

# ROAR!



**ISSUE 37 • NEW YEAR 2008**

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

## Regional Reps

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

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



### AVON

David Mair Bristol 0117 922 1906

### BEDFORDSHIRE

Carol George Sandy 01767 263092

### CLEVELAND & NORTH YORKSHIRE

Christine Jackson Saltburn by the Sea  
01947 840836  
[chrisjacks@supanet.com](mailto:chrisjacks@supanet.com)

### CUMBRIA

Jonathan Caton Kendal 01539 731985

### DERBYSHIRE

John Roberts Derby 01332 361234

### DORSET

Clive Brown Bridport 01308 422281

### ESSEX

Peter Zammit Benfleet 01702 551501

### HAMPSHIRE

Les Willoughby Winchester 01962 620012

### HERTFORDSHIRE

Susan Burrows St. Albans 01727 869709

### KENT (WEST)

Rosalyn Hiscock Pembury 01892 823171

### LANCASHIRE

Joan Whiteley Clitheroe 01200 422093

### MERSEYSIDE

Blanche Farley Liverpool 0151 924 4282

Anna Morling Newton-le-Willows  
01925 229648

### NORFOLK

Sandy Hyams King's Lynn 01485 542380

## Contents

Regional Reps .....	2
Notes from the Vice-Chair .....	3
My Story...By Sally Jenkin .....	4
Results from the Fatigue Questionnaire .....	5
Why I'm Keeping Mum About FAP .....	8
The Stressbuster .....	9
The Lap(-Top) of Luxury .....	10
Letters .....	11
Not So New Kid on the Block .....	11
Please Support the Red Lion Group .....	14
Committee Contact Details .....	15



### NORTHAMPTONSHIRE

Cynthia Gunthorpe Kettering 01536 482529  
David Smith Northampton 07768 400406  
[mansfieldsmith@hotmail.com](mailto:mansfieldsmith@hotmail.com)

### NORTHERN IRELAND

Sharon Hendron Lisburn 02892 661559

### SOUTH LONDON

Jonathan English SW12 020 8673 3092

### SOUTH WEST LONDON

Dec Odell-Athill W10  
[colin@odell-athill.demon.co.uk](mailto:colin@odell-athill.demon.co.uk)

### SUFFOLK

Anna Morling Leiston 01728 830574

### WILTSHIRE & DORSET

Bernadette Monks Salisbury 01722 327388

### YORKSHIRE

Sue Appleyard Huddersfield 01484 641227



better option for a professional flautist about to start a high-profile career.

Inez and I were moved to write a reader's letter to the magazine highlighting all the benefits of the pouch with a phone number for sufferers to contact.

Even more reason for that 'Wear your pouch with pride' campaign.

Perhaps it's time we started a 'Wear your pouch with pride' campaign. After all, the organisers of Remembrance Day are always urging us to wear our poppies with pride so why not have a slogan for pouchees too.

And for no better reason than knowledge – or lack of it. Although more and more UK and overseas hospitals are offering patients with uc, FAP and other colon complications ileo-pouch operations there is still a sizeable number that don't.

One clear sign of the global gastro gap was an article in November's SHE magazine – cleverly spotted by RLG membership secretary Inez Malek – about a young female music student who had an ileostomy after a series of severe uc attacks. The writer called the operation a lifesaver. But what she didn't mention was ileo-pouches. An internal pouch might have proved a

### Decisions, Decisions...and In-decisions

Oh dear. We all know about the critical funding shortages the NHS faces – with staffing and equipment problems, daily administrative snags and operation delays and setbacks. Well, as some of you already know, St Mark's Hospital's pouch support nurse Zarah Perry-Woodford and Angela Vujnovich, the hospital's stomacare manager, are about to start six months' maternity leave.

Question: Who will be giving vital support and phone cover for pouch and pre-op patients in their absence? Answer: Nobody.

It's simply not good enough. The committee are very concerned, as I am sure you are too, by this apparently thoughtless oversight. We can only assume such lack of cover is due to funding problems. St Mark's like many

other hospitals has been grappling with cash crises for several years now.

In a timely letter to Professor Robin Phillips, St Mark's Director of Surgery, our chairman Mike Dean has urged the hospital to find cover before the pair's maternity leave begins and thus prevent an "intolerable situation".

"Pouch support is such a vital element in preparing patients before, during and after their surgery that it is difficult to contemplate sending patients home without such preparation and back-up. To leave such a post without cover for at least half-a-year seems to be foolhardy – and indeed what are patients with problems expected to do?," he says.

Let's hope Mike's letter makes St Mark's wake up and see sense. Stop Press: We've just heard that the maternity cover has been provided after all. So thank you St Mark's.

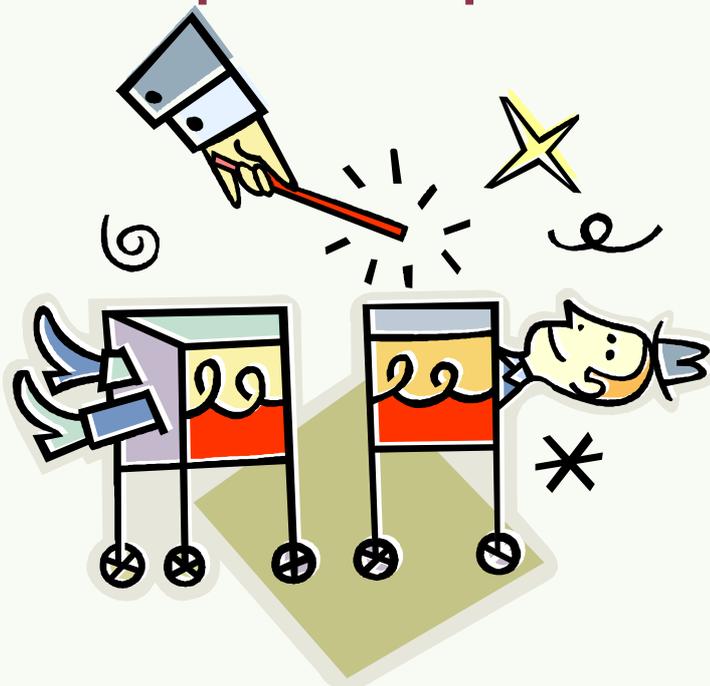
### A Festive Finale...

To end on a more seasonal note. The Red Lion group has donated a laptop to St Mark's pouch and stomacare departments. It should prove a real boon for data storage, weekly presentations and daily teach-ins. You can find out more on page 10.

Meanwhile the committee wishes all Red Lions and their families a very happy and healthy 2008.

*Christopher Browne*

## Roll Up, Roll Up for Information Day 2008



Saturday 26 April 2008

St Mark's Hospital

Watford Road

Harrow HA1 3UJ

- Agony aunt Virginia Ironside on her new pouch operation
- How pouches can affect male and female fertility by St Mark's surgical registrar Miss Julie Cornish
- More words of wisdom from RLG president Professor John Nicholls
- **See programme on page 13**

## My Story...by Sally Jenkin

After a proctocolectomy and a pouch operation, Sally Jenkin took two caesareans in her stride. Here she reflects on the perils of taking codeine after surgery and explains why both her children were born on a Wednesday.

I was diagnosed with ulcerative colitis in August 1993 when I was 28 – a diagnosis that began a journey that is all too familiar to most of us.

A few months later I was hospitalised for three weeks and spent the next three years taking every drug the doctors could prescribe without ever bringing my symptoms under control. My GP and I made one last attempt to control my symptoms with acupuncture and homeopathic medicine before I was referred to a surgeon. My reasons for wanting surgery were that first I never felt truly well despite a cocktail of drugs which were creating long-term health problems such as a reduction in bone density due to steroids and second I wanted children but could not entertain the idea feeling as ill as I did.

However when we discussed the operation my surgeon dropped a bombshell. He told me that while ulcerative colitis was unlikely to affect my chances of having a baby, a proctocolectomy with an ileo pouch would. It is not known why (although there are several theories) but may be due to tissue scarring of the fallopian tubes during surgery.

My husband Will and I decided my long-term health was the key priority and anything else would have to be assessed after the operation.

I had the surgery when I was 32 followed by a reversal of my temporary ileostomy five months later. It was a huge success and my surgeon advised me to wait a year to give my body a chance to recover before trying to conceive. He also said that if I got pregnant, he would advise me to have a caesarean section to protect my surgery from any stress natural birth might cause it.

Life was great again after the two operations and I have to admit it was more than two years later, after a lot of fun and travelling to make up for lost time, that we considered trying for a baby.

It took eight months for me to fall pregnant and once we had recovered from the shock, I thoroughly enjoyed

my pregnancy. Hormones slow down the movement of food through your guts while pregnant so while all my pregnant friends were complaining of constipation I was raving about the fact I was sleeping through the whole night without visiting the loo!! By the way, I never questioned the fact I was to have a caesarean as I had a huge amount of respect for my surgeon but a natural birth is possible so please do explore it if you find yourself post pouch surgery and pregnant.

At four months my surgeon, obstetric consultant and I had a meeting

as a result, the 48 hours post caesarean were not good.

Well, 2 ½ years later I was back in hospital for another caesarean (Thomas) with a consultant anaesthetist, gut surgeon and obstetric surgeon by my side and all went smoothly. I refused medication except Paracetamol and anti-inflammatories after surgery and it was a great experience. After all, a caesarean is like minor surgery after you have had a proctocolectomy!

I now have a five and a three year old that my surgeon calls his pouch babies. Both were born on a Wednesday



about the situation we found ourselves in – it was a first for us all. While the doctors were excited at the thought of a challenge during the caesarean, I had reservations. I had an irrational fear of being awake while they cut into me so a meeting was set up with the anaesthetist. He laid these fears to rest and a date was set for the caesarean. Anna's birth was a bit hair raising all round, though ironically this had nothing to do with the surgery. There was, however, one major mistake made by the person who wrote up my post operative pain relief. They prescribed a codeine based painkiller and my guts, that were already sluggish after the epidural, were brought to a halt!!! I was very sick and in such pain and discomfort because of this and

day as it was the only day my surgeon did c-sections. Anna, due on the 6 January, was born on the 19 December 2001 so that Christmas was not interrupted; whether it was for his sake or mine I don't know! Thomas was born on 2 June 2004 so that the consultant's annual visit to Wimbledon was not put in jeopardy. My sense of humour means I found this very amusing.

As for my guts, they have never been better.

For all those out there who are heading down the same road as me, I wish you all the best in starting a family post pouch surgery and my one bit of advice is to avoid those codeine based pain relief drugs post caesarean if you have one!!!!

## FATIGUE QUESTIONNAIRE



## LONG AWAITED RESULTS



Zarah Perry-Woodford  
Clinical Nurse Specialist  
Pouch Care  
St Mark's Hospital  
0208 235 4126  
zarah.perry-woodford@nwlh.nhs.uk

## SAMPLE GROUP

- Date Saturday 8<sup>th</sup> April 2006 (Pouch Information Day)
- Sample given to all participants (approx 80), **32** responded and were analysed
- Age of pouch between 4 months and 24 years
- Both male and female pouch owners of varying ages
- 13 questions asked

## MAIN QUESTION

Do you suffer from **CONSTANT** fatigue?

- **Yes**
- **No**
- **Sometimes**

## Results

<b>YES</b>	<b>NO</b>	<b>SOMETIMES</b>
9 (28%)	5 (16%)	18 (56%)

## Analysis

**NO (5 out of 32=16%)**

- Average age of pouch- established 3-20 years
- 1 patient did not have an ileostomy with his pouch
- 100% of patients with a pre pouch ileostomy confirmed fatigue with their stoma but resolved with a pouch
- 30% of this group **do not** check bloods yearly
- Managed symptoms by resting

### YES (9 out of 32=28%)

- Average age of pouch 1-14 years
- 67% of pouch owners felt fatigued with their stoma, 22% felt fatigued some of the time, 11% had no stoma
- 89% of patients noticed constant fatigue within the first year
- 67% of this group **do not** check bloods yearly
- One patient thought that there was not much that could be done, others rest, slow down, sleep, re-hydrate or eat carbohydrates

### SOMETIMES (18 out of 32= 56%)

- Average age of pouch 4 months-24 years
- 28% felt fatigued with their stoma, 50% felt fatigued some of the time, 11% had no stoma or could not remember, 11% did not suffer fatigue
- 50% of this group **do not** check bloods yearly, however 22% did not answer the question
- Symptoms managed by rest (if evening), slowing down, sleep or re-hydration

### Main Reasons for Fatigue

- Multiple operations- the pouch procedure is usually performed in two or three operations
- Complications during operation- blood loss, dehydration, prolonged operating time, difficulties during operation, sepsis
- Infection or slow recovery post operation
- Menstrual cycle in women
- Stoma problems - high output

- Abnormal blood results – iron levels
- Pre existing conditions- diabetes, heart disease
- Severe colitis
- Psychological issues and expectations
- Pre-conceived ideas about recovery process
- Stress
- Returning to work

- Making up for lost time in hospital
- Children- trying for a family or looking after the one you have
- Over active pouch and other unresolved problems
- Disturbed sleep
- Dehydration

- Lifestyle- activities such as gym, social life
- Generally feeling better therefore taking on too much
- Being able to detect warning signs of fatigue before you start compensating
- Patient increased age
- Pouch increased age

## Possible Hypothesis from Audit

- The older your pouch is the more likely you are to become fatigued
- Most patients initially feel fatigued over time with either a stoma or a pouch
- Fatigue gets better with a pouch
- The more aware you are of your blood results the less likely you are to become fatigued

- Only 1 person thought nothing could be done to manage fatigue. Most patients know when they are fatigued and **REST**.



## FUTURE



- More research to be done on fatigue
- More awareness of the condition
- More education to patients and medical staff
- More support for patients who are concerned

## FAP Information Day

10 November 2007



How many of us have had an endoscopy without knowing how it really works? Most of us I would suggest.

However both patients and technophobes were able to solve some of the secrets of this medical mystery by testing their skills on a dummy patient at the St Mark's Polyposis Registry's third FAP Information Day on 10 November.

The demonstration which was organised by St Mark's consultant Ripple Man was one of the highlights of the day. Others included talks on 'Inner Beauty – a Tour around your Internal Organs' by Jo Rawlings, 'Surgical Choices for FAP' by Sue Clark and 'Genetics and Predictive Testing' by Dr Siobhan SenGupta.

Almost 100 patients, their families and friends attended workshops on such lively topics as Warren Hyer's 'Polyposis for Teenagers', Zarah Perry-Woodford's 'Polyposis and your Pouch' and a session on 'Peutz Jeghers Syndrome' by Registry director Kay Neale.

The event was organised by Kay Neale, RLG chairman and secretary, Mike and Margaret Dean, and members of the St Mark's Polyposis Registry.

# Is

# 26 April 2008 in your diary yet?

See page 3

## Why I'm Keeping Mum About FAP – For Now

When her husband died of cancer, Red Lion Group commmitte member Morag Gaherty had to bring up their two young sons knowing they too faced the risk of getting FAP. This is how she dealt with it.

Back in 1995, when we first became aware of Brian's condition, I vividly remember sitting in John Nicholls's Harley Street consulting rooms discussing the implications of FAP.

"It's more a question of when, rather than if, you get cancer," he told us, going on to explain how an ileo-anal pouch (removal of the colon and surgically fooling the body into thinking part of the intestine is the colon) would slow things down.

Of course, our first thought was for Brian's future, but hot on its heels was a second thought. What about potential children? FAP or familial adenomatous polyposis is genetically inherited, so we would have to make decisions about how to manage this at a generational level, not just for Brian. And the odds are quite high, at around 50:50 for a child of ours inheriting the mutant gene.

On the children front, we first decided to wait to see what Brian's post-surgical quality of life was. And it was largely unaffected by his FAP, if we ignored the extremely liquid and smelly poos!

We took the view that it was worth the risk of our having children. This is partly because of our attitude to life in general: eliminating the risk of FAP (ie by terminating a foetus with the gene) doesn't eliminate all risk. A child can still be killed by another disease or by a

freak accident. In fact all of life is a risk, and the best thing to do is to manage that risk, not try to control every vicissitude. It's why I let my children cross the road on their own, incidentally.

Also, children with a family risk of FAP are generally tested for polyps at around 14, as the polyps generally don't show before then (though this is not always the case).

A lot can happen in the medical field in 14 or more years - gene therapy or other solutions could easily be a reality by then. And, if not, Brian had proved that an ileo-anal pouch was always a viable option.

So, we took the view that having children was for us. We went ahead and had two boys in 1999 and 2000 (not quite as punishing a schedule as it sounds as they were 23 months apart, one at each end of the two-year period!).

Then, unexpectedly, Brian died of cancer in 2005 after only eight days of illness, though he had probably had it for around six months. I don't need to tell you what a shock it was to be left with a four- and six-year-old year old, albeit fortunately in a good financial position (my husband always managed his risks holistically, and thought about the finances as much as the medical issues).

And now, two years on, those original concerns about my children's future

are still just as valid. As I have tried to tell my mother-in-law, without alerting her to the familial risk she is currently oblivious to, it is far harder to lose your child than to lose your spouse, however close you were.

In a sense, I am lucky. The mutant gene in Brian's blood was never identified before he died and there is now no possibility of doing so. Had we known the faulty gene, I would have to live with the knowledge that at any moment I could find out if either of my children have FAP.

Or choose not to find out.

I have a friend for whom the subject of her seven-year-old son having FAP has been raised.

By nature, she is a control freak and so of course she wants to know whether or not he carries the gene. And she wants to know now.

I have tried to advise her to get genetic counselling before she takes this step, because she has no idea of the Pandora's Box she could be opening.

What if her son does have FAP? How will that affect their family dynamic, if she spends the rest of his childhood thinking he is about to drop dead?

It doesn't help that she has already come into contact with FAP, in the context of her friend's husband dying at 44. And that she is a pessimist at heart anyway. And what happens not only to her son's childhood but also that of his older sister?

Me, I'd much rather have a normal family life and address the subject at a later stage. Delay rather than deny. That's what we did with Brian: we knew he was likely to die of cancer and at a relatively early age (though we had no idea how early, and that might have changed our decision to have children), but we chose not to share that information with other people or to live our lives as if there is no tomorrow.

Because human beings can't easily do that. We are a resilient species, and living as if there is no tomorrow is only really viable if there genuinely is no tomorrow to speak of. It's not something you can keep up for an unspecified period. Not if you want to stay sane, anyway.

And there are other issues to con-



*On the right lines: many people would approve of the way Morag Gaherty, with sons Tom (left) and Bob, has coped with the genetic risks of FAP*

sider. In the case of my friend's son, he is too young to be tested definitively: polyps don't normally show up until teenagerhood anyway, so a gastroscopy would be both traumatic and probably futile. It would only be any use if it would definitely show polyps. Lack of them at this stage proves nothing.

And there is no family mutant gene to look for, as there is no family history - the suggestion of FAP has probably been raised because of other medical features which cumulatively may point to this: cysts on the body, flecks in the eye etc. But these features might equally be totally irrelevant and indicative of nothing serious.

I have to say, my personal opinion is that the doctor involved might be accused of frightening a family when there is nothing that can really be done at this stage.

Although, to be fair, he probably assumed they had never heard of FAP and so would not appreciate its seriousness.

For me, I'm glad that I am forced to wait until my children are teenagers, at which point we will have a gastroscopy. There are a number of benefits to this. First, they can have a normal childhood.

Also, the chance of a new medical option being available by then is quite high, possibly even avoiding a gastroscopy in the first place. And even if there is not, their grandparents will probably be dead by then, which will remove one of the stresses that would inevitably occur (you want to see anxiety in action? Meet my mother-in-law - she has barely slept in the two years since Brian died, and that's without knowing the familial risk).

If I have to draw a conclusion for the benefit of any families who have a familial disease of any kind, it is this: think carefully before you rush to get information and have genetic counselling first if it is available.

You need to know how you will deal with the information if it is bad news, and you can't undo the knowledge once you have it.

It's all very well if the condition is something that can be controlled or even eliminated, but it's a different matter entirely if you find out only to be unable to do anything except watch its progress.

As they say in the Scouts, Be Prepared.

## The Stressbuster

If you were to name the UK's most stressful jobs, working in a television news-room would be one of them. Red Lion member Patrick Kehoe is a technical coordinator with the leading news channel ITN. So a man all-too-used to handling daily news bulletins about earthquakes, air disasters and civil wars. Then Patrick had to deal with his own bit of human drama. Read his moving and upbeat account of how he took on ulcerative colitis and won. Sir Trevor McDonald would have been proud.



My name is Patrick Kehoe and I had surgery in three stages in 2003, resulting in removal of my colon and rectum and the creation of a J-pouch. I would like to tell the story of my experiences both as a tribute to the extraordinary skill and commitment of the colorectal surgeon Professor John Nicholls and the entire team at St Mark's Hospital, but also in the hope that my story may give some reassurance to those about to embark on a similar journey.

I'm well aware that not everyone has a successful or positive outcome post-surgery and I apologise if reading this makes that fact more painful but I do think it's important that the good stories also get told.

At age 24 (I am now 47), I was rushed to hospital, in terrible pain and bleeding, and was subsequently diagnosed with ulcerative colitis (UC). For the next 18 years, my UC was controlled by a combination of daily medication and courses of Prednisolone (oral and enema) every 18 months or so whenever I suffered an inevitable flare-up.

I was fortunate in that I was never hospitalised or even off work in those 18 years and I managed to work through the flare-ups until the Prednisolone eventually kicked in and stabilised the ulceration, pain and bleeding.

All that changed in the summer of 2002 when it flared up again but this time, after several months, the Prednisolone had no effect. I became more and more ill and was hospitalised in October 2002 and blasted with a succession of intravenous doses of everything from Prednisolone, to Azathioprine, antibiotics, enemas, the lot! After two weeks in hospital things had sort of (!) settled down.

I foolishly went straight back to work, which is in the newsroom at ITN, often very stressful work involving erratic and anti-social shifts. Within two weeks I was back in hospital and there began the horrible slide into serious ill-health. Nothing worked, I lost over three stone in weight and the pain and associated blood loss was terrible.

Then for the first time the 'surgery bomb-shell' was dropped. I never thought for one moment, until that

point, that I could possibly end up having my colon removed; however, by the end of 2002, it was clear that I had no choice.

Thanks to a great friend who is a GP, I learnt of the specialist work carried out at St Mark's Hospital and requested that my GP refer me there to Professor Nicholls (president of the Red Lion group).

My annus horribilis was 2003. I was admitted to St. Mark's in February, too ill for surgery, and given three blood transfusions in the hope that, after a week or so, I would be strong enough to have my colon and rectum removed. I'm not going to lie – it was not a pleasant experience. Often the removal and construction of the J-pouch are done as one surgery but, in my case, I was not well enough to risk the second part of the process. Although once the colon was removed my recovery was rapid and impressive.

I now had a stoma and a bag and I have to say I was very fortunate as I had no problems with the bag. I ate and drank literally everything, even things like nuts which I love, by the pound without any ill-effects, blockages etc. It was reassuring to find that I could live with an ileostomy and that, if I had to have a permanent one, it wouldn't be the end of the world. But for me reconstructive surgery was always my

preferred path.

Six months later, I went in for round two. I had a second major operation and the j-pouch was formed. Again, not a pleasant experience, but my recovery was text-book, and soon, apart from the inconvenience and slight anxiety that went with still having a bag, my life was starting to get back to normal. I even bought a push-bike for the first time in 20-odd years, and hit the road – bag and all!

I also went back to work on a part-time basis between surgeries with the support and understanding of my employer and work colleagues. In December 2003, I had the third and final stage of the pouch operation.

Compared to the first two, this one was a doddle! Plus – I had the elation of having the stoma closed up and no longer needing the bag.

Since then I have never looked back. I have taken no medication at all since the first surgery, apart from a few sachets of Dioralyte and some Loperamide capsules if I'm on holiday in a very hot country and doing a lot of physical exercise, walking etc. After my first week back at work I stopped carrying a spare pair of (just-in-case) underwear. I also don't carry wipes or barrier cream with me and only use these at home in the morning and evening, without any ill-effects.

Fortunately, I have no anxiety or issues with continence though I do have occasional urgencies but never – so far – to a degree that I feel I'm not in control.

Since my surgery, I have holidayed in places as diverse as Cuba, Central America, Laos and in recent weeks, Tunisia and Libya, without any issue at all. Ironically, I seem to have a cast-iron constitution while in these countries, while many around me succumb to food poisoning and it's associated horrors. I do watch out for certain foods and ice and salads are a no-no. I walk for miles, I cycle, I swim, I eat and drink everything from curry to coconut, indiscriminately, just as I always have, and generally live a normal life.

I do go to the loo more often than I used to, although I don't count the number times or fret about it. I do get up once and sometimes twice in the night, breaking my sleep, and I am aware that I feel more tired than I used to, but as far as I'm concerned – I act as if I still have a colon.

Finally, I have to say that through all of the above my recovery was hugely aided by the support and prayers of a fantastic family and friends, and most especially, by my wonderful partner of 26 years, Colin, who's extraordinary strength and support got me through the darkest hours.

## The Lap(-Top) of Luxury



Here in all its glory is the lap-top donated to the St Mark's pouch and stomacare departments by the Red Lion group. The presentation was made by Red Lion secretary Margaret Dean (far right) to pouch support nurse Zarah Perry-Woodford (far left) and stomacare nurses Rebecca Slater (second left) and Sarah Varma (second right).

"We are all really chuffed as it's an ideal teaching tool. It will enable us to store valuable data, hold presentations and provide back-up for our latest diet, exercise and health products campaign," said Zarah.

## Letters

*Dear Christopher*

In answer to Heather Pearton's "Absorbing Stuff" (summer *Roar!*), I had my pouch made in 1983/1984. My life dramatically improved and I lived on a normal, good home-cooked diet with almost no exclusions. After about fifteen years or so it was mentioned by one of the nurses at an Information Day that we should have an annual blood test to check adequate absorption. Anyone enjoying a "normal healthy diet" gets all the vitamins needed from their food and there is generally no need to take supplements.

The blood test is: full blood count (I don't know exactly what that checks); urea; electrolyte; folate and B12. About two years ago my test showed that my B12 was low (I didn't feel any ill-effects) but now I go to my practice nurse every three months for a B12 injection.



When nurse specialists were introduced, one or two of those at St Mark's published pamphlets on topics like this. Maybe one of them could add this information to a diet advice sheet to be given to every patient.

Remember too that our GPs have to have a wide range of knowledge about many different conditions and it's hardly surprising that sometimes we know a little bit more about some aspects of our condition than they do, so don't be too hard on them.

*Best wishes  
Bob Gordon  
Uxbridge  
Kent*

*Dear Roar!*

A few years ago I wrote an article for *Roar!* on Uterine Artery Embolisation (UAE). I was hopeful that this procedure would, by cutting off the blood supply, rid me of a large fibroid which was at the back of the womb.

Unfortunately, as an MRI scan revealed, the first embolisation did not work at all. This was followed a couple of years later by a second UAE procedure. This time the blood supply has been stopped and the fibroid has reduced by approximately 50% in volume but is still the size of a tangerine and still causing me pain and other problems.

My gynaecologist has told me that now the blood supply has been stopped and that considerable time has passed since the operation, the fibroid will stay

the size it is. For anyone who has not had extensive bowel operations the next step would be a hysterectomy. He however said he would not attempt to perform this on me as I would no doubt have adhesions joining the bowel to the womb and it would be, in his words, a life-threatening operation.

At this year's Information Day I asked the question 'Is it advisable for people with pouches to have a hysterectomy?' The answer which was published in the summer edition of *Roar!* was not encouraging so it would seem wise for me not to pursue that route.

I wondered if any other readers have fibroid problems and whether they have come across any procedures other than embolisation or hysterectomy? I would really appreciate it if they could contact me either through *Roar* or via email [sathelen@yahoo.co.uk](mailto:sathelen@yahoo.co.uk).

Congratulations on the summer edition of *Roar!*. It contained some really useful articles.

*Kind regards  
Sally Thelen*

*Dear Roar!*

I am desperate to ask whether anyone has suffered from inflammation in the distal (the last part of the bowel) following J-pouch surgery. Does anyone know what can be done?

Please help me or if you can be of any help! My e-mail address is [rochellefreilich@gmail.com](mailto:rochellefreilich@gmail.com).

*Rachel Freilich*

## Not So New Kid on the Block

Although St Mark's consultant colorectal surgeon Sue Clark needs very little introduction, we thought we'd give her a warm – albeit belated – welcome in *Roar!*

When Sue Clark replaced Professor John Nicholls as a consultant surgeon in March 2006, she was by no means a newcomer to St Mark's. From 1995 to 1997 Sue spent two years as a research fellow at the hospital's polyposis registry and colorectal cancer unit. After a five-year spell of higher surgical training in the South West Thames region, Sue returned to St Mark's in 2002 for the last year of her training.

Sue's next post was in the polyposis registry and pouch unit at Mount Sinai Hospital, Toronto, Canada, a hospital with very strong links to St Mark's. She

also paid regular visits to the world-famous Mayo Clinic in Rochester, Minnesota, USA.

Back in the UK, Sue spent almost three years as a consultant colorectal surgeon at the Royal London Hospital setting up a family cancer clinic for patients with FAP and other inherited cancer syndromes. She also performed regular pouch and keyhole surgery at the Royal London.

Now as well as continuing Professor Nicholls's work she is assistant director of the St Mark's polyposis registry.



## About a Bowel

How much do you know about your insides? In this article, taken from the on-line encyclopedia *Wikipedia*, we take a closer look at the workings of the intestines and find that they can indeed move in mysterious ways.

In anatomy, the intestine is the segment of the alimentary canal extending from the stomach to the anus and, in humans and other mammals, consists of two segments, the small intestine and the large intestine. In humans, the small intestine is further subdivided into the duodenum, jejunum and ileum while the large intestine is subdivided into the cecum and colon.

### Structure and Function

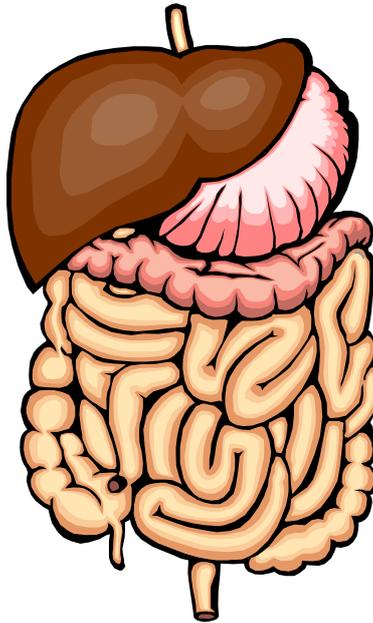
The intestinal tract can be broadly divided into two different parts, the small and large intestine. Grayish-purple in color and about 35 mm (1.5 inches) in diameter, the small intestine is the first and longest, measuring 6 metres (20 feet) long average in an adult man. Shorter and relatively stockier, the large intestine is a dark reddish color, measuring roughly 1.5 meters (5 feet) long on average. Both intestines share a general structure with the whole gut, and are composed of several layers.

The lumen is the cavity where digested material passes through and from where nutrients are absorbed. Along the whole length of the gut in the glandular epithelium are goblet cells. These secrete mucus which lubricates the passage of food along and protects it from digestive enzymes. Villi are folds in the mucosa and increase the overall surface area of the intestine while also containing a lacteal, which is connected to the lymph system and aids in the removal of lipids and tissue fluid from the blood supply. Microvilli are present on the epithelium of a villus and further increase the surface area over which absorption can take place.

The next layer is the muscularis mucosa which is made of smooth muscle that aids in the action of continued peristalsis along the gut. The submucosa contains nerves, blood vessels and elastic fibre with collagen that stretches with increased capacity but maintains the shape of the intestine. Surrounding this is the muscularis externa which comprises longitudinal and smooth muscle that again helps with continued peristalsis and the movement of digested material out of and along the gut.

Lastly there is the serosa which is made up of loose connective tissue and coated in mucus so as to prevent friction damage from the intestine rubbing against other tissue. Holding all this in place are the mesenteries which suspend the intestine in the abdominal cavity and stop it being disturbed when a person is physically active.

The large intestine hosts several kinds of bacteria that deal with molecules the human body is not able to breakdown itself. This is an example of symbiosis. These bacteria also account for the production of gases inside our intestine. However the large intestine is mainly concerned with the absorption of water from digested material (which is regulated by the hypothalamus), the reabsorption of sodium, as well as any nutrients that may have escaped primary digestion in the ileum.



### Diseases

- Gastroenteritis is inflammation of the intestines and is the most common disease of the intestines.
- Ileus is a blockage of the intestines.
- Ileitis is an inflammation of the ileum.
- Colitis is an inflammation of the large intestine.
- Appendicitis is inflammation of the vermiform appendix located at the cecum. This is a potentially fatal disease if left untreated; most cases

of appendicitis require surgical intervention.

- Coeliac disease is a common form of malabsorption, affecting up to 1% of people of northern European descent. Allergy to gluten proteins, found in wheat, barley and rye, causes villous atrophy in the small intestine. Life-long dietary avoidance of these foodstuffs in a gluten-free diet is the only treatment.
- Crohn's disease and ulcerative colitis are examples of inflammatory bowel disease. While Crohn's can affect the entire gastrointestinal tract, ulcerative colitis is limited to the large intestine. Crohn's disease is widely regarded as an autoimmune disease. Although ulcerative colitis is often treated as though it were an autoimmune disease, there is no consensus that it actually is such.
- Enteroviruses, named after their transmission-route through the intestine (enteric means related to intestine), are not normally associated with the intestine.

### Disorders

Irritable bowel syndrome is the most common functional disorder of the intestine. Functional constipation and chronic functional abdominal pain are other disorders of the intestine that have physiological causes, but do not have identifiable structural, chemical, or infectious pathologies. They are aberrations of normal bowel function but not diseases.

Diverticular disease is a condition that is very common in older people in industrialized countries. It usually affects the large intestine but has been known to affect the small intestine as well. Diverticular disease occurs when pouches form on the intestinal wall. Once the pouches become inflamed it is known as Diverticulitis, (or Diverticular disease.)

Endometriosis can affect the intestines, with similar symptoms and is a comparatively rare event (usually developing sometime after major bowel surgery). It is, however, hard to diagnose correctly, and if left uncorrected can lead to bowel infarction and death.



Red Lion Group

**RED LION GROUP**  
**ANNUAL GENERAL MEETING AND INFORMATION DAY**  
**SATURDAY, 26 APRIL 2008**  
**Himsworth Hall, Education Centre**  
**St Mark's Hospital, Northwick Park,**  
**Watford Road, Harrow, Middx HA1 3UJ**

## PROGRAMME

9.30 – 10.00	Registration and coffee		
10.00 – 10.15	Welcome/nomination forms		Mike Dean
10.15 – 10.45	<b><u>Seminar One</u></b> Evolution of the ileo-anal pouch		Prof. John Nicholls, Consultant Colorectal Surgeon
10.45-11.30	<b><u>Seminar Two</u></b> How I learned to love my pouch – most of the time		Virginia Ironside Well-known agony aunt and national newspaper columnist
11.30-12.30	<b><u>Seminar Three</u></b> The Brains Trust (Questions & Answers)		Miss Sue Clark – Colorectal Surgeon – St Mark's, and Dr Simon McLaughlin Research Fellow St Mark's Stoma care (speaker to be confirmed)
12.30-12.45	Red Lion Annual General Meeting		
12.45–13.30	<b>Break for lunch</b> – Coffee will also be served during the lunch break. Lunch and light refreshments can be obtained from the restaurant in Northwick Park Hospital.		
13.30-13.45	<b>Raffle Prize Draw</b>		
13.45 – 14.30	<b><u>Seminar Four</u></b> Surgical overview of pouch surgery		Miss Sue Clark – Colorectal Surgeon – St Mark's
14.30– 15.15	<b>Workshop 1a</b> Fertility and Pouches Miss Julie Cornish (Registrar General Surgery)	<b>Workshop 1b</b> Problem pouches and diet  Stoma care (speaker to be confirmed)	<b>Workshop 1c</b> Pouchitis diagnosis and management  Dr Simon McLaughlin Research Fellow St Mark's
15.15 –16.00	<b>Workshop 2a</b> Open Forum Female Pouch Owners Lorraine Howell	<b>Workshop 2b</b> Open Forum Male Pouch Owners Christopher Browne	<b>Workshop 2c</b> Open Forum Pouch Partners Mike Dean
16.00 – 16.15	Closing remarks		Mike Dean

## Why Roar! Missed Christmas

You may be wondering why this issue of *Roar!* is the 'New Year 2008' edition and not the 'Christmas 2007' edition that should have arrived on your doormat with your Christmas cards. Alas, I have to confess that I, the newsletter layout editor am to blame! While Chris made a valiant effort to send me the content in time to get the newsletter prepared and sent to the printers in time for Christmas I'm afraid that a series of misfortunes prevented me from doing so.

First of all there was the usual pre-Christmas cold. Another weekend was taken up with the christening of my new son, William (see picture) who was born in May. I had earmarked the weekend after that to polish off *Roar!* but unfortunately William had other ideas. The poor boy was afflicted with a nasty bout of bronchiolitis which required a stay of several days in hospital. This was a precaution allowing hospital staff to monitor his oxygen levels and be ready to apply a feeding tube if needed (one of the hazards of bronchiolitis in babies is that they go off their food and milk and end up dehydrated, something that can be life-threatening at that age). Fortunately, being a robust six month old baby William was well again after a few days, but poor old Mum needed special attention having spent two nights in a noisy hospital ward at his side. It seems that the bronchiolitis season runs from November to March each year, and nearly all children under four suffer from it at least once (although only a few need to be admitted to hospital).

One of the more amazing gadgets I saw in hospital (which I'm sure hadn't been invented when I was last in hospital for my pouch closure in 1992) was a device which shines a strong red light through the skin of the toe and then analyses the take-up of oxygen by the haemoglobin in the blood. This was taped to William's foot and as he wheezed and coughed, a read-out showed whether he was getting enough oxygen. Had it dropped below 90% or so, staff were ready to give him a helping hand with an oxygen mask. This is the kind of medical device I'm sure Dr McCoy would have been proud of using on the *Starship Enterprise*.

Once William had made a full recovery we were in the full throes of

Christmas and I had missed my deadline. New Year was spent on the Isle of Wight with friends, so it was not until January that I was able to finish off *Roar!* (interrupted by a dose of what could have been norovirus, but was probably simply gastric man flu). Anyway, I hope you enjoy reading this issue of *Roar!* even without the mulled wine and mince pies.

*Tim Rogers*



## Please support the Red Lion Group

Registered Charity number 1068124



All donations, however small, towards expanding the work of the group will be gratefully received. If you would like to send a donation please make your cheque payable to The Red Lion Group. And send it to: **The Red Lion Group Treasurer, Mrs Marjorie Watts, 11 Meadow Way, Upminster, Essex, RM14 3AA**

## Contact the Red Lion Group

### CHAIR

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

### VICE-CHAIR AND NEWSLETTER EDITOR (CONTENT)

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

### SECRETARY

Margaret Dean  
Address, and home telephone  
number as for Chair.  
secretary@redliongroup.org

### NOTES SECRETARY

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

### TREASURER

Marjorie Watts  
11 Meadow Way  
Upminster  
Essex  
RM14 3AA  
Tel: 01708 445199  
treasurer@redliongroup.org

### LIAISON OFFICER

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

### CLINICAL NURSE SPECIALIST

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

### NEWSLETTER EDITOR (LAYOUT)

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

### PRESS OFFICER

Stephanie Zinser  
Tel: 01932 867474  
Fax: 01932 867444  
pr@redliongroup.org

### EX-OFFICIO

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

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

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

### PRESIDENT

Professor John Nicholls

### PATRON

Claire Rayner

## Join the Red Lion Group

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

Visit Our Website

[www.redliongroup.org](http://www.redliongroup.org)

## Write for Roar!

### Ideas, Ideas, Ideas and More Ideas

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

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

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

That way we can keep your newsletter bursting with life and information and make reading about pouch issues fun and stimulating.

Please send your articles, letters and ideas to:

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

or  
cbrowne@brownemedia.co.uk

