yacht designer and competitor.



WINNING DUO: Simon Rogers (right) with trophy and one of his yachting colleagues

Continued from previous page

"If I hadn't been through this tricky period, I certainly wouldn't have been able to achieve what I have done. It was like a warning signal to slow down and review my life. Having a pouch has made me more compassionate and philosophical. Instead of going into things head first like a downhill skier I look at the human side when I am working on new projects.

"I am especially careful over what I eat each day and have a regular diet, though I sometimes gurgle after a meal and we all have a good giggle over it. Having a pouch has made me an altogether more interesting, easy-going person."

Simon's firm has been asked to design a boat for this year's prestigious America's Cup, an event the Americans have a habit of winning.

They'd better watch out. Simon Rogers has a habit of winning, too.

Simon Rogers says he is willing to talk to anyone who would like a sympathetic ear to help cope with their pouch. His phone number is 01590 672000

Hot-line to happiness

PHIL ELLIMENT



finds BT keeps its pledge as The Listening Company

I'M 40-YEARS-OLD going on ten! Ulcerative colitis struck in 1992 - and two years later I had an ileostomy.

After another couple of years I decided to gamble on having a Kock-pouch - perhaps my vanity took priority over everything else. To date, in the words of Edith Piaf, I have no regrets.

Ever since I left school at 15, I have worked for British Telecom, a company that likes to project a caring image. After you have read this, perhaps you can make up your own minds!

When I had my first operation, I was off work for three months on full pay.

The support I received from my manager and colleagues, both at home and in hospital, was overwhelming.

I returned to work on a

gradual basis, until I felt confident enough to do a full day. Actually it took just a week! Then it was business as usual.

I was grateful to be out of the home environment - three months off work sounds great but is, in reality, very BOOOOOORING!

Life went on. Then the decision to give vanity pride of place came upon me. The Kock pouch was formed. I was by then working in a different field at BT - the safety office.

Another three-month "holiday". Again support was at hand.

Before returning to work at London's Elephant & Castle my manager and the occupational health group made substantial changes to enable me to empty my catheter in a safe, clean and dignified manner.

The disabled toilet was totally refurbished and cleaned from top to bottom to bring it up to required standards.

However when I got back to work I found it very difficult to clean my instruments because of the tiny hand-basin.

I have since discovered this is a common factor in disabled loos - people always seem to assume disabled people have small hands! Why is this? Answers on a post-card, please.

While they were sorting out my little problem (ie. having a larger basin installed), my company sent me home so I would not have to suffer any further inconvenience.

Then, after all their sterling efforts, my job location changed. BT thoughtfully arranged for me to visit the new location in Bromley, Kent, to see if I would have any travelling problems.

I didn't. The travelling was fine. But the disabled toilet was not up to standard. So, again, BT modified it to suit my requirements. They also installed a cabinet for storage purposes.

When I moved to my new premises, a drink-making machine was installed plus a fridge to keep drinks cool, because of my high liquid intake.

I feel that BT have accommodated my problems in a thoroughly caring and dignified manner.

Don't think twice - it's alright

Why the Editor had a change of heart before his first op

I AM IMPULSIVE, short-tempered, and stubborn - pretty average failings really. But few people say I am faint-hearted.

Yet after booking myself into St Mark's Hospital one sparkling summer's day in August, 1991, I promptly booked myself out again two days' later.

The reason? I was put off by the finely-sewn creases I saw on the patients around me. I thought: 'There must be a better way than this.'

I was wrong. But I have no regrets. I did what I believed was right at the time.

You could say I have a habit of doing things a little dramatically!

I came back a year later and had my colectomy. It had taken me twelve months to reach the right decision.

So how have uc and a pouch affected my career as a journalist?

I am a good, if restless, newspaperman. After a successful early career with some big scoops and front-page headlines, I had several jobs (I was a Labour Party spin-doctor, Evening Standard caption-writer and chief reporter of a southern newspaper group).

Then I left the profession and started my own company.

The following six years were commercial torture. Bailiffs became personal



acquaintances, money was an unheard-of luxury, and I cheered every time I was able to pay the monthly mortgage.

During this spell, I found I had uc. It came in spasmodic bouts that were both unpleasant and upsetting.

The company was, I believe the direct cause. I decided to close it and drove mini-cabs to pay off my debts.

I also became a keen, if unwitting, naturalist, knowing the whereabouts of most of the copses and bushes in South Middlesex!

I don't think any of my passengers ever suspected I had uc. They were sometimes surprised by my rally-style driving, though, as we hurtled to the next destination - and the nearest loo or bush!

Then the uc became permanent. Neither acrobatic driving nor repeated doses of Asacol could budge it.

Nevertheless, I returned to journalism, working as a sub-editor on national newspapers (with a two-year spell on the Daily Telegraph).

During a six-month period on The Times, I inadvertently added two noughts to a headline about a company take-over bid (£400m instead

of £4m) as, in my anxiety to get to the loo, I pressed the wrong key on my pc.

My boss, who was the chief sub-editor, forgave me. But only just.

I found loo visits played havoc with my jobs at various newspapers, losing a regular Saturday shift on the Sunday Times sports desk, after nodding off a couple of times mid-story - due to lack of sleep.

It just wouldn't do. I'd be losing my marbles next.

I went to Harley Street, saw the Queen's surgeon, visited two world-famous healers, had acupuncture, used herbal and homeopathic diets, and basked in TLC. All to no avail.

I had no option but to re-book myself into St Mark's. This time, there was no hesitation.

Feeling as timid as anyone does before an op, I put on a macho performance, waving to my fellow ward members and joking with the porters as we wove our way to theatre via the ramshackle lift system at the City Road St Mark's.

When I awoke I felt elated, spurred on by two post-operative telephone calls from my brother and sister.

Then the pains started.

The cause? I later discovered I had an abscess in the lower abdomen. I went back to St Mark's two months later and had it lanced.

I had the closure four months hence, looking forward to a spell of media madness and mayhem. I wrote feature articles for The Times and a book about the history of the world's postal system.

Continued from previous page of the world's postal system.

But, gentle readers, my life became anally-challenged.

Suddenly, like an unwanted comet, a second abcess appeared and my efforts to wield pen, processor and phone were severely hampered.

I went back to hospital and let the shining instruments

do their nimble work. I awoke with glee - no longer a numbskull, but a free man!

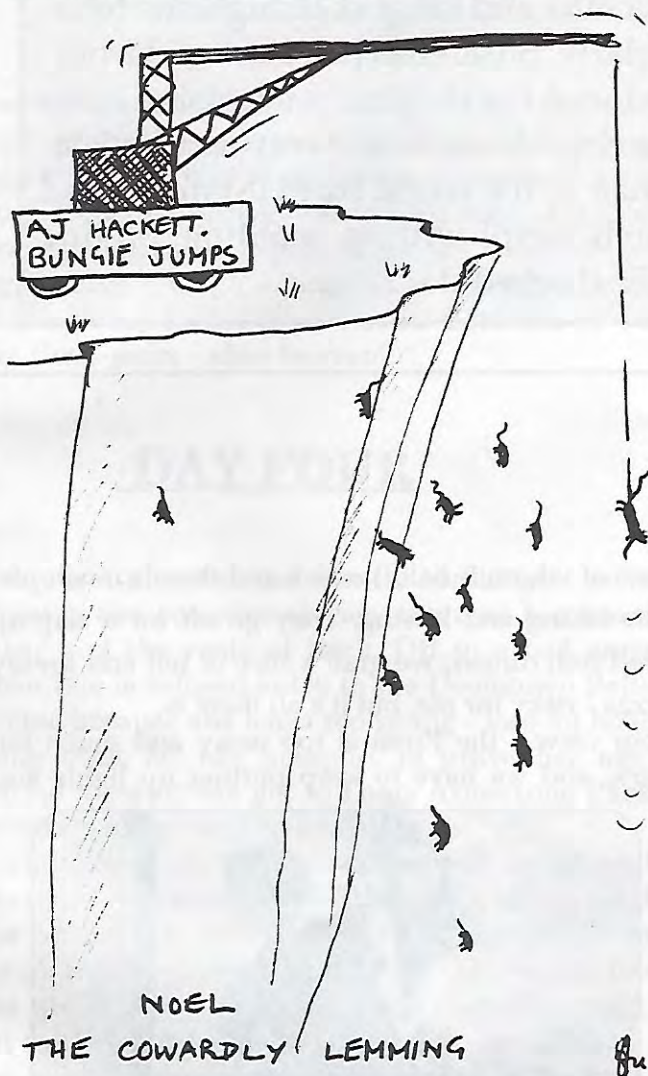
Free to write, sub-edit, enjoy, and go on exotic trips to Egypt, the USA and Australia.

Since then I have written another book, started a third, done a fair quota of broadcasting, set up and organised training courses for journalists, run PR campaigns, and

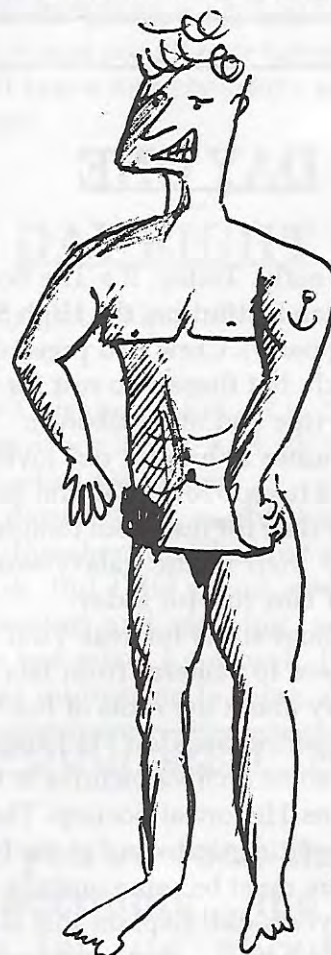
sub-edited on the newspapers again. I don't have the best pouch in the world, but it's mine and I'm optimistic.

I enjoy life and have found pouch know-how and determination the best ways to combat a very human condition.

The moral of this story? In the words of singer/songwriter Bob Dylan: "Don't think twice, it's alright."



JASON IN HIS
POSING POUCH.



The cartoons in this Summer's
issue of ROAR! are drawn
by Stuart Hiern-Cooke

A movie a day keeps Susan's pouch at bay

Television producer **SUSAN WALLS** had her colectomy two-and-a-half years ago. Since then, she has suffered from pouchitis and fatigue, though she feels much better if she eats well and rests regularly. Susan has just returned from New York and New Orleans where she produced the children's television series **The Scoop** (ITV, 4.45pm from June 24), starring Home And Away actress **Isla Fisher**, recently voted eleventh sexiest woman in the world by FHM magazine! So how did she survive three months' research, script-writing, scouting, producing and filming. Here is her final schedule.....

DAY ONE

Wake up very early. Today, it's *The Scoop* on that strange American institution, the High School Prom (school leaving party). Crew and presenter will start work after lunch, but there's no rest for the producer and director (me and my husband).

We've got costumes to hire for our lovely presenter Isla Fisher and a tuxedo for our sound recordist Tim, who's to be her date for the Prom tonight. Idly wonder how many men in the galaxy would love to swap jobs with Tim, just for today.....

At 12.30, the shoot starts for real. First we grab an illegal PTC (piece to camera) from Isla in Bourbon Street for a story about the roots of Rock (we didn't have a filming permit - so don't tell anyone).

Next we shoot some archive pictures at the wonderful New Orleans Historical Society. Then we meet our Prom kids getting dolled up at the hairdressers. Crew think there must be some mistake - Prom kids look about 40-years-old. Explain this is the look in New Orleans schools - very grown-up, slightly seedy. Weird. Beside them, Isla's s dewy rose - she looks like the teenager.

Spend ages shooting girlie make-up and hair stuff - I have to log every shot, so we can edit efficiently - then it's time for our Prom girls to get into their grown-up ball gowns. Now they look 50. Their dates

(one of whom is bald!) arrive and there's much picture-taking and kissing. They go off for a slap-up pre-Prom dinner; we grab a slice of hot and greasy pizza - risky for me, but it's all there is.

Poor crew - the Prom is too noisy and much too dark, and we have to keep putting up lights and



Screen break: Isla Fisher and Susan Walls

shutting down the music. We work until midnight, then the director invites everybody back to our room for the obligatory how-was-it-for-you conversation, over many bottles of beer. I wish they'd go back to their rooms. I need sleep!

DAY TWO

In a bad way today. Back when I had a colon, a flare-up was heralded by sore, swollen joints, fever and fatigue. Still get those nasties, even though my colon's gone; amplified by the long day and night, and probably that pizza. The others have fun at the N'awlins Jazz Festival (they saw The Doobies live!). I sleep and nurse my sore bits.

DAY THREE

Feeling much better. Spend morning shooting stuff at the Prom school (even the juniors look old!) and then off to New Orleans Superdome for a story on the technology behind the biggest indoor sports arena in the world. When we finish shooting, I have enough energy to go shopping with Isla, in Macy's shoe department. Between us we buy three pairs - shoe heaven!

DAY FOUR

Today is a physical and mental challenge - we're shooting two *complete* stories: the true history of poker and the roots of Rock. Off to a bad start when Isla is refused entry to the Doomtown Belle Casino because she looks too young - lose an hour going back for her passport to prove her age. Second disaster: we get to Louis Armstrong Park for music story, only to find it locked.

Eventually gain access and spend wonderful afternoon shooting with a brass funk band called The Lil' Rascals, who must be the coldest people on the planet. Getting a bit twitchy - the nearest toilets are half-a-mile away. (Didn't actually need, but could feel a bad day coming on.

DAY FIVE

Urggh. Feeling rough and ache everywhere, but the show must go on. Today it's an hour-and-a-half drive to shoot a rodeo story. Isla is a brilliant rider, and even has a go at steer wrestling; but we're outdoors in the burning heat, so I get dehydrated and exhausted. Make full use of nearby toilet. Today feels like a very long day.

DAY SIX

Up at 5.30am to drive down to the southernmost part of Louisiana for story on the state's unique white alligators. We do some impressive wildlife filming; but I need the toilet every hour. (Tricky on an alligator farm in the middle of nowhere...I commandeered a golf cart). At lunch we grab sandwiches then rush all the way back-to-back to New Orleans to film Disney On Ice at the Superdome. I manage to snatch a short sleep in the car, and feel slightly better. Isla still looks fresh and dewy!

DAY SEVEN

Another early start. Much harder to get going today. Don't know what I'm complaining about though - Isla has to do alligator-wrestling, as she releases 24 adult 'gators back into the wild. She gets 'gator guts and poo all over her good trousers, but she's still brave and cheerful - and fresh and dewy - Hrrmph.

DAY EIGHT

Bye bye New Orleans - we're off to New York for the second leg of our shoot. And, oh joy - an afternoon of sleep when we arrive.

I worked six days a week, twelve hours a day for four weeks altogether; and I didn't miss a single second of work. But I did spend most of the non-work time resting and sleeping; and I needed three days in bed when I got back. But at least I had something interesting to think about.

IS YOUR POUCH JUST THE JOB?

Now that you've read these five candid accounts, it's **YOUR TURN** to tell us about **YOUR** experiences of working with a pouch. Simply fill in the questionnaire we've included with **ROAR!** and let us know what you think!

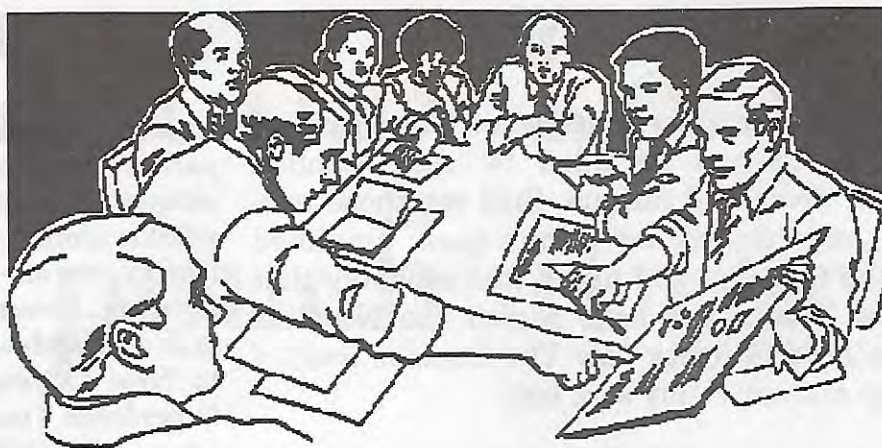
NEWS

FROM

AROUND

THE

REGIONS



A new **NORTHAMPTONSHIRE** group was formed on Sunday, June 7. Three Red Lion members and eight others (who are no doubt signing up this very moment!) attended the meeting at Northampton General Hospital. Northamptonshire co-organiser David Smith says: "We hope this will be the start of many successful meetings and get-togethers in the region". They are to hold a second meeting on Sunday, September 27, at Northampton General Hospital, between 2-4pm. Congratulations to all of you.

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MID AND EAST KENT REGIONAL GROUP is now up-and-running. The first meeting of Mid and East Kent Group was held on May 17, at the village of Sturry, near Canterbury. Seven members, plus partners and children, attended a lively and informative Sunday Lunch. Another is to be held at Ashford on Sunday, July 5. Kent co-organiser David Irving-James: "The mutual support of members within our group has started to pay dividends. We are able to talk through problems with personal experiences and home-grown remedies for finding comfort for those sore or itching areas we could never have talked about before. A friend on the end of the telephone who knows just how you feel when you are down, can put things in perspective and lighten the day." **NORTH KENT GROUP** is to hold its first meeting in September.

Point of interest

Four main Kent hospitals are now performing pouch operations. Several Red Lion members have volunteered to talk to prospective pouch patients at these hospitals.

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The year has got off to a roaring start in **NORFOLK**. A total of 52 people attended an Eastern Region Pouch Support Day at **DANSAC's** headquarters in Histon, Cambridge, on May 17. Highlights were a talk on Diet With A Pouch by nutritional nurse specialist Suzanne Wood and some catchy cabaret by actress and Red Lion member Sarah Myers.

Earlier in the year, reps from Cambridgeshire, Bedfordshire, Northamptonshire, Hertfordshire and Norfolk went to an **EASTERN REGION REPS DAY**. Held at Addenbrooke's Hospital, Cambridge, on March 28, reps and members of the Red Lion committee pooled their resources to help set up new regional groups. Their hard work has already borne fruit with this month's launch of the Northamptonshire group. The Reps plan to meet again in the autumn.

REGIONAL REPS

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

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Liz Davies Langley 01753 586593

CAMBRIDGESHIRE

Rita Deans St Neots 01480 403148

Joyce Shotton P'borough 01733 706071

CLEVELAND & NORTH YORKSHIRE

Christine Jackson Saltburn 01947 840836

CUMBRIA

Jonathan Caton Kendal 01539 731985

DEVON

Gill Tomlin Plymouth 01752 568643

DYFED

Briony Jones H'fordwest 01437 765359

Bruce Dibben " 01437 731436

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Kate Bosworth Brighton 01273 887102

Lisa Critchley " 01273 699286

ESSEX

Peter Zammit Benfleet 01268 752808

GWENT

Robert Challenger Cwbran 01633 866320

HAMPSHIRE

Phil Smith Portsmouth 01705 426541

Les Willoughby Winchester 01962 620012

HERTFORDSHIRE

Carol George Stevenage 01438 365707

KENT

Beverley Dallen Cranbrook 01580 850221

David Irving-James Folkestone 01303 277819

LANCASHIRE

Joan Whiteley Clitheroe 01200 422093

MERSEYSIDE

Blanche Farley Liverpool 0151 924 4282

NORFOLK

Sandy Hyams King's Lynn 01485 542380

Sylvia Mist Norwich 01692 580095

NORTHAMPTONSHIRE

Cynthia Gunthorpe Kettering 01536 482529

David Smith Northampton 01604 450305

SOMERSET

Clive Brown Chard 01460 234439

SOUTH LONDON

Andy Jones SE6 0181-690 1360

Jonathan English SW12 0181-673 2518

WEST LONDON

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WEST SUSSEX

Amanda Metcalf Arundel 01243 554257

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YORKSHIRE

Neil Anderton Leeds 0113 258 2740

Sue Appleyard Huddersfield 01484 311334

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

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



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