

ROAR!

A string of silver, spiky Christmas ornaments hangs diagonally across the upper half of the page. The background is a warm, golden-yellow color with a subtle, textured pattern. The ornaments are small and spherical with many sharp, radiating points, giving them a starburst or 'spiky ball' appearance. They are strung on a thin, dark cord.

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

Regional Reps

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

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Hello everybody! It's the Festive Season again – the time when our thoughts stray to summer travel and long weekend breaks in the Lake District. If you're prudent you'll probably book your summer holidays now rather than fall back on a last-minute surf through instantholidays.com or fastercheaperflights.net – although spur-of-the-moment holidays can be great fun too.

Anyone who is in poor health or recovering from an operation may not be able to travel. If you are one of those let's hope you get plenty of rest and can make plans for another time and another year.

You could also pick up some tips from the current *Roar!* as travel is our Christmas 2006 theme. You may not get the lowdown on exotic islands or Caribbean cruises but you will be able to pick up some useful tips on travelling with a pouch from Neil Basil, Margaret Dean and Tim Rogers.

Something to Roar About

Remember our summer competition to find the 10 funniest magazine titles rhyming with *Roar!*? Well, we've got a winner. He is David Kimberley who's wit could easily win him a job as a sub-editor on a magazine or newspaper.

David lives at Darwen near Blackburn, a small Lancashire town with an ancient cotton mill and 36 pubs. "It's an alcoholic town rather than a textile one," says an enlightened local historian.

Here are David's chuckleworthy entries. He sent us 12 titles instead of 10 but then the more the merrier

POUR – a periodical for wine connoisseurs

POUR ME MORE! – a periodical for addicted wine connoisseurs

FOUR – a journal on all things numerical

SNORE! – the magazine for heavy sleepers (especially those who sleep on their backs)

AMOUR – the monthly magazine for the romantic in you

FLOOR – a ground-breaking mag about good old-fashioned *terra firma*

WHORE! – A delve into the seedy life of a typical Jezebel. This issue looks at stilettos and fishnet stockings

PHWAURR! – a sizzling magazine of lovely beauties and hunks

SWORE – for reformed users of bad language

CHORE – a periodical for the down-trodden worker

SHORE – for the sailor who can't wait to return to dry land (no relation to Neil Basil then – ed)

And UPROAR! – this is what would

happen among the lion's share of readers if anything happened to *Roar!*

Absolutely right David and Congratulations – your prize is on its way.

Sandy Hyams, who's article about the good times and the bad is on page four sent in some beauties too. Here's a selection of them:

JAW! and its companion journal GNAW! – two magazines full of dietary tips

OUTLAW – the handbook of Nottingham Forest football club

SEESAW – a magazine for pouchees who cannot make up their minds

FLOOR – the carpet-layers' bi-monthly gazette

CARNIVORE – a cook-book for dedicated meat-eaters

It was difficult to choose a winner from two such witty entries. But we opted for David as it's his first contribution to the magazine – and we hope not the last.

Ideas, Ideas, Ideas and More Ideas

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

Christopher Browne

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And a very merry Christmas and a happy New Year to you all!



Pouch Pros and Cons

We are running a small series about members' best and worst moments with their pouches. Here's Sandy Hyams's story

Internal pouches – good or bad? Considering the alternative there is only one answer to this even though there are a number of pros and cons.

Just over 11 years ago on a Sunday in June I underwent emergency surgery to fit a colectomy for UC. Because my condition had deteriorated so rapidly I didn't even have a chance to see a stoma-nurse beforehand. I was just thankful to be alive.

As the thought of more operations appalled and frightened me I told my surgeon I would keep the ileostomy bag. However he did warn me that further surgery would be necessary to prevent cancerous cells forming in the future. What I didn't comprehend at the time was that living with a bag and all that entailed would change my entire lifestyle.

Knowing that another operation was on the cards whatever I decided led me eventually, after much research on the subject, to opt for the ileo-anal pouch. Once the pouch had settled down – in a matter of months – I realised it was the right decision. You could call it a gut feeling.

With a fully-functioning pouch I was free of the restrictions and problems imposed by the bag – ensuring I didn't run out of essentials, travelling with all the necessary supplies, pancaking

and ballooning, and searching urgently for a loo.

Another bonus was my body image. With a stoma I was certainly aware of that bulge on my tummy. Now I can wear what I like – including bikinis – with no fear of accidents (and there were many during the year of the ileostomy).

After more than a decade of living with a pouch I know I can eat and drink practically anything with no ill-effects. The occasional sore bottom is a small price to pay if I over-indulge or if something upsets me.

So far I have only compared life with an internal pouch against living with a bag and stoma. But I should

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Since my re-plumbing I haven't been able to enjoy a long walk without leakage. Even if I have just visited the lavatory, the mere motion of walking seems to bring on, well, a motion. So if I can't find a lavatory immediately I leak and then I get sore. I had hoped to start playing golf again but I would never make it round the course.

Something that embarrassed me pre-op is even worse now: the attendant noises when using a public convenience or loos in hotels, restaurants, airports etc. Originally it must have been caused by a childhood experience.

I don't embarrass easily but the unavoidable resonance of a voiding pouch has the ability to make me cower in the corner and not emerge from the cubicle until the room is clear (which can be a long wait).

We pouchees are indeed fortunate that medical knowledge and expertise have advanced so much in the field of colorectal surgery over the past 30 years. Whatever the disadvantages of an internal pouch, they are far outweighed by the benefits.



With a fully-functioning pouch I was free of the restrictions and problems imposed by the bag

really nominate the three best things about having a pouch versus the bad old days of living with UC. These would be no longer having to desperately look for a loo; being able to eat and drink what I want; and getting my life back again without being dictated to by my bowel movements.

For me perhaps the worst aspects of having a pouch are the fatigue and lack of energy. Not every day, of course, but sometimes it hits me for six. Shortly after surgery I put it down to getting over the anaesthetic post-op, but it gradually dawned on me that I just didn't have the stamina I used to have.

Around the Nation in a Yacht with a Pouch

Red Lion member Neil Basil competed in the recent Round Britain and Ireland Yacht Race. Neil who has had a pouch for only two years and his fellow crew-members came a highly impressive ninth in the arduous two-week race.

I'm sure we'd all like to congratulate the 26-year-old on his skill and staying-power and for raising just over £9,000 towards a National Association for Colitis and Crohns Disease (NACC) project into the genetic causes of ulcerative colitis.

As some of you already know, the Red Lion committee donated £500 to help the NACC project raise the £184,000 needed to pay for the two-year research. Here is Neil Basil's spirited account.

In August 2006 I competed in the 'Sevenstar Round Britain and Ireland Race' – a 1,789-mile yacht race around Britain and Ireland – to raise funds for an NACC research project into ulcerative colitis.

I have always considered myself to be quite a fit person and I have spent a lot of time sailing and racing boats since my ileostomy op in 2004, but I haven't done anything on this scale before. Although I certainly like to keep active and thoroughly enjoyed a short career in the Army. In 1999 I was diagnosed with UC and three years later had to be medically discharged from the Forces.

Now that I was back in 'civvy street' the illness never really concerned me too much. I was usually taking some sort of medication and had occasional poorly spells. But the idea of surgery was never discussed – in fact I didn't even know it was an option then.

Early in 2004 I became critically ill with campylobacter food poisoning and was admitted to hospital. I stayed for several weeks. Although I was very set against the idea of being cut open, I realised I would not live without surgery. My large bowel was removed and an ileostomy formed. I had to adjust to life with a stoma-bag stuck to my abdomen overnight – until that day I had not even heard of a stoma so I had a lot of speedy learning to do.

I left hospital in May 2004 emaciated and weak. I had been on my last legs when I went in. When I left I was a 24-year-old wreck, unable to walk more than a few feet and totally shell-shocked from the situation I found

yacht in the Army. I thought longingly about getting back on the water. A race would give me the ideal opportunity, especially as I had not yet gone back to work and wanted to keep as active as possible.

I did some research and got in touch with the skipper of a boat needing some extra crew. He allowed me to join them on a race the following weekend. It wasn't the most sensible thing I have ever done, as the race was the 'Round the Island' yacht race – 50 miles round the Isle of Wight. The weather was rough and I had only been out of hospital for six weeks. I also found it pretty heavy-going for my first offshore sailing experience. I didn't have the correct foul-weather gear and was inexperienced with a stoma-bag – particularly in a yacht race.

Happily my bag was still attached when we got back to Cowes! Neither did I have any mishaps during the race which started at 6am and lasted more than 12 hours. Me and the crew headed off to the pub to celebrate. Then it suddenly dawned on me that we would be staying the night on the boat and I did not have a sleeping-bag. So I snuggled up under my waterproof jacket. It was cold but bearable.

I was very glad to get home and was really wiped out for a few days. A couple



myself in and my new daily routine.

It was obvious that little steps would be the key, but I found my recovery was based on pushing myself a little bit further each day. Within weeks I was walking to the shops and taking the dogs out for walks and I knew that if I wore myself out I could rest for a day or two.

Then I remembered I had long wanted to get back into sailing. I had raced dinghies when I was a teenager in the Sea Cadets and spent a week on a



of months later I began to get back into my old routine. I regularly entered weekend races around the Solent [the stretch of sea separating the Isle of Wight from Southampton] and I spent a week sailing along the South Coast. In August 2004 I competed at Cowes Week and enjoyed some lively racing on the water plus the marathon après-sea social scene with my fellow yachties.

The offshore racing programme continued for two years and I bought a dinghy to practise and race on a local lake. I spent more time cycling and improving my fitness and generally got my life back on track.

Then I met my girlfriend Zoë, we bought a house together, and I decided it was time for a career change. It was clear that my stressful job had probably been a factor in my illness and as my interests were taking me in a very different direction I enrolled on a two-year college course in countryside management.

Although living without a colon was far from ideal – and like most people I had my own individual struggles along the way – it was clear that I would have to get on with my life. Overall I considered myself to be very lucky. Knowing I would need further operations to form an ileo pouch, I was becoming increasingly aware that there are many others who do not have quite such positive experiences. For some time I have been a volunteer on the Ostomy Lifestyle Careline, a telephone helpline for anyone who has had

stoma surgery of any kind and anyone else who may be affected like relatives or people expecting a future operation. Through the helpline I speak to many people who are struggling with their lives for a variety of reasons, some medical but more often due to misconceptions caused by ignorance and the general lack of discussion about our condition.

Intestines are not a subject we like to talk about publicly, so most of us are either badly informed or misled by the stigma associated with toilets, bags and bowel problems. Having bowel surgery is still seen by too many as the end of life as they know it. Sometimes otherwise healthy ostomates or pouchees become

isolated and unhappy when in fact a little human contact could make all the difference.

I thought of ways I could help and knew I needed to set myself a bigger challenge than I had before – something that would be an achievement for a non-ostomate and would stretch me in every conceivable way.

The Round Britain and Ireland Race which had only been held three times before interested me because of the rough and taxing conditions I and the crew would have to face. It was also the most challenging sailing event I could possibly enter – three times longer than the Fastnet Race and negotiating areas of the North Sea that are trickier and more unpredictable than the Atlantic. This was just the test of endurance I was looking for. I also remembered a

I had raced dinghies when I was a teenager in the Sea Cadets and spent a week on a yacht in the Army. I thought longingly about getting back on the water.





quote from the round-the-world-yachts-woman Ellen MacArthur: “Round the world, across the Atlantic, round Britain ... many sailors who have done these three might suggest that the rocky shores of the British Isles pose perhaps the greatest challenge of all.”

I joined a team put together to sail a yacht called ‘Incisor’, a Corby 45 with a successful racing history – it won the previous Round Britain Race in 2000. The crew of ten came from several different countries and we started training together at weekends. We also went on a sea survival course and did first aid training. We entered several qualifying races with mixed success, but we achieved what we needed to do to enter the race and were very pleased with our ability considering we had never before sailed together.

Then during a qualifying race to the port of St Malo in France, I began to realise just what I had let myself in for. Although I felt competent enough as a sailor and was getting stronger and bulking up for the race, I realised just how poor the quality of life would be on board.

The boat was spartan to say the

least. It was designed for racing and the comfort of the crew was a very low priority. It is cramped, especially for a boat of its size, and contains nothing more than a small gas cooker, a toilet that can only be described as treacherous, and a few foam-bunks to accommodate all ten of us for two weeks. What if I have a problem with the pouch? Or if I am taken ill? Or just need to go to the toilet too often?

These worries were further compounded by my experiences on our way back from St Malo. During one particular manoeuvre I managed to fall over several times and rip my trousers. I knew the Round Britain was ten times longer than this one – and probably ten times harder as well. At this point I really did wonder if it was such a good idea. Perhaps I was going too far this time and putting myself in a dangerous situation that could put my health at risk once again.

Too late though, the sponsorship money was flooding in and I was mentally committed to following this through come what may. By the start of the race in August we were gelling well as a team and were ready for anything.

As expected, the race turned out to be a major test of endurance – physical and mental – and we found ourselves battered by totally unprecedented wind

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conditions and storms, and of course, my own personal battle with the boat’s toilet!

Things started off as we would have expected, with a beat to windward along the South Coast and then across the

Irish Sea. That was fairly rough, constantly working against the wind and the waves to make pretty slow progress, but none of us minded particularly as we all knew that there are spells like these in any race. Unfortunately the situation did not improve as we had expected it to when we passed the Fastnet Rock, and the wind shifted to the north just when we too were heading north!

This turn of events was not good at all, as by now we were growing increasingly tired from the relentless crashing into each wave. Living in the cabin was always hard work too as it was at a steep incline and we had to eat, sleep and generally take care of ourselves while being thrown around by the Atlantic swell. The toilet was an even worse prospect, especially when you have to visit several times a day to empty an internal pouch.

Nutrition was an important priority. I lost about a stone during the race, even though I was aiming to consume more than 5,000 calories a day. We began to find the boil-in-the-bag food monotonous and unappealing. The boat too was exceptionally leaky, and became even more miserable once the bilges started filling up with diesel and effluent from the boat-heads (toilets).

This continued unabated, we saw no land for over a week, we negotiated thunderstorms, strong winds and bitter



cold, and the wind moved to the south once we reached Shetland, then back to the west again as we entered the English Channel. During the race we sailed downwind for less than five hours (a disturbing enough statistic as any boat-lover will know).

After twelve days and eleven hours we crossed the finishing-line in ninth place, exhausted, quite a bit thinner and with a pressing desire for a hot bath.

I am now in a position to look to the future feeling fitter, healthier and happier than I can ever recall. Although a part of me will never forget the trauma

of the last two years, the whole experience is now only a vague memory which serves to spur me on with the rest of my life.

Now that this challenge is out of the way I am thinking about my next step. I am already planning to enter the Fastnet Race next year, but I am also wondering what else I can do to continue raising funds and awareness for a subject that has had a significant impact on my life.

To read Neil Basil's full diary on the race or make a donation, please visit www.neilbasil.co.uk

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A Journey With my Pouch

When Red Lion secretary Margaret Dean changed her travelling habits she discovered an unexpected skill.

It is funny to think that until November 1996 I hardly had a care in the world and toilet problems were the last thing on my mind. Mike (Red Lion vice-chair) and I have always thoroughly enjoyed camping and especially the freedom that it brings. That all changed when Professor John Nicholls said “with your family history it must be preventative surgery Margaret” and I lost my colon.

The enormity hit me then and I wondered what life would be like. We had a large folding camper which used to sit outside the front of the house. I looked at it longingly knowing I would not be able to go camping again in it. The problem was that it had a very large awning with an internal toilet – well you can imagine that with an untrained pouch it was very scary and smelly. I couldn’t just pop into the awning and go to the loo like I used to without the usual reverberations sounding off every time! I became very self-conscious and decided there was no way I could camp again. The camper had to go.

I used to enjoy walking but as we all know the pouch has a mind of its own and it can become very uncomfortable especially in hot weather. A good tip I learned at one of the Information Day AGMs was when a member said: “I think I have cracked the problem. I use a tissue folded small between the cheeks which prevents rubbing”. I tried it and it works – although long walks are still not an option.

Also when we used to go out for the day we always made sure we parked within easy reach of toilets and the good old RADAR key certainly was essential equipment. I recall that when we were driving up Snake Pass in Derbyshire I had the urge to go and I asked Mike to keep an eye open for toilets. Lo and behold they appeared at a nearby viewing-point. There was also a disabled toilet where I could use the RADAR key.

By this time I was in trouble – I could feel I was beginning to leak – but what saved my day in the disabled toilet was hot and cold water. I emphasise the hot bit as it meant I was able to have a good bathe. What surprised me more than anything was to find such a toilet out in the wilds of nowhere. I suppose if we had had a copy of the RADAR key book which lists every disabled toilet in the country we would not have been so surprised.

Four years later I felt a lot more confident and Mike said he thought we ought to make the effort to visit my brother in Australia as I had not seen him for 25 years. It was daunting.



Could I actually go that far? Mike got in touch with Singapore Airlines and explained my situation and needs to them. They were extremely helpful and found two aisle seats towards the rear of the plane with a toilet close by. The stewardesses knew all about my condition and made sure I was comfortable. I did not have to ask for anything and plenty of water was supplied. It was comforting to know that if there was a problem the cabin crew would know about my predicament.

It is also worth noting that if you talk to the airline before going on a

long-haul flight they will do everything they can to help – or at least they did for me.

So Australia broke the taboo, but I must admit the thought of travelling to countries where you cannot necessarily rely on the water was a little frightening particularly as we pouchees need to drink up to two litres a day. Mike came across a special water bottle called an ‘Aquapure’ which filters water ready for drinking. I was quite pleased with the idea until he told me the cost which at that time was £29. I thought it a bit excessive but it works and I was thankful I had it with me.

My other comfort is a chair blanket which my mother-in-law gave me – she suffered from incontinence. You put the blanket under the sheets or on a chair and it gives me the comfort of knowing that if an accident should happen, particularly at night, it is not going to stain the mattress. It’s funny how little things like this can improve your life.

Mike and I now go on many days out, long days even, and my pouch behaves itself most of the time. It sometimes takes time for it to settle into a routine although understanding the pouch’s workings plus the acceptance that it’s here to stay certainly help too.

And hey, guess what, we have started camping again and taken matters even further. Instead of turning into a fishing widow I have taken it up myself. Much to Mike’s annoyance I am catching more fish than he is. Although he says it’s “beginner’s luck” I say it’s pure skill.

I now really feel confident, so much so, that we are planning an overnight fishing session in a fishing bivouac. I really thought I would never see this day.

The Aquapure Traveller bottle is available from Field & Trek or BW Technologies www.bwtechnologies.com on 08705 820000. The Ready Seat Protector which is 20in x 17½in costs £12.87 and is available from Clearwell Mobility (www.clearwellmobility.co.uk) 0845 2211222.

A Year in the Life of Zarah

They say time flies when you are having fun so I must really be having a ball! I cannot believe that a year has nearly gone by already. I vividly remember this time last year being extremely excited to be appointed the pouch nurse specialist at St Mark's Hospital and envisioning all the changes and new responsibilities I would have to take on.

I was a little apprehensive, as it was also rumoured that Professor Nicholls would be leaving and I was not really sure if it was the right time to take on this role. However I am pleased to say our new consultant Sue Clark has been a brilliant mentor and a great support, not only to me but also to the patients she sees or operates on. Dr Simon McLaughlin who recently joined the team has also helped me get up to speed with my clinic work, my pouch problem-solving and more importantly made me see some of the joy in pouch research!

Without my patients, I would not

and had to go off and find a doctor or had to wait while I was away on a training course. You will be glad to know that things are much improved now. It has been great learning from the people who actually have pouches and being there when you need me the most.

I would also like to thank those who supported my colleague Sarah Varma and me on our sponsored half-marathon in aid of the Red Lion Group, especially Mike and Margaret Dean for their much needed tea and sandwiches! At the April Information Day I asked some of you to fill in a questionnaire on Fatigue which I'm pleased to say has had some surprising results. Unfortunately you are going to have to wait until the next Information Day to know the outcome!

I am glad to say I have also passed my last degree module on Inflammatory Bowel Disease, have a sound knowledge of UC and FAP and feel a lot more confident dealing with any questions on these vital conditions. My clinic is now up-and-running and officially nurse-led, which means I can do things more independently. This gives me a great opportunity to meet some of you face-to-face and to offer direct help. I have also had the opportunity to work with the doctors who many of you meet in the clinic.

I have helped to devise a diagram for clinic so that all pouch patients get research-based follow-ups. Hopefully this will relieve any anxieties St Mark's patients may have and help them plan their next visit to the hospital.

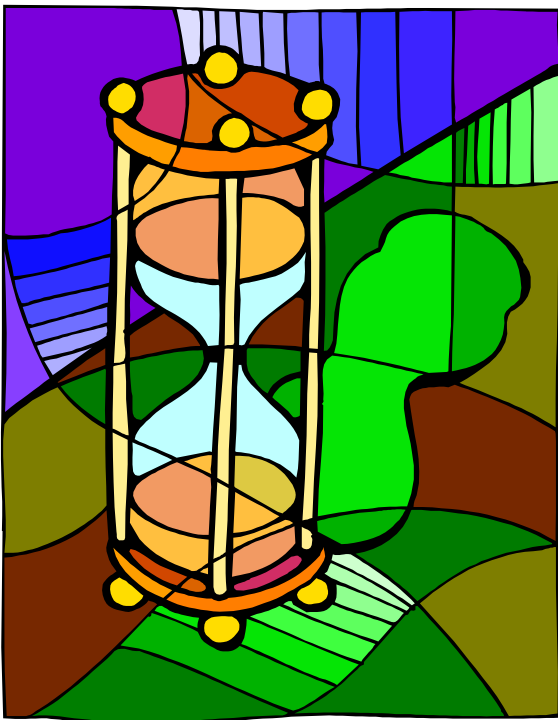
Another useful working aid is the telephone helpline folder I recently put together. This guides me and my stoma-care colleagues on the most up-to-date

advice in pouch-care.

Next year I hope to be more involved with the Red Lion Group, carrying out research and development on internal pouches and publishing articles and information to increase the knowledge of all those who look after pouch patients.

What a year it's been. Yet it feels like the journey has only just begun so thank you all for your support and understanding. I hope to hear from you soon.

*Zarah Perry-Woodford
Pouchcare Specialist Nurse
St Mark's Hospital*



have had the opportunities I have had over the last year to develop as a specialist nurse. It has been a greatly rewarding time and I have learnt so much about pouches and the people who own them.

I would like to thank all of you who have used my helpline and been patient when I was not quite sure what to do



Letters

Can anyone give me some advice?

I had ulcerative colitis which went ballistic in 1998 and led to an ileostomy followed by a reversal to the pouch in 1999. Then my life started picking up again and I was able to go back to work.

It wasn't easy though. I am a car mechanic and the physical nature of the job made it very tough. To be honest I never really regained all my strength, but after so much time off work business did pick up. I did have three stays in hospital with adhesions, but luckily they cleared with the customary four days rest and drip.



I have also had periods of anaemia. On the worst occasion my blood count went down to 4.8 after a blood test ordered by my GP. The hospital phoned me and said they had a bed waiting as I needed a blood transfusion. My girlfriend Denise drove me down there and when I walked into the medical assessment ward the sister-in-charge said she had expected me to arrive in an ambulance as the count was so low. But since then I've managed to get by as we pouchees are a resilient lot.

In the past 15 months I have suffered from pouchitis which seems to be growing chronic. Metronidazole did the trick at first and the worst of the symptoms (frequency and pain) seemed to clear up almost immediately, but whenever I stopped taking the metronidazole the pouchitis returned so I went back on it again. Various endoscopies have revealed that although the metro keeps the pouchitis at bay it hasn't got rid of it.

I also tried the new VSL probiotic without much success and am now back on the 'metro' again. During my last chat with my surgeon he revealed that he was a bit concerned that the lining of my pouch could become cancerous. Has any one else had experience of this?

I asked him if there were any alternative treatments and he couldn't really help me on that. Since then I have been surfing around on the internet and found many websites on the subject of pouchitis and although many of them are from overseas the drug Ciprofloxacin keeps cropping up as a fairly successful treatment of pouchitis.

Has anyone had any experience of Ciprofloxacin as a treatment for pouchitis? I would be grateful for any advice on this – my name is Simon and I can be contacted on Denise@dmartin25.wanadoo.co.uk

Dear Roar!

I had a letter published two years ago in your *Roar!* magazine about having exhaustion and no energy. I would now like to share my medical journey since then.

After blood tests it was decided that I had iron-deficiency anaemia and that I had gastric rush/hurry. This was decided after a barium meal travelled into my pouch in under an hour! Not only I was not absorbing iron, but also calcium!

I had my pouch back in 1988, and have been in fine health for 16 years or so, with only the minor hiccup.

As a result of my anaemia I have had to have four iron infusions this year. This can take from 5-8 hours as it has to be infused slowly and means a day off work.

Anyhow, the blood is sorted, but will I need infusions every 8-12 weeks...who knows?

The next step was to determine why and where, if at all, was I losing any blood.

Stool samples proved a loss of blood, then I noticed that I was indeed passing noticeable blood in stools; not a great amount but obviously enough to help contribute to anaemia.

I had a sigmoidoscopy which showed pouchitis and ulcers on my small bowel. How can this be? Inflammation was very evident on the screen,

along with lots of little white ulcers. I was shocked. Surely I cannot have ulcerative colitis back, as my large bowel had been removed!

I had a capsule endoscopy, which involved swallowing a small capsule containing a camera which download data to a box worn at my waist. This showed ulcers all over. After seeing the photos I asked myself how this could be.

After discussion with my consultant it has been decided that I have Crohn's disease. He thought I was very unfortunate to have this, having originally thought it highly unlikely that I would have it.

But my new consultant thinks I may have had Crohn's all along. My question is 'how?'. Surely if I had had Crohn's in 1988 I would not have been healthy for 16 years. I had check ups and nothing ever showed up: no ulcers, etc.

I am so confused by all of this. My original wonderful consultant checked histology from back then and thought it was indeed ulcerative colitis as did the consultant before him.

Maybe I am one of those very unlucky ones to have contracted Crohn's after having ulcerative colitis. Maybe I am predisposed to this kind of illness. Has anyone else had this?

I am now back on the horrible Prednisolone. I hate all the side effects. I was on steroids for years in 1983-1988 and hated them then. My bones are already thinning and I am getting osteoporosis in my hips and spine. Steroids will not help!

I would be interested to hear anyone's thoughts on this. I am so confused.

I have dropped to a four day week as I work at a young offenders' prison, teaching one to one on the wings. This is quite a demanding and draining job, but one that gives me huge satisfaction.

My employers have been wonderful and I so lucky to have their support.

I am down to see someone from Occupational Health in the next few weeks to see if they can help further.

At least I don't have to worry too much about losing my job, thank goodness.

*Yours, a very confused pouch patient/
Crohn's sufferer
Wendy Hinde*

The Joy of Jordan

Jordan is known as the Switzerland of the Middle East for good reason as Tim Rogers found when he travelled there in November.

My wife Natalie and I were scratching our heads for where to go for our next holiday. We are both keen scuba divers, but were looking for somewhere that would also feed our appetite for culture and ancient history. One country that fits the bill is Egypt. A few years ago we had the good fortune to spend a week exploring the ancient sites along the Nile followed by a week diving in the Red Sea in Sharm El Sheikh during the second week. This time round we found another country in the Middle East that offers the best of both worlds: Jordan.

Jordan has a reputation of being the Switzerland of the Middle East. Although it has no oil, its stable regime has attracted investment and expertise from other trouble spots in the area. As a result, the country shows little evidence of poverty and is home to an educated population that are warm, friendly and keen to maintain Jordan's reputation as a premier tourist destination.

We started our holiday in the capital, Amman from which we visited Rabadh Castle and the Roman city of Jerash.

Rabadh Castle, built in 1185, is situated on a hill and offers splendid

views into Syria in the north and Israel to the west. We could even see the famous Golan Heights, captured from Syria by Israel during the Six Day War in 1967. Sadly, two earthquakes in

occupants in the Middle Ages defending the Jordan Valley against the Crusaders. It was particularly unnerving to walk through the entrance under a slot in the ceiling designed to allow the



Rabadh Castle

1837 and 1927 took their toll on the castle, which has sunk by six metres over the years. There is still plenty of the castle still standing to explore and imagine what it must have been like for the

defenders of the castle to pour boiling oil on those attempting to gain entry by force.

The following day we visited the Roman city of Jerash. This has a triumphal arch dedicated to the Emperor Hadrian, a hippodrome (nothing like the one in Hammersmith), two immense temples to Zeus and Artemis, an oval forum and two (yes two) amphitheatres. Natalie and I have had the good fortune to visit the Roman amphitheatre in Orange, France, but enjoyed the theatres in Jerash all the more for the peace and quiet and absence of throngs of other tourists. (Jean-Paul Sartre once famously said that "Hell is other people", a saying that often selfishly comes to mind when exploring popular places of interest for tourists.) I had heard about the acoustics of amphitheatres, but was quite astonished when standing on the little marble circle in the centre of



Jerash

the stage of the southern amphitheatre and heard my amplified voice boom out exactly as if I had been speaking into a microphone feeding the electric speakers of a public address system.

Next came a visit to Mount Nebo, from where Moses glimpsed the promised land before passing away. As you would expect, the views were stunning. Continuing on a biblical theme we then visited the spot where Christ was baptised in the river Jordan. Over the last two thousand years the river has changed course, so the location is now a dried river bed with steps carved by early Christians leading from the ruins of an early church. We then walked down to the modern location of the River Jordan where we were greeted on the other side by smiling Israeli soldiers who took photos of us.

Our final trip from Amman was a visit to the Dead Sea. When booking the holiday, the idea of plastering myself in mud and floating in extremely salty water, alongside other tourists who were exfoliating layers of skin, did not remotely appeal to me. However, when we got there I got into the spirit of things and really rather enjoyed it. Natalie did not join in because she had recently fallen pregnant and did not want to risk slipping over in the mud, but I plastered myself with dark brown claggy mud with gusto before gingerly entering the water. The Dead Sea is the lowest point on the planet and so salty that you cannot avoid floating on the surface. It was just like lying on an inflatable lilo and I almost found myself drifting off to sleep.

Our next port of call was the ancient city of Petra. The site is situated in a basin among the mountains, accessible through a long natural crack in the rocks and is home to some stunning buildings and tombs carved on a grand scale into the rocks. Only 15% of the city has so far been excavated and even then it sprawls across many square kilometres. Natalie and I spent two days exploring the site, walking a total of at least 20 miles. Petra was estab-

became wealthy and were able to carve some truly spectacular tombs into the rocks and construct grand temples.

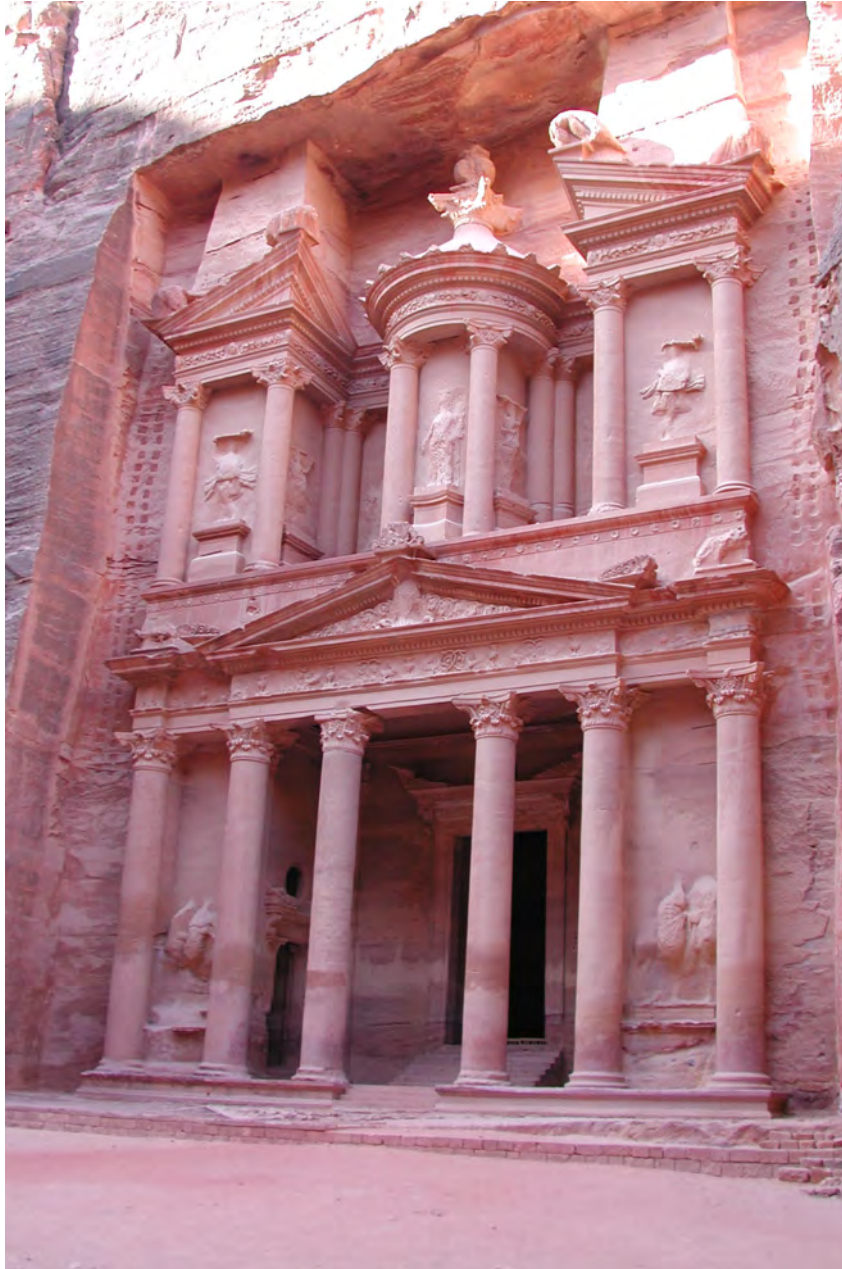
One particularly memorable outing was Petra by Night, where we walked back through the long 'suk' (the secret crack in the rocks leading to the city) illuminated by candles on each side before arriving at the treasury, where we were greeted by the echoing notes of a flute within the building which we enjoyed under the stars sipping mint tea.

Finally we arrived at the port of Aqaba on the Red Sea. The cultural side of the holiday over, I spent five days scuba diving. The diving was good, but spoiled in places by litter on the sea bed. The Jordanian people, who obviously take pride in their history and ancient monuments, do not yet all seem to respect another of their country's great tourist assets: the coral reefs of the Red Sea.

After the diving I finished off the holiday with a trip to Wadi Rum in the desert. The scenery was spectacular, and I was positively enveloped by the hear-a-pin-drop silence that hung over the desert and craggy rocks that glowed luminous red in the light of the setting sun.

I can thoroughly recommend a holiday in Jordan. Petra alone is well worth a visit.

The people are friendly and the Middle Eastern food most certainly agreed with my pouch. On our return, Natalie and I had withdrawal symptoms missing our diet of tabouleh (finely chopped parsley, onion, tomato, spring onion



The Treasury at Petra

lished by the Nabateans who were a trading people and took inspiration from the various cultures of their trading partners. The city is a natural fortress because it is surrounded on all sides by mountains and as a result the Nabateans



Wadi Rum

and lemon juice), fattoush (small piece of toasted pitta bread mixed with red pepper, cucumber, lettuce, olive oil and parsley) and of course lashings of hummus with practically every meal (including breakfast!). If you are looking for sun, sea and some heavyweight culture then you should certainly put Jordan on your list.



Please support the Red Lion Group

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

Write for Roar!

Have you had any interesting or amusing experiences that you think other people with pouches might want to read about in the Red Lion Group's newsletter *Roar*!?

We are particularly looking for pouch-related articles, but we are happy to publish practically anything.

Perhaps you've taken up a new hobby since having your pouch

operation? Or are there any clever little tricks or diet tips you've picked up that you'd like to share? We'd even be willing to publish an article about why having a pouch was a bad idea.

Even if you've never been published before please send us something.

You'll get the satisfaction of seeing your name in print and you may give hundreds of

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

If writing articles isn't your scene we are looking for other things too, 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.

Tim and Chris

