



ROAR!

ISSUE 41 • CHRISTMAS 2009

Newsletter of the Red Lion Group
St. Mark's Hospital • Watford Road • Harrow • HA1 3UJ

Regional Reps

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

If you would like to be a regional rep, please contact Inez Malek on 020 7581 4107 or liaison@redliongroup.org.



AVON

David Mair Bristol 0117 922 1906

BEDFORDSHIRE

Carol George Sandy 01767 263092

CLEVELAND & NORTH YORKSHIRE

Christine Jackson Saltburn by the Sea
01947 840836
chrisjacks1960@btinternet.com

CUMBRIA

Jonathan Caton Kendal 01539 731985

DERBYSHIRE

John Roberts Derby 01332 361234

DORSET

Clive Brown Bridport 01308 422281

ESSEX

Peter Zammit Benfleet 01702 551501

HAMPSHIRE

Les Willoughby Winchester 01962 620012

HERTFORDSHIRE

Susan Burrows St. Albans 01727 869709

KENT (WEST)

Rosalyn Hiscock Pembury 01892 823171

LANCASHIRE

Joan Whiteley Clitheroe 01200 422093

MERSEYSIDE

Blanche Farley Liverpool 0151 924 4282
Anna Morling Newton-le-Willows
01925 229648

NORFOLK

Sandy Hyams King's Lynn 01485 542380

Contents

Regional reps	2
Notes from the vice-chair.....	3
Through the keyhole	4
Travel insurance.....	4
Brains trust.....	5-7
Fantastic fifteen	7-8
Marathon man	9-10
A first class delivery	11
Letters.....	13
Committee contact details.....	15



NORTHAMPTONSHIRE

Cynthia Gunthorpe Kettering 01536 482529
David Smith Northampton 07768 400406
mansfieldsmith@hotmail.com

NORTHERN IRELAND

Sharon Hendron Lisburn 02892 661559

SOUTH LONDON

Jonathan English SW12 020 8673 3092

SOUTH WEST LONDON

Dec Odell-Athill W10

colin@odell-athill.demon.co.uk

SUFFOLK

Anna Morling Leiston 01728 830574

WILTSHIRE & DORSET

Bernadette Monks Salisbury 01722 327388

YORKSHIRE

Sue Appleyard Huddersfield 01484 641227

Front cover: *Snowy Tree I* by stock.xchng user kaxmopp

Back cover: *Christmas World Ball* by stock.xchng user guitargoa



How many pouchees have had babies? I'd like to think all or certainly most of those of you who have wanted to start a family have been able to do so with a relatively smooth, problem-free pregnancy.

The reason I ask this unusual-sounding question is that a few years ago some figures were released showing that only 50% of pouchees were able to have babies. It's a startling statistic that spurred much spirited debate.

I must say it's a figure I've always doubted, but then do any of us really know how many pouchees have had successful pregnancies.

Reading Helen Pitchford's charming account of the days and months before she gave birth (page 11) will give hope to many pouchees who ponder motherhood. What makes her story particularly heartening is that she got through her pregnancy with few hitches and a lot of commonsense.

I'd like to think Helen is one of a large and happy majority. So if you've had a baby with a pouch I'd very much like to hear from you. It will encourage others who want to start a family. And help prove the critics wrong.

Wet, Wet, Wet

I've been thinking about water a lot. As you do in November and when you get a series of emails about high water bills (we're including two of them in this edition of Roar).

The fact is that only pouchees who are claiming benefit can get discounts

for annual water usage. With one or two rare exceptions. One of these is Graham Livingstone who was charged a scandalous £1,167 for a recent bill. We are including his letter which shows Thames Water made allowances for the child tax credit he and his wife were claiming.

Just one little word of advice. If you're thinking of getting a water meter fitted you'll need to do some simple maths first. For it may cost more than the standard method – as some people have found to their cost.

I certainly turned down the chance of a meter as it would have cost me

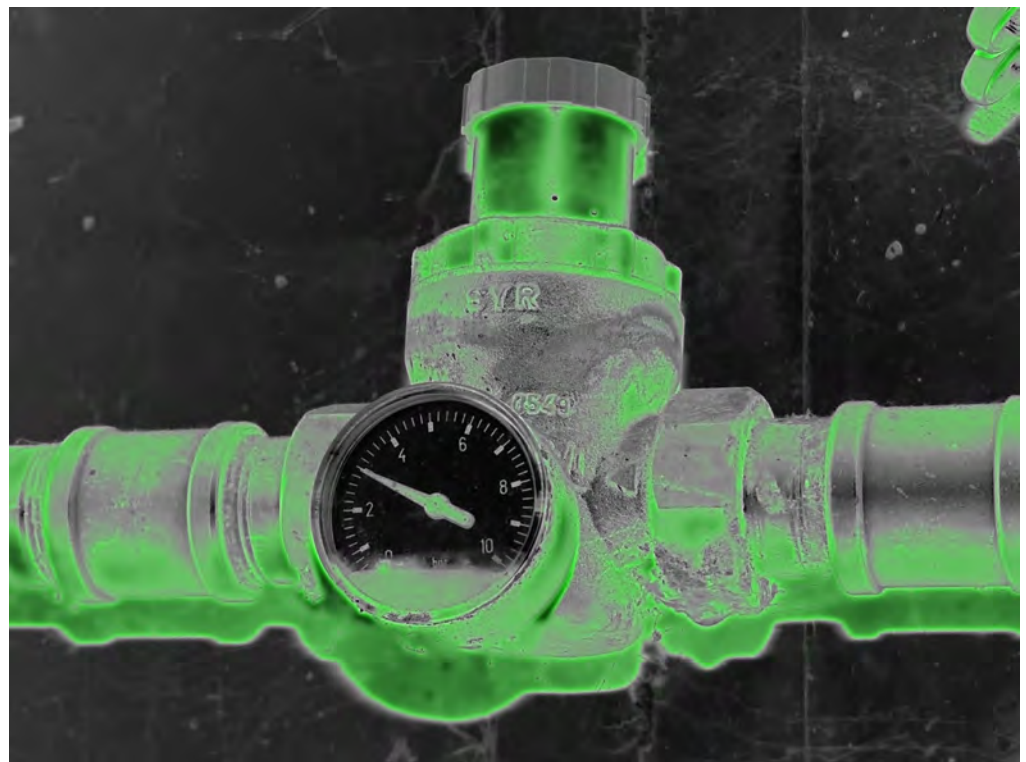
(page 11). We're awarding Andrew a £20 Marks & Spencer voucher for his spirited achievement.

It's Time to Spread Your Net

I hope he won't mind but I'd also like to say a large "well done" to Tim Rogers (Roar's co-editor) for designing such a user-friendly Red Lion website www.redliongroup.org.

Since he revamped the site I've been getting three or four emails a week about the catheter and water articles which he loaded recently.

The committee have just bought some more space, so we'll be loading more of your lively articles and copies



up to £100-a-year more. Others have switched and saved a sizeable chunk of money however. So make sure you do your sums.

This Sporting Life

Some of us are sporty. Some aren't. We've printed tales of intrepid sailors, runners, explorers and mountaineers to name just a few. Now a cyclist has joined this gutsy elite.

Find out what committee member Andrew Millis got up to when he decided to take a day off work one summer's day

of recent Roars.

So keep on logging. And talking of logs have a very happy Christmas and a healthy New Year.



Through the keyhole

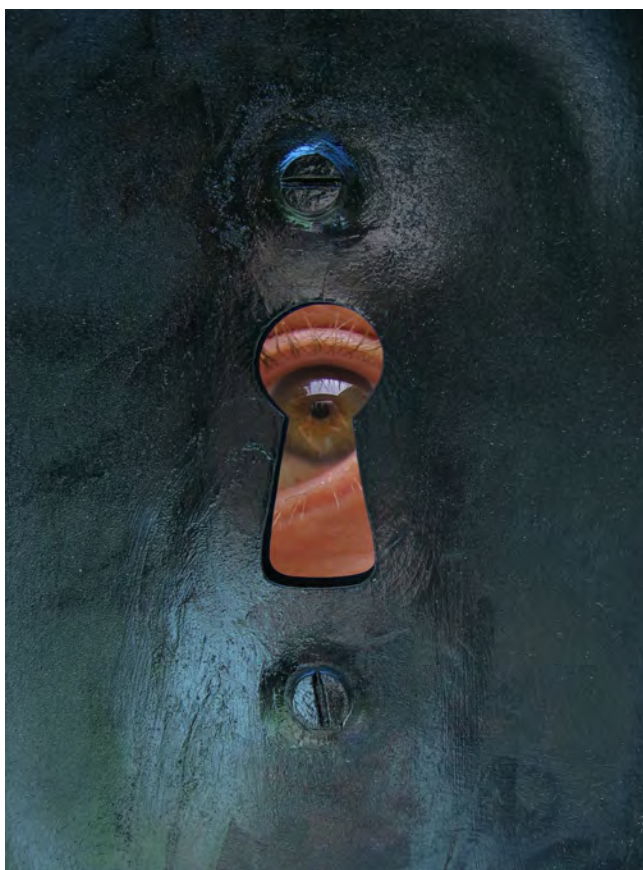
Jagged scars, heavy blood loss and slow recovery may soon be things of the past when keyhole surgery is used for colon operations, a group of 60 patients and families heard at St Mark's Hospital on 14 November.

Consultant surgeon Ian Jenkins, Guest speaker, told the Polypsis Registry information day that the surgery would lead to quicker operations and shorter stays in hospital. He showed pictures of a typical operating theatre and a video of a colon being removed by the keyhole technique.

Another highlight was a "polypsis for teenagers" workshop run by Warren Hyer, a St Mark's consultant paediatrician. In a fun presentation, Hyer said constant monitoring was the way to handle familial adenomatous polyposis (FAP) in children.

Patients could also allay some of their fears of endoscopies by testing their skills on a simulator aided by Sue Clark, St Mark's consultant colorectal surgeon, and Ripple Man, the hospital's clinical nurse specialist in polypsis.

Despite the rough weather, the turnout was high. The event was organised by Kay Neale, St Mark's polypsis registrar and our chairman, the ubiquitous Mike Dean.



Don't cover yourself with embarrassment

Next time you go on holiday check the small print of your travel insurance. You could be in for a shock...

What do you do on your summer breaks? Are you a "relax on a sunny beach" type, or do you prefer activity holidays like skiing, mountaineering or scuba-diving?

As anyone with a pouch or ileostomy knows, adequate travel insurance is vital.

You may well get free cover from your bank, building society or tour operator, but read the small print and you'll invariably find it doesn't cover the holidaymaker with a pouch.

Even if your pouch is usually above-average or trouble-free, poor or contaminated water, street-vendor food and a change of climate can cause unexpected health problems. Suddenly you'll find you need medication, hospital treatment or even an early trip back to the UK.

And if you've nothing to pay for it, you and your partner could find you've just had to pay for a very expensive holiday.

So if you're planning an overseas



break and are not sure if you have the right insurance cover, contact Freedom Insurance Services on 01223 454290 or www.freedominsure.co.uk.

They specialise in travellers with

pre-existing conditions and can advise you on the best options for you.

It certainly pays to travel wisely than to cover yourself in embarrassment!

Brains Trust

We are pleased to include a report on the “Brains Trust” a medical question-and-answer session which was held at last April’s Information Day. We are including it in this, the December Roar, as space reasons forced it out of the July Roar!

Here are some of your pithier questions...

PANEL: Dr Simon McLaughlin, research fellow, Imperial College London; Dr Parth Paskaran, former St Mark’s research fellow; Zarah Perry-Woodford, St Mark’s pouch support specialist

RED LION MEMBER: I have a W-pouch and have been diagnosed with proctitis in the stump. My question is will it now become ulcerative colitis and get into my pouch?

SIMON McLAUGHLIN: This proctitis is essentially the same as cuffitis: it means that there is some rectum left behind. It will not affect the pouch because the pouch is different. Cuffitis or proctitis is of large bowel origin, so just like ulcerative colitis, whereas the pouch is made from the small bowel, so the information cannot track from the retained rectal cuff into the pouch. Though it can give you problems and symptoms.

RED LION MEMBER: I have had my pouch for 12 years. Since the first five years it has got a lot better, but every week is different, literally.

ZARAH PERRY WOODFORD: I think we can probably have a chat because pouch function depends on lots of different factors.... it is not just one thing. So we probably need a history first. What are your main problems? First, do you have a routine in your life?

MEMBER: No. I wouldn’t say a routine but when it’s bad I don’t eat fibrous foods so no cereals or anything similar. I just eat the same old thing, bread, which is no good for anyone, but now the pouch is just pure liquid, nothing more, nothing less.

ZARAH: Have you had any investigations?

MEMBER: Yes. I’m on tablets and under the hospital, and the hospital is very good, but I just wondered why it goes suddenly and every week is different. I’m not moaning because my life is a lot better than it was a few years ago but sometimes it does get you down because you don’t know what’s going to happen each day. I did have pouchitis but that’s over now.

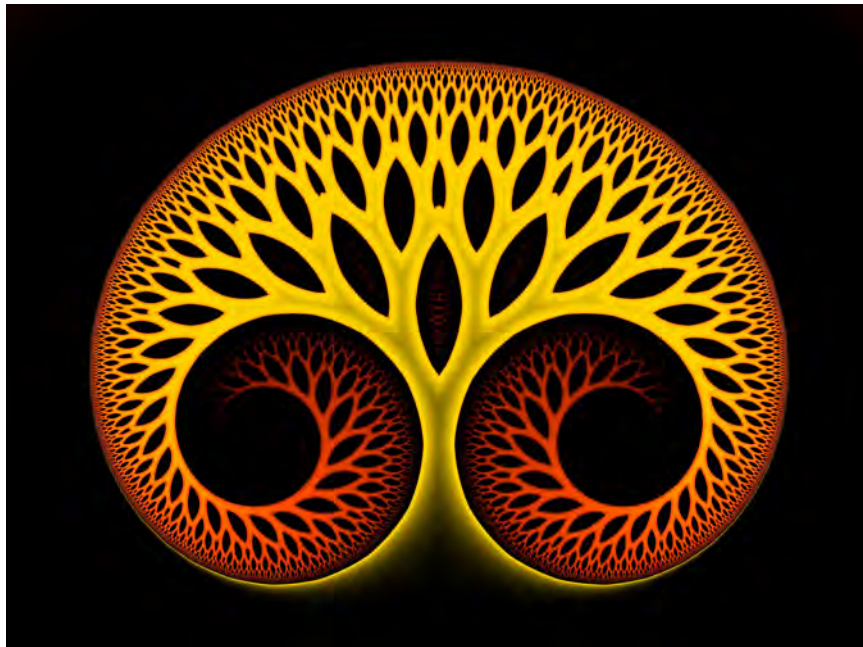
ZARAH: But you know when you have pouchitis. If you have tests done and you know exactly what you

RED LION MEMBER: I seem to get my pouchitis back with monotonous regularity every couple of weeks when I come off antibiotics. Is not the idea to have a blood sample?

SIMON: The answer is continuous maintenance treatment, to be honest, and treatment with an antibiotic.

MEMBER: Do we have any idea what triggers these recurrences?

SIMON: No. I have spent the last three-and-a-half years looking at this sort of thing, bacteriology and so on. Essentially we don’t know why some people have recurrent pouchitis. It looks as though it is probably more likely to be something wrong with the immune system whereby your body sees your bacteria as foreign and reacts against it, rather than different bacteria. The antibiotic seems to work by reducing the amount of bacteria and therefore the



are not suffering from, I say to most of my pouch patients that they need a routine. A pouch is going to work only as well as you let it work, so if you are going to eat at different times, you might find that your pouch function is not that good.

Stress affects your pouch function – a lot of people forget that. Hormones in women: I have started to notice that a lot of women complain of erratic pouch function in the light of their period or if they go into menopause. This is not evidence-based but it’s just one of those nursing things I am allowed to say. Again, I think we could have a chat later and see what your routines are and whether we can get something going.

amount of foreign material that stimulates your body’s immune system to fight it.

MEMBER: Probiotics don’t seem to improve a patient’s condition either. So is it a dead avenue, so to speak?

SIMON: I don’t think they really work, is the answer. What we do know for sure – and we have done a study here – is that antibiotic therapy does work and a majority of people stay well. Some people develop a resistance and we change the antibiotic but in the short term people do stay well – the short term as in several years. The majority stay on the same antibiotic for about three or four years.

ZARAH: May I just clarify good and bad bacteria? In theory we don’t

really have good bacteria, it is just levels of different bacteria. That is one of the explanations that a lot of people get confused about. They are all bacteria.

RED LION MEMBER: About a year ago, when I had my pouch, I was told that my frequency of going to the toilet would be five to six times a day. A year on, my frequency is almost double that, about 10 times a day. What are the major factors in dealing with frequency and how is it reduced?

SIMON: I think the first thing is to make sure that everything is normal with your pouch and that you are investigated properly to make sure you do not have any pouch problems. As soon as that has been done, we have to accept that everybody has a slightly different bowel frequency pre-pouch and post-pouch. The normal range of pouch frequency is something in the region of four to eight times a day. Some people will only open their pouch four times a day and some people more than that. Obviously there will be a small number of people who have absolutely no problems but their pouches open a bit more than others.

But I think the main thing is to make sure there is nothing wrong with your pouch and to find out if it is a little smaller than it should be, for example. Your frequency could be diet-related. Perhaps you could speak to Zarah about diet. Another thing to think about is are you taking Imodium or loperamide? You can take lots of loperamide quite safely and that may well reduce the frequency.

MEMBER: Does food make a difference?

SIMON: Definitely, and you may want to think about the times you eat during the day, whether you are eating lots of things regularly and when you sit down to have a meal. Activity makes a difference too. I am sure everybody will tell you that if you are doing more sport and outdoor activities, you will probably open your pouch more often. The pouch exaggerates everybody's normal bowel habits so what happens with those who don't have a pouch will be exaggerated with those who have one.

RED LION MEMBER: Professor John Nicholls pointed out that with Crohn's disease there is a poor outcome with a pouch. What steps are there to rule out Crohn's for patients in that group?

PARTH PASKARAN: Do you mean before the operation?

MEMBER: Yes, before the operation, so you can make a decision about whether to have a pouch or not. I was diagnosed with IBDU (unclassified inflammatory bowel disease) so it was either Crohn's or colitis. What can be done to try to help rule out one or the other?

PARTH: Obviously you had your whole bowel and rectal stump removed?

MEMBER: Yes.

PARTH: Well, that is very useful because your pathologist had the whole bowel, as it were, to work with. It is worth looking at your small bowel, perhaps with a small bowel follow-through, to see whether there is any evidence of Crohn's disease there. But Crohn's can also just be in the large bowel, so even if the small bowel is entirely normal, it isn't always hugely



helpful. Before deciding, you also need to consider what was happening to your large bowel in the past. Was the UC continuous or was it patchy and did you have any fistulas or anything like that?

Those who have indeterminate colitis that looks more like ulcerative colitis are much more likely to do well than those with Crohn's disease. Although not perhaps quite as well as those with confirmed ulcerative colitis.

RED LION MEMBER: What are the symptoms of pouchitis and how can you tell if you have it?

PARTH: It is very similar to ulcerative colitis. Most people complain of frequency and having to rush to the toilet. Some people get cramping and, very rarely, bleeding.

RED LION MEMBER: I had a pouch for 12 years and about five years ago I had a gangrenous small bowel which was very painful and I had to have quite a large section of my small bowel removed. After that, for a few months, I was really weak and poorly and now I have B12, I have injections every day and I have a follow-up every 12 weeks. Is there anything else I should be doing to complement the

B12 deficiency in B12? Does the injection have an impact on my absorption of Vitamin C or is that something else?

PARTH: I am sorry. Is your question that you are tired all the time?

MEMBER: No, I have the injections but do I need to do something else to assist my whole absorption thing?

PARTH: Was your pouch done for ulcerative colitis as well?

MEMBER: Yes.

PARTH: There has been no sign of disease again?

MEMBER: No, no ulcerative colitis.

PARTH: I think it is unfortunate that you have this gangrenous bowel. It is very rare. The average small bowel used for the pouch is between eight feet and 24 feet. It is a bit of a lottery over which part stays and which is moved. Obviously if you start cutting out more of it, you will become deficient in certain vitamins, unable to absorb nutrients and more important cannot absorb water. You lose a lot of water through your pouch and it will make you feel very tired and dehydrated and run down. Simon has done some work on this and before Simon, Mat Johnson, a nutritionist specialising in pouches, did some too. If you have an inflamed pouch anyway, you are going to be deficient in things like folic acid, Vitamin D and iron. It is important to keep these things topped up. If you are worried about your specific case, you can see a dietician. It is usually worth checking twice a year for vitamins. Make sure your diet is maximised to get what you need, so that you have the bit of bowel you have left working as well as it can.

ZARAH: One other point is that pouch patients should have their bloods checked every year. Also make sure you are seeing your GP annually and asking for things like Vitamin B12 to be done.

RED LION MEMBER: Do all vitamins absorb or not? Tablets or liquids – which is the best one for absorption for pouch patients?

SIMON: That question is impossible to answer really. Pouch patients do have some problems with absorption partly because their gut transit time – the time things take to leave your body, is much shorter, so there is less time for them to be absorbed. The terminal ileum, the small bowel

where vitamin B12 is normally absorbed, is in the pouch so it is quite common that pouch patients have problems absorbing vitamin B12. The difficulty is that you can have up to 12 years of vitamin B12 stored in your body, so some people will become B12 deficient very quickly. We know from experience that people seem to get low in iron quite often and some of that is probably due to low-grade pouch inflammation.

RED LION MEMBER: When I went to the doctor my sodium levels were really low. It actually turned out that when I'd had the pouch I'd been dehydrated a lot of the time. I had been taking Lucozade and similar drinks because I thought that was the right thing to do but it wasn't because you have to balance salt and sodium don't you?

ZARAH: There's no need to drown yourself in salt but salt is not a bad idea. It functions the same way that long-term sugars do. The message is everything in moderation: have some salt but don't overdo it. Simon will say this as well: there are no huge restrictions on how much you drink as pouch patients.

SIMON: Drink what you want, basically. Everybody will find that certain things don't agree with them.

RED LION MEMBER: Can you clarify whether ulcerative colitis is an auto-immune disease? I had always thought it was and it was indicated to me this morning that it may not be. What's the answer.

SIMON: I agree it is not an auto immune disease. You can split hairs about that. It is not a classic auto immune disease. For a long time the question has been what causes ulcerative colitis. Some people believe it is all to do with bacteria. Some believe there is a problem with your immune system and that it is an auto immune condition. But currently it is not classified as an auto immune condition and, to be honest, more and more research has shown that it is a combination of changes in bacteria – and viewing the bacteria as bad – and a slightly different immune system.

MEMBER: Is it hereditary?

SIMON: There is a hereditary component to it. It is not one of those diseases that you definitely pass on but there is an association of risk in your children or in your brothers and sisters.

Fantastic fifteen

Fifteen years ago in 1994, Tim Rogers went to the Grand National at Aintree and lost £20. But the following day he and Rachel Nicholson Abedi chaired the first ever meeting of the Red Lion Group.



A small band of us had been meeting once a month or so on a Thursday afternoon to plan the launch of the Red Lion Group. When the big day arrived we did not know quite what to expect. Dansac kindly sponsored the event by laying on the venue in the beautiful grounds of Syon Park in south-west London and Mr John Nicholls, one of the surgeons who pioneered the procedure, agreed to give a talk about the history of the pouch operation.

As Rachel and I sat nervously at the front of the conference room we counted that almost 100 people had turned up. Rachel stood up and spoke about the origins of the group which was the brainchild of her and the stoma-care nurse at St Mark's Hospital Celia Myers. Then I spoke briefly about the events that had led to this first full meeting before introducing Mr Nicholls.

Mr Nicholls' talk was entertaining and informative. We were told that ulcerative colitis drives people to surgery in many ways. Some need it because the urgency ruins their lives. Others find that their health gets eaten away and they lack the energy and vitality to do things that everyone else takes for granted. By having an ileostomy people's health is restored and they can go out and about safe in the knowledge that they are not suddenly going to

have to go any moment.

People have a pouch operation for purely cosmetic reasons and so it is crucially important that people only undergo the procedure if they really want it. The operation is not suitable for sufferers of Crohn's Disease. The operation has evolved over the years thanks to the genius of some gifted surgeons to arrive at today's state-of-the-art 'W' pouch.

There was an animated question and answer session after Mr Nicholls' talk. The question of cancer-risk in pouch patients was raised. Mr Nicholls said that although there had only ever been one case of the beginnings of cancer in a pouch (in Sweden) he insists that each of his patients undergo a biopsy every year. Not all surgeons follow this example, including some at St Mark's, and this was perhaps the biggest talking point of the day.

The question of conception, pregnancy and birth came up. Mr Nicholls recommended that women with pouches give birth by Caesarean section to minimise any damage to the bowel, but there is absolutely no reason why people with pouches should not have children. Indeed it turned out that there were three or four mothers with pouches at the meeting.

The problems of UVitis (an eye disorder) and arthritis linked to ulcera-

tive colitis were also discussed. Some patients had been led to believe that a pouch would cure them of these disorders. Mr Nicholls said that the links between ulcerative colitis and UVitis and arthritis were still obscure but great progress was being made, as it was in the search for the origins of ulcerative colitis itself. He told one questioner that there was every chance that by the time her son grew up ulcerative colitis will have been eradicated through genetic engineering.

On this high note we filed out of the room to sample the delicious catering of Syon House, our appetites in no way diminished by the full colour slides of pouch operations that Mr Nicholls had used to complement his talk.

After lunch about 50 people who were keen to get involved in running the group stayed on. We rearranged the chairs in the conference room to make it a bit more informal. During the discussion that followed it became clear that the day had been a great success. People found it a relief to be able to talk to fellow pouch patients and swap hints and tips. Up until today most of us had had to learn how to live with our pouch without the benefit of talking to someone else who had already been through it.

It was soon apparent that some of us had been through quite different experiences. One of those present said he only goes twice a day. This made those with 'bad pouches' rather peeved. However there was plenty of common ground and everyone came away having learnt something. Some of the things we talked about were:

- Condensing Mr Nicholls' talk into a leaflet to be given to people considering having a pouch.
- A diet sheet someone had been given by Northwick Park Hospital. This recommends that people with pouches eat high fibre food to absorb more water, consume fewer sugary snacks between meals and take fluids in between rather than with meals. It also lists foods that might increase bowel movement and cause anal irritation. Full details of the sheet will be given

in the first newsletter of the Red Lion Group.

- Distributing an in-depth questionnaire in order to assess why some people had relatively good pouches while others experienced problems. Those present said they would not be offended by very personal questions of a lavatorial nature if it helped shed some light



on this mystery. It was generally agreed that people with pouches had been through so much it would take quite a lot to offend them! Even so, if and when such questionnaires are sent out, it will be made obvious that people need not answer questions that make them uncomfortable.

- Producing a fact sheet for employers and GPs whom many in the room found were rather ill informed about pouches.
- 'Can't Wait' cards for use in shops and to jump lavatory queues when nature calls loudly. There was widespread interest in these cards which are available from the National Association of Crohn's and Colitis (NACC) and several stomacare companies. Unfortunately one person had been refused the use of the lavatory in the shop of a major high street pharmacist who had actually sponsored her card.
- Getting out of jury service. One person had managed to get exemption from jury service because he

was fearful of interrupting the proceedings of the court by putting his hand up and running off the lavatory every five minutes. This was a handy tip because normally only people registered disabled can avoid jury service. There was a consensus that we did not want people with pouches to be thought of as disabled.

- Worries about high water bills for pouch patients who tend to flush the lavatory more than most people.
- The question of free prescriptions. Most people undergoing a pouch operation have an ileostomy while the pouch is healing and so are entitled to free prescriptions. Some people continue to make use of free prescriptions after their ileostomy has been closed, while many choose to start paying. Because free prescription cards have to be renewed at regular intervals it was acknowledged that most people with pouches would be forced to pay prescription charges eventually. Some people resent this because they are dependent on 'thickeners' like loperamide and codeine phosphate.
- Whether ulcerative colitis causes premature menopause leading to osteoporosis. Someone showed the group a newspaper article advocating the use of hormone replacement therapy (HRT) for past sufferers of ulcerative colitis. Not everyone agreed that this should be taken as gospel however.
- The bizarre finding of research that suggests that smoking is good for controlling ulcerative colitis. Some people gave anecdotal evidence that their disease had been less of a problem while smoking than when trying to give up. Some medical trials are being carried out to study the effects of nicotine patches on sufferers of ulcerative colitis.

As the afternoon drew to a close we split into regional groups and took down each other's names and addresses. The day had been more successful than I could have possibly imagined. The group seemed genuinely excited about building up a support network of people with pouches. As I drove home I could not help thinking that this was the beginning of something big.

Marathon Man

Red Lion committee member Andrew Millis cycled 127 miles in a day but took two days to recover. Here is his story...

How far can a man with a pouch (and the wrong side of 50) cycle in a day? That was a question I asked myself this summer, not long after my 50th birthday.

So I chose a date, and booked the day off work. I told my boss that if conditions weren't perfect I would be at work and the idea would be forgotten.

Now, the level of fitness is obviously a factor in getting the answer to this question, and although I do a lot of cycling, it is only a 14-mile round trip to work each day. On the evening before the chosen day, I packed my pannier bags with a change of clothes, tore some pages out of a road map, got together a puncture repair kit and a few tools and a pack of Lucozade Sport, and went to bed early.

The next day I studied the national weather forecast, looking not just for rain but, just as important, wind. An 8mph wind was the most I had to worry about, so, suitably consoled, I went to bed early once more.

I got up at 4.30am, had a bowl of Shreddies, and very quietly left the house. As it was near the summer solstice, I was in bright daylight, with that lovely crisp air that you get early on a summer's morning. By 5 o'clock, I was on my way.

I had decided to head south west from my home in Fleet, north Hampshire. Not only would that keep me away from London and its traffic, but I could follow a railway line that gives me a direct route home. By 5.30, I was through Basingstoke, and going well. My first problem occurred about 15 miles from Basingstoke, when I tried to stay on the A30 and avoid joining the A303. I took a wrong turn and found myself in a dead end. I went back and tried again at the confusing junction. I took another exit, and found myself on – the A303!

I actually covered some good miles

on that road. The lorries going past at 70mph, often with their horns blaring and not missing me by too much, actually wafted me along, and I did several miles at 23-24mph. One police motorcyclist went past and looked at me, as if to say “does he really want to cycle on a dual carriageway?” but he didn't stop. The problem was the debris on the edge of the road. There were bolts, glass, rubber, even the odd shoe. Before long I had a flat back tyre, thanks to a shard of glass. Fortunately it was near a small lay-by.

I repaired that without much trouble but when I pumped up the tyre, it was still leaking air. However the noise of the lorries meant I couldn't hear the air escaping. I couldn't get

eggs, a second sausage, fried bread until my plate was piled high. I also used the toilet, more out of precaution than need.

The pouch was working perfectly and I had 48 miles showing on the clock.

The A30 from Salisbury is a charming road. There are some lovely villages on the way. Shaftesbury I thought was very pretty, with many neatly cared for houses and gardens. It must be on a hill as leaving the town I could freewheel for almost two miles without using the pedals. I pitied anyone having to cycle in the other direction!

By now I was feeling a bit uncomfortable in the saddle, and I couldn't find a hold on the handlebars that suited me.

However the thought of the next town, Yeovil, pulled me along as it was my target for lunch.

The sign “Yeovil, Somerset” sounded far enough away to sound impressive. A colleague from work rang, and when I said I

had got to Yeovil for lunch, he was gobsmacked. I didn't tell him I had left at 5 in the morning! Lunch at a pub, with 97 miles on the clock, was disappointing. The only thing that really appealed was lasagne but it was reheated and dried out. I also had a toilet trip, with the pouch again working perfectly. I had not had a single murmur from it, and thanks to a softer saddle, no discomfort either.

It was after lunch that the trouble started. Having been seated for an hour, my leg muscles seemed to have set in that position, and getting up was hard! I was now stiff, and getting back on the bike took some determination. My speed now fell quite a lot, and small hills meant going down several gears rather than one or two. In fact some hills I had to go down to the very bottom gear which I had never



away from the road either because of a barbed wire fence between the road and some woods.

“Hang on”, I thought, “I have got some pliers with me!” Being then able to get into the woods, I found my leak (the valve) and sorted it out. I was back in the saddle but I had to leave the A303.

I really enjoyed the next road – to Salisbury. There is so much to see when you're cycling that you never notice from a car, for example all the Army stuff around the “Wallops” (Nether Wallop, Over Wallop and Middle Wallop etc).

Then just before Salisbury, I stopped at a Little Chef type place and had breakfast. This was about 9 o'clock, having lost an hour over the puncture. After doing all that exercise, I felt I could order extra bacon, more



done before. It felt like climbing up on all fours.

On one twisty hill I gathered a nice traffic jam behind me, starting with a 40-ton artie truck, which had difficulty finding the right gear to follow me at 6mph! It wasn't pleasant having him an inch behind my back wheel.

Then, still on the A30, I arrived at Chard. This is a place to remember (or try to forget). It has a high street on a 1:10 hill (or thereabouts). But unlike any reasonable hill, it doesn't stop after the town, but keeps going for seemingly mile after mile until my legs felt like they were splitting apart. Eventually it ended and I felt I must have been able to see the earth's curvature. If anyone else is thinking of going in that direction, let me remind you it is NOT cycling country!

I struggled for 2½ miles after lunch and then for another 30 miles, motivated by a sign for "Honiton". A mile-and-a-half before the town I passed a sign saying "Welcome to Devon". YES! At last I could say "I've cycled to Devon". But everything ached—my hands, shoulders, neck, legs. Never a murmur from the pouch

though. Just another mile-and-a-half after that sign, I left the main road to Honiton town centre, and limped along looking for a hotel.

I was giving up. I had had enough. There is a lovely hotel in the High Street, and I checked in at 5 o'clock. "We don't get many people arriving

bed at half past 7! After 15 minutes of Coronation Street I feel asleep (well you would, wouldn't you), and didn't wake till 8am the next day. Not even my pouch woke me up.

I walked quietly to the station, and came home by train. The only cycling I did was the two miles from my local station, but that was hard enough.

So the answer to my earlier question: "How far can a man with a pouch (and the wrong side of 50) cycle in a day? is 127 miles in 9 hours 5 minutes, but it took me two days to recover!



A first-class delivery

Marriage, moving house and the birth of a baby are probably the three biggest events in most of our lives. Owning a pouch probably runs them pretty close. Here Red Lion member Helen Pitchford gives a moving account of how she coped with pregnancy and a pouch.

I had my pouch fitted in 2001 – three years after I was diagnosed with uc. I chose to have the operation after an ileostomy and a colectomy.

My partner Gary and I spent 18 months trying to conceive – without success. So my gynaecologist suggested I try a course of the popular fertility drug Clomid. To our delight, I was pregnant within a month.

Seven weeks later I asked the gynaecologist if I could have a c-section (caesarean operation) because of my pouch. I also reduced my nightly dose of codeine to protect my baby.

As the foetus grew, so did the pressure on my pouch which meant I had to visit the loo more often. To help me empty properly I pressed gently on my lower stomach each time I went to the loo.

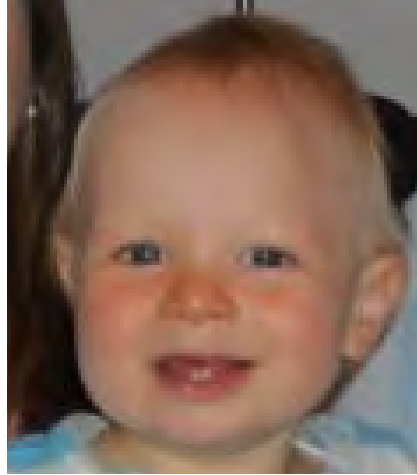
I later had a Nuchal scan in case the baby had Downs Syndrome. After getting the all-clear, we told all our friends and relatives the great news – I was expecting.

In week 20, I had a scan to check that all the baby's organs were developing properly. We then went to my gynaecologist and talked about how the baby would be delivered and he told me the pros and cons of a natural delivery versus a C-section. I could feel the baby kicking which was such a great feeling. We also had a heart monitor to hear the baby's heartbeat. It sounded as if he had hiccups!

I started to feel constipated in week 25. Although medication was recommended I found prunes worked just as well!

I had an-

other appointment with the gynaecologist who told me my surgeon had recommended a c-section due to possible surgical damage to my sphincter muscles that could not be



repaired and would leave me with a permanent ileostomy. I finally decide to have the c-section.

The following week I started five weeks of ante-natal classes. I loved every minute of being pregnant. I did think it might not be so straightforward with a pouch but all was going

well and I was feeling great. Then in week 34, I finally went on maternity leave from my job six weeks before the baby was due.

Two weeks later – on 5 July, 2009, my water broke at 8am. Then I started having contractions. When I got to the hospital they were happening every 5-6 minutes. The nurse gave me my own room after I explained I had a pouch and would need the loo more frequently than most people.

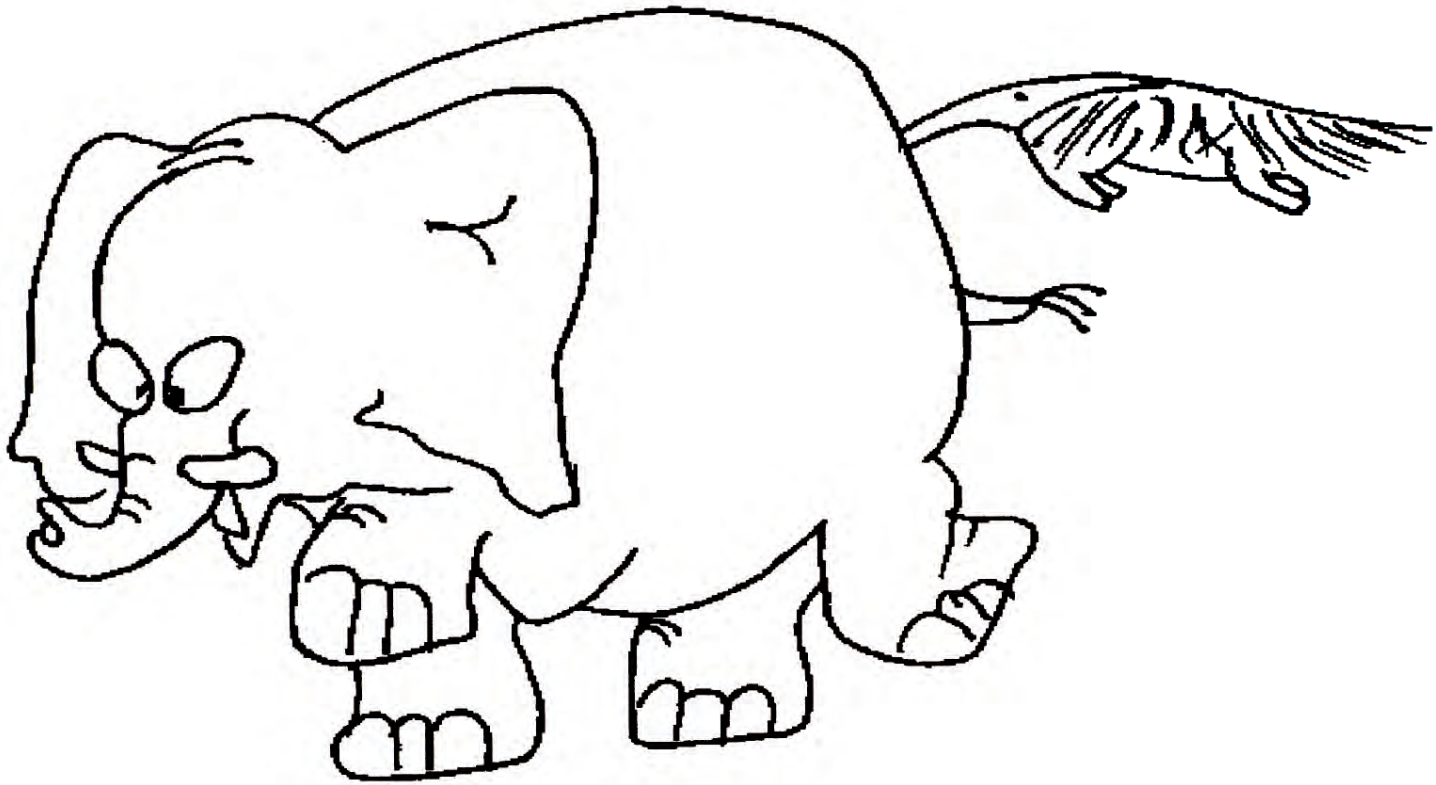
Our son Jack was born at 10.56am and weighed 6lb 12oz. After the delivery, my consultant said he wanted to see what a pouch looked like. He said the surgeon had done such a good job that he couldn't see anything different about my colon area.

I stayed in hospitals for three nights.

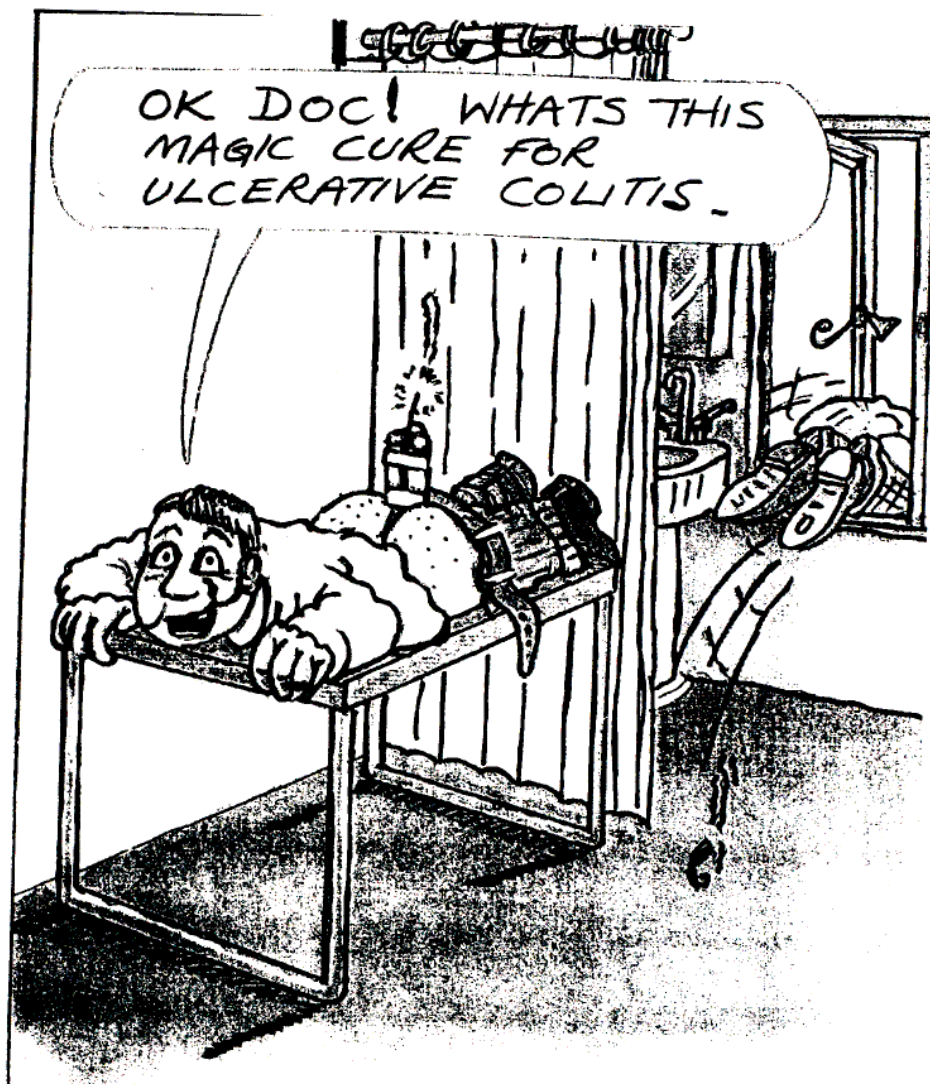
The day after we got home, my midwife came to see me and said she was amazed that I was up and about and bending over to change Jack. I told her that compared to pouch surgery, having a c-section is a walk in the park!

I'm delighted to say that having a pouch hasn't prevented me leading a full life and caring for Jack in any way.





All animals learn by trial and error which foods cannot easily be digested. The anteater is no exception.



LETTERS TO THE EDITOR

Dear Christopher

I have just read the article about water charges on the Roar website.

I have had my pouch for nearly 20 years. Eighteen months ago I was paying £23-a-month for unmetered water. However when I switched to a meter my bills started at £15 increasing to £28 pm – and so more than I was paying for unmetered water. Thames Water Authority have just sent through a revised bill saying my bill will rise to £44 pm.

After Thames Water raised my monthly charge to £28 pm, I phoned them and they advised me to go on to their Watersure Tariff and to apply for a discount because of my pouch. I enclosed a letter from my GP with my application and got a response back in July saying that as I was not on any benefit I did not qualify for the medical discount.

It meant that I was totally misinformed by Thames Water on the phone and I also had to pay £15 to my doctor's surgery for the letter which was a complete waste of money. My latest bill for £44 pm is ridiculous and I wonder whether you can offer any assistance.

I live on my own with occasional visits from my sons who are both away at university so there is no way the water authority can justify this enormous monthly instalment.

I look forward to hearing from you.

*Yours sincerely
Jane Humphries*

I wrote to Jane and suggested she spoke to Thames Water on the phone or

wrote to one of their managers, pointing out that she has a disability, lives on her own and is struggling to pay her monthly water bills (Ed).

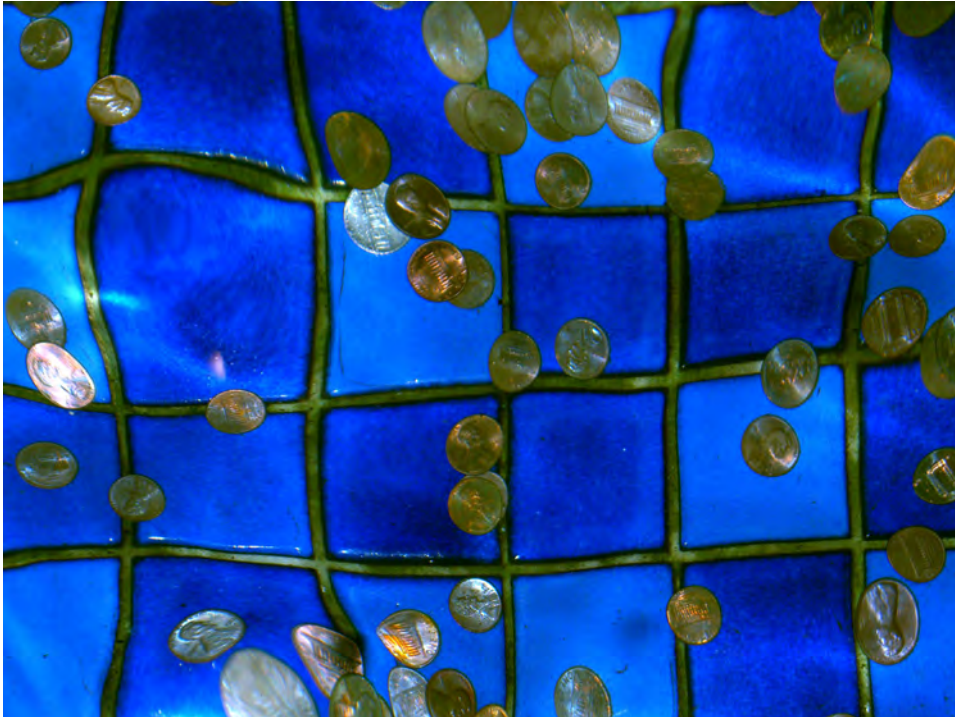
Let's hope they leant Jane a sympathetic ear.

However high your water bills, Roar! has discovered that the UK's water authorities will only give discounts if you are claiming benefits.

But Graham Livingstone and his wife who are not on benefits have written to us with some encouraging news.

In December, Graham wrote to us and said his 2008 bill for unmetered water at his three-bedroom house in Plymouth was £1,167. Not only that, he said his bill was about to rise again.

Here is his latest letter:



Hi Chris

Since I was last in contact with you there has been some good news about our water charges. Due to changes in our circumstances, our level of Child Tax Credit has increased above the basic rate so we were able to apply for capped water charges.

I completed the application, obtained a letter of support from my GP and have just heard that my application has been successful. It means our charges will now be capped at £489.

It's still over double the amount

people pay in other regions but it's a lot less than the £1,167 we paid last year.

Meanwhile on a different subject...

Dear Editors

Re: osteopaenia/osteoporosis and calcium supplements

Many people are unaware that as well as maintaining adequate calcium levels, it is important to have good levels of vitamin D to be able to absorb the calcium. Supplements are available but an excellent way of absorbing vitamin D is to expose yourself to 15 minutes' sunlight a day.

Doing it behind glass or using sunblock does not have the same effect (hence the increase in Rickets

in Australia). In the UK, sunlight is the correct wavelength between March and October but it is fat soluble so we store it over the winter months.

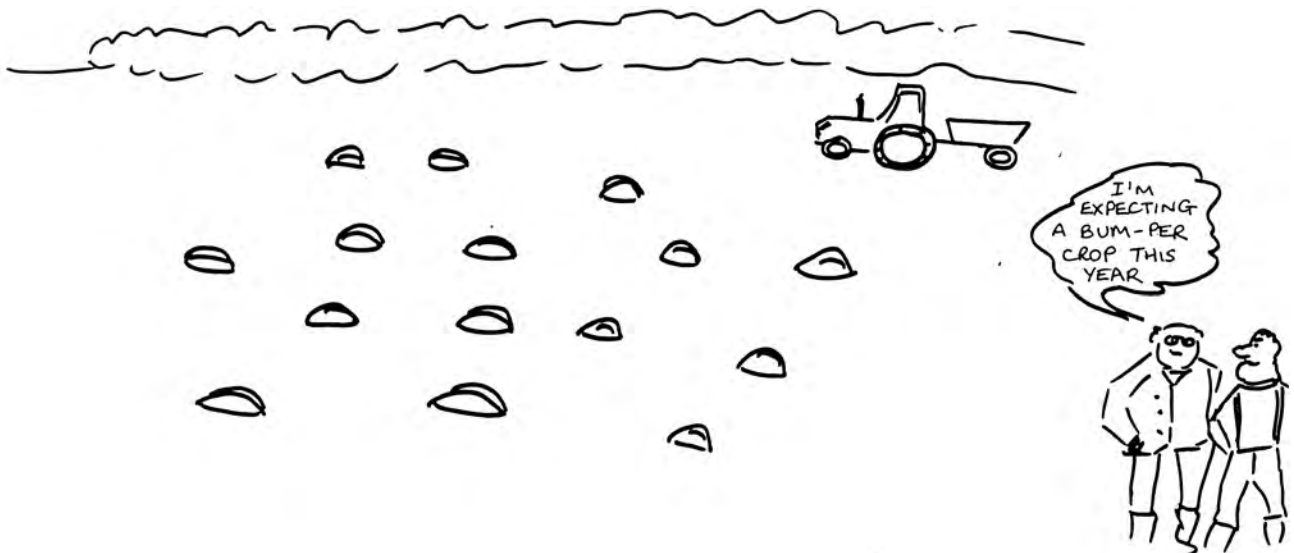
Other techniques that help improve bone density are: walking 15 minutes a day and cycling. While gentle press-ups against the wall can help strengthen the

bones in your wrists. Check with your doctor or physiotherapist if you have any concerns about exercise.

If, however, you have been prescribed calcium and vitamin D supplements by your doctor, don't stop taking them but augment the effects by walking outdoors 15 minutes a day.

I was unable to take the supplements for some time but my bone density still increased by walking my son to and from school.

*Theresa Parr
Theresaparr@talktalk.net*



"Sponsorship is a sign of the times"

Archive online

You can now download 31 past issues of Roar! from the Red Lion Group website.

As well some great cartoons (some of which have been reproduced in this issue – they seemed too good to only print once!) there is a wealth of articles and stories spanning 15 years of the Red Lion Group.

Newsletters available on-line are:

- Issues 1 to 4
- Issues 13 to 23
- Issues 25 to date

The newsletters can be downloaded as high resolution PDFs so you can enjoy these back issues in all their glory.

Visit www.redliongroup.org and click on the Archive menu on the left.

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**

Contact the Red Lion Group

CHAIR

Michael Dean
9 Mornington Crescent
Hadleigh
Benfleet
Essex SS7 2HW
Tel: 01702 552500
chair@redliongroup.org

VICE-CHAIR AND NEWSLETTER EDITOR (CONTENT)

Christopher Browne
89 Fulwell Park Avenue
Twickenham TW2 5HG
Tel: 020 8894 1598
vice-chair@redliongroup.org

SECRETARY

Vacant

NOTES SECRETARY

Christine Lawton
19 Nathans Road
North Wembley
Middlesex
HA0 3RY
Tel: 020 8904 7851
notessecretary@redliongroup.org

TREASURER

Marjorie Watts
11 Meadow Way
Upminster
Essex
RM14 3AA
Tel: 01708 501273
treasurer@redliongroup.org

LIAISON OFFICER

Inez Malek
33 Trevor Square
London
SW7 1DY
Tel (home): 020 7581 4107
liaison@redliongroup.org

CLINICAL NURSE SPECIALIST

Zarah Perry-Woodford
St Mark's Hospital
Northwick Park
Watford Road
Harrow HA1 3UJ
Tel (work): 020 8235 4126
pouch@redliongroup.org

NEWSLETTER EDITOR (LAYOUT)

Tim Rogers
30 Amberley Gardens
Epsom KT19 0NH
Tel: 020 8393 6968
newsletter@redliongroup.org

PRESS OFFICER

Vacant

EX-OFFICIO

John White
44 France Hill Drive
Camberley GU15 3QE
Tel: 01276 24886
john@redliongroup.com

Morag Gaherty
16 Hill Brow
Bearsted
Maidstone
Kent ME14 4AW
Tel: 01622 739034
Fax: 020 7691 9527
morag@redliongroup.org

Lorraine Howell
125b Welldon Crescent
Harrow HA1 1QJ
Tel: 020 8723 4801
lorraine@redliongroup.org

CO-OPTED MEMBERS

Andrew Millis
Yvon and Andy Sutton

PRESIDENT

Sue Clarke

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!

Ideas, Ideas, Ideas and More Ideas

Yes Tim Rogers and I thrive on them for it's ideas that make *Roar!* the readable package we like it to be.

Whether it's something that happened to you on the way to work, an interesting holiday or personal experience, an insight into your life with a pouch or a lively letter, please don't hesitate to send it in.

But then if writing articles isn't exactly your favourite pastime, we are always looking for cartoons, jokes, crosswords and competition ideas too.

That way we can keep your news-

letter bursting with life and information and make reading about pouch issues fun and stimulating.

Please send your articles, letters and ideas to:

Christopher Browne
Roar! Content Editor
89 Fulwell Park Avenue
Twickenham
Middlesex
TW2 5HG

or cbrowne@brownemedia.co.uk

Visit Our Website

www.redliongroup.org



