

ROAR!

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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.

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



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My Pouch and Me!

When I was fourteen, I was diagnosed with chronic ulcerative colitis. I'm 27 now, and over the years I have had countless stays in hospitals (and most of the time the food was very good!).

As the years rolled by, the UC was starting to affect my liver, and tests showed that I had developed PSC (primary sclerosing cholangitis), a bile duct disease.

Early cancer changes were also found in my colon, so – in January 2003 – I was given the news by my consultant that the whole colon had to come out. I was pretty taken aback, as I wasn't really expecting it at that point in time. But, if it had to come out, it had to come out!

I then saw the surgeon, Mr Jones, who explained both procedures to me (the pouch or the permanent bag option). He sent me home to think long and hard, although it wasn't really that long or that hard. I really didn't want a permanent bag, so the internal pouch won hands down.

The operation was set for July 31st 2003, and I can honestly say that I was petrified the night before. And I don't even remember going down to theatre.

I slowly came round about 8 hours later in the high dependency unit. The operation had taken over five hours, and I was in recovery for nearly three. I can't tell you how relieved I was to see my family, as I had been convinced that I would not wake up!

That was my first big operation completed.

My colon and rectum had been removed, and an internal pouch had been created. Oh, and I also had a temporary ileostomy. Being in hospital just under two weeks was a bonus – especially when about three weeks is apparently the norm.

When I got back home, the district nurses came very day to treat and dress the drainage site. They came for quite a few weeks because I had an infection there, and needed antibiotics.

As for coping with the ileostomy, I have to say I hated having it, and found it extremely troublesome. What a relief, when 4 months later I was able to have the reversal.

I had no fear of this operation as I knew that I would be getting rid of the bag! I was put on a drip before the reversal, and the proce-

dures took about 50 minutes, with a further 20 minutes in recovery. Then I was taken straight back to the ward.

Before surgery, some people had said that, in the beginning, I may be going to the toilet 20 or 30 times a day, plus quite a few visits at night, which I was not looking forward to. Maybe I was just lucky, or maybe they were just being cautious, but when my pouch started to work, the most I was going during the day was 6 or 7 times, and about 3 at night. So this was very pleasing and a huge relief, as I had been planning to install a library area in the bathroom if I was going to spend so much time in there!

There was only one minor problem while I was still in hospital. A couple of days after the reversal, my small intestine started to get sluggish and I didn't feel well at all. The doctors sent me for an x-ray at nine o'clock at night and the problem was trapped wind – and lots of it!

Apparently, my small intestine was like an inflated tyre and the gas needed to be expelled as soon as possible. I

did all I could to get rid of the wind, by manoeuvring into various positions back on my bed. And when it started, there was no stopping it!

I'm happy to say that my pouch worked fine after that, and four days later I was allowed home.

The pouch has been up and running for many months now, and I haven't really had any problems, "touch wood".

I go to the toilet about three times a day and sometimes once at night. I watch what I eat very carefully and I avoid all the foods that can cause a blockage (like seeds, skins, nuts and indigestibles). I don't drink any alcohol, for the sake of my pouch and my liver.

I also have the odd yoghurt, as this helps the digestive tract and intestines, and at least I can still eat as much cheese as I like, which is good news for my bones, as I also have osteoporosis.

Incidentally, I've put some weight on. After the reversal, I was 6 stone 1 pound. Now I am 7 stone 6 pounds – and counting!

I heard that nicotine gum can settle the pouch if it is very active and causing discomfort. I have tried chewing just half a piece when needed, and it has worked. The pouch goes quiet soon after taking it, so now I always keep a packet in the medicine cupboard, just in case.

Whenever I venture out and about, I take a small bag of emergency supplies with me. This consists of a toilet roll (essential), wipes and an extra pair of briefs. But I've never need to use them once. I think I've got pretty good control down below!

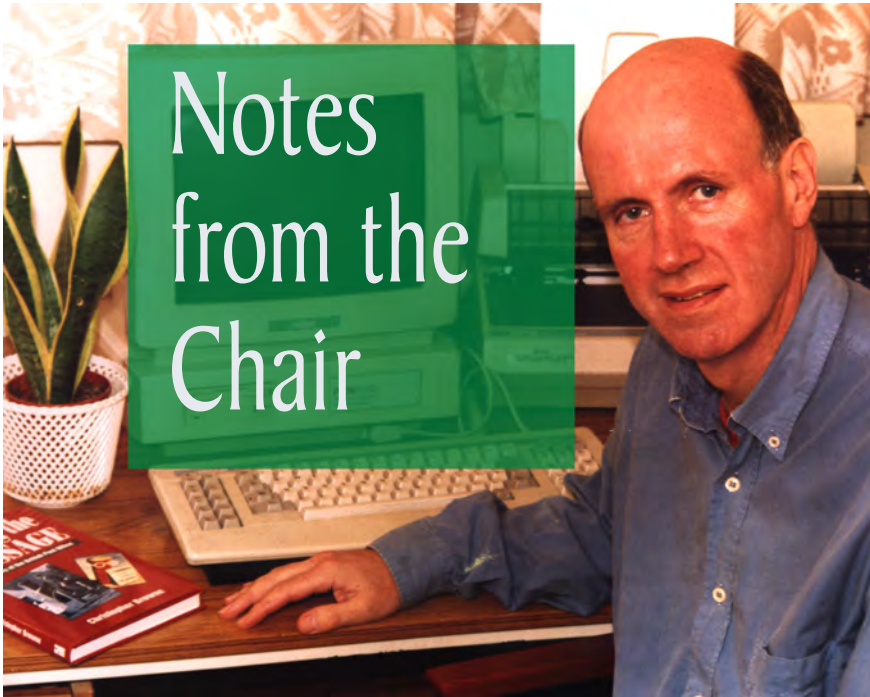
I also try not to lift anything heavy, or do anything too strenuous, as I still find that I do get tired quite easily.

So there you have it – an internal pouch can become your friend if you treat it right. I have remained positive throughout – and having faith helps! You *can* live a good life with your pouch.

As a final word, I would like to thank all the individuals who treated and cared for me during this time.

David J Kimberley





Notes from the Chair

A Tale Of Three Professors

Hello everybody

Don't you just love that phrase "It's official". It means all those rumours and speculation we've been hearing recently are true, no argument. I mention this because in the last *Roar!* I said two specialists believed there would be a cure for ulcerative colitis in five years and that I would ask our president Professor John Nicholls about it. And what did he say?

Yes, he too thinks a cure will emerge, in five to ten years this time. It's infectious, if you'll excuse the pun, and heady stuff and really does mean we are getting close to that "It's Official" phrase. After all, Professor Nicholls, Professor Brian Gazzard and his senior registrar at London's Chelsea and Westminster Hospital are unlikely to all be wrong.

Let's call it the Tale of Three Professors. For when Professor Nicholls went to an ulcerative colitis master-class at Oxford's John Radcliffe Hospital recently, the chairman Professor Derek Jewell, another uc pioneer, said he too believed a cure was imminent.

As Prof Nicholls says: "Trials have shown that germ-free mice don't get ulcerative colitis, but when bacteria is introduced into their systems they invariably do. Bacteria is the front-runner of UC's probable causes and as soon as this is confirmed, a cure will follow very soon."

I can hardly wait and neither, I'm sure, can you.

Making Waves

It's been a good year in other ways too. Information Day had a pleasingly high turnout and some informed and lively speakers. Then in August a Red Lion member, Round Britain yachtsman Simon Rogers, was featured in the Daily Telegraph's health pages. Press officer Stephanie Zinser and I got the Red Lion phone and website contacts in too all in the spirit of good marketing of course. If you'd like a copy, email me on chair@redliongroup.org and I'll send one out to you.

Members Ahoy!

I hope you've all had a good year, and hopefully holiday, too. Just one more item of news. The committee are running a membership drive. If you too have a friend, relation, colleague or fellow out-patient who'd like to join the group, please contact membership secretary Marion Silvey (email liaison@redliongroup.org) who'll send out a membership form. Spreading the Red Lion message around your hospital a timely word or two with your stoma-nurse can work wonders for us is the best public (or patient) relations we can get.

Have a healthy and happy rest of year and we'll speak soon.

Christopher Browne

My Story...by Sarah Harrison

I am 15 years old and have a very rare disease called idiopathic pseudo obstruction.

My problem started when I was just six weeks old and doctors put it down to my mam being over protective.

But after a number of operations and lots of stays in hospital they came up with this only a year ago!

I had my first operation when I was six weeks old and they treated me for constipation.

When I was three years old I had a nasogastric tube put into my nose and every night I was attached to a drip. I had that until I was 11.

After that I had a operation called the ACE where you have to have a tube into your stomach and medication put through every day.

I had that for a year but it never worked so I had it reversed and went in for a colectomy. That made me very ill and I went down to 5 stone.

I was in hospital for weeks. I thought that would be the end for me but worse was still to come.

I settled down for a few months after that but then the pain came back so I got rushed back into hospital. They did a second colectomy and took all of my bowel away apart from a tiny little bit which wasn't diseased. That was when they said I had this disease.

I still wasn't pain free. In fact I was in agony but I had learnt to live with it by then as it has been a part of me since I can remember.

I stayed like that with a lot of medication until January this year when I got rushed back into hospital. They took me straight to theatre and when I came back I had a colostomy bag which has totally ruined my life. I have no confidence and no friends and I don't go out of the house.

I am now waiting to go in for the pouch operation. I am really really scared but hopefully it will work and I will be able to lead a happy and normal life, one that I've never had before.

I hope that one day my day will come and I will wake up pain free. Thank you for reading this, it means a lot.

Letters

Following the delivery of my second daughter by caesarean section in December 2003 I have been diagnosed with a calcification or rock of 8 cm diameter in my pouch. The consultant terms it an enterolith.

This was discovered on an x-ray and I am awaiting its removal either rectally or by surgery to the pouch. At present it is occupying between one third to a half of my pouch.

I have been told this is a very rare phenomenon and that it forms in the same way as a mollusc makes a pearl. I am feeling a little bewildered by this news and not looking forward to yet more surgery. I am worried that it might form again in the pouch once removed as the consultant has no idea what has caused it to form in the first place or how long it has been in my pouch.

I would very much like to know if anyone at St Marks can throw any light on this. My pouch is certainly not functioning well at the moment and though I can laugh at being compared to a mollusc I am concerned about the future of my pouch. I just hope that somebody out there can tell me I'm not unique in having this happen!

Amanda White

Dear Editor

I was most interested to read the letter from Sally Thomson, in the Summer 2004 edition of *Roar!* I too have suffered from tiredness since my pouch operation several years ago. It came to a head last year when I needed three months off work with what my GP described as burn out.

Having got flu, I failed to recover my strength and energy. Now, a year later, I am off work again with 'chronic exhaustion'. I had been wondering whether this resulted from my illness and surgery. I don't think it my age (mid fifties), as my 90-year-old father seems to have more energy. Having interrupted sleep every night certainly does not help and I sometimes wonder whether this has a cumulative effect, by having to get up at least once and sometimes twice every night.

Since I first had ulcerative colitis over 20 years ago, I have tried to carry on as normal a life as possible, particularly with regard to my employment as

a local government officer. I too was left in much better health after the removal of my colon and the majority of my colleagues have no idea that I have 're-arranged insides'.

However, you do not always realise gradual changes to your lifestyle to compensate for the tiredness, but looking back, I realise how concentrating on carrying out a satisfactory days work has impinged on my home and social life.

At times, I have sat in the office at the end of a days work and needed to summon the strength to go home. Then when something is planned or suggested as an evening activity, I really don't feel I want to do anything. Week-ends seem to pass by in a haze, recovering the week's exertions.

All the usual blood tests reveal nothing untoward and at present I am awaiting an appointment to see my consultant.

Whilst I have a very good GP, it appears he has very little in depth knowledge of the implications of life with a pouch and I had a similar experience with my employer's occupational health adviser. I had to explain the nature of the surgery to both.

I would be most interested in the responses to Sally's letter and to know how common this problem is. If it is common, perhaps it might be a good subject for a future article in *Roar!*.

Yours faithfully
Harry Johnson

Dear Newsletter Editor

I was asked some time ago if I would be prepared to give advice to prospective pouch patients. I said that I would be happy to and was recently contacted by a man who is shortly going to have the first part of a two operation procedure.

We talked at length about all the

problems and benefits of having a loop stoma and eventually an ileo-anal pouch. He seemed quite reassured by our conversation until I mentioned regular post-operative checkups. At this point it became obvious that he had fear of any type of anal intrusion (a fear shared by myself).

I wrote a letter a couple of years ago, which was published in *Roar!*, on the subject of sedation for any type of anal examination and particularly sigmoidoscopy. It seems that the doc-

tors at St Marks do not read *Roar!* as they are still not routinely offering sedation by Midazolam as a means of relieving the indignity and pain of such a procedure. In fact they seem quite surprised when asked for sedation.

I am due for my annual checkup in June and I know that I will still have trouble convincing the doctor that I am not going to submit to an examination without sedation, and therefore the examination will not take place.

Good luck to you all at your check-ups.

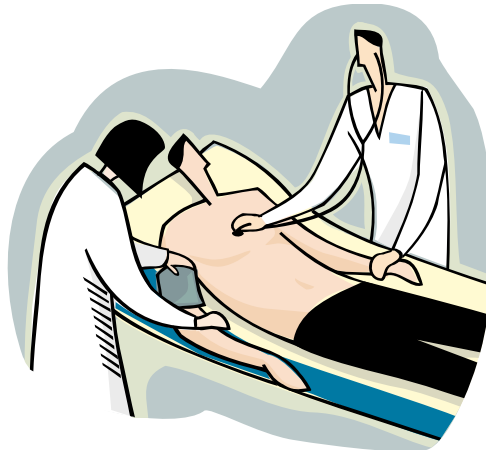
Best regards,
Ray Farley

Dear Editor,

I am 44 years old and had a pouch operation way back in 1989, due to UC, in one stage. Just recently I have had to start taking Warfarin, an oral anticoagulation drug, which thins the blood. This is because I have just had a blood clot in my right leg (DVT), and a small bit broke off and went into my lungs (PE).

I am on quite a few different drugs due to Seronegative Arthritis. I was wondering if anyone else with a pouch had any sort of blood clot and any side effects at all from taking Warfarin.

Thank You
Mrs Pauline Pettitt



My Story...by Allison Fergus

I warn you, we don't shirk from printing your experiences, good and bad, but Allison's story is not for the faint-hearted....

We hardly ever hear about the bad sides of a pouch and how it's not always as wonderful for some as it is for others. It's only right for us to know the good *and* the bad sides of a pouch. I have had a terrible time with mine.

In July 1996, at the age of 20, after suffering from Ulcerative Colitis for a number of weeks, I had the whole of my colon removed and a temporary ileostomy formed. In June 1997, I had the pouch constructed, and in February 1998 I had my eagerly awaited reversal.

More or less straight away, things didn't run smoothly. I had pouchitis within a short space of time, and severe erythema nodosum on my legs. Things eventually settled down, but over time I had constant re-occurrences of pouchitis, erythema nodosum, severe anal fissures that never really went away, abscesses in my pouch, mouth ulcers, loss of appetite, pain on emptying my pouch, loss of blood the list is endless.

I've lost track of the number of examinations of my pouch under anaesthetic (20+), and the number of times I have been prescribed Metronidazole!!

Things carried on like this for six years, until August 2003, when it was discovered that – after another bout of pouchitis – I now had a pouch-vaginal fistula. This caused me a great deal of distress, as the pain and discharge from it were unbearable.

In October 2003, I became severely ill and, after being rushed to hospital yet again, it was discovered that my pouch was in a very bad way indeed. Not only was the fistula getting worse, but I also had a sinus

going backwards from my pouch. At the end of the sinus was a large abscess that had turned septic. I was in severe pain, had fever and was vomiting non-stop. My body was slowly being poisoned.

To make matters worse, the abscess was near the base of my spine and pressing on the sciatic nerve, and the pain was unbearable. I couldn't walk, it was so severe.



After six long weeks in hospital, I finally went home with an endless supply of antibiotics. A further MRI scan at a later date showed a slight improvement in the pouch, but it was decided that a temporary ileostomy would be best, in order for the pouch to heal, fistula to close, and basically to give my body a rest and to let me feel well again.

In March 2004, I had the loop ileostomy made and – even though it was devastating for me to be going back to a “bag” – I had no fight left. I knew it was the best decision, and my

only way of ever moving forward.

I immediately felt relief after the operation: no more pain!!; no more fistula discharge; no more feeling sick every time I ate; I could sit down without pain from the fissures. I was off a lot of medication and a huge weight of worry had been lifted from my shoulders.

Even though I was originally diagnosed with UC, and further testing has proved it definitely was UC, it is now thought that I have Crohn's disease, based on the symptoms I had with my pouch. However, tests and biopsies have all come back as inconclusive for Crohn's. If I go back to my pouch, I have been told that I will need medication for Crohn's, otherwise I will more than likely experience all the same symptoms again.

For the first time in six years, I feel as though I've got my life back and I am finally free of pain. I'm now beginning to wonder whether it is worth going back to my pouch. Surely I should stay with an ileostomy, as it's made me feel the best I've felt in such a long, long time. Surely my health means more to me than a badly-behaved pouch? Who knows? Maybe next time

around it would be wonderful for me.

All I know is that at some point in the future I have a big decision to make – pouch or permanent ileostomy?

I'm happy for those people who have a healthy pouch, but people need to know that it's not great for everyone, and there are problems with it. I don't ever regret having my pouch. I always remained optimistic through the bad times that it would settle down for me, and fought so hard to keep it. I'm just sad that it has not gone as I would have liked.

A Pouchie Goes Backpacking...by Kate Wright

I've just returned from 5 months back-packing around Australia and I've got lots of stories to tell so I thought I'd off load some of them on *Roar!* readers as I think my friends and family are just about sick of hearing: "When I was in Australia...". At least you have the option of turning the page when you've had enough!

If you read my article published earlier this year you'll know that I had my pouch surgery in April 2003 and the ileostomy reversal in August 2003. All the thinking time I found myself with during my recovery, led me to make a few important decisions about my life, and ultimately led to my six year relationship ending, selling my house and taking the exciting decision to go travelling.

I checked with Jo Sweeney and other health care professionals about whether this was a reasonable thing to be doing with a new pouch but everyone was very encouraging and said that as long as I felt well enough to do it then I should go for it. So in February of this year I set off for Oz, with the comforting thought that if proved to be too much of a challenge I'd just hop on a plane back home.

I started my travels in Sydney and had a wonderful time getting to know the city and surrounding areas. I found the harbour to be every bit as beautiful as everyone says it is, and on a sunny day – there's plenty of 'em! – the light reflecting off the water and the opera house tiles is just dazzling. The beaches, the bush and the mountains in the Sydney environs were also stunning. I had my breath taken away more times than I can remember.

Adjusting to the climate and the backpacker lifestyle proved challenging at first. It's hard to get into routines and keep healthy when you're on the move all the time, and carrying your life around in a 16 kilo bag! But after finding myself exhausted and run down a couple of times I soon learnt that my health had to be a priority. I quickly got into the habit of drinking plenty of water, eating a healthy diet taking vitamin supplements and also dehydration drinks on a regular basis to help my body cope with the heat and humidity.

After leaving Sydney I travelled

up the East coast as far as a place called Pomona (a couple of hours North of Brisbane). I stopped off at country towns, harbours and beautiful beach resorts along the way. I then took a flight to Melbourne and hired a car so that I could drive along the famed

journey that I could do anything that I wanted to do, and could have done before my op, but that I might have to do it in a slightly different way.

For example I did a very strenuous four hour walk in the Grampians – a mountain range in Victoria. I enjoyed every minute of it and felt in no way hindered by my pouch. However when I joined a two day tour to "Kangaroo Island" I found myself sitting in the back of the minibus on the afternoon of day two while the rest of the group went on a hike.

The reason being that we'd had lunch an hour or so ago and I hadn't been able to use a toilet afterwards. As a result of this I cancelled a two week tour I had booked and made plans to do the same trip independently so that I could do things at my own pace and plan activities to fit in around meal times.

So, my new plans took me into



Sydney Harbour Bridge from the ferry

"Great Ocean Road" and through the Grampian mountain ranges to Adelaide. I discovered at this stage of



Kayaking on the Bellinger River in New South Wales

the heart of Australia known as “The Red Centre” which I reached on a legendary train journey called “The Ghan”. The journey took 21 hours but passed quickly, playing cards and swapping stories with my fellow travellers.

When we reached our destination of Alice Springs we were stunned to find that it was actually a red and green centre and it was also pouring with rain. They’d been having very un-seasonal weather (half their annual rainfall in the week I was there) and the River Todd - normally only seen once a year - was flowing.

The rain did stop from time to time and I spent a week in the centre visiting the Alice Springs School of the Air, The Royal Flying Doctors Service, and famous landmarks such as Uluru (Ayers Rock) and Kata Tjuta (The Olgas).

Because Uluru is such a sacred place to the aboriginals who own the land I decided not to climb it and instead did an aboriginal tour of the rock and learnt about their beliefs and



A brief dry interlude in the Red Centre

way of life.

My final two destinations were both in Northern Australia, the first being Darwin in the Northern Territory. I saw two incredible national Parks called Kakadu and Litchfield, went to the night markets on the

beach and got to see crocodiles in the wild. From here I flew to Cairns in Northern Queensland and spent a relaxing week in Port Douglas, snorkelling on the Great Barrier Reef, walking along the beach and resting up so I was ready to face the return journey home.

I had a stopover in Bangkok for four days which was exhilarating, exciting and completely different from anything I’d experienced in Australia.

Contrary to my fears that travelling might be detrimental to my health I’ve come home feeling far better than when I left. Being in a new environment gave me the confidence, and more importantly the desire, to

expand my diet. When I left the UK I was still nervous about eating many foods, but after a couple of months in Oz I found I was eating EVERYTHING...loads of fresh fruit, salads, cereals, olives, popcorn (free on movie nights at some of the youth hostels), Thai, Chinese, kangaroo burgers (yummy!), crocodile (yuck!)...you name it I’ve eaten it!

I only had one bad experience with food and that was in Bangkok on my way home. I ordered a very mild prawn curry, but clearly my idea of *very mild* is not the same as your average Thai chef’s idea of very mild. Stupidly, I ate it you can guess the very painful ending of this story! My lesson well and truly learnt, the next day I did a Thai cookery course and made a delicious (not to mention mild!) red curry with duck.

So now I’m home. Broke, unemployed and incredibly happy, I’m looking forward to the next adventure which will no doubt include getting a job, finding somewhere to live and readjusting to the real world! Best wishes to everyone who reads *Roar!*



Me and a sea cucumber on the reef

View from the Poop Deck

Red Lion Group PR Officer, Stephanie Zinser, talks to world-class yachtsman and yacht-designer Simon Rogers about how ulcerative colitis and a pouch have impacted his life.

When you're a teenager participating in sport at the highest level, you don't think about anything but the sport itself. You certainly don't think about what might happen if you develop a life-threatening gut illness that takes you literally to the edge of life rather than to the edge of success in international competitions and you don't realise the impact it might have on your future.

When Stephanie Zinser interviewed Round Britain Yacht Race record-holder Simon Rogers, he explained how he had spent his teenage years as a phenomenally fit student, accomplished yachtsman and international skier.

"I was always training and probably one of the fittest people I knew," he says, but not what we couch-potatoes think of as "fit" ie walking up a flight of stairs and not getting breathless, perhaps, but Super-Human Fit.

Simon put in hour after hour of ski training at altitude, where the air is thin, and where normal bodies struggle to cope under conditions of inadequate oxygen, creeping lethargy, light-headedness and nausea. It was Simon's "gym", if you like.

Simon believes his ulcerative colitis started in 1984 towards the end of the Sardinia Cup in which he was competing at the age of 18. "I was part of the team, and as we brought the yacht home, the whole crew except for me were taken very ill indeed. There was an enormous amount of stress trying to get the yacht safely home virtually single-handedly," he explains. This, and the stress of exams ("I was never a natural student," he adds wryly) are what he believes to have been the switch that flicked on his illness.

"From then on, whenever I became very fit, my uc would flare up and I'd become ill. The frustration was enormous for an athlete who had his sights on an international career as a top yachtsman and skier. It definitely affected me and psychologically

I found it very hard to become ultra fit because whenever I reached that level my uc would attack. This fear of being ultra fit has stayed with me and, even now, after being free from illness for years, I still hold back. Although I'm never going to be able to do a Round The World yacht race again (because I'm not quite fit enough), I've at least had the chance to compete at the highest level and been able to tick

all the boxes," says the 38-year-old.

Simon has a string of sporting



accolades. Last summer he broke the Round Britain Powerboat record for boats of 30ft and under (33 hours, 11 minutes and 4 seconds), and his career as a yacht designer is also taking him to new peaks. His company, Rogers Yacht Design based in Southampton, recently launched a 70ft whale and dolphin research vessel for the IFAW (International Fund for Animal Welfare), with Pierce Brosnan and his wife Keely Shaye Smith at the launch. His company are also designing two yachts for the Volvo Ocean Race (formerly the Whitbread Round The World Race).

So how has having a pouch changed Simon's life? His first operation was in 1987 just before his 20th birthday, and used as a national training video for trainee gastro nurses and

surgeons. Not only was he one of the earliest pouchees, he believes he is one of the luckiest, with a wonderfully behaved pouch. "After the reconnection was done, I had the most immense itching which drove me nuts for about two weeks. But it's been

terrific ever since. I've had pouchitis three or four times since the operation, but not for the last 10 years," he explains. "My pouch has been my saviour. It's absolutely fantastic. I cannot imagine not having one, and I couldn't have done all the things I have done since, without it," says Simon.

The yacht designer goes to the loo about five to six times a day. "Sometimes I get very bad wind [especially after a boozy night], which can be a problem for my crewmates on a small yacht, but I've found that igniting a match in the loo seems to get rid of about 80 per cent of the smell, although I have sometimes wondered that in too small a space, I might go up with it!"

Simon is happily married to his business partner Rebecca, and they have two children four-year-old Hattie, and new arrival

Tom, who is just two weeks old. Partly because of his new role as a father, Simon prefers to spend more time on design than competition, although he still participates in shorter races and a few overnights.

"Having been through this does change the way you think about life. I live for the day now, and enjoy every one as it comes. I am aware that I am one of the lucky ones with a near-perfect pouch. I was a confident and sporty person before, I came out like that afterwards, and I'm always happy to talk about it," he says.

Simon positively invites Red Lion members to contact him about pouch problems or similar issues. He can be contacted on 01590 672000 or www.rogersyachtdesign.com.

Stephanie Zinser

Family Planning Survey: Results and Analysis

Way back in the mists of time (in 1996, to be precise), we undertook a family planning survey. We decided it was time to reproduce the original survey and results, for the particular benefit of those members who have joined us in the last few years.

The family planning survey sent out with newsletter three did in fact address different issues for men and women. In preparing the questions, I thought that men were more likely to be primarily concerned about the effect of the surgery on sexual function, whereas the women were more likely to be primarily concerned about their ability to bear children.

One (female) member (OK, let's get the sniggers about male appendages out of the way now, please!...) pointed out the difference between the questions and suggested we were being a bit sexist. I do plead guilty, but for the reasons outlined above.

Our chairman, Martin Peters, argued (quite correctly) that sex is an important issue for women as well as men, and we will happily address that issue in more detail if members want. However, Martin's wife agreed with my own assessment of what the two sexes would most like to hear about, so he was outvoted in this instance! We would certainly like to hear your views about this, ladies.

A second point to bear in mind is that our survey provides the only collected information so far that surgeons in this country will have about these issues, and so it is very important research in its own right. However, please bear in mind that the sample size is not large in overall terms, and so it is dangerous to quote percentages. The responses received are detailed separately.

We had 26 male respondents and 29 female respondents, which was an excellent response rate. The few responses we had to the family ques-

tions were in the negative, so there is not much to say about this. No news is good news, really, given that we asked about problems.

Of the male respondents, just under half received medical advice about the effect of the pouch on sexual function before surgery, either from the consultant or the stoma nurse.

surgery. Whether this is because most consultants are men, and therefore are more likely to offer information that they themselves want, we do not know, although this is likely to play at least a subconscious part. Consultants and stoma nurses, take note!

In terms of "customer satisfaction" levels, all 12 of the men who

received pre-op advice felt that they had been given sufficient and reasonable advice. For the women, again, the results were less encouraging: of the 16 who received pre-op advice, 7 (less than half!) said that they had received sufficient and reasonable advice, and 4 were actively unhappy at the level of advice they received.

However, to be fair to surgeons, unless they have personal experience of performing a number of pouch operations on women, where are they to get the information from? (which is precisely why we're doing this survey).

Our hearts go out to one couple who felt very upset by their consultant's dismissive (to them at least) remark that "we know what we're doing" when they raised the subject: what he was unaware of was that their only child had recently died, and so the subject was particularly important to them. They were too caught up with emotion to be able to press the matter.

Of course, it is right that medical staff should remain objective in order to carry out their jobs, but equally they must remember that family planning is not an objective subject for the people involved; on the contrary, it is very emotive. Having to have major surgery is itself often traumatic



One individual had a rather nasty experience: "nothing discussed apart from a statement at admission warning of possible impotency". Hardly the best time to find out such information!

As for the women, again around half spoke to someone about the effect of their surgery on family planning prior to the operation.

However, there is one very big difference between the men and the women: for the men, the subject was raised by the consultant or stoma nurse in around $\frac{3}{4}$ of the cases where pre-op advice was given. For the women, it was almost exactly the opposite way around: $\frac{3}{4}$ of women obtaining pre-op advice only got that advice by raising the subject themselves; it was not volunteered.

This is a shocking but sadly not surprising result – apparently it is common to find that men are more likely than women to be volunteered information of this nature with any major

enough, but the additional burden of not knowing how it will affect your chances of having children is a very real worry.

Children

Anyway, onto the subject of children. Happily, most men felt that the surgery had not affected their chances of fathering children (with 3 successes by our respondents in this area to date!). One member reported that he had not been producing sperm since the operation; his doctor had told him that this may well improve with time – without knowing the facts, this comment suggests that the problem may be more psychological than physical. 3 others were unsure of the effect of the pouch surgery. One said “I don’t know about sperm count but my libido and potency have been drastically reduced”.

I must stress that problems with sexual function and potency (for both men and women) are notoriously difficult to pin down. I read somewhere, for instance, that as many as a third of couples who have difficulty conceiving do so for no discernible reason. It seems that stress probably plays a large part in such cases: many people know couples who have adopted because of apparent infertility, and then gone on to have a baby as well.

And, of course, major surgery of any kind often affects libido for some time after the surgery. That is certainly not to say that we underestimate the problems encountered by this respondent; but the good news is that only 2 or 3 members out of over 400

people on our database have mentioned potency as a post-op issue. I would suggest that a visit to the GP might be worthwhile, to see if there are other reasons for the loss of libido and reduction in potency.

As for babies being born to female pouch patients, five women re-

spondents have had post pouch babies. This may not seem many, out of 29 respondents, but I know of at least two women who have had post pouch babies and did not send in their questionnaires (why not?!) and one other who is currently expecting. Also, one of our five respondents has had not one but four post pouch babies, while another has had 2. So we know from the survey about 9 babies, not 5.

And two respondents asked about contraception, so we assume that at least some of our 29 are trying *not* to get pregnant at the moment!

As you might expect, the pouch did cause some minor problems during pregnancy: leakage for one, obstruction on delivery for another, pressure on the pouch for a third, leading to increased stool frequency, and a general level of stress for the other 2 mothers. But on the whole, these were minor irritations in the grand scheme of things rather than major problems. Which is all excellent news.

As for actually having the babies, a caesarean (elective or otherwise) was the usual method, and certainly this has been publicly recommended by Mrs Nicholls at St Marks in the past, as it puts less strain on the pouch than a

than for her number one child.

Remember, mothers-to-be, even if you have a pouch, it is still your right to choose where and how to have your baby. You must do what is right for you. However, you should ensure that your midwife is fully aware of your medical situation, and feels confident about dealing with your delivery – your own nerves may be frayed enough at childbirth without having to worry about someone else’s!

We would certainly not recommend a home birth for baby number one, however, in case there are unforeseen problems caused specifically by your pouch. By number two, you should have more idea of what to expect.

In terms of the births themselves, 7 of the 9 reported no problems caused by the pouch. Of the remaining 2, one reported a problem with scar tissue from the pouch operation which resulted in increased blood loss, and the other had faecal leaking, as well as not making it to the elective date. Again, these are just two areas to be aware of, and maybe to draw to the attention of the medical staff involved, so that they know what to expect. But faecal leaking is certainly not a problem for pouch patients only – giving birth is often a far from dignified experience!

The most significant post-birth problem reported was one doctor’s inability to understand the mother’s need for medication – so do make sure your delivery attendant is properly informed about your pouch surgery and your medical needs.

The important thing to note is that 5 of the 9 births were attended by medical staff with no previous experience of pouch deliveries, so the results above are probably pretty representative. (The other 4 are just one woman giving one midwife or doctor lots of



normal delivery.. However, two of our 9 babies (both born to one mother) were delivered normally. Not only was this mother not put off by her first birth experience, but she even had the second baby at home! And, more importantly, she rated it a much better birth (and post-birth period)

pouch delivery experience – if she hasn't learned about pouches by now, she probably never will!). Having a baby after pouch surgery is nothing to be feared, any more than any woman is naturally apprehensive about the physical demands of having a baby. Pouch patients are normal people, too!

Pregnancy

Now, the difficult area. We do know that a number of our female respondents are trying to get pregnant, but to no avail so far. As mentioned before, this may or may not be related to the pouch – it is difficult to say.

Obviously, as one woman found out, it is difficult to get pregnant if you are on lots of antibiotics or other pouch-related drugs, because you're simply not well enough to conceive. Similarly, we have heard that drugs taken during fertility treatment may be a problem, perhaps because of poor absorption. One contributor currently on such treatment says that her fertility consultant has little consideration for her pouch when he pokes her about.

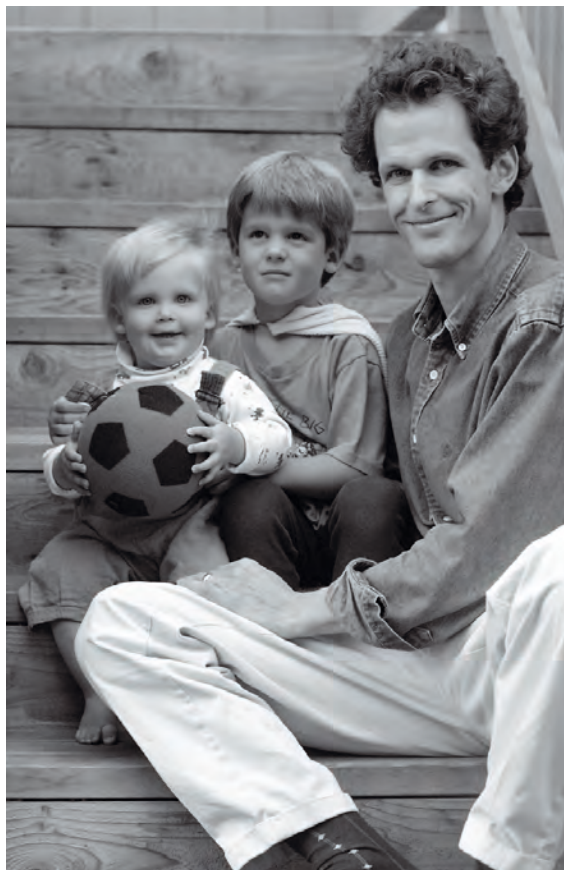
There can of course be physical obstacles to conceiving, caused by the pouch surgery itself, although we know of only one case of this from the survey: one contributor's fallopian tubes were damaged when her pouch was formed. It might be wise, therefore, to get your surgeon's advice at an early stage as to how the pouch fits in with your "womanly bits" when considering pregnancy for the first time.

Overall, it seems that, if you can get pregnant, having a post-pouch baby need not be any different from having a non-pouch baby. However, it's the getting pregnant that might be a problem. Please note the "might". All we can suggest is that you rule out any other physical causes, try not to worry, and get practising (which, after all, should be the fun bit!)

Finally, on the need for more information about family planning at the time of making a decision about surgery, the results were fairly clear:

23 of 26 men said a resounding yes, and 25 of the 29 women did so also. A few respondents made it clear that, although important to them, the question of family planning never even occurred to them at the time they were considering having a pouch, as there were so many other things to think about at the time, so a booklet would have helped jog the memory.

One point that was made by a male respondent was that "if you have to have surgery, you'll have it regardless of effect on sexual function", which is certainly true for acute and emergency cases, but other patients may have the option to defer their surgery until after having a family. One woman pointed out that there would probably be more important issues at the time. Also, people's needs change, and advice about family planning implications is obviously not going to be as relevant to a girl of 12 as to a woman of 24.



Please do keep up informed about progress with post pouch pregnancies and babies in particular, as the more information we get, the more information we can provide for others who need it. I do hope this article will prompt some of you to write in with

your comments and experiences, for us to publish on the letters page.

Peppermint oil—a note of caution

Every pouch patient and ileostomist knows that taking peppermint oil is the answer to most wind problems. However, one of our pouch patients was advised both by an aromatherapist friend and by her stoma nurse that peppermint oil should not be taken while pregnant.

Unfortunately, I do not know why this is, or what happens if you do (perhaps someone could enlighten us?). However, it is a precaution worth taking.

Things to think about

"I have been told that pregnancy makes Crohn's better and colitis worse", wrote one woman, who in fact had her pouch surgery because of acute case of colitis, and sadly found out she was 10 weeks pregnant when she had the operation, but lost the baby. None of the nine successful pregnancies in our survey reported this problem. Perhaps stoma nurses/consultants have comments about this?

One woman wrote: "I have been told my illness and surgery would rule out adoption". However, we can report that a late survey response (too late to be included in the above numbers) was from a mother who had adopted a baby post pouch, so this does not appear to be true in all cases. Our advice is to investigate further, and we would also like to know if any other members have received this advice.

The above survey and analysis were written in 1996. Since then, more scientific studies have been done into this same area. Their results have generally supported what we discovered as long as 8 years ago: that pouch surgery does not affect your ability to deliver a baby, but may indeed affect your ability to get pregnant in the first place. I believe current advice from St Marks at least is to consider completing your family before having surgery, if your condition allows it.

Morag Gaherty

Male Pouch Patients: Fathering Children

1. Before you had your pouch surgery, was the effect on sexual activity discussed? Who was this with?

Consultant	9
Stoma Nurse	3
Not discussed pre op	14
Total	26

2. Who prompted the discussion?

Consultant	8
Stoma nurse	1
You and/or partner	3
Not discussed pre op	14
Total	26

3. Do you feel you were given sufficient and reasonable advice?

Yes	12
No	9
Didn't think about it	1
None required	1
No comment	3
Total	26

4. As far as you are aware, has your surgery affected your chance of fathering children?

Yes	1
No	17
N/A (eg previous vasectomy)	5
Don't know	3
Total	26

5. Do you think that written information on sexual function should be made available to all male potential pouch patients at the time when they are considering surgery, so that they can discuss matters with their consultant?

Yes	23
No	1
Possibly	1
Discussion rather than booklet	1
Total	26

Female Pouch Patients: Having a Baby

1. Did you discuss family planning issues as part of your decision to have a pouch? If so, with whom?

GP	2
Consultant/surgeon	10
Stoma nurse/registrar	3
Anyone and everyone!	1
No-one	13
Total	29

2. Who prompted the discussion?

You and/or partner	9
Consultant	4
Stoma nurse/registrar	1
Mutual/can't remember	2
No pre op discussion	13
Total	29

3. Do you feel you were given sufficient and reasonable advice?

Yes	7
No, N/A, no advice	17
Don't know	1
None needed	1
At time yes, with hindsight no	2
Told no info available but "should be OK"	1
Total	29

4. Have you been pregnant since your pouch operation?

Yes (*)	5
No	24
Total	29
(*) 9 babies in total	

5. Did you have any difficulties caused by the pouch during your pregnancy, or were you conscious of additional stress specifically because of worries about the pouch? If so, please give details

None stated	4
Leakage	1
Stress	2
Obstruction on delivery	1
Increased appetite and pressure on pouch affected stool frequency	1
Total	9

6. What kind of delivery did you have?

Normal (hospital)	1
Normal (home)	1
Vertical elective caesarean	1
Elective caesarean	3
Caesarean (unspecified)	3
Total	9

7. Did you have any difficulties caused specifically by the pouch at the birth? If so, please give details

Scar tissue caused problems including increased blood loss	1
Faecal leaking in first stage of labour and not making it to elective date	1
No	7
Total	9

8. At the birth, were you attended by someone with experience of pouch pregnancies?

Yes ("after 4 with same, should have some experience!")	4
No	5
Total	9

9. If the answer to * was no, did this increase your anxiety about the delivery?

Yes	1
A little	2
No	2
Total	5

10. Did you have any post-birth problems caused by your pouch? If so, please describe

Diarrhoea and faecal leaking, and doctor's inability to understand need for medication	1
No/none remembered	8
Total	9

11. Do you think that written information covering these issues should be made available to all female pouch patients of childbearing age at the time when they are considering surgery, so that they can discuss family planning possibilities and the associated risks with their consultant?

Yes	25
No (more important issues at the time)	1
No comment	3
Total	29

A Message From the Treasurer

It may be of interest to members to know that I have sent in the Gift Aid claim for the year ended 5 April 2004, and this was for £1,161.72.

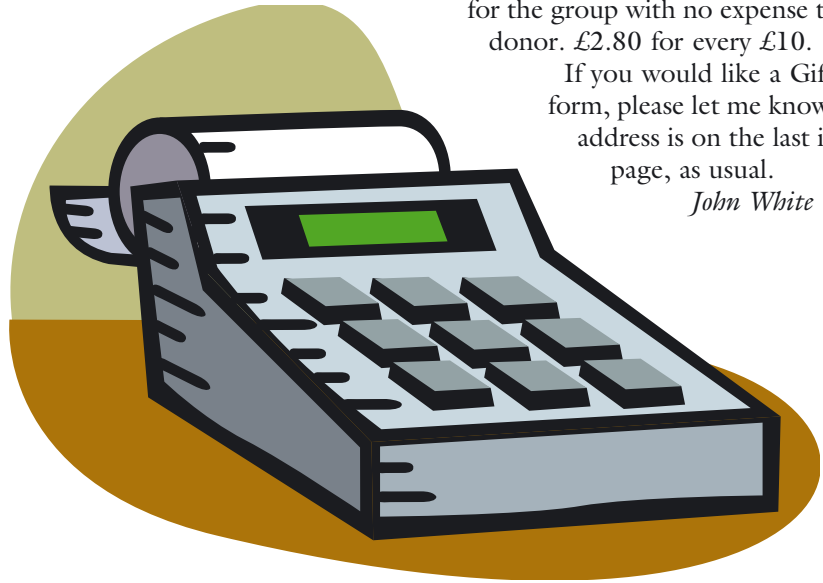
I had 63 new forms signed up during the period 6 April 2003 to 5 April 2004. Perhaps you may not realise that I can claim back to 6 April 2000 for all monies paid to us by

those members signing new forms, so it does involve quite a lot of "trawling".

With this fine total, it was worth all the effort. Next year's total will of course be far lower unless I can get another 63 members to sign forms!! 161 members have signed Gift Aid forms, and I really would welcome lots more. It is a way to obtain funds for the group with no expense to the donor. £2.80 for every £10.

If you would like a Gift Aid form, please let me know. My address is on the last inside page, as usual.

John White



Get it in
Your Diary
Early!

Red Lion
Group
Information
Day

Saturday
30 April 2005

Please support the Red Lion Group

Registered Charity number 1068124



All donations, however small, towards expanding the work of the group will be gratefully received. If you would like to send a donation please make your cheque payable to The Red Lion Group. And send it to:
The Red Lion Group Treasurer, Mr John White, 44 France Hill Drive, Camberley, Surrey GU15 3QE

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Join the Red Lion Group

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

Visit Our Website

www.redliongroup.org

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.

