

ROAR!

ISSUE 36 • SUMMER 2007

Roar! is the newsletter of the Red Lion Group
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Regional Reps

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

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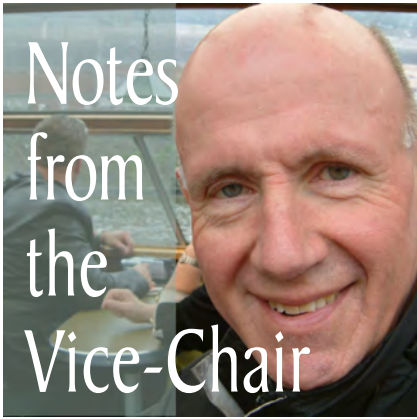
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Just as the prime minister isn't a Brown with an 'e' neither is the new chairman of the Red Lion Group. Mike Dean will put right the faltering policies and electoral oversights of the previous chair and we all wish him a very happy and successful time of it. Not that there is any comparison between leading the country and running the RLG of course. The latter is a far tougher task. Although I'm confident Mike will do as good a job of it as he did last time.

This was just one of the many events, happenings and highlights at this year's Information Day on 28 April. And what a day it turned out to be too! It started with the St Mark's conga – a seemingly endless convoy of members, friends and families threading their way up the stone steps of the education centre. So endless in fact that before long we realised we were in danger of breaching Health and Safety rules. Heaven forefend. H&S states that seminar room four must not hold more than 100 people in case of fire hazards, blocked exits etc. The final tally came

very close but no stern-faced officials with clipboards were seen lurking behind the speaker's rostrum.

First up was Red Lion president Professor John Nicholls. Once again he gave us his unique take on pouch surgery and once again everyone was literally begging for more. This time they got it – even if it was in a slightly different guise. Knowing the professor's time is precious the committee decided to hold a question-and-answer session to cover your comments and concerns about pouches. We called it 'The Brains Trust' after a popular BBC TV programme of the same name. The panel of four handled it all with aplomb. The questions were concise, the answers pithy and both sides came away satisfied. What more can a learned Red Lion want? We plan to hold a similar Q&A session next year. Perhaps we'll call it 'Any Questions' after the Radio Four show this time. Find out more about this year's on page 9.

What else did the Big Day have to offer? There was an inspired talk by our resident yachtsman Neil Basil (we featured him in the December 2006 *Roar!*). Crewing a yacht in the Round Britain & Ireland Race as he did needs courage, skill and stamina. He also had a pouch. Gale-force winds, a cramped cabin and a gravity-defying toilet. Nothing seemed to deter him. Though perhaps you don't have much option when you're trying to steer a rampaging yacht in the middle of the Atlantic Ocean.

There were three themed workshops this year (thanks to the day's two main organisers Mike Dean and Zarah

Perry-Woodford). There was one on aloe vera by Dorothy Norris (see her article on page 10), another on fatigue and tiredness by the great Zarah P-W herself – we'll print a full report of her findings in the next *Roar* – and finally 'Manifestations of FAP' by Kay Neale, polyposis registrar at St Mark's. There was also a lively talk on 'Probiotics and Pouchitis' by St Mark's research fellow Dr Simon McLaughlin. Some of us have tried probiotics in one form or another. But just how effective are they? The promoters have been fulsome, the professionals open-minded. You can read Simon's wise words on page 11.

The raffle raised more than £100 and the AGM was brief – and it was none the worse for that with all the other events going on. There were two committee changes. Mike and I swapped roles as chair and vice-chair and Des Ash resigned from the committee. Thanks very much for your help in 2006/2007 Des. The rest of the committee Margaret Dean (secretary), Christine Lawton (notes secretary), Marjorie Watts (treasurer), Inez Malek (membership secretary), Tim Rogers (layout editor), Stephanie Zinser (press officer), Morag Gaherty, John White, Lorraine Howell and Zarah Perry-Woodford (co-opted committee member) were re-elected. You can read the chair's and treasurer's reports on pages 17–18.

So there you have it. Enjoy *Roar!*, have a great summer and keep all those articles and letters a'coming!

Christopher Browne

Absorbing Stuff – Can you help?

After having UC in December '96 I had a colostomy in February '97 and I had my pouch created in October '98/January '99, and from some of the horror stories I've heard am doing remarkably well!

My partner has studied nutrition at a basic level and so when I suffered from terrible rolling stomach cramps he suggested I cut out sugar. I did this and within 24 hours the symptoms disappeared. I continued without sugar for a couple of weeks and whatever had been living in my gut and had sparked the cramps, died off. I was then able to re-introduce sugar into my diet and was fine.

I do occasionally get these bouts

of cramps, usually after I've had a broad-spectrum anti-biotic for something completely unrelated, and if I go to my GP all I get is anti-spasmodics and a strict disbelief of anything possibly living in my stomach which could cause these symptoms.

After much argument they sometimes give in and request a stool sample, but they only test this for basic bacteria and not parasites or candida.

I also have concerns about whether my body absorbs many of the vitamins and minerals it's supposed to. My transit time can be as little as 1 hour so I can't be getting much goodness from that food! I currently take a large amount of vitamins and minerals (Mul-

tivitamin, Zinc, Iron, EPA, GLA) and I feel much better for it. I also have concerns over what medication my body absorbs – we did have a minor panic as to whether my contraceptive pill was being absorbed (**that** was a fun couple of weeks spent waiting for results!)

I would be very interested in playing 'guinea pig' if any nutritional/medical professionals want to do some research into what my body now absorbs.

I know that GPs come in for a lot of unnecessary stick but I really do wish that more of them were open to the idea of candida living in a stomach. There must be some drugs that could be used to sort out these problems rather than just dealing with the symptoms.

I hope that someone can help...

Heather.pearnton@gmail.com

Aloe Vera – Magic, Miracle or Myth?

Information Day speaker Dorothy Norris explains why she believes this famous plant has genuine healing qualities. Dorothy trained as an NHS nurse and midwife and later lectured at London's South Bank University. She was recently appointed Director of the Aloe Vera Information Service.

'You're always so tired and irritable,' commented a colleague after a particularly heated exchange. I apologised. 'Why don't you see your friend and order some of her aloe vera?' she suggested.

I was hesitant. I ate fresh, organic food from our allotment and took supplements to ensure I stayed healthy. And I was still tired. 'Aloe vera! Another wonder plant! Another load of claims! Humph,' I thought to myself... I then decided I couldn't make a judgement if I didn't try it. I bought some aloe vera juice from the local health food shop and felt no different. 'That's it then,' I concluded.

Then something I read caught my eye and I decided to research aloe vera and the aloe vera associated products that were currently being sold.

Aloe vera is a succulent. It belongs to the same family as garlic, onions and asparagus. There are around 250 different types of aloe. Only four or five of them have documented medicinal benefits of which Aloe Barbadensis Miller is the one classed as the true aloe and is most commonly used in aloe preparations.

It is known on every continent in the world and has names like *Burn Plant*, *Healing Plant*, *Medicine Plant*, *Wand of Heaven*, *Potted Physician*, *Silent Healer*, *Heaven's Blessing*, *Plant of Life*. It grows wild in hot, dry climates gathering up desert nutrients from the soil.

Aloe vera is neither a magic plant nor a 'cure-all' but, because it acts in two major areas of the body, the epithelial tissue and the immune system, its effects are widespread. Epithelial tissue is our outer skin *and* the lining of every organ of the body. Healthy linings are important for protection and to help our organs work more effectively. A healthy immune system keeps the whole body working more efficiently and helps us to feel good.

It is the constituents of aloe vera that intrigue me and I'll explain how it works:

1. Saponins: naturally soapy substances that are useful for cleaning the skin and digestive tract. They are also antiseptic.

2. Lignins penetrate: the epithelium taking the nutrients of aloe to the deeper layers of the dermis (skin that cushions the body from stress and strain). The skin looks healthier and more supple after use. When aloe is taken just before food or medication it helps the absorption of the nutrients as well as the medication.

3. Anthraquinones: their action is



Dorothy Norris

anti-viral, anti-bacterial, anti-fungal, anti-inflammatory and analgesic so that topically aloe vera is useful for Athlete's Foot and insect bites. Taken internally aloe vera helps fight off infections and any situation where there is inflammation or pain like ulcerative colitis and arthritis.

4. Aloe vera contains a good supply of nutrients. The amount depends on how and where the aloe plant has been grown. When grown in organic conditions in full sun aloe will be full of:

a. A wide range of vitamins including vitamin B12

b. Many minerals including calcium, sodium, iron, potassium, chromium, magnesium, zinc, manganese and copper.

c. Amino acids – the building blocks of enzymes. Twenty amino acids have so far been identified and all of the essential ones.

d. Enzymes help digestion by breaking down the food we eat.

These substances all work together so that aloe vera is a good daily tonic for everyone and may be the reason that people who drink it daily feel so well. It

is also useful during pregnancy and breastfeeding when extra nutrients are needed and in any situation where someone has lost their appetite.

5. Salicylic acid has anti-inflammatory, analgesic and anti-bacterial properties. Thus drinking aloe vera or applying it to the skin will help inflammatory or painful conditions like irritable bowel syndrome, diverticulitis, ulcerative colitis, arthritis, insect bites and eczema.

5. Fatty acids. These are plant steroids that have anti-inflammatory, analgesic and antiseptic properties so people with eczema, rheumatoid arthritis and asthma will benefit from drinking aloe vera.

6. Sugar of which the long chain sugars are the most important to help the body's immunity return to normal. These help to keep a healthy immune system for everyone and help it to return to normal for people with eczema, asthma, rheumatoid arthritis and many other conditions.

Once I studied the constituents of aloe I began to understand why so many people find that drinking it helps with a wide range of conditions. Aloe vera is an adaptogen – meaning the body takes out of the gel what it needs to help the condition from which it is suffering. The gel therefore doesn't help a symptom directly but rather helps the body to heal itself. The gel also appears to help restore the body's balance.

The fact or fiction about aloe vera depends, it seems, on the way the aloe is produced and stabilised. I have found that in order to be effective the drinks must contain more than 80 per cent of the inner gel of the plant – the rind is good for compost but not as a food! Products for the skin and hair for instance should have aloe vera as the first ingredient, not just somewhere in the ingredients list.

It is only then that aloe vera can be found to be the 'magic' people claim for it. Certainly my family and I have noticed we have plenty of energy, sleep well and wake refreshed and that our skin glows, our hair shines and that our nails are strong. For us it was a very good decision to drink aloe vera!

Spare a Thought for the Other Half

In December's *Roar!* Sandy Hyams wrote a moving account of the pros and cons of living with a pouch. Here Edwin Hyams tells it from the partner's point-of-view

Ever since my schooldays many, many years ago I have been hopeless at writing anything unless it was a letter starting: "Unless payment is made within seven days, legal proceedings will be instituted without further notice". However despite the danger of my journalist wife Sandy drastically rewriting everything I say I would like to describe my own feelings and responses to life with Sandy and her pouch.

I learned many things during her illness. Thinking back they come to me piecemeal but the most outstanding memory is of how our dogs sensed the stress that I was suffering and the support they gave me. Every evening when

I rang one very close relative to give her the latest report she told me she was too busy to talk as she was cooking supper for her new boyfriend. The world is made up of many different kinds of people. I also had confirmation that the only certain thing in this life is that everybody dies.

Early in Sandy's illness she was referred to a physician I shall call Mr X. This doctor was supposed to be an expert on uc and related illnesses and had written many books on the subject. When Sandy went to undress ready for his examination he said to me: your wife seems very worried. She is I replied and more than anything else she is petrified

On the day of the op I arrived from Norfolk to stay a few days in a Cambridge hotel to be near my wife. There at the hotel reception desk was a note from Richard Miller asking me not to worry. Everything had gone well. Truly that man deserves every word of praise you can give him.

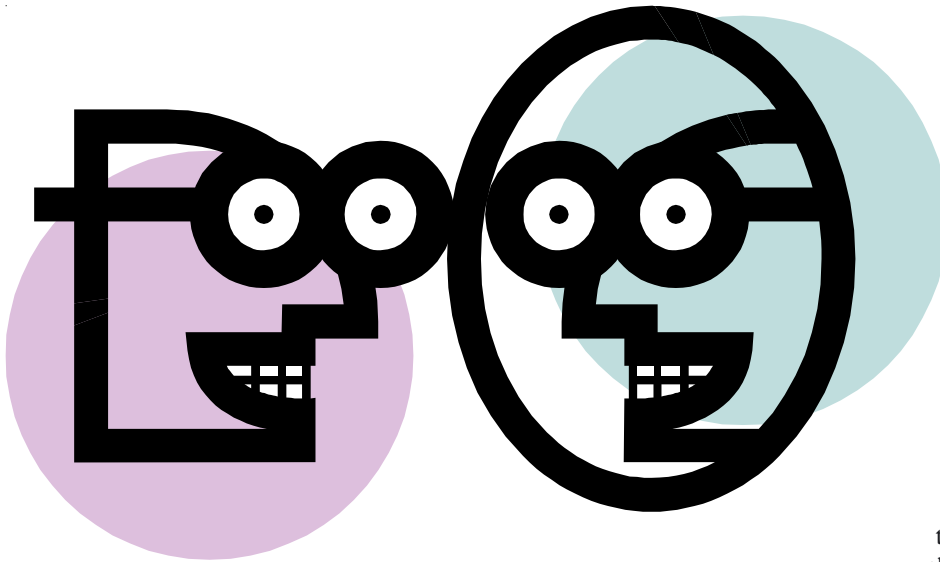
Mr Miller told Sandy there was a possibility he could reverse the bag and give her an internal pouch. In particular I was told not to assert any pressure on her one way or the other. For 12 months or so Sandy put up with her bag doing everything she needed to do although she was a very sad person, especially when she wanted to wear a bikini on holiday and she would dissolve into tears when she looked at herself in the mirror. Again I had great difficulty in not interfering but like Mr Miller I kept quiet. She then decided to have the reversal which went through very smoothly, again under the expert blade of Richard Miller.

Since then which was 10 years ago thanks to the skill of Mr Miller and the blessing of God she has been as near normal as possible but obviously putting up with the inconvenience which all users of a pouch have.

I speak to many people whose partners have been ill who appear to think that they have suffered more than their partner. I have never heard so much balderdash in all my life. Yes I suffered. Yes I worried. Yes I was unhappy. But none of it compared with the look on Sandy's face before the operation and when she'd come round from the anaesthetic and was on a morphine pump. Nothing in the world could have been as bad as what she suffered at that time. The onlooker suffered, yes, but not to that extent. Anyone who says they suffered more than their partner, to me, is a very selfish person.

Apart from being depressed, anxious and distressed before, during and after the operation, it has made me come even closer to Sandy. Of course I do not thank the illness for this but it makes me feel very humble.

Very nicely put Edwin. I'm sure Sandy's very proud of you (ed).



I came back from the hospital I sat with a bottle of wine and a dog on each side of the chair his nose across the arm watching me. It was wonderfully peaceful and comforting. The other uplifting feature was that it increased my belief in God. Watching Sandy in the hospital when she looked as if she was dying (at one point her face was the same colour as the pillowcase) and then the delight when she came home, upheld my faith in prayer.

On the reverse side was the reaction of many friends and relatives. You really learn who your good friends are by the invitations you have to dine with people (perhaps they just felt sorry for me a man cooking and eating alone) and the many telephone calls asking after Sandy's health. Conversely when

about having an operation followed by a bag. "My dear fellow," he said. "I can guarantee 100 per cent that neither of these events will ever happen." What a conceited oaf! Any half-decent doctor or lawyer knows that, apart from death, nothing is 100 per cent certain.

A few weeks later Sandy was admitted to hospital under Dr X and treated with steroids for two to three weeks. When I visited her one Sunday afternoon she said: "I am getting better aren't I?" She looked as if she was on her last legs. I was sitting at home one evening when the hospital rang to tell me she needed to have an emergency operation. Thank goodness for a wonderful surgeon named Richard Miller. Not only was he expert at his job but he was also one of the kindest of people.



Sue Clark



Alison Culkin



Simon McLoughlin



Zarah Perry-Woodford

The Brains Trust Answers Your Pouch Questions

We've got a new gig for Information Day. It's called the Brains Trust and judging by your responses on Saturday 28 April it's an all-time, all-conquering hit. It replaces an equally popular gig called His Master's Voice. At least it doesn't replace it as HMV is irreplaceable. But it gets equal top billing.

His Master's Voice as most of you know is our annual review of the pouch by Red Lion president Professor John Nicholls. He gives us all the latest research data on colons and surgery and always leaves us clamouring for more. So this time we decided to follow his talk with a question-and-answer session and called it the Brains Trust.

The panellists were Sue Clark – St Mark's Colorectal Surgeon; Alison Culkin – St Mark's Dietitian; Zarah Perry-Woodford – Pouch Nurse Specialist; Simon McLoughlin – Pouch Research Fellow.

Red Lion secretary Margaret Dean took notes

Does every pouchee experience bleeding from the pouch? If so what should they do about it and is there such a thing as a bleed-free pouch?

A number of you still have an anus and anyone with an anus can get piles (haemorrhoids) which often bleed. The anus is a poorly-designed organ and delicate pile tissue can easily tear and bleed. The pouch too is a delicate organ that suffers from scratches, lesions and pouchitis which can all lead to bleeding. As there is a very remote possibility of cancer you should get a check-up if you notice bleeding. Contact your pouch nurse or raise it at your next follow-up appointment.

Why do pouches continue to fail after their so-called trial period?

At first it was thought that everything would be OK after the first year. But some people appear in clinic many years after their operation. This is often due to infections and fistulas which you may have had in a mild and undetectable form for some time but which are now causing you problems.

My pouch is three months old. Is it safe to take Imodium on a daily basis?

Yes. It is safe to take Loperamide (Imodium) but people tend to rely on it too much or else use it incorrectly. The best advice is to take one or two tablets half-an-hour before a meal or earlier in the day. By doing so you shouldn't have to use the toilet so much

at night. A three-month-old pouch is still a very new one. The professional view is that it takes six to 12 months for your pouch function to settle down. If you still find no improvement after that contact your pouch nurse or medical team.

Why should pouchees take electrolytes?

Not everyone needs electrolytes as regularly as the literature states. However persistent tiredness is often a sign of dehydration and in this case electrolytes are necessary. For some people taking salt with food may be the answer. Electrolytes are not too pleasant to drink so many people choose to drink them cold. They can be stored in the freezer (to make them semi-frozen) and then gradually defrosted during the day.

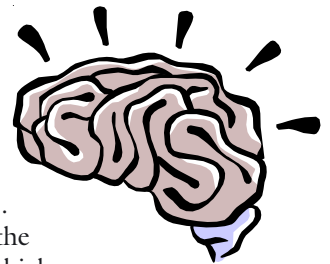
In the 27 years I have had a pouch I have always used a catheter. Why is the catheter rarely discussed?

A Medina catheter (displayed to audience) is used to evacuate the pouch – although not many people need them. The first pouches were known as 'S' pouches. Because of their shape owners often had problems evacuating which is why an extra support like a catheter was needed.

Then came the 'W' pouch which was a very good one but complicated to make. Although the 'J' pouch is the current favourite as it is easier to make than the 'W' and works just as well.

Why or when is it necessary to have a pouch refitted?

There are several reasons for pouch failure and a twisted pouch is one of them. If all the options have been tried and there is no risk of infection having a new pouch can be a good idea. The success rate is 30-40 per cent. If the patient is unwell and there is infection and/or scarring and function is poor the success rate is about 25pc. Patients



must be told what having a new pouch entails as well as their chances of success so they can use the information to make their own decisions.

Is it advisable for people with pouches to have a hysterectomy?

A gynaecologist should perform the operation with a pouch surgeon in attendance as it can be complicated and the pouch may be at risk. St Mark's Hospital does not have a specialist gynaecologist service so you should go to a hospital that has one.

I had my pouch closure last July and I am going to the lavatory 10 to 15 times a day and during the night – although it's worse at night. What can I do?

A Medina catheter may help you as your pouch may not be emptying prop-

erly. It may be kinking due to the force of emptying and going three or four times at night. Or your pouch may be inflamed. Two possible remedies are: Diet – change your meals around so breakfast and lunch are your main ones and you have a light meal in the evening. Or altering your meal frequency and eating small and often sometimes helps. Occupation – many pouches say being occupied at work or having a hobby often takes their mind off wanting to go to the lavatory. It is when you are relaxing and doing nothing that your mind tends to return to the question of lavatories. If you are still not happy discuss your problems with your pouch nurse or medical team

Fertility – what are the chances of conceiving with a pouch?

Figures show that the chances of getting pregnant are reduced by 50 per cent. Scarring around the pouch or the fallopian tubes sticking together can lead to infertility. IVF treatment can help by helping to move the sperm to the egg. Although there are successful pregnancies without treatment caesarean section is generally recommended for delivery.

Hasn't there been some research into ways to help adhesions?

The closure part of the operation can cause adhesions. A spray was thought to reduce adhesions but in pouch surgery it would stop the joins in the pouch bonding and thus cause leakage. It is thought that tissue spray can be used on the abdominal wall but this is still being researched.

Because of the location of the surgery for female pouches are there any smear test complications they need to know about?

Obviously the nurse or doctor carrying out the test should be told about your surgery. It may also be more uncomfortable than previously as the angle of the uterus may be altered by surgery or become slightly stuck by post-surgical adhesions.

How do surgeons choose between 'J' or 'W' pouches and what are their capacities?

The 'W' pouch has a greater capacity but the functional difference between 'J' and 'W' pouches is marginal. If the 'W' pouch was easy to make with less joins and using less bowel, it would probably be used more often.

As modern surgery needs to be simple, easy and safe, and a 'W' pouch is trickier to make than a 'J' for many surgeons yours may prefer to use the latter. Their capacities are: 'J' 300 ml and 'W' 500 ml.

I have had two spells of pouchitis since I had my pouch fitted two years ago. Each time I have taken the antibiotic Metronizadol. Am I doing the right thing?

First you need to have a pouchoscopy to assess the condition of your pouch. You could well have inflammation and probably need to take another antibiotic called Ciproflaxacin. Taking Metronizadol on a long-term basis can cause side-effects such as a metallic taste in the mouth and nausea and is not really recommended for more than six to 12 months. Contact your medical team.

What a Difference a Pouch Makes

Red Lion committee member Lorraine Howell was taking up to 40 tablets a day before her pouch operation. Here in the second of our series on "The Pros and Cons of Pouches" the former ulcerative colitis (UC) sufferer gives us some handy hints on pouch care.

The Pros

1. *Ouch-itis.* I have no more pain and medication. When I had UC I took large quantities of steroids and painkillers which meant I had no real quality of life. I spent most of my time either in pain, on the lavatory or trying to remember which tablet to take.
2. *Food for Thought.* I can now eat a far wider variety of food without either pain or discomfort. When I had uc I had to stick to soft foods and liquids. Since the pouch operation I have put on three stone (I was six stone when I had surgery). It seems as if I have been making up for the lost time ever since.
3. *Light Relief.* A pouch is perfect in many ways and your stool consistency varies with what you eat. I know it varies from person to person but I find the transition time from food to evacuation is about three hours compared with many times a day. Because I go regularly I feel healthier and have more control.

The Cons

1. *Sore Point.* Some creams and oils stain clothes. Metanium ointment can be effective but it stains underwear. However I find Ostoguard barrier cream with lavender and aloe soothing and stain-free while Andrex toilet tissue with aloe is gentle and cleans effectively.
2. *Block Tactics.* I always avoid eating whole mushrooms and fresh mangoes. A small mango I once ate caused a blockage which had to be cleared many hours later with the aid of a drip in the A&E department of my local hospital. My advice is to find out which foods cause you blockages and then make a list of the foods to avoid.
3. *Sound Effects.* When I go to a public loo I try to use the one that is farthest from the entrance to avoid embarrassing smells and noises. I always take an Ostomist Odour Neutraliser with me to clear the air and give me the courage to face the next person using the loo. I find a box of matches works a treat – but **do not** use them on aeroplanes. I use Neutradol odour destroyer at home. I find it's hygienic and works a treat.



Probing Probiotics

Are probiotics the great cure-alls they're often made out to be, or something of a doctors' dilemma? Here's what St Mark's research fellow Dr Simon McLaughlin had to say about them at Information Day.

Definition of probiotics

- Probiotics are living bacteria which when taken by mouth colonise the bowel and exert positive health benefits.

Rationale for use in pouch patients

- Pouchitis is almost certainly due to an imbalance between good and bad bowel bacteria.
- Antibiotics make the disease better
- Probiotics should encourage "good" bacteria to grow

Probiotic effects

- Compete with bad bacteria and stop them multiplying
- Direct production of beneficial substances
- Beneficial effect on immune system
- Increase the range and type of bowel bacteria

Problems with buying probiotics

- They are not all the same
- Unregulated industry
- The bacteria need to be *alive*
- The *right* bacteria need to be *in the container*

■ Hamilton-Miller JM, Shah S, Winkler JT. Public health issues arising from microbiological and labelling quality of foods and supplements containing probiotic microorganisms. *Public Health Nutr* 1999;2(2):223-9.

Problems with probiotics

- Need to take them forever
- Killed by antibiotics
- Expensive
- Not available on the NHS

Pouchitis

- 20-50% of all patients will get it at some time
- Most patients are easily treated
- Most will not get it again or very infrequently

Chronic pouchitis

- 3 or more episodes a year
- Antibiotic dependent pouchitis
- Antibiotic resistant pouchitis

Common misconceptions

- Probiotics *treat* pouchitis
- Probiotics will treat pouchitis that has failed to respond to antibiotic treatment
- Probiotics will cure *any* pouch problem

Gosselink study

- Single probiotic strain; *Lactobacillus rhamnosis* GG given for 1 year
- 78 controls
- 39 patients given probiotic
- 7% vs 29% developed pouchitis within 3 years
- No significant difference in the development of chronic pouchitis

■ Gosselink MP, Schouten WR, van Lierhout LM *et al.* Delay of the first onset of pouchitis by oral intake of the probiotic strain *Lactobacillus rhamnosus* GG. *Dis Colon Rectum* 2004;47(5):676-84.

Kuisma study

- 22 patients with previous history of pouchitis and pouch inflammation but no symptoms
- *Lactobacillus Rhamnosus* GG or Placebo given for 3 months
- *Lactobacillus* was present in stool samples in 40% of patients
- No changes occurred in stool frequency or at pouchoscopy

■ Kuisma J, Mennala S, Jarvinen H *et al.* Effect of *Lactobacillus rhamnosus* GG on ileal pouch inflammation and microbial flora. *Aliment Pharmacol Ther* 2003;17(4):509-15.

VSL#3

- The most studied probiotic in pouch patients
- 4 strains of *Lactobacillus*
- 3 strains of *Bifidobacteria*

Gionchetti study

- 9 month study, randomised placebo controlled
- 40 Patients with chronic pouchitis
- 3 of 20 patients taking VSL#3 became unwell
- All 20 patients taking placebo became unwell

■ 1. Gionchetti P, *et al.*, Oral bacteriotherapy as maintenance treatment in patients with chronic pouchitis: a double-blind, placebo-controlled trial. *Gastroenterology*, 2000, 119: p. 365-9.

Mimura Study

- 1 year study, randomised placebo controlled
- 7 patients from St. Mark's
- 29 patients from Bologna, Italy
- 17 of 20 patients taking VSL#3 remained well at 1 year
- 1 of 16 patients taking placebo remained well at 1 year

■ Mimura T, Rizzello F, Helwig U *et al*. Once daily high dose probiotic therapy (VSL#3) for maintaining remission in recurrent or refractory pouchitis. *Gut* 2004;53(1):108-14.

Prevention of pouchitis with VSL#3

- 40 patients randomised, placebo controlled, 1 year study
- 8 taking placebo developed pouchitis
- 2 taking VSL#3 developed pouchitis

■ Giordani P, Rizzello F, Poggiani G *et al*. Probiotic therapy to prevent pouchitis onset. *Dis Colon Rectum* 2005;48(7):1493-4.

Cleveland clinic Study

- 31 patients with *antibiotic dependent* pouchitis
- Patients given 2 weeks of ciprofloxacin *only*
- 6 patients remained on VSL#3 at 8 months
- *However*; pouchoscopy was unchanged
- 25 patients became unwell

■ Shen B, Brzezinski A, Fazio VW *et al*. Maintenance therapy with a probiotic in antibiotic-dependent pouchitis: experience in clinical practice. *Aliment Pharmacol Ther* 2005;22(3):721-8.

My experience at St. Mark's with VSL#3

- 7 Patients given VSL#3
- 2 Patients have remained well for more than 3 months

Why has it not worked as well?

- Our patients may have worse pouchitis
- Results in the real-world are always worse than a trial

How else can I prevent pouchitis?

- Avoid anti-inflammatory drugs:
 - Aspirin (unless prescribed by your Dr)
 - Nurofen/ibuprofen
 - Voltarol/diclofenac
 - Celecoxib etc (unless taken for FAP)
- Avoid risks of food poisoning
- Have any stricture dilated and use your dilator!
- Try and avoid stress!!

■ Shen B, Fazio VW, Remzi F, Brzezinski A, Lopez R, Lavery JC, Brzezinski A, Sherman JC, & Lashner BA. (2007) Effect of Withdrawal of Nonsteroidal Anti-Inflammatory Drug Use on Ileal Pouch Disorders. *J Dig Dis*.

VSL#3 costs and availability

- Now available from Boots *without* prescription
- Cost: £13.50 for 10 sachets; £60 per month
- Keep in the Fridge

How to take VSL#3

- Depends on what you are taking it for:
 1. If you have pouchitis, you need 4 weeks of antibiotics first
 2. Ensure you *definitely* have pouchitis first
 3. To prevent pouchitis; just take it

Dose of VSL#3

- Take 2 sachets per day
- Mix with water or sprinkle on food
- Best taken last thing at night

Take home messages

- Probiotics are not NHS treatments
- VSL#3 and Lactobacillus rhamnosus GG may be helpful
- Probiotic therapy is probably not as good as originally hoped
- Probiotics are unlikely to cause you harm



Letters

Dear Roar!

I had the pouch in 1997 and leaking was not too much of a problem until I had my son in 2000 which means I have to wear protection all the time.

Has anyone any ideas how I can improve this?

J Teasdale
Gosport
Hants.

Dear Sir

Just an idea. Would it be possible to video the talks from Information Day and then send them out as a DVD to whoever requests them for a fee.

I would like this service and would be pleased to donate. It might also be another good way to raise money.

J Brooks
Maidstone
Kent



Chairman Mike Dean replies:

"Thank you for your letter. I have noted your comments but we are only a small charity and the costs involved in making a video of a presentation of this nature would be prohibitive bearing in mind the minimum number of copies we would have to order."

"This would also be compounded by the fact that we would have to do this via two medias ie VHS videotape and DVD."

"While I appreciate your view that it would generate money we do not generate sufficient funds for the initial outlay or the helpers to do the actual filming. We are normally short of helpers to run Information Day anyway."

"It's a bright thought though and we will discuss your idea at the next committee meeting."

Dear Tim

Red Lion AGM

I just wanted to congratulate the Red Lion Group on the organisation of the last Information Day. I have not attended for several years as I now spend most of my time in Southern Ireland so it is not always as easy to be there. However this year I decided to make the trip as the programme looked very interesting.

The seminars were excellent and I am sure most of the audience learnt something new from them. I have had my pouch since 1990 but there are still occasional challenges so it is good to be kept up to date with new developments. I really appreciated Professor Nicholls giving up his time to give an overview on pouch surgery, which he

did in a very clear and concise way. The Brains Trust was also an excellent idea and one, which would be good to be repeated.

Neil Basil's talk 'Around the Nation with a Pouch' was a good inclusion in the programme. I really admire people like Neil who refuse to let their medical challenges get in the way of their life.

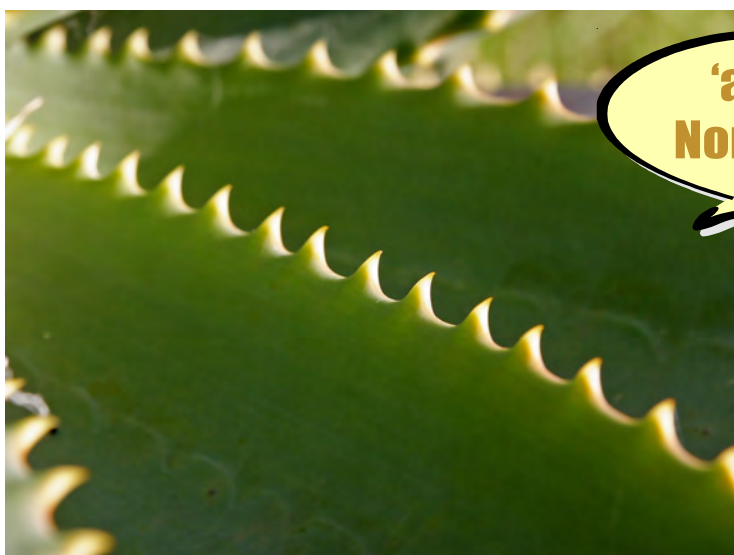
I am sure that his talk will have encouraged many a new pouchee. Since my operation I have taken up skiing and horse riding and as long as I take my pouch into consideration, it certainly doesn't stop me enjoying these sports. Again, I think that a similar talk from someone as positive as Neil would be good for all future Information Days.

The only part of the programme which I found disappointing was the Open Forum for female pouch owners. It was very disorganised and no-one chaired it so everyone was talking at once. It was a real shame as I think there were some interesting points made.

Perhaps for another year we could be asked to send in questions and then make sure someone acts as chairperson. This would also enable intimate topics to be discussed without the person being identified.

As with most organisations there are a few people who do all the work and the rest of us benefit. May I take this opportunity therefore to thank all those involved in the organisation of the Information Day.

Yours sincerely
Sally Thelen



**'allo
Norbert**

*If plants
could speak
to cars...*



**'allo
Vera**

AGM Chairman's Report by Christopher Browne

Have you noticed how charity has become this year's buzzword? Whether it's Age Concern, Narcotics Anonymous, Alcoholics Concern or Cancer Research there is a charity for practically every ailment or medical condition ever invented.

And apart from the UK's national obsession with property many of us want to do our bit for something worthy whether it's a green cause, our local environment or simply helping the poorly 93-year-old who lives in the cottage with the red chimney at the end of the road.

I'm sure most of you have had at least 25 circulars from different charities over the past 12 months, plus numerous online alerts from this good cause or that

Then there are the television spectacles like 'Live Aid' and 'Children In Need' or public feats of endurance like the Moon Walk, a 26-mile night trek around London which my cousin bravely joined last month, and the 2007 London Marathon which raised more than £40 million for many good causes including the 49-year-old woman who knitted her way round for dementia research even though she had a nasty stitch.

Not forgetting the swimathons, bikeathons and climb-a-French-Alpathons and former England cricketer Ian Botham's regular hikes from John O'Groats to Land's End in aid of Leukaemia Research.

I'm sure most of you have had at least 25 circulars from different charities over the past 12 months, plus numerous online alerts from this good cause or that or if, like me, you work

from home door-to-door visits from charity canvassers.

A quick surf of Google will show you there are 168,000 registered charities in the UK. At least 10 of those are in our own specialist field including Oxford's Kangaroo Club, Manchester's Joey Pouch Association, the Plymouth Possums, NACC or the National Association for Colitis and Crohn's Disease, the ia which is now called the Ileostomy and Internal Pouch Association, CICRA, the Crohn's in Childhood Research Association, and the Pouch Owners Club from south-east London.

This year we at the Red Lion Group decided to donate to another charity ourselves even if it was one in our own field. After discovering one of our members Neil Basil was taking part in the 'Round Britain Yacht Race' in aid of a NACC research project into the causes of ulcerative colitis how could we refuse?

What else has the group achieved this year? Well, we've donated £2,000 towards Susan Clark's research and pouchcare department

Anyway we donated £500 to his superb feat in which the yacht he crewed came ninth – as he told us in his excellent Information Day speech earlier today.

What else has the group achieved this year? Well, we've donated £2,000 towards Susan Clark's research and pouchcare department as our treasurer Marjorie Watts will explain in her Treasurer's Report, we're making plans to alter the website with an updated format, an online manager to monitor articles and entries and to make it a key recruitment and information source.

We'd welcome your ideas on this.

Another project that seems to be developing nicely is a set of Red Lion greetings cards. We've discussed this at committee and looked at the costings and decided it could work out rather well. We think a pack of five cards would be a neat way to do it. So far

Another project that seems to be developing nicely is a set of Red Lion greetings cards

we've adopted one of Christine Lawton's photos and we need four more designs or photos. So if anyone is interested in creating a card or two I'd really welcome your ideas however zany or conventional, colourful or upbeat.

Well. It's almost time to say goodbye. I've enjoyed the past year and I hope you have too. I find being a member of the committee is a bit like being part of a large family. One day there'll be a message from Mike Dean

Today marks the end of my three-year spell as chairman

saying ... "Have you remembered to update our records with the charity commissioners" or another from Marjorie Watts about a financial matter or two. Then I might phone Inez Malek our liaison officer on the latest membership figures and so it goes on.

Today marks the end of my three-year spell as chairman and I wish my successor whoever he or she may be the very, very best. I'll continue to edit Roar with Tim Rogers and really value any contributions you may have to offer from time to time (actually I'd love some letters for the June edition. Hint, hint, hint).

So long and it's been real.

AGM Treasurer's Report by Marjorie Watts

Hello, I am glad to be with you this year, let's hope next time I'll have both my limbs in working order!

Now firstly I wish to thank Brian Withers the Auditor for all his efforts again this year. This is my second year as treasurer which means I am getting more familiar with the regular happenings of the Red Lion Group.

I hope you have a copy of the accounts for the year ended 31 December 2006. Subscription income is £70 less this year, due to a total membership of 302 compared with 310 at the end of 2005. Many thanks to the 161 members who pay by standing order, this is most helpful.

Donations have increased, caused by the many donations from members and a very generous donation of £200 by a mother of one of our members. The sale of merchandise increased in 2006, due to the sale of greetings cards produced by Christine Lawson and Stephanie Zinser's book *The Good Gut Guide*, in addition to the Red Lion merchandise. Please don't forget to visit that table today!!

Income from interest has slightly improved. We are particularly grateful for the response of tax paying members, who have completed the Gift Aid form. As a result, Gordon Brown has repaid us tax of £900. The form only needs to be completed once, but if you have signed more than one, do not worry, I have all the copies filed in case the Inland Revenue wishes to call!

The Sponsored Half Marathon in March last year (in which Zarah Perry-Woodford and Sarah Varma sportingly ran) achieved £709 for which the Red Lion Group is most grateful.

The attendance at last years Information Day was lower than in 2005 which naturally resulted in less income.

Regarding the expenses; the cost of meetings shows an increase because the administrative costs (paper, postage, printing) of the AGM/Information Day have been allocated to this section this year. Other committee meetings are usually held by phone conference call costing between £26 and £28 a meeting.

The Printing and Postage of *Roar!* is more expensive this year, because, as you know postage has increased and we also published three issues. The website costs are higher due to renewal of the

domain name, 'redliongroup.org', this lasts until 2011. The annual website hosting costs are also included.

The excess of income over expenditure has enabled the Committee to donate £2,000 to the St Mark's Foundation, to be used by Sue Clark in supporting research into internal pouches.

The other donation of £500 was made to the National Association for Colitis and Crohn's Disease (NACC) for research into ulcerative colitis via a sponsorship of Neil Basil in the Round Britain Yacht race.

The Committee has been reviewing our assistance in cases of hardship. This was first reported on by the Treasurer at the AGM in 2001. At the time he said:-

"One thing I have been asked to bring to your attention is that the committee have decided to put aside each year the sum of £500 which can be used if need be as a grant for any of our members who are in need of assistance. Several are on income support but from my experience, one finds that they are usually too proud to ask. It is better if the request comes from the medical social worker and no money would be paid to the individual in cash.

The maximum we would pay in any one year would be £100 and it would be for help in the purchase of an item for medical needs, i.e. fridge, washing machine etc. Receipts would be required. Each application would be discussed fully by the committee and a majority decision would be needed before the grant was made. It would not be a foregone conclusion. If no money was paid out one year it doesn't mean that that the following year twice the amount would be available."

In 2006 the Committee decided that the maximum amount of any one grant should be increased to £150 and any payments to an individual would be on a once only basis.

Returning to the Accounts, with an excess of Income over Expenditure of £262 together with the balance brought forward at the start of the year the Red Lion Group ends 2006 with a healthy balance of £8,141.

A word of caution; basic income is not rising, but the expenses are, so careful consideration needs to be given to how we address this situation.

Thank you for your attention. If you have any questions for me or other committee members we will try to answer them.

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 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

Write for Roar!

Ideas, Ideas, Ideas and More Ideas

Yes Tim Rogers and I thrive on these for it's ideas that make Roar the readable packs we like it to be. So whether it's a crossword, quiz, article, letter, a piece of news, a cartoon or something funny that happened to you on the way to work please send them to: 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.

Please send them to:

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Visit Our Website

www.redliongroup.org

