



# ROAR!

## **ISSUE 32 • AUTUMN 2005**

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



## Regional Reps

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

If you would like to be a regional rep, please contact Marion Silvey (phone number on inside back page).



### AVON

David Mair Bristol 0117 922 1906

### CLEVELAND & NORTH YORKSHIRE

Christine Jackson Saltburn by the Sea  
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### CUMBRIA

Jonathan Caton Kendal 01539 731985

### DERBYSHIRE

John Roberts Derby 01332 361234

### DORSET

Clive Brown Bridport 01308 458666

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Peter Zammit Benfleet 01702 551501

### HAMPSHIRE

Les Willoughby Winchester 01962 620012

### HERTFORDSHIRE

Carol George Stevenage 01438 365707

Susan Burrows St. Albans 01727 869709

### KENT (WEST)

Rosalyn Hiscock Pembury 01892 823171

### LANCASHIRE

Joan Whiteley Clitheroe 01200 422093

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Anna Morling Newton-le-Willows 01925 229648

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### NORFOLK

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### NORTHAMPTONSHIRE

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### NORTHERN IRELAND

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### SOUTH LONDON

Jonathan English SW12 020 8673 3092

### SUFFOLK

### WILTSHIRE & DORSET

Bernadette Monks Salisbury 01722 327388

### YORKSHIRE

Sue Appleyard Huddersfield 01484 641227



Does anyone remember the early *Roars*? Loveable, personal, readable little packages they were too even if they lacked today's sleeker, glossier look. Some featured cartoons by a certain Brian Gaherty. His style was unmistakable and we'd all look forward to giggle-time with Gaherty. Then of course there was his unforgettable 'The endoscopy is nigh'. Geddit?! Typical Brian.

The Gahertys, Tim Rogers, me and a few others helped form the first Red Lion committee. I got to know Brian as a quiet, gentle person with an impish sense of humour. If ever a topic strayed into over-serious or slightly-too-earnest mode, a merry quip from Brian would quickly restore harmony. He was RLG chair for two years and a regular committee member too.

Brian, who was the husband of *Roar!* co-editor Morag and the father of their two young boys, died last month and we'll all miss him very much. We also send our very warmest and heartfelt wishes to Morag and her young family. A fuller review appears later in this edition.

## Seeing Red

How many of you voted Labour at the general election? I only mention it because if you wore your brightly logoed Red Lion sweatshirt on the 6 May you might have been signed up as a party member. But then charities don't do politics and although Information Day was on the eve of May Day, no one was overheard singing the 'Red Flag'.

We'll never know the lefties, righties and pinkos among us and we're not too bothered as most of us like keeping our politics to ourselves. Although you wouldn't know it from all the pre-election phone canvassing. I was phoned by two parties wanting my vote and almost said 'yes' to both when they didn't try to sell me a kitchen or conservatory.

Actually I'm more of an also-ran than a political activist. After voting by post I almost forgot about the election. But Information Day was different. I got a real buzz out of that. In our dark, sober suits Michael Dean and I might have been mistaken for two tellers at an exit poll as we ushered in members that day. Though they might have changed their minds when they heard our raucous cheering as the numbers crept over the 100 mark.

Although last year's turnout of 72 was good, this year's was a splendid result. A timely one too as it marked Red

Lion's 10th anniversary. Yes, it all began in the summer of 1995 when Tim Rogers and several others met up and decided to set up a support group. Well done Tim!

This year's Info Day was decidedly unsummery however and it couldn't have been easy dragging yourself to a station or driving down the M1 on a dull April Saturday. But you did and on a bank holiday at that. The talks and workshops were weather-defyingly warm and un-dull.

We'll start with some behind-the-scenes gossip: you know I can't resist it. Did you know that the moment his talk was about to start Professor Nicholls was mid-surgery at the operating theatre? So what did we do? Panicked and prayed for divine intervention of course until Joanna Wagland gamely agreed to swap slots so our president could speak later. A very big thank you to Joanna—and remember: you heard it here first.

Talking of gossip, the journalist Virginia Ironside may have worked on a few red tops (tabloid newspapers) in her career, but only as a respected agony aunt, not a gossip-writer. Virginia, who currently writes *The Independent's* 'Dilemmas' column, spoke about living with ulcerative colitis. It's not the most endearing of topics, as we all know, but she has the gift of making it funny—very funny. The ordeals that she, like many of us, has suffered in shops, restaurants and parties became moments of mirth particularly the toilets that kept flushing like flash floods at Amsterdam's Skipol airport.

But there was compassion in Virginia's humour and she managed to pass on some sage tips from even the most hilarious of her stories.

### A Prescription For Success

Caring for a pouch can be costly as anyone who pays for prescriptions or buys over-the-counter medication knows. Do you pay for yours? I only ask because during the AGM several members said they were unable to get exemptions from GPs.

If your GP won't help, you have two options. You can either do as Dr Martin Peters, a previous Red Lion chair, did and write to your area health authority (Essex in his case) pointing out that you have an internal version of an ileostomy which is prescription-exempt.

Then state clearly that like most ileostomy-holders you need creams, tablets and medication to cope with pain, soreness, irritation and bleeding.

If that doesn't work phone me on 020 8894 1598 and I'll send you two Roar articles that have done the trick in the past.

We've fixed a date for next year's Information Day. It's **Saturday 8 April**. So jot it down ready for your 2006 diary.



*Pet Passports prove to be a success with owners and pets alike*



*...So I thought I'd replace your colon with another punctuation mark*



*In a bid to recycle waste, pouch surgeons turned their attention to the playground*

Brian Gaherty

## Holiday Insurance

It's that time of year again when we all troop down to the travel agents to pick up our brochures and look at all those holidays in exotic places, or even closer to home. Once we have chosen our dream holiday the question of insurance looms and this is where the nightmare begins. What type of insurance do I need? Do I have to take it out with the travel agent or can I buy elsewhere? What do I have to disclose and will I be covered?

It is a potential minefield and I thought that I would give you some pointers as to what you should or should not do.

Buying cheap is not always the answer as was clearly indicated in the Press last year when a holidaymaker bought an insurance policy but did not read the small print. This resulted in the person having an accident which was alcohol related and the claim was refused. She did not read the small print of the travel policy where it clearly stated that no claims would be met where alcohol was involved.

Now, we all have a drink while on



holiday and it is easy to forget when we are having a good time and enjoying ourselves that should an accident befall us we would not get paid if we took out this type of policy.

The other most important thing is the non-disclosure of facts. This is frequently overlooked and often leads to claims being rejected. A simple message would be **any medical condition, irrespective of the length of time it has been diagnosed, should be confirmed to insurers.** Insurers will ask "have you been to see a doctor or visited a hospital within the last year?". Many of us go for our annual check-up and it should be pointed out that this is only a check-up and not a recurring problem, but if there is tell them. You

may get a loading which in most cases is an increased excess for any one claim, but this is better than having a claim refused. Yes, I appreciate we all have pouches but it is important to stress that although we may not have any side-effects it is still a condition which should not be overlooked. The

same procedure should be followed for any medical condition so that there can be no equivocation with the insurers regarding non-disclosure and, therefore, no excuse for refusal of a claim.

It is worth noting that in some instances it is cheaper to buy an annual policy than two separate policies, should you be in a position to travel more than once a year.

Finally, one thing to note is that you do not have to take the travel insurance that is offered by your holiday provider. It is not compulsory to take their policy if you have your own travel insurance in place. The travel company or agent will need to know the details of your travel policy.

My company JLT, who are essentially commercial brokers, do operate travel schemes at their Birmingham branch. Should you wish to avail yourself of their services contact Brian Birch on 0121 224 6934. It is important to note that prior to the issue of a policy you will be asked to call 0800 281 488, a health screen service for insurers. The operator will ask you what type of policy you are interested in buying and will go on to discuss all your medical conditions. Bon voyage

*Michael Dean*

## United Arab Emirates Medication Alert

It is of particular interest to pouch owners to learn that codeine is a banned substance in the United Arab Emirates—and follows the recent news that a British traveller to Dubai was held in prison after traces of codeine were found in her urine.

Codeine phosphate is a drug quite commonly used by us to reduce frequency—and indeed as a regular traveller to Dubai, I have often taken my codeine phosphate into the country, being blissfully ignorant of what might have happened to me if my bags had been searched and the medicine found.

And I'm not an innocent abroad when it comes to the Middle East. I spent thirteen years of my youth living in Abu Dhabi. I considered myself to be very well-versed in what one must and mustn't do in this region of the world—and yet, this was news to me!

Interestingly, despite a fairly thor-

ough web-search I cannot find a definitive list of which drugs may or may not be banned in the UAE. I am comforted by finding that even respected travel authorities like MASTA have also been unable to obtain up-to-date information on which specific drugs are banned in the UAE.

However, they do offer a few words of advice: "Codeine is banned in some countries and the presence of some drugs in the body may be classed as possession. Travellers to the UAE on prescription medicine should ensure that they have their prescription from their doctor. If taking codeine, you should consider changing to an alternative if this is possible. If not you could look at whether it is possible to obtain permission to import personal supplies. The embassy in London should be able to help with this."

*Stephanie Zinser*





## The Death of Brian Gaherty

First of all, I must apologise for the delay in publishing the Summer edition of *Roar*. We were all aiming to get it to the printer's by the end of June, which meant me getting the final copy to Tim for typesetting by the middle of that month, when life suddenly stopped going the way we planned it.

I'm sorry to tell you that my husband Brian died suddenly—after only eight days' illness—in early June. It turns out he had extensive cancer throughout his digestive system, from the stomach right through to secondary cancers in the liver, and had done so for around six months, they estimate. We just did not know it.

According to our GP, who has now seen all the hospital results, it is astonishing that he was at work until a week before he died—and he was only off for that week because we were in France on holiday.

For the last ten years, since his surgery for familial polyposis, Brian has read the stories in *Roar!* (and heard many more besides) of people whose lives are controlled by their illness or their surgery, and thanked his lucky stars he was not one of them. Apart from needing to go frequently, pungently and squelchily to the toilet, his surgery did not really affect his life to any great degree.

Yes, he had periodic check-ups from both ends, endoscopy and gastroscopy, but they were routine monitoring measures. And yes, we knew that having had polyps in the colon meant he would (and did) develop polyps in his duodenum, which in turn meant that the risk of him dying of duodenal cancer was far higher than for other people. Brian always assumed he would not live to see his children to adulthood. I used to tell him he was being overly theatrical, but it seems he was simply prescient.

We have lived the last ten years of

our married life with the potential for development of the polyposis as background knowledge. We chose not to share that information with our families, for the very simple reason that Brian's mother in particular would not have slept for the last ten years, if she had known, and every phone call with her would have involved a health bulletin. That is not how we chose to live our lives.

The great irony is that it was not the duodenal polyps which turned malignant—no obvious malignancy was apparently found there. The tumours (plural) were all in the stomach, and I suppose it is even possible they were unrelated to his FAP—I

going on 30) looking over at me saying "We know better, don't we, Mum?", because he knew Brian was coming home to die.

But we *are* coping, or at least we seem to be. After all, when you have young children, you have to, don't you? They can hardly get themselves up, fed and ready for pre-school and school on their own. Maybe this is where I actually have it easier than my own father—with no dependents or job to keep him busy, he has all the time in the world to mourn the loss of my mother, and I don't think it is any easier two years on than the day it happened.

And maybe I'm still in shock, anyway. After all, it was only seven weeks ago as I type, and do people who are in shock know they are in shock? No doubt I will find out in due course.

I do know that I will be ambushed emotionally by the little things, not the big ones, because it is exactly what I warned my father about when my mother died. The first time the boys requested pancakes was a very soggy moment, because that was something Brian always made with them

on a Saturday night. There will be many more such moments, though I suspect none of them will be on the obvious dates, because both of us were famously forgetful of birthdays and anniversaries anyway!

What I don't know is how prior knowledge of Brian's premature death might have changed our decisions, had we been privy to it. Would we have had children earlier, to give him more time with them? Would we even have had children in the first place?

Brian's mother just thinks I'm being brave when I say I feel it must be harder for her as his mother to see her son dying first, than it is for me. It is just not right, not in the natural order of things. She's wrong. I'm not being



don't know: I haven't yet asked, though I am sure I will in due course.

People ask me how I'm coping, especially with two children aged four and six. Tom is too young really to understand, though he is beginning to appreciate that Daddy is not coming back.

Once the cancer was confirmed as terminal and very advanced on the Wednesday morning, Brian opted to come home that afternoon (typically for him, his main concern was that the boys' last memory of him should not be in hospital with tubes all over him).

I cannot tell you which was more heartbreaking: Tom cheerfully saying "Daddy's coming home to get better, isn't he Mummy?" or Bob (aged six,

brave at all—I'm trying to come to terms with the fairly horrific idea that it may happen to me too, some day in the future. Losing your partner is one thing, but to lose your flesh and blood before their proper time must be something else entirely. I haven't told her the boys have a 50 per cent chance of inheriting FAP, and I suddenly realise why proper genetic counselling is a good idea: if I could find out tomorrow, would I do so? Should I do so? I have no idea of the answer to those questions, but that does not stop me asking them.

When we talked about starting a family, knowing the 50 per cent risk, it never even occurred to us not to have children. After all, Brian had not even been ill when his polyps were diagnosed, and he had adapted to his pouch extremely well. It hardly interfered with his life. We therefore worked

on the assumption that if any children of ours inherited the FAP, they would either have the same surgery in due course, or have gene therapy if that were available by then. I suppose the reality of potentially dying young was not really something we factored in to the equation.

Despite all the fresh doubts that these thoughts raise, I look at our two boys and of course would not have changed the decision to have them for a moment. Brian lives on in them, so they are my ongoing link to him, for one thing. Without them, I would have nothing left of him, and no doubt his death would have affected me very differently, as a result.

All I can say is: the future will bring what it will bring, and we will just have to deal with it when it happens. That was our decision then, and I still feel it was the right one. After all,

you can bring a perfectly healthy child into the world, and just as easily lose them to a car accident or worse. Risk can never be eliminated, only factored in and accepted. Coming to terms with that simple idea makes life a whole lot more bearable.

In the meantime, I will be stepping away from editing *Roar!* for the time being. I'll still be on the committee, and no doubt I will be persuaded to contribute an article or survey from time to time. But I can't see me being able to carry on my role as newsletter co-editor at present. Please therefore do continue to send copy for *Roar!*, but to Tim Rogers using the address/e-mail address on the back page. Thank you for all your support over the last ten years. It has been a privilege to be in contact with so many helpful, kind and sometimes also brave people.

*Morag Gaherty*

## Letters

*Dear Editor*

I am a member of The Red Lion Group, and we have a group in Norwich. We meet regularly, about every six weeks.

I have had my pouch for about 12 years, as I had it after the birth of my daughter who was 14 on the 12 July. Early on, I experienced lots of problems; it is slightly better now, though I have had a bad year with blockages. Of our group of eight, most have had the pouch for ten years or more and are wondering what the long-term problems of having a pouch are.

I know about the tiredness and anaemia. I also have sporadic arthritis, as does another of our members. I find that if I eat little and often that helps, and also if I eat most of my meals during the day not in the

evening, when I am very tired. But doing it this way means I miss meals with my family, as I can't manage a large meal at that time of day.

I have been admitted with the blockages and had a series of tests. They found that I have a stomach ulcer, which hasn't helped. I had a barium meal and this showed that my small intestines had settled in my pelvic area. I get pain around the old stoma site and colic: lots of wind, which can be uncomfortable. I have no appetite at the moment, which doesn't help.

I am 50. Most of our group are in the 45-60 age range and we all have problems but manage. I take HRT and noticed a lady writing in *Roar!* about the effects on older woman with the menopause and

pouch.

We would really like to hear from any readers (especially female) who

have had the pouch for the length of time we have had it and what experiences and problems they have had. As a group we are really interested in others who have had the pouch for ten or more years.

*Sue Allen*

*Dear Newsletter Editor*

I have just read the latest newsletter from cover to cover as usual and was very humbled reading the letters and the results of the survey. It's nice to know that there are others out there like me going through the same type of problems.

I am the Red Lion rep for our area, after having the pouch for ten years. However the letter from John Drasar moved me to tears. His story was very much like mine in a way, starting with an inept GP who fobbed me off for years saying I had a tummy bug when the symptoms first presented themselves.

I also find it impossible to go back to nursing due to joint pain and tiredness etc and I have been a lone parent for the last decade or so. As for John, money is very tight here as well. I spend sleepless nights worrying over money. My washer just died this morning and I don't know what to do next. I will get my head round it soon. My







father has been a great financial help but I do feel guilty asking for things.

But the crunch was then when John said in his letter that he was waiting to die and that it would be a relief to go. It just shows he is not getting the psychological support he needs. Well I feel for him.

I have found out in the last couple of years that my daughter who is nearly 16 has UC too but we just have to keep going. I'm lucky as both my teenage daughters support me but I don't think a lot of people understand all that you go through when you have UC. I can not imagine what it would be like to want to die. I regularly talk to others via the phone about UC and the pouch surgery and would love to find out how they are all getting on.

I know every person's UC is different and everyone's reaction to it is different. We each cope with things in a different way but being a member of a support group does help or we wouldn't be here. I only wish that people who need the support ask for it.

*Chris Jackson*

P.S. If at first you don't succeed, try, and try again. Then give up. There's no sense in being a damned fool about it.—W. C. Fields

*Dear Newsletter Editor*

As a pouchee of 13 years, I felt I had to pass on this amazing new cure for sore and itchy bums. In 1992 I had surgery at St. Marks under Professor

Nicholls for ulcerative colitis, and was given a new lease of life with a pouch.

This worked very well for about the first five years, and I was able to eat most things that were previously banned, apart from the odd spate of pouchitis.

Then gradually over the next five years things started to go wrong. I was becoming more explosive at toilet times, with certain foods irritating my bowels, especially spicy foods and nuts. This got to the point that I was being forced to spend more and more time in a hot bath, as this was the only thing that gave me relief.

All the barrier creams that St Marks had given me to try had not worked. In some cases they caused more irritation than before, and I consequently became so sore that my bowel movement ceased to function properly due to the pain caused by the inflamed area.

St Marks then tried every x-ray and scan possible to find out the cause of this problem, but to no avail. I was now forced to drastically alter my diet, as so many things were causing blockages and great pain. At this time I was using zinc and castor oil cream to try and relieve the soreness.

One day I ran out of the stuff, and my wife then said would I like to try some Germoline ointment instead, which I did. The result has been amazing. A little dab of Germoline after every visit to the toilet has meant no more soreness or irritation; my bowel movements have consequently become more regular and although certain foods still cause a problem, e.g. mushrooms, peas, sweet corn and nuts, they do not cause any pain. Now while I do not know if this situation will stay the same in the future, I felt that I had to pass this on to any-

one suffering from the same problems that I had. I know I sound like a salesman for Germoline, but I'm not!

*Anonymous*

Please keep those letters coming. We all love hearing from you. If you have any comments to make about the letters or articles in this *Roar!*, please let us know by post or email. After all it's your magazine and everything that's in it is for you and about you. You can send letters or articles to:

[newsletter@redliongroup.org](mailto:newsletter@redliongroup.org)



# Familial Adenomatous Polyposis Information Day

If you want to find out more about FAP and its causes, come and listen to a talk by Professor Robin Phillips at the St Mark's Polyposis Registry Information Day at St Mark's Hospital on Saturday, 12 November. The day is in aid of FAP or Familial Adenomatous Polyposis and will cover surgery, post-surgery, the risks of inheriting FAP and workshops (see programme below). For more details, contact the organiser Kay Neale on [knneale@btconnect.com](mailto:knneale@btconnect.com) or [info@polyposisregistry.org.uk](mailto:info@polyposisregistry.org.uk).

## St Mark's Polyposis Registry Familial Adenomatous Polyposis Information Day

**Saturday 12 November 2005**

St Mark's Hospital  
Northwick Park, Watford Road  
Harrow, Middx, HA1 3UJ

### Draft Programme

9.30	Registration and coffee	
10.00	Welcome	Mike Dean
10.10	Surgical Choices for FAP	Professor Robin Phillips
10.30	Questions to Professor Phillips	
10.40	After Surgery - the Nurse's Clinic	Jacquie Wright
11.10	Polyposis – how did that happen?	Sandra Burke
11.40	COFFEE	
12.00	At risk of inheriting FAP – blood test or bowel examination?	Kay Neale
12.30	Inner Beauty	Jacquie and Sandra
13.00	LUNCH Coffee will be served light refreshments can be obtained from the restaurant in Northwick Park Hospital	
14.00	Polyps and you	Ripple Man
14.30	<b>Workshop 1</b> – DIY Endoscopy <b>Workshop 2</b> – Polyposis is not just polyps	Ripple Man Sandra + Jacquie
15.15	<b>Workshop 3</b> – Polyposis Partners <b>Workshop 4</b> – History and Research	Mike Dean Kay Neale
16.00	Closing remarks	Kay Neale

All enquiries about this event should be via Kay Neale at [kneale3@btconnect.com](mailto:kneale3@btconnect.com) or at [info@polyposisregistry.org.uk](mailto:info@polyposisregistry.org.uk). Discount parking has been arranged at £2.70, vouchers to be obtained from Kay Neale.



## RED LION AGM 30 APRIL 2005 REPORTS

### Chair

Christopher Browne said 2004-2005 had been overshadowed by the Indian Ocean Tsunami on Boxing Day followed by a remarkable global fundraising effort and £300m from UK donors to pay for relief work. The UK's charity-giving was now a global talking-point said Christopher, who described how his brother and two nieces, holidaying in Krabi, an island off Thailand's south coast, had only narrowly escaped the giant waves.

It had been a productive year for the Red Lion group, he said. Although membership had dropped slightly to 308, we had made up for it with at least 20 more members and visitors at the big day than last year. Among the highlights were an article in the Daily Telegraph about Simon Rogers, a successful boatbuilder and former Olympic yachtsman who had a pouch fitted when he was only 20. Very good exposure then in PR terms, while our newer, brighter, glossier Roar magazine continued apace, and pre-op patients had received invaluable support from members throughout the year.

Just as the Chinese calendar has its Year of the Dog or Year of the Monkey, ours was the "Year of the Lioness". A quartet of them, in fact. Joanna Wagland, St Mark's pouch support nurse, did some fine unstinting work helping members and those interested in joining us. Membership secretary Marion Silvey performed a magnificent double, recruiting both members and hospital stoma-nurses. Morag Gaherty was resident superwoman, juggling a successful business with raising two small sons and editing Roar. Stephanie Zinser meanwhile had handled the national media with aplomb and been elected a trustee of the St Mark's Foundation.

The chair singled out the efforts of the vice-chair and secretary, Mike and Margaret Dean, over the previous 12 months. Mike had done so much behind-the-scenes organisation that he, the chair, had been left with little to do apart from opening meetings and standing around looking cheerful, he said. Christopher thanked the committee for their valuable work and members and visitors for donating their bank holiday to charity.

### Treasurer

I am again able to report a quite successful year for the Red Lion Group. The income figures are down mainly because we had two large donations in 2003. However, the high income figure was achieved because of the magnificent sum of £1,177 I was able to claim for gift aid. I really am grateful to all those members who have signed the forms as it does make a difference and costs nothing to the donors. The amount to be claimed this year (2005) will not be as much as we will not have had the large donations. If you haven't signed a form and you pay income tax, please ask me for one.

Subscriptions were slightly up which was good as it meant we have kept our membership. Bank interest was almost double, mainly because of the balance kept and the rise in deposit rate.

On the debit side we didn't make any donations in 2004 but intend to do so this year. Printing and postage for *Roar!* were slightly up and will unfortunately increase this coming year due to the higher postal charges. Our travelling expenses are almost nil due to the fact that our committee meetings are made by telephone link ups. The web site expenses are an on-going item as it is important that the site is revised occasionally.

Membership is just over the 300 mark now and I must thank Marion Silvey for all the work she does in this respect. We seem to work well together even though there is quite a long distance between us.

This year I have finally and definitely decided to retire. I am not quite as well as I was and whilst I have enjoyed the last six years I feel in my ninth year it is time to hang up my pen (or is it mouse these days!). I will be only too happy to give the new treasurer any advice needed. Please will someone step forward as it isn't too onerous and no travelling needed and expenses can be claimed. You don't have to have a computer as I still keep the hand written cash book going as well.

If you have any questions I shall be pleased to try to answer them.

*Editor's note: The position of treasurer has been filled by Marjorie Watts.*

### Liaison Officer

To date we have 306 paid members on the database. 25 members have not renewed this year, despite reminders. We have 28 medical members—in the main, stoma nurses.

Once again, over the last year I have been contacted by a number of people—usually those about to undergo surgery—who wish to speak to a member.

I would like to thank all those people I have phoned, who agreed to share their experiences. I always seem to find myself desperately short of matches as I often have to look for a particular age range, a certain sex, a one-, two- or three-stage operation. Sometimes I can only find four or five matches and then discover they haven't all agreed to be contacted.

Can I please ask, if any of you who on your original application DID NOT tick the box stating you agreed to be contacted and were willing to talk to others, please reconsider. If you are unsure as to whether you ticked the box or not, would you be kind enough to leave your name with a committee member and I can then check the application.

### Tribute to a Treasurer

We're already missing John White our friend and treasurer since the group began in 1996. John was a NatWest bank manager until 1989 when he became administrator of the St Mark's Research Foundation and the 150th Appeal Fund. Three years later John was asked to be treasurer of the Friends of St Mark's. Until we snapped him up, of course. The rest, as they say, is hospital history. John's handed an unruffled set of books to Red Lion member Marjorie Watts who pluckily agreed to be our treasurer at April's Information Day. So welcome to the jolly band Marjorie.

Happily, John has agreed to stay on the Red Lion committee—a thoughtful gesture as it means we won't miss out on his merry quips and amusing emails. Enjoy your retirement in Camberley, John—and see you at the next meeting.

*Christopher Browne*

## Sandy Hyams Receives Some Boneshaking News

Did you know that having bowel disease could put you at risk of osteoporosis? No, I didn't either—until my local GP surgery targeted women over 50 with a questionnaire on the subject.

Osteoporosis is called “the silent disease”, as often the first sign you have it is a broken bone, typically the wrist or hip, after a minor fall. It affects one in three women and one in 12 men over the age of 50, a fact which startled me.

The osteoporosis questionnaire is part of a country-wide project with selected general practices taking part. Its objective is to try to reduce fractures and to offer preventative treatment. The special projects nurse evaluated the questionnaires received, to assess the likelihood of osteoporosis developing, and invited those she found with a higher than average risk of fractures for a follow-up appointment. To my surprise, I was one of those contacted.

However, when I read through the National Osteoporosis Society (NOS) booklet that she gave me, I realised that it was not so unexpected. Among the many factors which can increase the risk of the disease are the following:

- long-term use of corticosteroid tablets
- medical conditions which affect the absorption of food, such as Crohn's or ulcerative colitis, as well as gastric surgery
- medical conditions that leave people immobile for long periods of time
- low body weight.

How many sufferers of bowel disease could not tick off two or more?

The good news is that osteoporosis can be treated and prevented. A calcium-rich diet and weight-bearing

exercise, among other things, have been shown to benefit your bones and strengthen your skeleton. The recommended daily calcium intake for adults is 700mg. One third of a pint of milk, a yoghurt, 1oz of cheddar cheese and 4 oz of boiled spinach, for instance, will take you comfortably into the safety zone.

I was delighted to read that vitamin D is needed to help the body absorb calcium, as the major source is sunlight. But I was a little unsettled to learn that too much animal protein, caffeine and *salt* can reduce the absorption rate. What would I do without my regular shots of coffee? And how could I cut down on my necessary salt intake (for which I now have a craving)?

Apart from HRT (hormone re-

placement therapy), which for many years was the only treatment available, since the 1990s there have been other

non-hormonal drugs on the market prescribed for osteoporosis. However, many of these have various side-effects, notably affecting the digestive system, causing nausea and diarrhoea. Tell me about it!

It appears that my risk of osteoporosis is only medium. At the time of writing I am waiting for a doctor's appointment to see what happens next. If you want any more information on any aspect of this condition, you can

phone the NOS helpline on 0845 450 0230.



## Please support the Red Lion Group

Registered Charity number 1068124



All donations, however small, towards expanding the work of the group will be gratefully received. If you would like to send a donation please make your cheque payable to The Red Lion Group. And send it to: **The Red Lion Group Treasurer, Mrs John White, Marjorie Watts, 11 Meadow Way, Upminster, Essex, RM14 3AA**



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## Join the Red Lion Group

- Newsletter three times yearly with all the latest news, views and events
- Membership is £10 (£5 for hardship cases, and free for under 16s) per annum
- Write to Liaison Officer at the address above for a membership form

## Visit Our Website

[www.redliongroup.org](http://www.redliongroup.org)

## 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 people an insight into an aspect of their condition they hadn't noticed before. Most important of all you'll make the life of the newsletter editor a little bit easier.

If writing articles isn't your scene we are looking for other things too, including cartoons, crosswords and jokes.

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



