

ROAR!

ISSUE 51 • SUMMER 2016

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 David Skinner on 01708 455194 or by e-mail at liaison@redliongroup.org.

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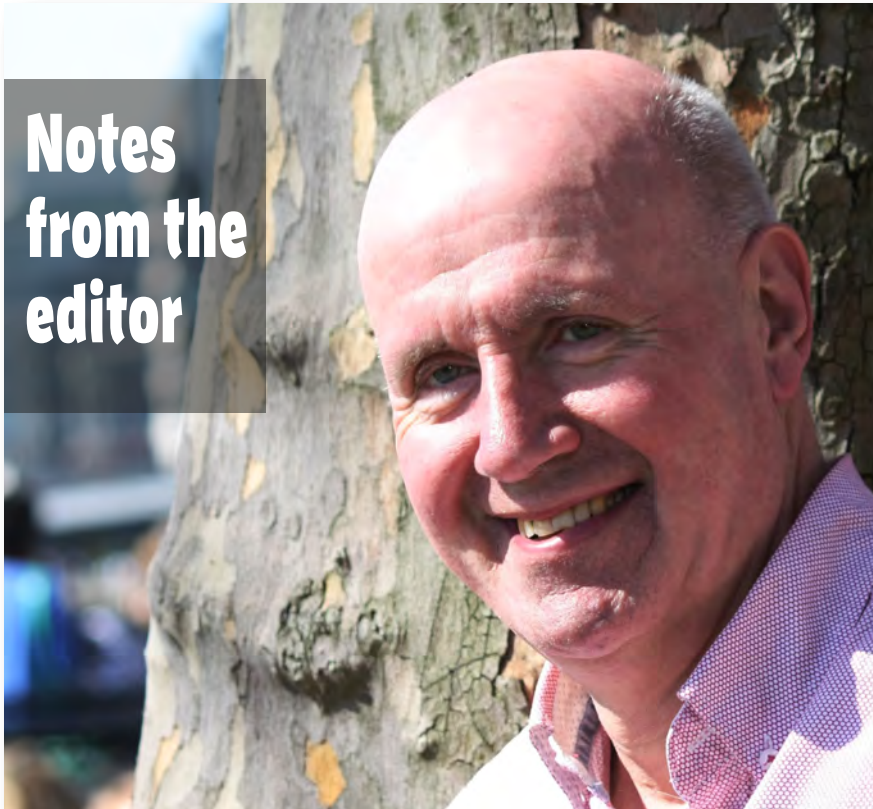
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All donations, however small,
towards expanding the work of the
group will be gratefully received. If you
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Lion Group and send it to: **The Red
Lion Group Treasurer, Paul Mulot,
103 Whitehill Road, Hitchin, SG4 9HT.**

Notes from the editor



You couldn't make it up! Once again the May sunshine beamed down on 60 plus Red Lion members, families and health professionals at this year's Information Day at St Mark's Hospital. It seems to happen every year and adds some welcome summer lustre to the day.

It turned out to be a special day in other ways too. Ably planned and organised by outgoing Chair Lisa Allison, the day started with an enlightening history of the pouch by our patron, Professor John Nicholls. The talks that followed were both varied and topical. Two research fellows who recently joined St Mark's, Mr Guy Worley and Dr Jonathan Segal, discussed key projects into the surgical control of uc and coping with pouchitis – both of which were aided by an £8,000 donation from RLG. You will soon be able to read the transcripts of these talks on the website (www.redlion-group.org).

Do you suffer from poor posture and/or frequency? If you do, you'll be encouraged by the tips and advice from committee member and professional physiotherapist Theresa Parr on pages 7 to 8 of this issue. As

Theresa reveals in the article and her Information Day talk, pelvic floor exercises and posture are much more than just catchy phrases favoured by fitness gurus.

Another health issue raised during the Information Day workshops was how to treat the various skin irritations and ailments suffered by both men and women after pouch surgery. There seem to be no clear answers to this, so if you have any ideas or pet formulas you would like to pass on please write to

Roar! (cbrowne@brownmedia.co.uk) so we can include them in the next issue.

To continue our medical theme, one of the

more startling findings of the past year was RLG secretary Sarah Bowes-Phipps's discovery of clear hereditary links in some uc and Crohn's sufferers. To find out more read her very moving and insightful article on pages 11 and 12. It's probably one of the first cases of authentic medical research by a Red Lion member and certainly a scoop for Roar!

But Red Lion members' exploits don't end there. We've the story of a marathon man with a difference who overcame a series of medical

crises while he waited...and waited ...and waited for his pouch operation (pages 4-6) and the Red Lion Group's very own version of Iron Man 3 – the mind-boggling fundraising feats of our new Chair David Davies (page 13).

And where better than Facebook to tell your pals and colleagues about these types of experience which, dear readers, you can now enjoy doing! For thanks to Sarah B-P we have our own Red Lion Group Facebook page. Co-editor Tim Rogers tells you more about the site and how you can join it on page 8.

And finally please join me in extending a very big thank-you to Lisa for her warm, efficient and hands-on stewardship of the group for the last four years – how time flies.

Happily, though, Lisa is staying on the committee as our Hospital Liaison. Her successor is Mr Iron Man and we wish you a very successful tenure David!

• Some of you will remember John White who was treasurer and a member of the RLG committee for many years. Sadly John, who lived in Camberley, Surrey passed away in March this year. The Red Lion Group wishes our condolences to his nearest of kin.

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redliongroup.org

Browse nearly every copy of Roar! that has ever been published (including issue 1 from 1994) at redliongroup.org/roar

For on-line support and advice from other members or to share your views about any aspect of life with a pouch, please visit our on-line discussion forum at:

redliongroup.org/talk

We've the story
of a marathon
man with a
difference

Winning a marathon the John Weight way

The Red Lion member's operation at St Mark's Hospital was confirmed and booked. Now all he had to do was wait for his admission date. What could possibly go wrong? Quite a lot, it seems

Twenty-six years on and it's "no colon and still rollin'" to echo Laura Quigley's moving account in the Autumn 2015 issue of Roar! My two-stage operation happened a long time ago and I've been meaning to write a 'pouch story so far' article for Roar! for some time – so now that I've retired, here goes.

It all started in 1979 when I was diagnosed with uc, or was it Crohn's? It took doctors 10 years to decide before they erred on the side of ulcerative colitis in all probability. My bowel healthcare problem had been getting progressively worse. I was down to 9st 4lbs and a daily dose of steroids was not having any apparently beneficial effect.

Surgery was suggested several times but a colostomy bag for an active young man was not an acceptable option for me.

In 1988, I was referred by my local consultant to Central Middlesex Hospital for an in-depth internal examination. At the end of my stay the specialist consultant came to my bedside and told me that my large bowel lining was showing signs of dysplasia (a pre-cancerous stage) and that surgery was now very strongly recommended.

I was stunned but I still expressed my reluctance to go down this path. However, he went on to tell me of a relatively new surgical procedure involving the formation of an internal 'pouch' instead of the traditional colostomy bag. This seemed too good to be true. He asked me if I would agree to a referral to the consultant surgeon John Nicholls at St Mark's Hospital, then based in London's City Road. He was the pioneer of this technique who later became a professor and, of course, a patron of the Red Lion Group.

Several months passed before I travelled to City Road to meet Mr Nicholls. He was very direct in his approach and very thorough in detailing the surgical procedure involved supported by some freehand sketches – a wondrous piece of re-



John Weight feeling on top of the world at Plateau Rosa in Zermatt, the famous Swiss ski resort

plumbing and not without risks that he was also careful to explain.

Statistics at the time recorded a 1 in 10 chance of failure – an acceptable risk I thought, not that I had much choice now so an inpatient stay was booked for the stage one operation – a colostomy and the construction of a 'J' pouch. The stage two closure would follow two months later. I could just about cope with that!

My employer agreed to give me four months' paid leave so all I had to do now was wait.

My first inpatient booking was postponed so all plans and arrangements had to be stood down – which meant another long wait.

Felled by a parasite

In the meantime, I thought I would spend a weekend in Oxford visiting friends and taking my mind off the impending ordeal and perhaps enjoying a curry and a few beers. Unfortunately, it was not the curry that put me back in hospital again but the cryptosporidium parasite that was piped in that weekend from Farmoor Reservoir that supplies Oxford's water.

The news bulletin at the time advised children and the elderly to take extra care as the "parasite can cause gastrointestinal illness with diarrhoea in humans".

So for someone like me with uc it was a disaster!

I spent two weeks in High Wycombe General Hospital on 40mg of intravenous prednisolone before my condition was brought under control. Once back on my feet and feeling better I returned to Oxford – this time to include a light game of tennis. But it wasn't long before the ambulance was on court – I had ruptured my left Achilles tendon!

I put this rather unfortunate accident down to the fact that my muscles and tendons must have been weakened by the earlier high doses of corticosteroids.

So, off to Oxford's John Radcliffe Hospital (JR) for a knee-high plaster cast with an embedded high heel to reduce the strain on the tendon. It would be some months before this would be removed and my rescheduled bowel operation was only a few weeks away!

A colon-free future

The taxi arrived alongside the entrance steps to St Mark's Hospital. The driver jumped out and opened the rear door for me as if this was a celebrity arrival – get me out of here! I struggled to extract myself from the rear of the taxi holding a pair of aluminium crutches loaned by the JR. Once afoot there was no stopping me as I hopped up the entrance steps. There was no going back!

The pre-admission nurse looked a little perplexed. I tried to pretend this was just another routine hospital visit – I'm a regular now, well into double figures since the start of my UC. She filled in the requisite pre-admission forms and checks and then disappeared. Half an hour later she returned – "I've spoken to the surgical team and they can rig up a hoist for your [plastered] leg". It seemed like a marathon getting this far but I was 'in' and Mr Nicholls would very soon be scrubbing up.

And so it came to pass that I slowly emerged into a new world without a colon, a tummy with a railway track of staples down the middle and tubes coming out of every orifice! "Are you awake Mr Weight – would you like a sip of water"?

Within hours I was being escorted around the ward with one crutch and a saline drip instead of the other to avoid any risk of deep vein thrombosis.

My progress was good and I was discharged after two weeks with ample supplies of colostomy bags and stoma templates. I bought a pair of high-waisted trousers to make life a little more comfortable. The promised two-month wait for the return leg became three before I was finally booked in for the closure. At last I would be 'normal' again, all joined up and no plastered leg encumbrance this time.

The next 10 days in St Mark's passed fairly quickly – getting used to my new bowel configuration and getting fit again by walking up and down the stairs to the courtyard garden as often as I could with the occasional loo stop. The nursing staff omitted to tell me about the pouch stool acidity caused by the residual gastric acid so I was a little sore initially. The acidity would have been neutralised by my large bowel had it been present. So this was the time that meticulous cleanliness and barrier creams entered my life.

Two months after being discharged and I was back for a post-op review. I had been getting leakages, typically when out shopping. My pouch output seemed quite fluid. The consultant thought I might have pouchitis and prescribed 500mg Metronidazole suppositories. I have been on them ever since – over 26 years. Without them I simply could not survive.

For years now I have been using two to three suppositories a week on average – they seem to keep the inflammation in check even though repeated use of antibiotics is generally not recommended. Some years later another consultant suggested a two-week blitz of Ciprofloxacin and Metronidazole tablets to completely remove the inflammation rather than maintain it at a low level. However, within five days of completing this regimen the pouchitis had returned.

Stretched on a wooden door

For the first 10 years of living with my pouch I was not troubled with it at all. I put weight back on, I travelled all around the world, played football, windsurfed, skied and swam – life was back on the fast track save for a few unpleasant derailments – the dreaded adhesions and attendant

agonising bowel blockages.

Most times these would sort themselves out within a few hours or overnight. However, on four occasions a hospital inpatient stay was necessary – twice in Luton, once in Walsall and once in Male in the Maldives. The Walsall stay was the scariest – no bowel movement for seven days. The surgeon was seriously considering operating when suddenly there was some movement. I think it must have been the onset of panic. I can't say how happy I was to get out of there unscathed!

The Maldives experience does merit some mention as the costs were covered by a Red Lion Group recommended insurer at the time. The episode occurred the day before we were due to leave Komandoo Island to return to the UK. After a night of severe colicky tummy pain my wife called the island resort reception for a doctor. The nearest was stationed on a larger island nearby, a 30-minute high-speed motorboat away. On arrival the doctor administered some painkillers and muscle-relaxing medication and arranged for a transfer to a hospital in Male.

I had to go back on the motorboat with the doctor to the neighbouring island where I would catch the scheduled seaplane flight to Male, the capital city. My wife frantically packed our suitcases while I looked on helplessly. Four of the resort staff turned up with a wooden door that had just been removed from its hinges – this was the best they could do for a stretcher! – I was loaded on board and lugged along the sandy track through the palm trees to the jetty, stopping along the way for each of the bearers to change corners and swap load-bearing arms. Overhead the sun burned down both blinding and cooking me on this makeshift hotplate. By the time we reached the jetty the colicky pains had returned. I was carefully laid down to rest while my wife settled the hotel bill and the boat was prepared for departure.

I don't remember much about the sea or air journey to Male, just the acute pain and the concerned faces of helpers and onlookers. At the airport, a water taxi and then an ambulance ride got me to the allotted hospital. I was put on a drip and given some more medication and

allocated to a room with two single examination beds but no bedding. My wife checked in at a nearby four-star hotel – the one the BA pilots used as it turned out.

By 5pm that day my bowels started moving again and I began to feel a lot better, even so I had to spend the night at the hospital for observation. The other spare bed in my room was in continual use with the coming and going of local patients and their families – I think it must have been an A&E side ward. At one time a pregnant woman was there with an extended family of about eight people. It wasn't possible to get any sleep until about 1am when everyone had eventually filtered away into the night.

The next morning I needed to get discharged quickly – as there

was every possibility I could still catch my 10:00am BA flight home and return to the original holiday schedule. A young man from a local travel service company that our tour operator used to facilitate the transfer of its clients to and from the outlying islands turned up early to help me with my discharge. He had visited me in hospital the night before and was thus au fait with my predicament. He was an absolute star – helping with the discharge process, arranging the preparation of my hospital bill and getting the medical report written up for my insurer – and all before 9:00am! A truly amazing achievement!

I grabbed all the paperwork and ran with my supporter to a waiting cab. My wife was there with our luggage in the boot. We rushed to the

airport and ran to the BA check-in desk. They were waiting to rush me through as my wife had chatted up the BA pilots the night before and explained my predicament.

I got to my seat and looked around at all the people meticulously stowing away their hand luggage as if nothing had happened. I had just travelled through some seemingly highly eventful time-warped journey and been deposited in seat 36B. "Did you enjoy your holiday," asked the lady seated on the aisle side of me. "Beautiful place, lovely people," I recounted – "still, it will be good to get home".

Since that day all has been well, touch wood. No further adhesions and no flare-ups. It has been an eventful marathon – 26 years rather than miles and I'm still rollin' along!

FASCINATING FACTS

- St Mark's Hospital Foundation raised £2 million – some of it from RLG – in 2015 towards life-saving research
- 50,000 people with bowel disease are treated at St Mark's every year
- There are currently 40 research projects at St Mark's developing new treatments to save lives and restore the quality of life
- Thirty-two world-leading gastro surgeons and gastroenterologists and 322 dedicated medical and research staff work 24/7 treating patients and saving lives at St. Mark's Hospital
- St Mark's is the number one specialist bowel disease hospital in the world.

Pouches, posture and pelvic floors

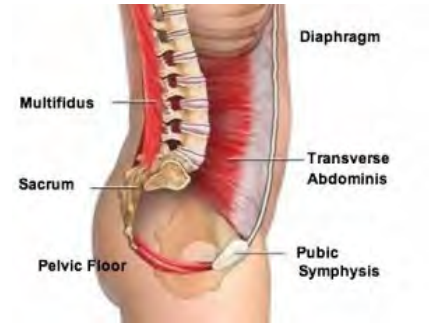
Red Lion committee member and physiotherapist Theresa Parr gave a hands-on Information Day talk on posture, interacting with her audience to show how exercises can help improve pouch control. Here is a summary of her talk.

Theresa started her talk “Postures and pouches” by telling Red Lion members and friends how she has been using pelvic floor exercises since she was a student. She said she was ‘pleasantly surprised’ how quickly the exercises helped her regain pelvic floor control after her pouch closure.

Using a diagram (see below) she then explained how a person’s posture can affect their pelvic floor.

ably knew the basics of pelvic floor exercises, Theresa said that “as a reminder, you should feel as though you are squeezing as tightly as possible around the vagina and anus if you are a woman or feel your testicles lifting if you are a man.

It can help to imagine that you are picking up a coin with your bottom. Hold for five seconds, relax for 10 seconds then repeat. Try to repeat the exercise five times in a row, five

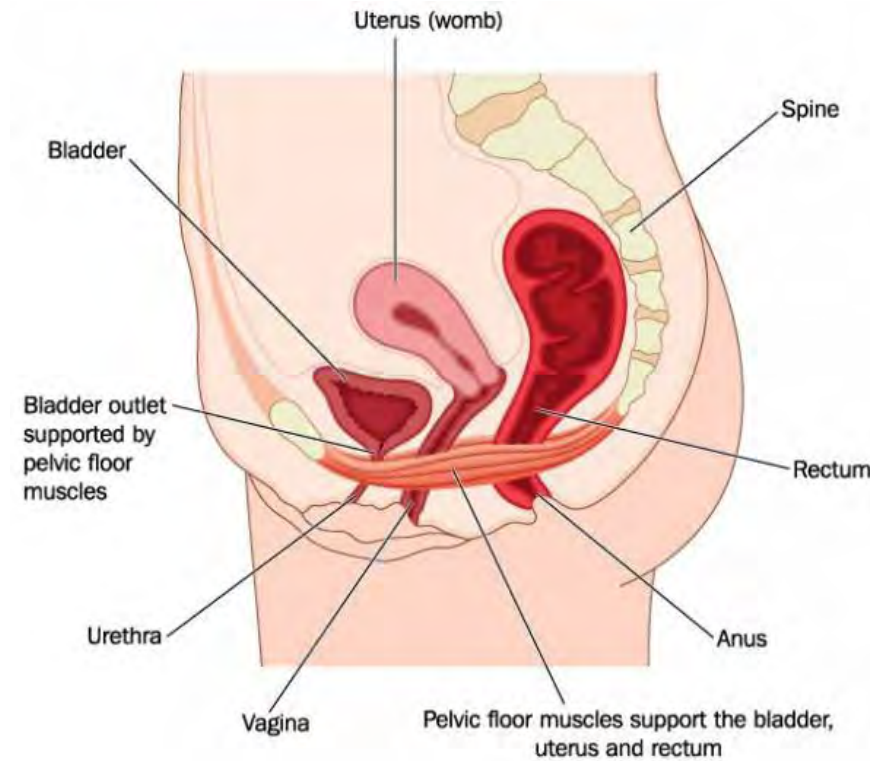


easily is to sit on the toilet with your knees higher than your hips, leaning forwards and bulging your abdomen out. “The process tilts the pelvis forward and so helps to open the pelvic floor which makes it easier to open your pouch,” she said.

Good posture was another important way to help support pouch control, said Theresa.

“As with pelvic floor exercises, it is important to do postural exercises regularly and frequently,” she said. “If you do them religiously, they will become part of your normal way of life. Eventually, you won’t even have to think about doing them as you will be doing them automatically but that does take time, effort and commitment initially.”

The exercises won’t be the answer to every poorly functioning pouch, she said, “however it can make it easier to achieve good muscular control of the pelvic floor which helps to reduce leakage and control urgency and frequency, so making many everyday situations easier. Hopefully, your back may also feel happier.”



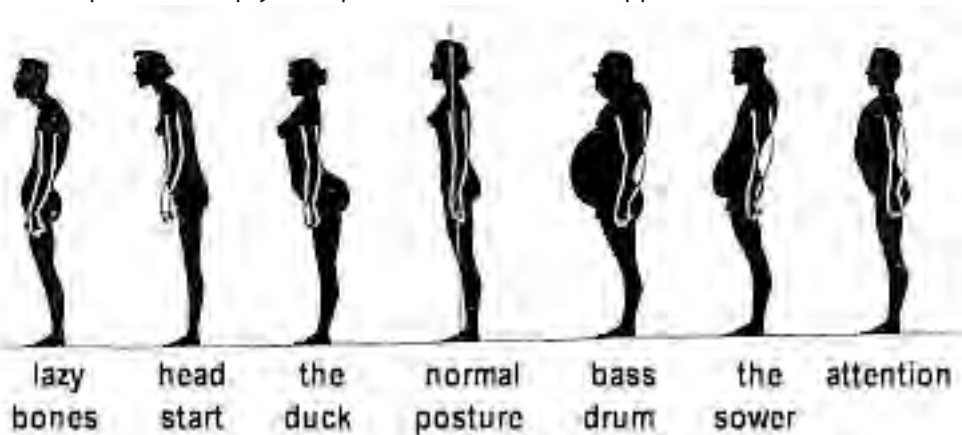
As the diagram shows, the trunk forms a cylinder with the spine and its muscles at the back, and the diaphragm – the large breathing muscle – at the top (see diagram above, left). At the front of the cylinder is the abdominal wall which holds the stomach muscles, while underneath is the pelvic floor. All these areas are interconnected.

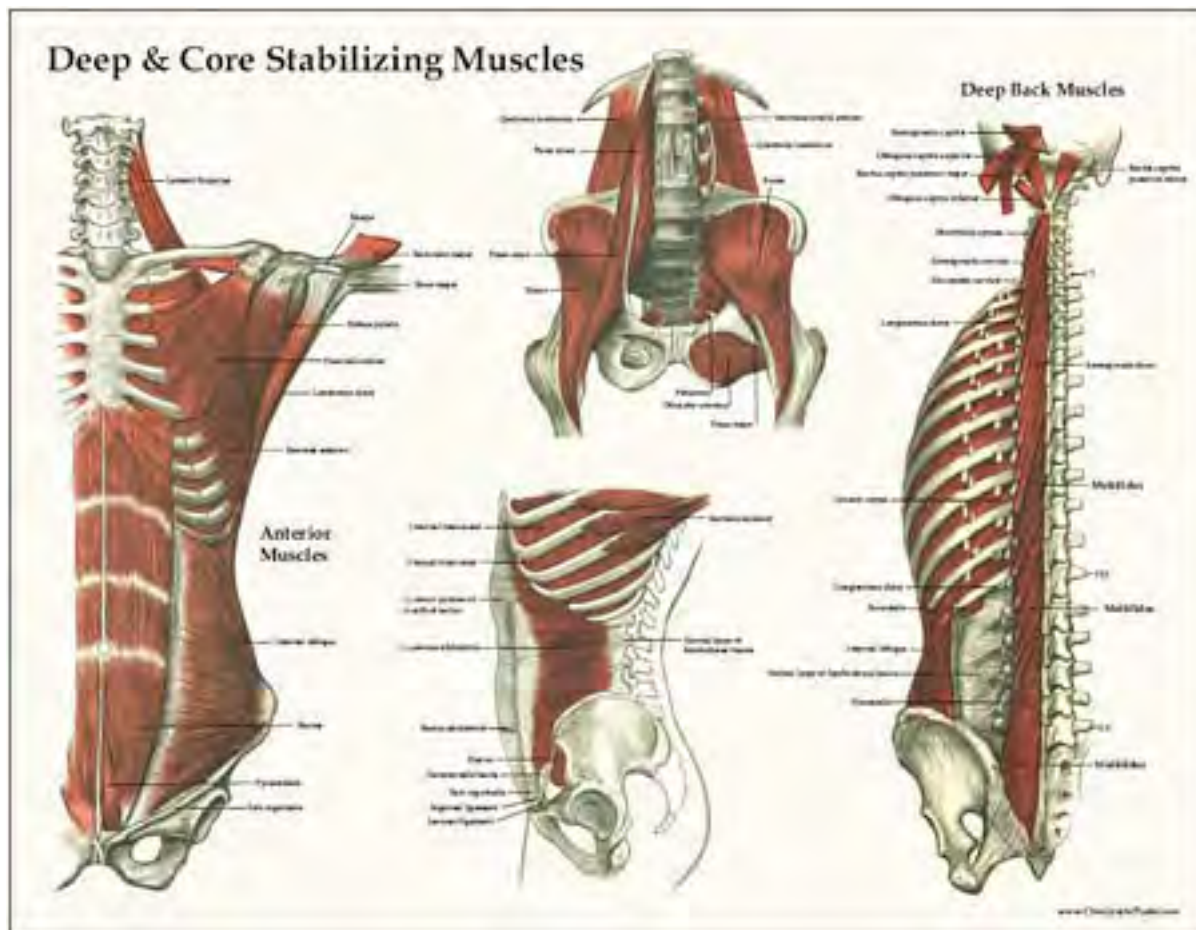
The abdominal wall and the back muscles are made of superficial and deep muscles. The superficial ones move the trunk while the deep ones help to maintain good posture.

Though most people prob-

times a day and incorporate them into everyday activities,” she said.

Another technique that helps patients’ empty their pouches more





However, every person's back and pouch are different, she observed. "If you are struggling with any of the exercises or they are making you worse, then please discuss the matter with your pouch nurse, continence specialist or physiotherapist."

Ironically "many serious athletes with a wonderful six-pack can still have poor postural control because they do not use the deep transversus abdominis muscle that lies beneath this layer and which helps to give the body core stability. Conversely, less athletic people can have good core control especially if they have done yoga or Pilates," she said.

Visit our Facebook page!

The Red Lion Group website contains a wealth of fairly static reference material, but if you're looking for something a little bit more interactive and dynamic you should visit our Facebook page.

Type www.facebook.com/Red-Lion-Group-240314279320575/ into your Internet browser and catch up with the latest news in the pouch world and chip in with your thoughts and questions.



A message from our new Chair

Some encouraging words from Lisa Allison's successor

Lisa has finally handed over the reigns of RLG Chair and I am absolutely delighted to be taking on the role. As some of you will know I had my pouch op some 32 years ago and had lived in the wilderness since then getting on with life and totally unaware that a patient group such as Red Lion Group even existed.

Three years ago a chance detour (I got lost) on the way to a meeting in Northwick Park Hospital meant I found myself on the fourth floor of St Mark's and looking at a door marked "Pouch Nurses". So it was then that I first met Lisa and found out about the RLG and weeks later found myself at my first Information Day. And what a revelation it turned out to be.

Lisa's cheery and positive disposition was immediately apparent at that first meeting ("you're lost aren't you?") and I have been hugely impressed by her efforts going back to 2012 when she first took on the role.

On behalf of every RLG member, the committee, the president and patrons may I extend a heartfelt thanks to Lisa. She is a very busy person who has managed to balance many commitments and she can now perhaps take a step back and concentrate on her studies and her career. However thankfully she will be continuing to serve on the RLG committee as Hospital Liaison.

The RLG constitution emphasises education, reassurance, advice and information-sharing and the Committee has done a fantastic job in making these ambitions a reality for many pouchees and potential pouchees. I am looking forward to working with the rest of the Committee in the coming years and further benefiting from their wisdom and humour.

I'd like to think we could reach out to every pouchee or potential pouchee and offer them the RLG

support, should they feel the need to reach out.

I would also like to think we could raise the awareness of this procedure so that eligible patients have the same opportunities as ourselves. And I'd like to think we could continue to raise funds to support research into pouch-related issues, such as the enormous donation made to RLG last year which is referred to in the Notes from the Treasurer on page 16.

The Red Lion Group is your support group. So my final point is to encourage you to speak up, write in and email us with your questions, concerns, criticisms and, hopefully, some praise. It's your feedback which helps us to fill future editions of Roar and the topics for the annual Information Day. So please feel free to contact us, we'd be delighted to hear from you.

DAVID DAVIES

Everything you always wanted to know – but were sometimes afraid to ask – about pouches

A must-read guide to life before, during and after pouch surgery

How do you describe a long, complicated and highly technical operation in layman's terms? With difficulty – unless of course you turn to a book like Zarah Perry-Woodford's "Ileo-anal Pouch Surgery for Ulcerative Colitis".

St Mark's Hospital's Lead Nurse for Pouch and Stomacare first thought of writing the book while studying for her Masters Degree in Gastro-Intestinal Nursing. "I realised there was a real need for an introduction and guide to going into hospital and having a pouch," she says.

Another reason was time – or lack of it. "Nursing staffs are under such pressure in the NHS that we simply don't have sufficient time to give people the information they need and what they can expect to happen when they are first admitted for surgery," she says.

The 118-page book is concisely written with graphic – sometimes raw – illustrations of some of our unmentionables!

And it needs to be. Whenever you talk to someone about their bowels, prepare for an uninhibited guide to something that is both very personal and, in social terms, very private.

The book is a stage-by-stage handbook about the ileo-anal pouch and what it means to have one with an introduction by Professor John Nicholls, Patron and former Clinical Director of St Mark's and co-founder of the modern pouch.

It begins with a guide to the digestive system, with an overview of ulcerative colitis, how to prepare for surgery and the pros and cons of having a pouch.

It has detailed diagrams of stomas, stoma bags and stomacare, discusses lifestyle, sex and fertility and has some key medical advice such as ways to avoid dehydration, the best anti-inflammatory drugs and tips to reduce wind.

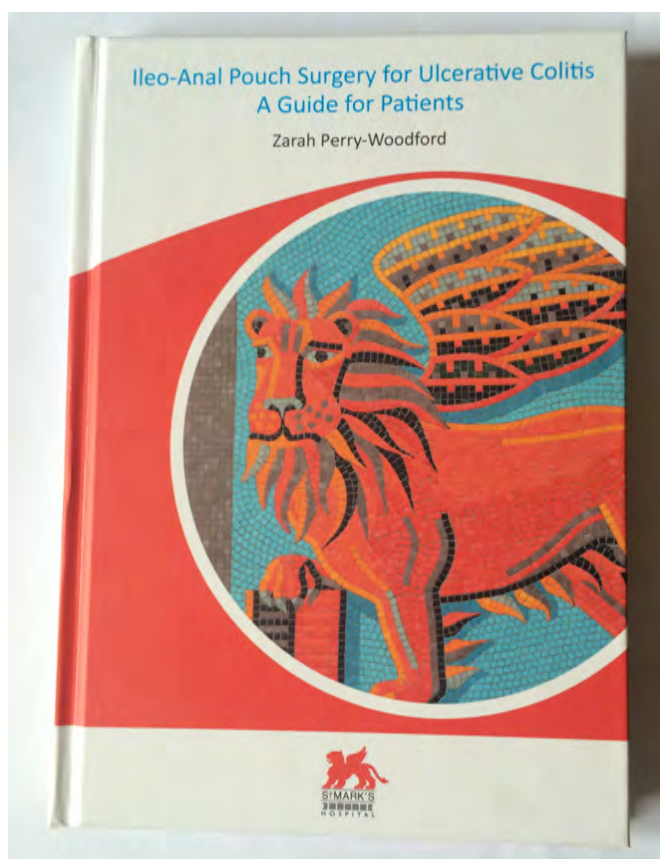
It also includes some invaluable advice such as how to apply for a free European health insurance card

(EHIC), radar keys, guides to the UK's loos and where to buy them and a smartphone app that shows the best walking and driving routes to certain relief!

It even has case studies that describe pouch patients' experiences and ends with a list of pouch and

stoma support groups including the Red Lion Group of course.

Zarah is offering the book free to her St Mark's patients who are about to have surgery. For the rest of us it is a very affordable £10. Contact info@stmarksacademicinstitute.org.uk or 020 8235 4046 to obtain a copy.



Zarah Perry-Woodford signing copies of her book

The missing link - have the gastroenterologists and researchers been overlooking something?

What are the chances of a young mother, her father and her baby son suffering from uc? Read Red Lion Secretary Sarah Bowes-Phipps' story and find out

Around a year and a half ago, when my son Albert was just 21 months, we learned the devastating news that he had ulcerative colitis (uc). He had been suffering with blood in his stools for about six

from diagnosis for my situation to become life-threatening. Before the New Year was in I had undergone an emergency total colectomy.

Fast forward 14 years, I reflected on my own situation. With a poorly

fraught.

Numerous trips into London for tests and finally an endoscopy (requiring general anaesthetic) eventually reached the diagnosis my husband Steve and I had both



Sarah and Steve Bowes-Phipps with their sons Albert (centre) and Lawrence

weeks which was not just emotionally heartbreaking but also physically exhausting for us all, as we endured the six-times-a-day battle that was his nappy change.

He fought and clawed at us through every painful wipe; it was more than any parent could bear.

We are not strangers to this condition as I myself experienced similar symptoms back in 2001 at the age of 21 and a diagnosis of uc was made in late October of the same year. It took a mere six weeks

functioning ileo-anal pouch, numerous fistulas and a relatively dire future for my pouch, I was adamant that my baby son would not suffer the same fate.

He was fast-tracked through the hospital systems and seen by fantastic consultants at both St Mark's and the Chelsea and Westminster hospitals respectively. The next few weeks were really tough but Albert battled through them like a brave soldier. I was also eight months' pregnant by this stage, so things were beyond

expected but feared – indeterminate colitis.

He was prescribed an oral medicine, Sulfasalazine, which we administered to him by syringe four times a day. This was by no means an easy feat but we got into a routine and his health gradually began to improve.

Then just a week after Albert's diagnosis, his baby brother Lawrence also decided to make his arrival by emergency C-section. While Steve looked after me and the baby, my parents took on the role of nurse to

Albert. It worked though and within four weeks Albert was in remission.

Quick diagnosis

It has been a year since his diagnosis and we look back now with a strong sense of how fortunate and lucky we have been. He received prompt and superb medical attention, a quick diagnosis and a treatment plan that proved to be fast and effective.

Presently he is still on medication. However we may make a decision in the future to attempt to gradually wean him off to see if he truly is in remission as we would like to avoid unnecessarily over-medicating.

We have also been warned that, although management of this condition in young children is generally very successful, we must not become complacent as things may change at puberty.

We will face that hurdle when we get to it but for now we rejoice in Albert's good health.

Through of all of this a niggle has settled in at the back of my mind:

Will Albert's brother suffer the same fate? There must be an hereditary link – Albert, my father and I all have uc. The team at Chelsea and Westminster Hospital were amazed to learn of this.

First, they had never diagnosed any child as young as Albert with colitis and, second, they had not heard of the condition being diagnosed in three generations of the same family. This was very interesting and through writing this article I hope we may learn some more about how genetic factors may have a part to play in this condition.

Dr Warren Hyer, Consultant Paediatric Gastroenterologist at St Mark's, writes:

Chances are you'll know a family

where a parent and a child both have colitis. Although colitis in children is uncommon, there is compelling evidence that inflammatory bowel disease (IBD) has a genetic predisposition.

As many as 30% of children with new onset IBD report another member of their family previously diagnosed and IBD stems from an interplay between genetic, environmental and immunological factors.

If you have the susceptible gene, then a combination of host and environmental factors creates and then

The risk is more apparent with cd. With an affected parent, a child has a 10- to 20-fold increase risk of cd, and with an affected sibling a 25- to 40-fold increased risk. This translates to the reality that the single greatest risk factor for developing cd is having an affected first-degree relative.

Over 100 proposed genes have been identified as linked with the onset of IBD, some of the genes exclusively to cd; others to both conditions.

These genes affect the way the cells in the gut wall behave, and a disruption of the cell barrier function leads to stress in the gut wall, inflammation and damage.

But the known genetic associations explain only 20% of the genetic contribution to IBD susceptibility, so there are many more genes and other factors still to be identified.

A compounding influence on the increased risk of IBD within the same household, will be the home environment. Family members share the same risk factors within the home and lifestyle

such as diet, climate, tobacco exposure, infections etc. Members of the same family are also likely to have similar microbiome (or, to put it simply, biology) which also impacts on their risk of contracting IBD.

So you shouldn't be surprised if within your family, there are two or more affected members with IBD. Nor should you feel any blame or guilt for carrying an at-risk gene. For we all carry many such genes which can be turned on by environmental factors, and it is our lifestyles and affluent westernised environment that should be held culpable for the rising prevalence of IBD.

Fortunately, we are the genetic outcome of our parents – whether good, great or with affected guts!



Albert at the wheel

perpetuates an abnormal immune response to gut flora.

Much is known about the genetics of colitis in adults and children. For ulcerative colitis (uc), there is a genetic contribution, but this is more apparent in Crohn's disease (cd). This is demonstrated by recent studies of twins. If you consider a pair of identical twins, the concordance rate (the rate that both twins are affected by the same condition) is 14-19% for uc and 50% for cd.

A family affair

If you have a first-degree relative with IBD – ie father, mother, sibling or child – then you have a 10-fold increased risk of developing colitis compared to the general population.

RLG's action man and his tales of derring-do

Phew! If you want to know how much activity a pouch can stand read our new chair David Davies's account of how his charity raised almost £2 million from such events as Arctic kayak marathons, climbing the UK's highest peaks and cycling from John O'Groats to Lands' End

Playing rugby has been one of the great joys of my life as a pouchee. After my final closure at Bristol Royal Infirmary in 1985, I resumed my rugby-playing career with boundless enthusiasm, first with Clifton Rugby Club, near Bristol, and then, after I moved south, with Beckenham in north Kent.

My final game was playing for Beckenham Veterans at France's famous Montpellier Rugby Club at the age of 40. The red wine after the game was so irresistible that I was found by friends several hours later asleep in the toilet just as the coach was about to leave on the journey back to the UK. Ooh la la!

Another highlight of my rugby days was playing at the famous Middlesex Sevens finals at Twickenham in 1990 where my team's role was as a warm-up act to keep the crowd entertained between the semi-finals and final. A great event and a huge privilege!

These memories would not have been possible but for the great work of my surgeon, Professor Neil Mortensen, and his staff at Bristol, and the pioneering pouch-work of Professor John Nicholls and his colleagues at St Mark's Hospital.

Post-rugby and a few of my fellow players and great friends decided to give something back. Although we were lucky enough to be blessed with healthy children, we realised that many people are not so lucky. So we set up a charity to raise money for terminally ill and disabled children.

This is our 10th year and we have raised almost £2 million which I'm very chuffed about. Most of the money was sourced from the two main fundraising websites JustGiv-

ing and Virgin Money Giving.

But what is pertinent to you, dear reader, is that I've done quite a few fundraising events which show that having a pouch is no barrier to leading a normal life – with the occasional completely abnormal adventure.

Ten years ago I completed a 127-mile kayak race non-stop from Devizes to Westminster Bridge. I competed with my brother and it



Marathon man: David Davies at the finish of a long-distance cycling event

took us 35 hours, which was very slow and with a very heavy boat, but we finished! In 2008 I travelled to the northernmost region of Norway to kayak in the sea above the Arctic circle. This was a week-long adventure, camping out on beaches at night and kayaking in a wild and freezing cold sea during the day.

The biggest challenge was the dehydrated food, which we reconstituted for our meals but which didn't have much fibre and was very high in

salt content. Plus the fact that there were no toilets as the islands were uninhabited! On the last day there was a race over 26 miles in a very lively sea and with a nasty headwind. But the pouch was no barrier to finishing the course.

Over the years I've completed many other events. The Dublin marathon in 2010, annual bike rides from London to such major European cities as Bruges, Amsterdam, Cologne, Paris, Brussels, Ypres and Rheims. I swam in the World Winter Swimming Championships in Rovaniemi in Lapland in 2012, clambered up Snowdon, Ingleborough and Scafell Pike, cycled the South Downs Way and supported a team cycling from Lands' End to John O'Groats in 72 hours. That was probably the hardest of the lot!

It's been a truly wonderful journey that continues this year with an event to walk 100 miles in May; the Tenby Sportif in July; a kayaking and cycling assault on the Great Glen Way from Fort William to Inverness this month and a big bike ride in Ireland in September.

During these activities one has to be well prepared and careful with the pouch, of course. Readers will understand the need for decent nutrition and the use of isotonic drinks before, during and after an event to prevent dehydration and the need for barrier creams to protect the sensitive area around the bottom (particularly if the event involves sitting on a razor blade of a bike saddle for 10 hours each day!). And the need to carry soft toilet paper around with you in case of emergencies.

But, all in all, I take the view shared by many in our community, that life is for living and it's better to rejoice in what you have than mourn what you don't have.

Information Day 2016



Above: (l-r) RLG Secretary Sarah Bowes-Phipps, St Mark's Research Fellow Guy Worley and outgoing RLG Chair Lisa Allison at Information Day. Below: Red Lion members enjoy an al fresco lunch on the balcony at Information Day



Chair's report for 2016

The committee have had three telephone conferences in the last year (June and September 2015 and January 2016) and in February we had a face-to-face meeting in central London which went very well. As of February there are 294 members on the database which includes healthcare professionals.

One copy of Roar! was produced in 2015. Chris Browne does a brilliant job of putting everything together and Tim does the layout. Chris is always on the lookout for articles, letters and puzzles so if anyone has got anything they would like to be put in the next publication please contact Chris. We aim to get the next issue out in July/August so please get writing if you'd like to!

Tim Rogers has continued to do a great job with the group's website. We recorded the presentations for the first time last year – these are available on the website with the transcribed versions having been printed in Roar!. We are going to try and record the presentations again today so that the information is captured and is accessible to a wider audience.

As those of you who are members will know we make a donation to research funds at St Mark's Hospital each year and this goes towards funding research into pouches. In October two research fellows started in post and they have very kindly agreed to present what research they are doing today.

I have been chairperson since May 2012 and announced at last year's AGM that I would be stepping down this year. I really feel that somebody with a pouch should lead the group and move everything forward; with my other commitments I am unable to do the role justice.

David Davies has agreed to take over as chair just after Information Day and Andrew Millis has agreed to continue as Vice-Chair. We have a brilliant committee who are very supportive – if anybody would like to join then please let me know. I will still be involved with the Red Lion Group in my role as a pouch nurse.

The date of the next Information Day is Saturday 13 May 2017.

LISA ALLISON



RLG Patron Professor John Nicholls with outgoing Chair Lisa Allison at Information Day

Notes from the treasurer

Income for 2015-2016 was maintained at a similar level to last year with £2,245 from membership fees and another £782.50 in generous donations from members.

I am also very pleased to say that after the committee's appeal for gift aid last year we managed to raise a magnificent £1,449.12 from the government's gift aid scheme for the years 2013/2014/2015.

I am delighted to say that we have sent a cheque for £8,000 to St Mark's Hospital Foundation to help fund ileo-anal pouch projects. Professor Sue Clark, Consultant Colorectal Surgeon and Dean of the St Mark's Academic Institute, was fulsome in her thanks for the dona-

tion, saying: "I should be very grateful if you would let all concerned know how hugely grateful we are for this donation, which really makes a difference to the work we do."

Gift Aid Reminder

As you can see from the amount raised for the past three years, gift aid is a significant resource for us. So if you haven't done so yet, please sign the declaration form on the back cover to enable me to claim gift aid on your behalf. This will not cost you a penny. The only requirement is that you are a 25p-in-the-pound taxpayer – so you can raise another £2.50 for the Red Lion Group from your £10 subscription.

After all it's FREE money from the government. Wonderful!

Fundraising

If you have any bright ideas for fundraising projects, please let the committee know by contacting me (p.mulot@ntlworld.com) or Roar Editor Chris Browne (cbrowne@brownemedia.co.uk). It might be something you can do locally as a family or neighbourhood group or else something the group can work on as a team. Any ideas, however large or small, will provide the cash to help us fund vital research programmes and help us to support YOU the members.

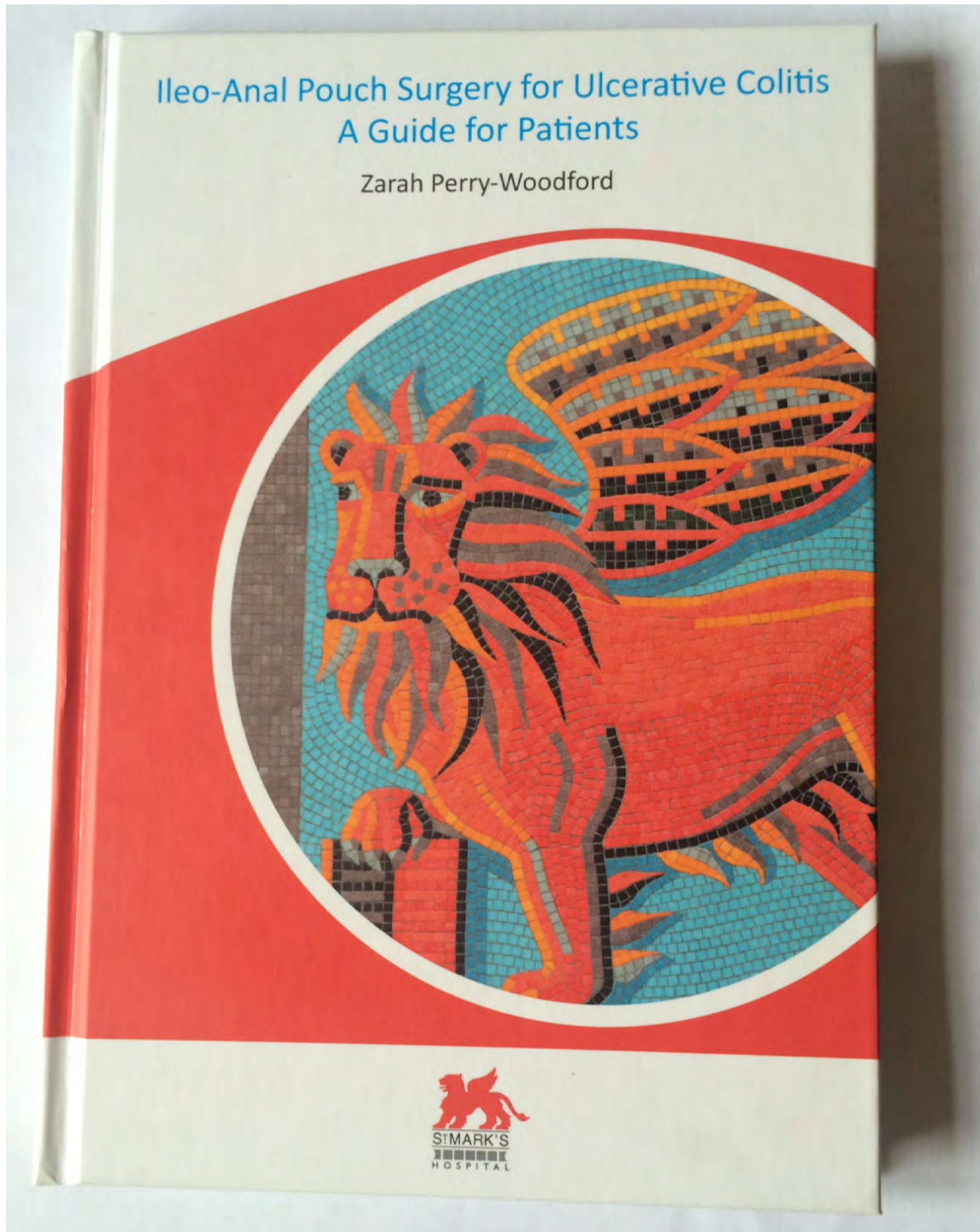
PAUL MULOT





A few moments of humour and relaxation on a sunny Information Day

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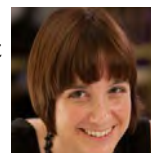
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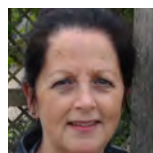
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Professor Sue Clark

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Professor John Nicholls



Lynn Faulds Wood

Join the Red Lion Group

- Newsletter twice a year with all the latest news, views and events
- Membership is £10 (£5 for hardship cases, and free for under 16s) per annum
- Write to the Membership Secretary (see above) for a membership form

Write for Roar!

Ideas, Ideas and More Ideas

Yes, Tim Rogers and I thrive on them for it's ideas that make *Roar!* the readable package that we all 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 in-

formation and make reading about pouch issues fun and stimulating. Please send your articles, letters and ideas to:

Christopher Browne
Roar!

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cbrowne@brownemedia.co.uk

Please email
membership@
redliongroup.org
if your email address or
contact details change



AUGUST 2015

To: The Treasurer

THE RED LION GROUP (REGISTERED CHARITY NO 1068124)

Please send this form to Paul Mulot, 103 Whitehill Road, Hitchin, Hertfordshire, SG4 9HT, United Kingdom

I request that ALL subscriptions and donations that I have made to the Red Lion Group for the last four years, and ALL subscriptions and donations I make thereafter, be treated as Gift Aid donations. I confirm that I currently pay, or will pay, an amount of Income Tax and/or Capital Gains Tax that is at least equal to the amount to be claimed and I expect this situation to continue. (Current tax reclaim is 25p in £1 or £2.50 for £10). I am under no commitment to make any further donations and I may cancel this declaration in respect of future declarations at any time.

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