

ROAR!

ISSUE 26 • SUMMER 2003

***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 Red Lion Group rep, please contact Morag Gaherty (phone number on back page).



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It's Time For a Chat...

By Stephanie Zinser, Author of *The Good Gut Guide*

When women's popular magazines start sporting headlines like 'The Good Poo Guide' and 'The Bottom Line', and when a certain recently-launched gut book outsells a celebrity sex manual, one has to reckon that a fundamental shift in popular views might be under way.

The shift is not that people are suddenly suffering from an epidemic of botty problems. The shift is that finally they're starting to *talk* about them.

And as a group of pouchies who have gone all the way through the pain, and survived to emerge victorious the other end (apologies for the pun), we're possibly more qualified to talk than most.

And talk we must. We must talk our little chins off.

Talking, as I've discovered (and I have practised a lot) can do several things. Many of which are ultimately great for people like us.

Firstly, talking about a taboo subject like bowels will break the taboo down. Bottoms are one of the few things that we (especially Brits) have great trouble talking about. Goodness knows why. We can laugh about them, but cannot talk seriously. I'm sure Freud would have said we were all sexually repressed and anally retentive. Or something like that. He's probably right, but he's also dead.

So, if we can break the taboo, people will find it easier to talk, and medical information will be exchanged more readily. Because of this, people won't as often fail to spot the signs of a bowel problem early enough, will get treated more quickly (and more successfully), and fewer people will end up with ileostomies and pouches.

Pouch patients are in a unique position because we can tell success stories. We can show people that even after extensive surgery and removal of various seemingly-important 'bits', that the majority of us can still function normally and lead active, fulfilling lives. It's a great message of hope, especially when you remember that people are generally quite terrified of losing body parts.

The media, of course, loves messages of hope. And if the taboo starts

breaking down because of all this talk, and if we Pouchies start showing ourselves and our normal lives - and offering messages of hope - then the chances are that a glamour or celebrity angle might soon follow. We know that some celebrities have been brave enough to speak out already, we just need a few more. Statistically, they are out there.

Think about how, in the last few years, we've seen increasing numbers of supermodels sashaying down the catwalk, waving their bras and raising money for breast cancer research. This is what I'm hoping will ultimately happen, but on the bowel front. Think along the lines of Naomi Campbell waving her thong, like a cowboy trying to lasso a feisty heifer, as she parades down the runway raising cash for research into inflammatory bowel disorders and you'll have the right image. (Naomi might hate it, but tough. It's my image).

And so, we reach the stage where bowels are the newest media darling, the celebrities are rushing out in droves to talk about their botties and their battles with Crohn's, or bowel cancer, or IBS, and we've managed to talk our way to a mountain of high-profile funding.

All that's left is for a few canny scientists to apply a little of their well-funded brain-power to the problems, and voilà! We have more cures for some of the worst bowel diseases.

Sorted.

But unfortunately for pouch-owners, there's more talking to do. Yes, it's fine that we can - and must - inspire the general public to greater bowel health, but we can - and must - also help each other. Pouches have been around for a few years, but really, in the grand scheme of things, not nearly long enough to answer the questions and solve the problems that we regularly face.

I'm referring to daily pouch dilemmas like how to maintain or achieve continence; how to manage the consistency of pouch output so that we can cope with it; how to deal with pouchitis, especially when it's chronic or recurrent; how to cope with the demands of preg-

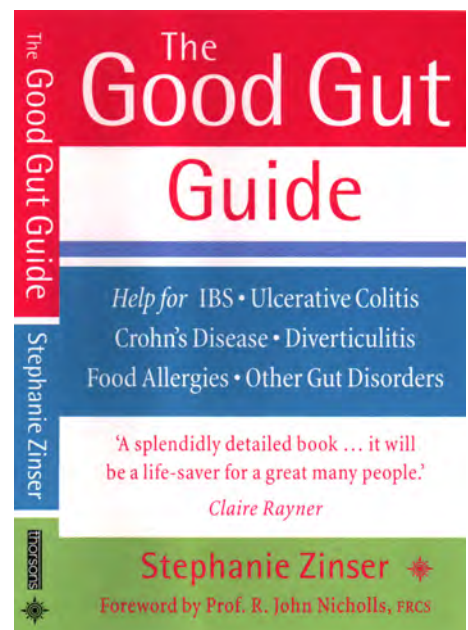
nancy or the frustrations of infertility - the list is extensive, but I think you all know the sort of problems I'm talking about.

They're important for us, and there are few definitive answers or solutions to many of them. If pouches were a new drug being worked on by a pharmaceutical company, we'd still be in the Research & Development Phase.

So we need to talk to each other about these problems. We must share our experiences and offer camaraderie, and also swap information. We also need to be happy speaking out to our consultants and surgeons about what seems to work and what doesn't - and we must tell them when things aren't right. *It doesn't matter that they saved your life - your life has also got to be worth living.* And when you're in the bathroom up to thirty times a day, it can easily feel like it's not. As one surgeon I know says, "we have to innovate to try and rectify these problems. But we won't know they exist until and unless pouch patients keep the pressure on us".

Bottoms may not (quite yet) be the new sex, but with a little more chat, who knows...?

The Good Gut Guide is available to order direct from ThorsonsElement at the special price of £8.99 (rrp £10.99) including p&pp, by ringing 0870-900-2050 and quoting department 711R.



New Red Lion Group Website

At the time that Brian originally wrote it, The Red Lion Group website was pretty good. Apart from which, who actually used the internet much, back in 1998?

But life moved on, everyone got a computer and home internet access, and suddenly our website (last updated April 1998) got a bit out of date. The good news was that the technology has also improved dramatically in the meantime as well, so current websites are much funkier than before.

Tim Rogers, our Newsletter Co-Editor, took on the challenge of completely rewriting the website, and the new one has just recently been launched. Being database-driven rather than html-uploaded (this will mean something to at least 3 of you), it will be much easier to keep up to date, and we'll hopefully be able to include links to current related news.

I'd urge you to take a look. Previ-

ous newsletter articles will gradually be included, and there's a full search facility as well. In fact, rather than tell you all about every little thing, I'm just going to push you online and ask you to tell *us* what you think. What's good about it, what's bad about it, what you'd like to see more of or less of etc.

The best review of the new website www.redliongroup.org will win a prize. If you're looking at the website, I know for a fact that you've got internet access, so why not e-mail your review to us? All the committee members now have new e-mail addresses, which will be much easier for you to remember without having to locate a back copy of the newsletter.

I, for example, am now contactable on either letters@redliongroup.org or newsletter@redliongroup.org.

Mike, our Chairman, is contactable on chairman@redliongroup.org.

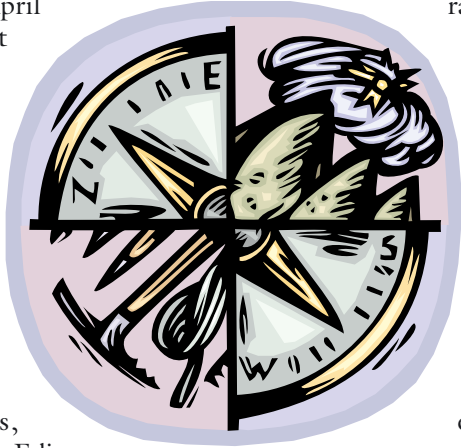
Can you guess Christine Lawton's e-mail address if I tell you she's the secretary? Yes, well done, it's secretary@redliongroup.org.

The others are on the back page of the newsletter. The beauty of this is that as committee roles change, the permanent e-mail address for that role will simply redirect to the new committee member in that position.

If you're ever in any doubt, just make sure it goes to someone@redliongroup.org and Tim can forward it on to the most appropriate committee member.

For that matter, if you want to e-mail anyone who has contributed to Roar, just e-mail it to theirfullname@redliongroup.org and we'll forward it on. Great stuff, technology. I love it when it works.

Morag Gaherty



There Be Dragons

Behind every Red Lion a feisty Welsh dragon is trying to get out. At least, that was the impression I got at the AGM and Information Day at St Mark's Hospital on April 12. One moment I was chatting about the Millennium Stadium with Dr James Powell from Cardiff, the next discussing the appeal of BBC Radio Wales with two other young members from the Valleys.

I also had a lively exchange with Philippa French, a Red Lion member from Harrogate who works for the BBC and wants to help raise our profile in the North-east. It was that sort of day, with just over 70 members, relatives and friends from London, the Home Counties, Lancashire, Yorkshire and Wales among others visiting Harrow, Middlesex in the mid-April sun.

And the letters and feedback show a great time was had by all. Our annual get-together gives all of us - poussees, relatives and health workers - a chance to talk openly about pouches, something that is not always possible at work or when visiting friends. Here,

we're a bunch of dedicated pros ready to share our views on healthcare, harmony and happiness. I mean where else can you get free tips on diet, exercise and general fitness? If you went to a health club or a Cannons gym it'd cost you up to £50 an hour.

And no one is better equipped to explain the ways and wiles of a performing pouch than Dr Sarah Mills, a clinical research fellow at St Mark's. In her talk "Probiotics and Pouchitis" she said pouchitis was the commonest problem former patients face. Almost all those who get it had UC, 42 per cent suffering acute attacks while a smaller 13 per cent end up with chronic problems. Sarah explained how re-

cent tests show that tablet versions of probiotics (tiny bacteria in food) can help cure some of the more familiar pouch difficulties. It was a brave and spirited talk that she gave at very short notice after another speaker was unfortunately unable to attend.

Incontinence expert Professor Christine Norton told us that many of the UK's 500,000 sufferers are too embarrassed to seek help because of its taboo nature.

Apart from old-age, one of the commonest causes was anal sphincter injury after childbirth, said Prof Norton. In her talk, simply titled "Incontinence", she said St Mark's recently introduced a bowel diary to

help patients control attacks. Imodium and codeine tablets, sphincter exercises and anal plugs also helped to stem outbreaks. Prof Norton advised sufferers to log on to www.bowelcontrol.org.uk, an incontinence website.

Red Lion president, ileo-anal pouch pioneer, former St Mark's clinical director and one of the world's leading colorectal surgeons, Prof Nicholls gave us an incisive talk on recent pouch research.

Two key points he raised were that salvage surgery is not always the answer to chronic pouch problems and that a recent study by the Danish surgeon J Olsen shows that ileo-anal surgery might reduce a woman's fertility by up to 50 per cent. Though remember this is research, not fact, and does not affect a women's ability to bear a child once she has got pregnant.

And what of the future? Prof Nicholls said he would like to see one-stop, multi-use units set up at UK hospitals. These would enable patients to get surgical, medical and general health advice at the same place, encourage quicker aftercare and help stem some of the long, anxious waits patients and relatives may face.

Chairman Mike Dean led a good-humoured and informative AGM. He said printing problems had given Roar something of a "roller-coaster" year, though editors Morag Gaherty and Tim Rogers managed to produce two excellent colour editions.

Mike said that though food was not on the menu this year due to the hefty £800 bill we had to stump up for 2002's Information Day, members and visitors had donated £2.50-a-head to cover tea, coffee and administration. Finally, he asked members to note down the date of the next Information Day and AGM - **Saturday, 24 April, 2004**, at St Mark's.

Treasurer John White reported a "quite successful year". Though income was less than in 2001/2002, print snags meant Roar's costs were lower than usual and we donated £2,000 to the St Mark's Foundation for pouch research. Without this item, we would have shown a surplus of £1,774 for 2002/2003. John said he was willing to be treasurer for another year, though he may have to stand down in 2004. It goes without saying

how grateful we are to you, John. We'll sorely miss your humour, wisdom and efficiency.

Marion Silvey, membership and liaison officer, said we had 316 Red Lion members on the database, 36 of them new ones. She said that during the year she had put eight people who had pouch difficulties in touch with members facing similar problems. She said she aimed to write to 66 lapsed members to find out their intentions and put a reminder in Roar for anyone to contact her if their phone numbers change.

After lunch in the St Mark's canteen and restaurant areas, we listened to a Red Lion who has recently become a bit of a star - namely Stephanie Zinser. She told us about the events that led up to her new book, *The Good Gut Guide*, which was published in April. She said that whenever she tried to talk about her problems as a young mother with uc, she usually faced either cold indifference or plain old-fashioned ignorance. So, after a pouch operation at St Mark's, she decided to close some of the British taboos about bowels and guts with a comprehensive study of everything from the common tummy ache to serious bowel cancer. Her quest has more than succeeded.

The 272-page *The Good Gut Guide*, published by Thorsons, a Harper-Collins imprint, is selling extremely well in the UK, USA and several other countries, and Stephanie has given numerous talks and radio interviews about it. If you haven't yet ordered your copy it costs £10.99 and is on sale at all good bookshops, or use the special offer code on page 3 (valid until 3 September).

Stephanie's lively, amusing and human talk kept us riveted for 40 minutes - it could have lasted four hours and we would have still been enraptured. She described those undignified moments we've all had while shopping in Tesco, dancing at a friend's party or enjoying a meal in a local restaurant - moments that outsiders often don't understand or simply dismiss with a shrug of the shoulders.

However it is those close to us who suffer most. "There is nothing worse than watching someone you love suffering and not being able to do anything about it," she said.

Stephanie revealed that 30,000 people suffer bowel cancer (the second commonest form of cancer) in the UK each year; the average person produces 25 litres of "wind" (farting to the initiated) a day and, like Dr Sarah Mills, that probiotics could be the key to many a pouch problem. Stephanie, who writes about health for the Daily Mail, The Sunday Times, Daily Telegraph and London Evening Standard, said she wrote the book as a guide for laymen, patients, GPs and health specialists. Her talk was followed by a lively question and answer session.

How do you follow that? you might ask. With difficulty. Our solution was workshops. Members, relatives and friends joined in discussions led by Kay Neale, registrar at St Mark's polyposis registry, Sarah Varma, a St Mark's specialist pouch nurse, and Dee O'Dell-Athill, a former pouch patient, on Manifestations of Familial Adenomatous Polyposis, Anal Skincare, and Having and Raising a Family after Pouch Surgery, respectively.

A second workshops session for pouch owners and partners was led by Mike Dean, Morag Gaherty (briefly, when not chasing a 2 year old around), myself, Brian Gaherty, Red Lion vice-chairman, Christine Lawton, Red Lion Secretary, and Marion Silvey.

We should offer a huge vote of thanks to the committee generally, and specifically to Mike Dean (and his wife Margaret) and Christine Lawton, who did most of the organising of a truly splendid day.

Also, especial thanks go to Sarah Mills for agreeing to talk at short notice; to Sarah Varma, who stood in so ably for Joanna Sweeney, Red Lion's clinical nurse specialist; to former Red Lion Group Secretary Inez Malek, who managed to conjure from such sources as Champneys Health resorts and the Courtauld Institute Gallery an alluring array of raffle prizes; and, finally, of course, all you Red Lions who attended - not forgetting a Welsh dragon or two.

So pleased was Mike Dean with the response that he and Joanna Sweeney have already booked the speakers for next year's AGM! I can hardly wait.

Christopher Browne
Red Lion PRO

Editorial

Time to go to press again. This time I'm determined not to be late, helped by threats by certain members of the committee of possible unspecified personal injuries to befall me (I'm joking – I don't think violence was actually included on the agenda at our last telephone conference).

This last quarter saw our annual Information Day and AGM at St Mark's Hospital, for which Chris Browne has done the write up. It was a great day, although I'll have to admit to not having seen much of it. Our 2 year old Tom had burned his feet the weekend before, and it was quite useful to be able to call on the services of a specialist nurse to change his dressing while we were at St Marks. It probably made a nice change for Sarah, looking at something other than someone's bottom or tummy! Anyway, we were really grateful. Thank you. And I apologise for missing the workshop I was supposed to be co-hosting – as those of you in there know, once Tom had got his feet sorted out, there was no stopping him from running manically around, and it was easiest to remove him so you could get to talk properly!

Inez Malek organised some fantastic raffle prizes (what an address book that girl must have!) for us, some of which have not yet been won. I can't tell you what's left, but I know there are some pretty fantastic things still available. So we've decided to offer a *prize for the best letter* which means it is about time to get out your pen and a piece of paper and start writing. I'll hear no excuses. You'll find me deaf to your pleas and entreaties.

General feedback about Roar newsletter is generally very enthusiastic, but it has been mentioned to me that some readers consider it is not positive enough about life with a

pouch. There is a slight dilemma here, common to every support group, in that the people who are the most vocal tend to be the people with the most extreme experiences, and those are usually bad ones when it comes to medical support groups.

We know that a large proportion of pouch owners are very happy with their condition after surgery – even if it is not perfect, it is often very much better than their pre-surgery life. But, equally, people who are happy with

that this newsletter is read by lots of people considering pouch surgery and we don't want them to be put off by too much doom and gloom – a healthy recognition of the failure rates and potential complications is one thing, but balanced against any risk there has to be potential reward: a chance to get back to a normal life, and we mustn't forget that. Let's tell it like it is, for so many of you.

Finally, I need to make clear that whenever an article or snippet has no apparent author, it has not in fact sprung direct from an eternal spring of any kind. It was written by me. I don't write my name against everything because otherwise you'd see it all over the place and it would get pretty boring – I kind of assume everyone knows it is me by now. Whenever a piece is contributed by someone else, they are mentioned (or mentioned as anonymous, if they prefer) in the introductory paragraph. The one exception to this



this change tend not to be the people who write about it. It's akin to the recognised phenomenon that contented people tend not to make great writers or artists. (That's how I reconcile myself to the fact that JK Rowling is rather richer than I am, by the way).

Anyway, I'm having none of your excuses. I want a 500 word essay from each and every one of you on what having a pouch has done to improve your life. Oh, OK, I'll accept any length paragraph or article from any of you. But please write. Remember

is purely because of poor proof-reading on my part last issue: Chris Browne was inadvertently not credited with his article called Life as a Pouch Owner. My apologies, Chris. Thanks for contributing to this issue, despite being treated so badly in the last one. I'll try not to let it happen again.

Right, I think that's everything ticked off – apologies offered, threats issued (thinly disguised as requests for articles). Time to get on with this issue...

Morag Gaherty

Dancing For Charity

Sharon Hendron, our newest rep, tells us how life has changed since she last wrote in to us...

I had my colon removed in December 1997 due to Ulcerative Colitis. After a few complications and 3 more operations, I had my pouch successfully connected in August 1999.

Last time I wrote in, I was awaiting surgery for a hysterectomy due to suspected endometriosis. Gynaecologist Dr Harper assisted my bowel surgeon Mr Maxwell (my guardian angel) to carry out the required surgery at the Royal Victoria Hospital, Belfast. Although no evidence of endometriosis was found, I am now virtually pain free.

On the pharmaceutical front I no longer need pain killers, nor do I take imodium. I take vitamin drinks and HRT, and have recently discovered the wonders of Yakult!

I went back to line dancing 5 weeks after surgery. Every year the line dance club to which I belong sponsors a charity and any money raised through line dance demonstrations, the 5 hour sponsored line dance and monthly social nights goes to that

popular charity.

Last year we raised £5,000 for RVH Colo-Rectal Fund. This year's charity is Alzheimer's Disease.

I am now 33, my son is almost 10, my daughter is 7 and I feel great. I have now started my own line dance classes for beginners and hope they get as much enjoyment out of it as I have.

Also, I have put my name forward to be the Red Lion Group rep for Northern Ireland. I'm sure I'm not alone in saying that I hate having to go to hospital, but being able to talk to people there in a similar situation to myself always helped.

If I could be of help to anyone, even just to lend a sympathetic ear, I'd like to do it.

Please feel free to write
8 Ivy Hill
Lisburn County Antrim
Northern Ireland
BT28 3SG
or phone 02892 661559.

We could even arrange to get together for a bit of craic!

Sharon Hendron



Letters

Dear "Royston Lady"

So sorry to hear about your problems. Please get yourself an appointment with Prof Nicholls at St Marks Hospital, London. The hospital is world-famous for specialising in bowel disorders and he was a pouch pioneer.

Mine was done 13 years ago and I've been trouble-free since (after a lengthy initial stay in hospital).

Please see him, it's what he does!

Best Wishes

Sandra Darvill



Here are some of the comments providing feedback on our annual Information Day and AGM in April

Thank you all for all your extremely hard work to make last Saturday such a wonderfully informative day. We learned such a lot which could never have been found out by reading alone. I wish you continued success.

Thank you so much for arranging such an informative day. It was so useful to meet people in similar circumstances. It would be good to have regular localised venues to meet IBD sufferers, especially for the younger ones, who feel so isolated.

I am enclosing my evaluation form which I forgot to leave behind yesterday. However, it gives me the opportunity to say "thank you" to you (Mike Dean) and the others who organised the AGM and Information Day.

I found it very useful indeed, not just to listen to the speakers, but also to the other participants. It helps to know that other people have similar experiences with their pouches!

The Roar magazine is excellent and has some really interesting and useful articles. I've only contributed once, but I'll certainly do so again if I feel I've something worthwhile to write!

Change of Address

Our Liaison Officer, Marion Silvey wants to check on your (residential) movements...

Have you changed telephone number or moved address since you joined the Red Lion Group? Don't forget to let us know of any changes.

When you completed your membership form, if you ticked the box saying you would be happy to talk to others of your experiences, I need to

be able to contact you!

Also, if you pay by Direct Debit we can't tell if your address has changed since the previous year. I know there are so many people to advise when you move or change telephone number, but please put 'Red Lion Group' on the list - thank you.

Anal Skin Care Workshop

What follows is a reproduction of the handout for Sarah Varma's popular workshop at our Information Day, on the topic of anal skin care:

Avoiding and Treating Skin Irritations

Skin is the body's largest and most visible organ. How we look and feel is important to both our wellbeing and how others see us. Advertisers often make comparisons with "perfect baby skin" as a ploy to sell their skincare and beauty products, and this adds to the idea that all babies have blemish-free skin, when in reality we know this not to be quite the case. The care of adult anal skin can be likened to that of babies and many of the recommended remedies are similar.

From a recent quality of life study (Bond and others 1997) it was found that the consistency of motions varied between firm, soft, loose or liquid. A total of 54% of the respondents reported that they never had a problem with leakage of motions from the pouch, whilst the remainder said it varied, generally requiring the use of a pad. Some respondents leaked only mucous. Overall, 85% of respondents reported some degree of anal soreness or irritation on a regular or occasional basis.

It would appear that even with good personal hygiene to this particular area, anal soreness and itching are quite common.

The Skin and Digestive Process

In order to understand why anal soreness occurs, it is important to know how the skin and the digestive process interact. Skin is composed of two principal layers of tissue glued together by biological adhesives. Injury can peel the layers apart and/or induce blisters or bulky eruptions.

When you eat, food is mixed with digestive juices (acids and enzymes) to liquidise and break down the food ready for the intestines to start absorbing the nutrients. In the ileum

(small intestine), more digestive juices are produced, to help with the absorption of nutrients, most of which occurs at this stage. This means that the contents of the ileum are quite fluid-like.



Normally, the large colon would reabsorb excess liquid, to give a formed motion, but following your operation to remove this, the digestive juices remain present, and are very easily able to damage normal healthy skin. If you find that your pouch output is frequently high (8 times or more

per day), then sore skin is inevitable, as your bottom is not ideally suited to this new environment.

Hints and Tips

1. Keep the area clean by washing and drying the anal area after every bowel motion
2. Have regular baths or use a bidet. Portable bidets are available from some chemists or from Salts Healthcare 0800 626388
3. Patting the area dry afterwards with a soft cloth/flannel/towel is better than rubbing with a rough flannel/towel
4. Renew cloth/flannel/towel linen on a regular basis
5. If the anal skin area is not broken, the use of moist toilet tissue or baby wipes can be useful. Bear in mind that these wipes do contain alcohol, so will sting if your bottom is sore
6. Avoid using soap to the anal area, as it can leave a residue, resulting in itching and irritation
7. Keep area dry at all times, if possible avoiding excess moisture
8. Avoid perfumed talcum powder
9. Wear cotton underwear, as it absorbs moisture and allows air to circulate

10. Avoid firm foundation garments if you are sore. Stockings may be preferable to tights, for instance
 11. Use a good recommended barrier cream each time you pass a motion
 12. Avoid excessive use of ointments and creams
 13. Consider thickening your bowel motions by changing your diet or taking stool-bulking agents such as Imodium, Codeine Phosphate or Lomotil
- Seek medical help, should the problem persist

Don't be a party pooper!



Visit our new website

www.redliongroup.org

Your Questions Answered

By our Pouch Specialist Nurse at St Mark's Hospital, Joanna Sweeney

I had my ileostomy closed 3 months ago and I'm planning a holiday in Florida next month. Is it too early to travel abroad?

If you feel well, then relax and enjoy your holiday. However, now that you have a pouch you need to consider how hot weather, a change of diet and of surroundings might affect the function of your pouch and hydration. Preparation is the key.

Things to remember before travelling:

- Medications such as anti-diarrhoea drugs (Imodium) which you can buy from the chemist.
 - Rehydration solution such as dioralyte
 - Possibly oral antibiotics such as metronidazole or ciprofloxacin for pouchitis, however, you would have to discuss this with your GP.
 - Supplies for anal skin care
 - A letter from your GP outlining your past care in case you require treatment abroad.
 - Travel insurance. Check it covers preexisting medical conditions
 - Request aisle seating on a plane to allow easy access to the toilet
 - You should be drinking the equivalent of 8-10 average glasses of fluid a day (1.5 - 2 litres) and adding at least a teaspoon of salt to your food over the day. If you are visiting a hot climate you need to increase your salt and fluid intake.
 - Know the symptoms of dehydration such as dry skin and mouth, which are: feeling thirsty, light-headed and tired. Passing small amounts of dark coloured urine is also a sign. Another one is experiencing 'cramp-like' pains in your stomach and/or hands and feet.
- Most importantly, enjoy your holiday!

I had my pouch formed over a year ago and I still experience a lot of discomfort from wind particularly bloating at night. I often have

to get up during the night to release the wind. Is there anything I can do to reduce wind?

Look at your diet and the way you eat. Certain foods are known to cause excess wind such as beans, green vegetables, onions, milk, spicy foods, beer and carbonated drinks. Bearing these foods in mind, experiment with your diet by trial and error to work out which foods cause you the most problems.

- Chew your food well, eat slowly and try not to gulp and swallow excess air.
- Try not to talk when you are eating.
- Eat regularly and don't skip meals.
- Eat a snack between meals.
- Pour carbonated drinks into a glass and allow to stand for 10 minutes.
- Don't chew gum, drink through a straw or smoke.
- Fennel, mint tea and live yoghurt may help reduce wind.
- Talk to your chemist about peppermint capsules and other wind remedies.

To reduce wind at night, try eating your main meal at lunchtime and then a small fairly bland meal early evening. Try to get rid of excess wind before going to bed at night by either sitting on the toilet, massaging your abdomen may help, or by lying down on your side with your knees up or lying on your tummy.

I have had an ileo-anal pouch for 5 years with no problems. I know a fellow pouchie who has had several episodes of pouchitis. What is pouchitis?

Pouchitis is inflammation inside the pouch and it can occur in those individuals who had a pouch formed for ulcerative colitis. It occurs in about 10-20% of people with pouches, some people may never experience an episode of pouchitis whilst others have several. It is generally easily treated with a course of oral antibiotics such as metronidazole or ciprofloxacin. If the inflammation persists topical steroid enemas and oral steroids can also

be used to treat the condition. Pouch excision (removal) due to chronic pouchitis occurs in only 3% of patients.

Symptoms include:-

- Urgency
- Bloody diarrhoea
- Pain
- Nocturnal incontinence
- Increased frequency
- Sore skin
- Feeling generally unwell

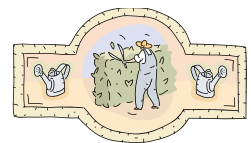
A true diagnosis of pouchitis is based on clinical symptoms, endoscopy and histology (from a biopsy). Often it is not feasible for the patient to have endoscopy and biopsy at the onset of symptoms and they are treated based on symptoms

If you have a question to ask Joanna, please send it to her using the contact details on the Committee Members page of this newsletter. Replies will be published in future editions of Roar!

Membership Drive

We have just launched a recruitment drive to attract new Red Lions to our den.

So we need to tap such usually reliable sources as hospitals, private patient lists and friends of friends. If you had your pouch operation at a regional or lesser-known hospital (e.g. not St Mark's or Oxford Radcliffe hospitals)



could you please let me have the name, address and phone number (plus the name of the main stoma nurse, if possible).

We can then extol the virtues of being a Red Lion and hopefully attract some new pouches to our cause.

Please contact me at pr@redliongroup.org, 020-8894 1598 or 89 Fulwell Park Avenue, Twickenham, Middlesex TW2 5HG.

Many Thanks.

Christopher Browne
Red Lion PRO

A Pouch Goes to Hollywood

Once upon a time, Hollywood seemed an exotic location, the kind of place you would want to visit, at least once in your lifetime. But then Susan Walls sent us more information about life on the west coast of the US of A.....

Imagine: a year in sunny California. That sounds like a lovely, relaxing experience, no? I certainly thought so – the day my husband got offered a contract with an LA television company I said “Yes!” and punched the air like they do in the movies. Sunshine! Beaches! Fresh air for the baby!

A small annoying voice in the back of my head said, hang on, you’ll be a long way from your doctors, from friends and family, and the support network that helps you get through the week with a 2 year old child and a chronic illness.

But I told it to stop being pathetic – it’s not like we were going across the Kalahari desert.

As it turned out, the voice was right. Though still annoying. And small. Here are five good reasons why sunny California is not the perfect place for a pouch and its owner.

1. American toilets are crap. No really. Americans can send men and women into space and back. They invented modern computing, and the internet. But they can’t build decent toilets.

Join my family one Sunday morning as we’re preparing to take the baby to the beach: the washing machine has just started its spin cycle, my husband is finishing his shower, and I go to the loo one last time before we set off. And yes, maybe I do use too much toilet paper and baby wipes (if you’re the owner of an overactive pouch, you’ll understand). Plumbing overload alert! Brown stuff starts to gush UP the bath plug hole, and over the top of the toilet. Within minutes, we’re ankle-deep in sewage. We’ve been living in LA for three months,

and this is our second major flood; we have mini-floods every other day. And every one of our many visitors blocks the loo the second day after they arrive: that post-jet-lag-that’s-better-my-system’s-back-to-normal-moment is too much for our toilet; my husband has to do complicated things with coat-hangers for ages to get things moving again.

On this particular flood day, our

lob everything down the loo - which then blocks, so they have to call out the Russian plumber, who gets very rich and laughs at them because they can’t build toilets or pronounce foreign names.

So for the entire year we lived in America, I had to put up with an unreliable and often unusable toilet. Which is not good because when I have to go, I HAVE TO GO!!!



2) Flushing the toilet is expensive in LA, and pouch owners flush a lot – I do what passes for poos 10-20 times a day. But Los Angeles is a desert: most of its water is piped in from the greener pastures of Northern California. Which costs big bucks. So water bills are high. You see where I’m going with this? I thought of contacting someone on the council to discuss my special

landlady summons a Russian plumber to fix things. His name badge says Sergey. I learn many interesting things from Sergey: 1) His name is Sergé, but he writes it with an ‘ey’ so that Americans can pronounce it. 2) All plumbers in LA come from Eastern Europe (why this should be, I’m not quite clear, but I think it has something to do with 3) Russian toilets are brilliant, but Americans can’t build toilets properly, nor can they fix them. 4) You should put your used toilet paper and baby wipes in a container by the side of the toilet, in the European fashion. Americans don’t do this, apparently, because they’re delicate souls who can’t bear smelly things, so they

case, but was warned against this idea by neighbours. Seems you don’t want to go getting embroiled in American officialdom; it’s like being stuck in the seven circles of Hell. So while we lived in LA, we paid around \$5 a day for the stuff that comes out of the taps and flushes the toilet, which makes even Yorkshire Water bills seem like a bargain.

3) Dehydration is a serious problem in Los Angeles. Summer temperatures in the San Fernando Valley can reach 120F, which is Kalahari-desert-hot. Most people forget (if they ever knew) that LA is, in fact, a desert, and a silly place to build a city: in an earthquake zone, with little natural

water, and blisteringly hot daytime temperatures. (But on the plus side, the light was nice for making movies.) Even normally-plumbed, fully-coloned humans get dehydrated in LA. The day our air-conditioning broke, the baby's face went as red as a baboon's bottom, and I drank my entire stash of electrolyte powder.

4) Then there's the problem of child-care in Los Angeles. I don't know how other parents of small children cope with a pouch and a toddler. (In many ways having a pouch is much like having a two-year-old: both poo all the time, throw wobblers when they get tired, and make you feel knackered. So having a pouch *and* a toddler is like having two pouches, if you will.)

I depend on good child-care to give me a break. Before we moved to America, my little boy went to a child minder for a couple of mornings a week, but they don't do child minders in LA because of high insurance costs. You can get a nanny to work from your home, but most Los Angeles nannies speak exclusively Spanish – one with even a few words of English can command \$20 per hour.

There are lots of pre-schools, but they're laughably expensive: around \$400 a month for just two mornings a week. So for the first few months of our stay in California, I looked after my boy Sam 24/7. But I knew it wasn't going to work the day I fell asleep in the park, standing up.

Eventually, I found out about a network of state-registered Home Day Care Centres, which are like home schools. They offer affordable child care, and probably saved me from complete physical breakdown.

5) Finally, there's the health insurance thing. We had no medical cover: my husband has a preexisting condition too, so insurers weren't keen on us – they wanted more than a thousand dollars a month from each of us for even basic cover.

So a trip to the doctors to get more Cipro cost \$150, every time, and a ten-day course of drugs cost a further \$40-60 dollars, depending on which discount drug store I went to.

So our year in LA wasn't a lovely relaxing experience. But it was a fantastic adventure. And it prepared us for our next trip – across the Kalahari desert.

EU 'Ave Got To Be Joking

Got another EUA looming? Here are Roar's Rules for getting through it in style!

Going into hospital is horrible. We understand that doctors need to 'have a look around' at what passes for our bowels, but god, it's an unpleasant experience. Still, it doesn't need to be a soul-destroying one – just take some tips from the celebrities who look glamorous and rested after a gruelling transatlantic trip. Here's how to make like Kylie and emerge glowing from your long haul EUA!

Problem: dehydration. Hospitals are overheated, crowded and airless places, much like the cabin of a 747.

Tip: Celebrities swear by Elizabeth Arden 8-Hour cream to get them from London to LA with glowing skin. Also, take a leaf out of J-Lo's book, and drink at least a litre of water an hour (*after* your anaesthetic of course, it's so not a good look to be vomiting all over the place!)

Problem: the shivers. Once you come round from your examination, the overheated air will feel cold and clammy. Celebs keep cosy and comfy in-flight in their Juicy Couture sweats and a pashmina – but unless you want to excite who-does-she-think-she-is looks from the nursing staff, you should maybe keep that look for lunch at Harvey Nichols.

Tip: Boden has a brilliant range of colourful and cosy sweatshirts for that post-procedure shivery feeling. Also, check out the *Next Directory* for stretch cotton leisure-wear – great for lounging around on that lumpy hospital bed!

Problem: cold feet. (Literally, not metaphorically that is: you're a worldly-wise, well-travelled hospital-goer – nothing freaks you.)

Tip: To keep your tootsies protected on the long trek to the

loo, try some flowery flip-flops – the *Roar!* fashion desk loves the *Next Directory* and *O'Neill* ranges. (Please, please, no horrid flowery nylon slippers. Hospital is a depressing enough place without flowery nylon slippers, thank you.)

Problem: the smelly thing. If you get the bed next to the loo, you don't have so far to walk, but you're in for a stinky time.

Tip: we recommend making up a spritz-bottle of lavender or neroli oil, mixed with water, to keep your area fragrant and lovely, and your skin hydrated. (If you're a man, two things to say: 1) what are you doing reading this girly-magazine nonsense? And 2) try bergamot oil instead, so you won't smell like a big girl's blouse.)

Problem: the neighbours. You didn't draw the bed next to the loo, thank goodness, but they've put you next door to the 76-year-old who's delighted by her 52 operations, and wants to tell you all about them.

Tip: take your Walkman, with lots of lovely classical and relaxing music, plus an eye mask to put on if she really doesn't get the message!

Susan Walls



Aloe Aloe Aloe What 'Ave We 'Ere Then?

The following information leaflet was made available to participants at the Information Day. I believe it to have been provided by Red Lion Group members who are also agents for Forever Living Products, listed at the end, but I have long been aware of the reputed properties of Aloe Vera.

I must also say that I have tried Aloe Vera gel in a “drinkable” format from Forever Living Products and in all honesty have to tell you that it was a very loose interpretation of the word “drinkable” – I thought it was foul!! But I’m sure many people will put up with that if it delivers results for them. I have reproduced the handout here, for those who were unable to pick up a copy.

Aloe Vera (Aloe Barbadensis) is a plant with the appearance of a cactus which flourishes in a warm dry climate and is part of the lily family. Inside the leaves of the Aloe Vera plant is a thick clear gel which has been found to be a natural source of many nutrients, and can be taken as a liquid dietary supplement or combined with other ingredients to form creams and lotions.

This gel contains 75 different components. These include:

- Vitamins A, B1, B2, B3, B5, B6, B12, C & E
- Minerals such as calcium, zinc and potassium
- Amino acids for protein building
- Enzymes used in the digestive system
- Saponins, which have natural cleansing and antiseptic qualities
- Lignin, which has the ability to enter the skin
- Anthraquinones, which are said

to have antibiotic, antiviral, antibacterial and anti-inflammatory properties

Therefore it has been stated that Aloe Vera increases healing by providing nutrients, reducing infection, promoting cell growth and by its anti-inflammatory action.

Aloe Vera is said to be most effective in skin disease such as burns, ulcers and eczema, and for bowel complaints, especially diarrhoea, constipation and colitis.

Aloe Vera was used by early Greek doctors and ancient Egyptians to treat wounds, infections, burns and stomach disorders. In 1968, Dr Bill Coats was successful in patenting a stabilisation process that preserves the gel in an “essentially identical” condition to the raw gel from the plant, as processing destroys many of the essential properties. The International Aloe Science Council monitors and examines the quality of Aloe Vera products, and therefore when buying a product it should have the Seal of Approval shown on this page.

It is important to note that although there has been much written on the benefits of Aloe Vera, there is currently no validated research to prove or disprove these claims. However, some have found it very helpful. Some



people with bowel control difficulties have found that it helps to reduce flatus (wind).

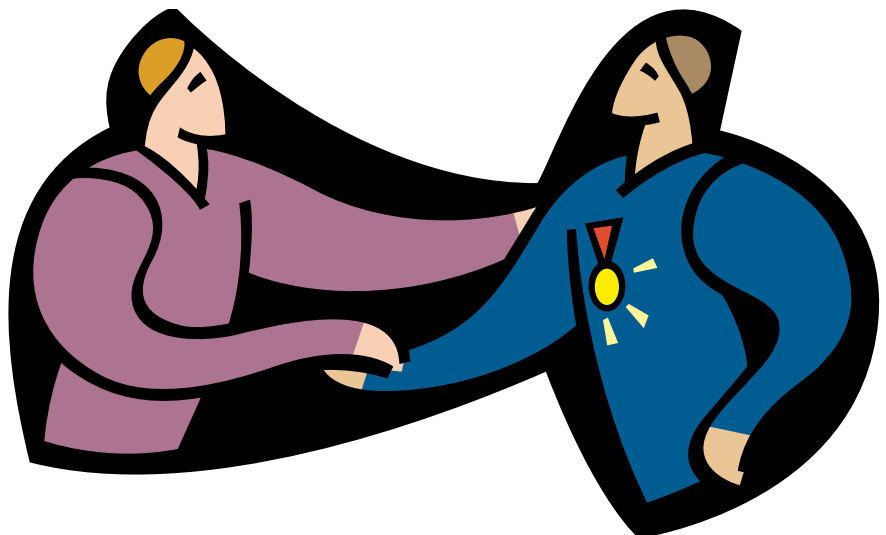
Useful contacts for information and products:

Forever Living Products
Freephone 0800 854871 or e-mail janerubin@aloevera.co.uk for details of your nearest Distributor
ESI Laboratories
38/39 St Mary Street
Cardiff
CF1 2AD
Tel: 01222 388422
Bee Well Health Care (covering M27/28/29)
Bolsover Business Park
Station Road
Bolsover
Chesterfield
Derbyshire S44 6BD
Tel: 01246 824634

Question: What's the first date you should put in your 2004 Diary?

Answer:

Saturday 24 April 2004
Red Lion Group Annual General Meeting
Don't Miss It!



'We Soldier On'

Alexa tells us her story and gives us an insight into how the Red Lion Group and others have helped her deal with her medical condition and lifestyle.

I gain tremendous benefit reading Roar. It, and other journals, have been a 'life line' for me. I read lots of material in hospital, looking for different information than I look for now.

Lying in hospital for endless, scary hours attached to a drip stand, this reading helped provide a vital link to reality, as I searched the pages trying to learn as much as I could. But it also assisted me greatly when I returned home, wondering if I would ever have any sort of life again that the caring nurses promised me, let alone the quality of life that in fact I do now have compared to when I was ill.

Now, however, I read looking for tips on how to deal with diet, job prospects, decent barrier creams, how to cope with tiredness at the end of each day etc. This helps find ways to live with an ileo-anal pouch, not to become the athlete that I used to be, but assists in finding ways to *cope* with life and daily reality.

I was diagnosed with ulcerative colitis (UC) in 1997, however I had problems for ten years on and off before that. Determined to avoid conventional medication, I refused doctor's suggestions and opted to change work and try to reduce stress. I changed my diet drastically (non meat, non wheat and non dairy), stopped drinking alcohol and drank *aloe vera*. As the colitis progressed rapidly into 1998, I saw a nutritionist who informed me that I had *candida* and should avoid all sugar content (no fruit, no fruit juice, no chocolate). I

seemed to be living on rice, soya and fish.

Having little effect, and becoming increasingly desperate to stop in excess of 20 visits per day to the nearest loo, I finally gave in to Doctor's advice and commenced medications *azacol*, *lansoprazole* (*zoton*) etc. When I developed lumps on my skull and severe headaches, I stopped tak-

my colon and opted for a temporary loop ileostomy. I was hospitalised in July in England but an attack of appendicitis was not diagnosed, nor when re-hospitalised 3 weeks later, abroad. The appendix ruptured during this time in hospital but again was not diagnosed, by which time I was air ambulated back to England. I was informed that I survived the burst

appendix and full peritonitis, due, firstly, to high antibiotic levels and, secondly, because the appendix ruptured quite by chance back into the digestive track and not into my abdominal cavity.

Lying on the stretcher landing in Iceland and before Gatwick, I recall thinking between shots of medication, well if I have to go this is a hell of a way to do it, in a rocket crossing the Atlantic with two pilots and two nurses,

Rocky and Liz from Colorado.

Having arrived in Gatwick, I was taken by ambulance to London. I vaguely recall watching the ambulance chasers rushing behind us to get through traffic lights through parts of south London and hoping we would not have to stop abruptly, in case I was sent flying out of the back door in nothing but my hospital gown and weighing a mere 6 ½ stone.

I was too ill to be operated on, and when I returned several weeks later for surgery I was still not well enough to have the two stage pouch surgery. My new surgeon, Professor John Nicholls, removed my appendix and colon in September, leaving a mucus fistula (preservation of the rectal stump) and he created my pouch



ing this medicine, and turned to homeopathic medication, even more convinced that will power and mind over matter would conquer this wretched illness, conning myself that I would soon be jogging and back on the squash court again.

Finally in May 1998, with constant rectal bleeding, greatly impaired walking due to swollen arthritic ankles (arthritis being a potential side effect of UC), arthritis spreading up to my knee joints locking them and disabling me, so I could only get out of bed by dropping onto the floor on my knees and crawling backwards down stairs, I accepted that I was not winning. I was admitted to hospital for three weeks.

The first surgeon wished to spare

subsequently in January 1999, removing the rectal stump at the same time. A stitch next to the stoma (my third by this time) tracked under the skin and became infected.

By then, my weak immune system could not combat infection and gangrene set in, which made bag adherence on floating flesh a nightmare. Additionally, this third stoma was flushed, so acidic ileo output was often squeezed up under the bag flanges and onto abdominal skin, thus digesting the skin. A convexity belt and bag assisted bag management and prevented leakage until the next operation. Poor Professor Nicholls received many calls from me by then begging for the next operation.

Within months of closure in March 1999, I must have been over enthusiastic and over exuberant about life, and split my central scar top to bottom (no doubt tree climbing or something equally daft). This was rejoined September 2000, but I tore it again last year (2002) lifting a heavy suitcase, which will require further surgery one day.

If one day my pouch doesn't work and I have to go back to an 'ostomy', catheter, whatever, so be it. I am me. I know I can live with a stoma. I console myself that however I excrete digested food, it is just leaving an exit. I recall the painlessness and ease of a 'well behaved' stoma, far fewer internal gut wrenching 'gripes' and enjoying swimming (although often grabbing a towel to hide an occasional air filled bag)!

So IF I am having a bad day and want the relentless exhaustion, anal soreness, dizziness, whatever I am feeling, to go away; I say slow down, tell work sorry you may fire me, but tomorrow is another day and I will feel better again. The downside however, is that some of us can't just say fire me. Life does go on and many can't just say let me have a half hour nap behind the desk. So we do need to find ways to cope and that's where I find reading journals, newsletters and finding tips a great asset.

Life may have moved on from the hospital bed, but I still have to function. I have to work. I cannot wait for someone to feed me. So I do welcome suggestions from as many sources as possible (articles including literature to assist understanding: job applica-

tions forms, employment rights, social security benefits, travel insurance, how to achieve better salt, mineral and electrolyte absorption, achieving correct balances: magnesium, vitamin B ranges, antioxidant complex, vitasorb B and B12 etc).

I find it tough when I am having a bad patch or by the end of the day when my pouch needs emptying and the havoc inside my abdomen takes me home to simply rest or find a bathroom for ½ an hour. Often people say 'oh you look great', but when my gut is doubled up, I want privacy and time to deal with my pouch.

I do not want sympathy and adamantly refuse help, but sometimes I just want 'acceptance' or need an 'allowance' for my length of time in the loo especially after midday. Even now a mistaken smile, as I sit, may still be a grimace. Yet still determined to be the old me as far as feasible, I put on such a good front *'with this ability to elude'* (SA Sheffield – see below).

If anyone asks why am I so tired, my simplistic explanation is that I live with diarrhoea all the time, therefore my body needs regular daily water replenishment as the main water absorbing organ (other than the kidneys) has been removed i.e. the colon,

whose main function is to also assist absorption of the majority of essential electrolytes, mineral or salts. I draw a comparison to running a car with petrol but without adding oil. And my pouch is not as large as my rectum and colon were, so when my pouch is full, I feel the most bizarre gripes, rumblings and pressure on my bladder. There is no hanging around.

I want to thank you all for **your** articles. I know the pain and suffering, the hurdles some of you have had to climb and the pain that can for some still come and go. I know the euphoria those who can travel have felt, to have conquered so much, but for me my gratitude and euphoria is felt every time I step into a bath unaided. And while I am grateful to be alive, even now I still have to fight a certain amount of depression when I have bad days. As hard as it is to read some of the more painful articles, I feel empathy for others, knowing I am not alone.

As an aside, if possible take a minute to thank loved ones. Some have suffered more than we realise on this hard road, and finally thank you S.A. Sheffield, who wrote 'The Real Me' in NACC Experiences Spring 1998, Journal 37, page 25.

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, Mr John White, 44 France Hill Drive, Camberley, Surrey GU15 3QE

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** To fill this position please
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Professor John Nicholls

PATRON

Claire Rayner

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

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,

Visit Our Website

www.redliongroup.org



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.



