ROAR!

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

How a pouch pioneer found love — see page 9

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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Please support the Red Lion Group

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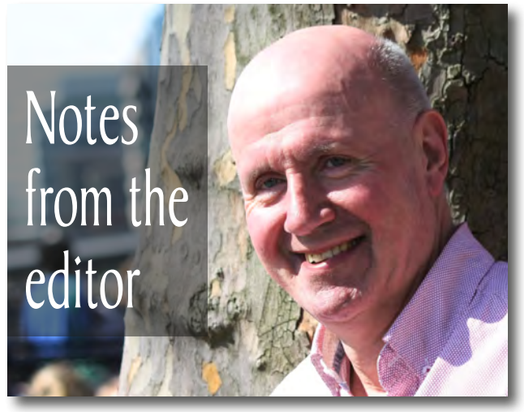
All donations, however small, towards expanding the work of the group will be gratefully received. If you would like to send a donation please make your cheque payable to The Red Lion Group and send it to: **The Red Lion Group Treasurer, Mr Preash Lad, 62 Peartree Avenue, London, SW17 OJG**

Front cover: *Purple Iris* by Christine Lawton
Back cover: *Hillsborough Castle Lake*



One-woman shows – they're a rare and often quirky species. Most of you'll remember Victoria Wood and her performing piano, Catherine Tate, of course, the irrepressible Jo Brand and that loud and lary lassie from Tyne and Wear, Sarah Millican. But have you seen the show featuring Lisa Allison.

She may not forgive me for saying so, but our lively chair almost single-handedly planned, organised, hosted and presented this year's May 13 Information Day. OK so the rest of us were happy to act as her willing helpers, but it was Lisa who held it all together and even managed to give one of the talks.

Happily the weather was fine and sunny – it always is on Information Day (it should be included in every national weather forecaster's curriculum) – and a lively group of 60 plus members, friends and families mingled over a summer buffet of soup, sandwiches, cakes and refreshments (though more of that later) at St Mark's Hospital's Himsworth Hall education centre.

Then it was time for the Lisa Allison Show. Brevity is the secret of any successful AGM. Which ours certainly was with two pithy reports from the chair and our outgoing treasurer, Marjorie Watts (you can read them both in this issue). We gave a warm welcome to our new treasurer, Preash Lad, who has written about his recent trip to south-east Asia specially for Roar, while the rest of the committee were re-elected en bloc (you can see a list of officers and committee members and their contact details on the back cover of *Roar!*).

The line-up of speakers – we've featured two of the talks later in this issue – covered such topics as the history of the pouch and laparoscopic surgery (Janindra Warusavitarne, St Mark's consultant colorectal surgeon), pouch problems and the role of the pouch nurse (Lisa Allison, Red Lion chair and St Mark's pouch clinical nurse specialist), pouchitis (Dr Yih-Harn Siaw, St Mark's research fellow in gastroenterology) and medication and pouches (Rasha Salama, St Mark's specialist pharmacist).

We also asked the former England rugby skipper Lewis Moody to speak about his on-pitch and off-pitch travails with ulcerative colitis (see the main article in the Christmas 2012 Roar). But he was otherwise engaged. We are trying to persuade him to talk to us at the 2014 Information Day on Saturday, 10 May. So watch this space.

There was however a slight glitch that Lisa more than ably handled. We were only given enough food and beverages for about 10 people instead of 60 plus. And the reason? G4S, the security and facilities company, that was so publicly criticised for its security arrangements at the London Olympics, was the provider. Lisa managed to muster extra supplies and when she later spoke to G4S about the problem, the company did at least agree to waive their fee. Next year we'll do our catering in-house.

One of the highlights of the day was the three workshops for male and female pouch-owners, their partners and friends. It's the rare intimacy of being able to talk about your problems with fellow pouch-owners or partners that makes these sessions so rewarding. One red Lion member even admitted it was the first time he had ever spoken to another pouch-owner in 32 years. Your feedback forms were equally revealing with such comments as: "I really valued meeting other people and sharing experiences", "I very much enjoyed the discussion at the end with female pouchees", and "I liked hearing about other people's experiences and receiving advice." One member said the May event was her 12th information day.

Once again catheters were the dominant topic in the male workshop and I still have an ongoing correspondence with at least three members about how and when to use them. Lisa has written a very useful and reassuring guide later in this issue which should answer many of your questions. If you still need a few tips from a veteran user, don't hesitate to email me at cbrowne@brownemedia.co.uk (I make take a few days to reply, but don't worry I will definitely do my best to help you).

Apart from the mechanical issues, your main concerns have been about how and when to use them when you are at work and what to do about social events, lunches and dinners. They were mine too when I started using one. Lisa and I will do our best to help you.

A very happy rest of summer to you all and enjoy the latest *Roar!*

Christopher Browne

What a difference a diet makes…

When Red Lion vice-chair and marathon runner **Andrew Millis** changed his eating habits, it turned him from a better-than-average competitor into one of the leaders of the pack.

I have suffered from varying bouts of chronic pouchitis for two to three years now. So I take antibiotics which helps to transform my pouch output into stools – they are never seen otherwise – and at the same time very easily help me to put on weight.

I always take antibiotics before I run a marathon to help me digest and absorb enough carbohydrates for the actual race. Sometimes I eat even larger quantities to keep my weight and strength up, only for my stomach to rush it through even faster, leaving me with even greater hunger pangs – just like a treadmill of eating really!

Interestingly, I was recently sent an article from a medical journal that said for running, a diet should be "high protein, high carbohydrate but low fat, with the emphasis on low fat". So I stopped eating all food which had high levels of saturated fat…out went cheese, chocolate (that was hard – I still suffer from cravings and my children don't know what to get me for birthdays any more!), pasties (a single Ginsters pasty is three-quarters of your maximum saturated fat intake in one go, while a bar of plain chocolate blows it completely), pork pies, biscuits and cake.

Instead I ate more fruit, low fat yoghurt, skimmed milk, and ready-made meals with low fat content at work. My weight fell by over a stone (and I wasn't overweight before) but my pouch function has markedly improved.

I now have stools most of the time – without antibiotics. But the best trick is how much faster I can run – for several weeks, every time I went out for a run it was a faster time than I have done before. It was the main reason behind the shock I had when I finished the Stockholm marathon on 1 June this year in 3 hours, 1.57 minutes, which, even in my wildest dreams I never thought I could achieve (I came 395th out of 21,600 runners from something like 86 countries). [*This is an outstanding time for any marathon runner – Ed*].

Mind you, I can feel the difference when I sit down on a hard surface as I don't have much fat to cushion me anymore! While my wife compliments me with words like "emaciated" and "anorexic"!

One observation: the Swedish obviously have a tendency to be pro-British. I had not just one but several groups who broke into singing "Rule Britannia" when I ran past in my union flag kit. There were also plenty of British among the spectators who gave me a rousing cheer or two.

It was the best response I have ever had to my colourful kit. I wore my patriotic outfit in two previous marathons, getting no response at all in Vienna and very little in the Finnish capital of Helsinki.

A message from the chair

Lisa Allison, clinical pouch nurse specialist at St Mark's Hospital, describes her first year at the helm of the Red Lion Group committee.

As you will know from the last issue of Roar and the 2013 subscription renewal letters, I took on the role of chairperson of the Red Lion Group at the 2012 Information Day.

So here's a bit about myself – I completed my nursing degree in 2001 and was fascinated with all things bowel related from the moment I started my training! I did my training at the Oxford Radcliffe Hospital where I was aware of pouch surgery happening and I then moved to the Royal Marsden Hospital in London where I dipped in and out of various cancer specialities but mainly concentrated on gastro-intestinal and urological cancers.

I came to St Mark's Hospital nearly three years ago as a specialist nurse and initially looked after patients with stomas for part of the week and those with pouches for the remainder of the week. For the last 16 months I have been looking after pouch patients full time – as there is more than enough work to keep both myself and my St Mark's colleague, Zarah Perry-Woodford, busy!

I have learnt a huge amount over the last few years but there is always more to digest! For this reason I have recently embarked on my masters degree which will take three years to complete. I thoroughly enjoy what I do and am very lucky to work as part of a fantastic team. I do not have a pouch myself but feel that as chairperson of the Red Lion Group I can support the committee and help people with pouches who are not just at St Mark's but all over the country and beyond.

I have never been a chairperson before so it has taken me a while to get to grips with the role! The first task was to chair the telephone conferences that the committee holds every three months or so. I found the whole telephone conference set-up quite amusing at first but soon got used to it. As long as there is an agenda, everybody doesn't speak at once and someone is able to note the main points then we get sorted quite quickly. We have also had a couple of face-to-face meetings at St Mark's which are much easier than over the phone.

I see the Red Lion Group as supporting people with pouches by producing *Roar!* twice a year, holding the information day at St Mark's once a year and having a website that can provide information when needed. Ideally it would be possible to match prospective pouch patients with someone who has been in a similar situation and been there and done that with a pouch, but as I have found in my clinical role this can be very difficult to get right so that it benefits both parties.

I know that members of the committee who all have a pouch are more than willing to speak to people about what having one is like. Improving links with IA (the Ileostomy and Internal Pouch Support Group) is on the list for things to work on. Having an up-to-date website is also key for any organisation in this day and age and it is something we are currently trying to achieve. We have looked into revamping the whole site but this tends to cost thousands of pounds and still doesn't get over the difficulty of finding new material and putting it on the site. If there is anyone out there who would be willing to search for pouch-related information and has the technical skills to put it on the site we would be delighted to talk to them!

If anyone has any other ideas as to how they would like the Red Lion Group to support them further then please let me know on chair@redliongroup.org or 020 8235 4126.

Anagram Time!

Can you work out the names of the St Mark's Hospital staff hidden in these anagrams?
If you're really struggling (it is pretty tough) then visit the St. Mark's website **www.stmarkshospital.org.uk** where you can find a list of staff that work there.

- a sculker
- sob enigma
- dozy, deaf wrap horror
- aha trials
- ills on alias
- posh bill in rip
- injure raw and a variants

Hint: The names include consultants and some of our favourite nurses!

Temples, beach parties and eye-catching scenery – but please don't mention the chickens

Red Lion Group treasurer **Preash Lad** recalls some of the highlights of his recent trip to South East Asia.

In 1997 I was diagnosed with UC. I was 17-years-old and after suffering with the condition for another 15 years I elected to have one stage ileo-anal pouch surgery in the summer of 2011.

One of the main reasons I elected to have the surgery was to improve the standard of my life and to be able to do things which were not possible with the disease. Now having undergone laparoscopic (keyhole) pouch surgery I have a new lease of life, so I decided to give my pouch a really good test to see how it copes with the rigours of travelling in South East Asia.

Louise and Preash (centre) join in the New Year's Eve celebrations in Hanoi

It was my second visit to the region and my destinations were Vietnam, Cambodia and Thailand. I was travelling with my good friend Louise, who like me also managed to get a whopping five weeks off work. There was a slight concern with the locations I was going to as if I became ill with my pouch it might present problems with treatment in remote areas. However in my opinion that would have defeated the object of having the surgery as I am determined to live my life to the fullest!

Saying that I made sure I was fully prepared when going out. I spoke to my nurse Zarah Perry-Woodford, St Mark's clinical nurse specialist, about what precautions I should take while travelling. I made sure I had a supply of Ciprofloxacin, Metronidazole and Diaralyte in case I had an outbreak of pouchitis and also the usual suspects like Buscopan and Loperamide readily available if required. Zarah also reiterated the need to stay hydrated at all times particularly because of the hot weather.

Louise and I arrived in Vietnam to be greeted with what can only be described as rubbish weather! Fortunately we had both packed hoodies which turned out to be a saviour as we wore them daily for the first part of the trip! We travelled from the north of the country to the south starting in Ha Long Bay, a world heritage site. There are spectacular views of thousands of limestone islands; unfortunately the cloudy/rainy weather meant the views were not as spectacular as some of the postcards you may have seen.

Our next stop was Hanoi where we spent New Year's Eve. I expected we would be partying into the early morning however North Vietnam still has a very reserved outlook as it is still a communist country. We celebrated on the streets with the locals and then the police cleared the crowds and I was tucked up in bed by 12:30am on New Year's Day – or 1 January, 2013!

Louise and I then travelled to central Vietnam stopping at Da Nang, Hoi An and Nha Trang. Fortunately the weather started to heat up and we could finally lose the hoodies. We then travelled to Ho Chi Min City or Saigon which is one of my favourite places. It had much more of a lively buzz than the last time I visited and it is the complete opposite of Hanoi with plenty of market stalls, restaurants and bars – all open into the early hours.

Our mode of transport varied throughout our trip including plane, boat and bus. The bus journeys were certainly not how they were advertised by the travel agents, or else we were rather unlucky as we ended up on the local bus with no air conditioning, people sleeping in the aisles and caged chickens at the back! Still it added to the experience and makes a story to bring back home.

We spent five days in Cambodia visiting Phnom Penh first. We visited the S21 prison and The Killing Fields (the real-life version of the famous film of that name) where you get a true glimpse of Pol Pot's awful regime of genocide upon his own people. It was a very sombre experience but something I'm glad I've seen. The rest of our Cambodian visit was spent in Siem Reap exploring the temples with Angkor Wat being a truly stunning piece of architecture.

Our final leg of the trip was spent in Thailand in the Thai Islands. We spent two weeks island-hopping in Ko Samui, Ko Phi Phi and Phuket. We spent the majority of this time relaxing on beaches during the day (obviously I

Rythmn and booze: Preash and Louise (centre with hats) enjoy a roadside beer - at 40p a pint!

The Hindu temple of Angkor Wat, the world's largest religious monument, near Siem Reap

A good match: Preash and Louise try on the local headgear

Sunset strip: Admiring the evening view in Phi Ley Bay, a small island near Phi Phi

Preash with a Thai long-tail boat on Maya beach, Phi Phi Island

needed to work on my tan!) while the nights were spent partying on the beach.

I've got to say my pouch survived its first major test with flying colours. I did go to the toilet more than my normal routine in the UK, however I could hold on without problem for hours if necessary and there were toilets accessible pretty much everywhere. My diet was good and I was able to eat everything I wanted however I did choose to go veggie at various stages during the trip as I wasn't keen on seeing chickens festering away outside in the sun.

However, the rice and noodle dishes went down particularly well!

Probing the mysteries of pouchitis

The Red Lion Group recently donated £5,000 towards a St Mark's study into pouchitis*. Here is an edited progress report from the project's lead investigator St Mark's and research fellow **Dr Jonathan Landy.**

Almost a third of ulcerative colitis (uc) sufferers will need an operation to replace their large colon with a pouch. And of that 30 per cent, as many as half will suffer inflammation of the pouch – otherwise known as pouchitis. These are two of the key findings of a study into the condition by a team from St Mark's Hospital.

So what are the symptoms of pouchitis? You will need to go to the loo more often and you may well experience bleeding, stomach cramps and urgency – a feeling that you need to go to the loo urgently to avoid an accident.

It is also the cause of approximately 10 per cent of pouch failures, with the pouch being replaced by an ileostomy, either temporarily or permanently.

However there is still a lack of understanding about the causes of pouchitis. Previous studies, including a recent study by the St Mark's team, suggest the following factors:

- Bacteria caused by a bacterial imbalance in the pouch
- A patient's immune system
- The function of the patient's natural barrier of the gut lining

The project's aims are to study the changes in the natural barrier function of the pouch lining and the key cells that contribute to the immune response. "This is with a view to assessing their roles in the breakdown of tolerance and the onset of inflammation in response to the bacteria present in the pouch," says Dr Landy.

By doing so, the study will help to pinpoint the "key mechanisms responsible for pouch inflammation and the factors responsible for inflammatory bowel diseases as a whole" and help find potential therapies to treat pouchitis.

Over the past 12 months samples have been taken from the small bowel and pouch of patients six and 12 months after their pouches started functioning. Biopsy samples were also collected from patients with colitis and healthy individuals undergoing colonoscopy. "This has been with a view to understanding the changes in the key immune cells and the key proteins controlling the integrity of the gut barrier that occur in the functioning pouch – and may predispose to pouch inflammation," says Dr Landy.

From these samples, researchers were able to look at dendritic cells (the generals of the immune system which determine whether its response to the gut's contents is tolerance or inflammation). They also studied key immune cells and key anchors of the cells known as 'tight junctions' that form the barrier of the gut lining. The researchers also assessed the chemical signals that drive inflammation.

In his summary of the study's findings, Dr Landy says the research could well help to

- Assess the risk of developing inflammation before it occurs
- Intervene to prevent the development of inflammation
- Target therapies to one or more causes of inflammation to treat it more effectively when it occurs.

As Dr Landy points out: "Bowel problems do not attract the same attention, and therefore awareness, as some others [conditions]. But the pain they inflict on sufferers can be all-consuming. Our doctors will remain committed to the field, continuing their long tradition of identifying best practice through research and communicating this to the medical community."

** A study of the interactions between the microbial environment, host immune system and barrier function in the development of pouchitis.*

What's the secret of a successful marriage? A spell in hospital, some pioneering surgery and a few handwritten notes

When teacher **Stephen Want** went into hospital he found love was the best drug he could ever have been prescribed.

It all started with a few handwritten notes. After a long and painful spell of ulcerative colitis, 23-year-old Stephen Want knew he had little choice but to go into hospital for a bowel operation.

He went into the Royal London Hospital in London's Whitechapel where he had the first two stages of a pouch operation, returning several months later for the final closure.

But before the operation, Stephen found he kept going to the loo. Sometimes when he got up in the night he'd find it easier to sit at the desk used by the ward's night staff which was near the entrance to the toilet. "It saved me having to go back to bed every time I needed to go to the loo. It also helped me to relax and forget about my problems," he says now.

What also kept Stephen's spirits up was the light-hearted banter he enjoyed with the nurses. "Two of them gave me their phone numbers which made my stay in hospital a whole lot more bearable," he says. One young night nurse even passed little handwritten notes on to the 23-year-old.

When Stephen left hospital three weeks later, he asked the young night nurse out on a date. "Her name was Mary and she was a 19-year-old student nurse. She was the only one who hadn't given me her phone number, so I had to ask her for it before I was discharged from hospital," says Stephen.

The pair started going out and, as the relationship developed, Mary visited Stephen at his home in Cheshunt in Hertfordshire. A few months later he got his first job as a teacher while Mary started training to be a midwife. They eventually got married and are now the proud parents of a grown-up son and daughter.

But this charming little tale of love among the hospital beds has an unexpected twist.

It happened in 1980 – or 33 years ago – and when Stephen went into hospital his surgeon was no less a figure than Sir Alan Parks, the founder and pioneer of the ileoanal pouch. When Stephen had his operation he was only the 16th patient to have ever had a pouch fitted.

"The whole set up was very different then and the pouch operation was still at a very early and experimental stage. My house surgeon scribbled a little drawing on the back of a piece of paper which was meant to represent a pouch. Instead of watching a DVD of a pouch operation as most people tend to now," he says.

After an operation to remove Stephen's large bowel, Sir Alan [who was also a consultant at St Mark's Hospital which was then in London's City Road] said there were a number of possible options he could consider. "He said that as my rectum was fairly badly diseased he would give me a loop ileostomy instead of an ordinary one before I had the pouch operation," says Stephen.

Everything went to plan, Stephen was discharged from hospital and he and Mary have never looked back since.

"My pouch has been almost trouble-free apart from a short period 11 years ago when I was treated for a fissure. And to think it all started with a series of notes," says Stephen, who recently joined the Red Lion Group.

Everything you ever wanted to know about using a catheter – but were afraid to ask

You may be a little timid about putting a tube up your backside, but you're not alone! Seek professional advice and you may find it's the best thing you have ever done. Here RLG chairman and St Mark's Hospital clinical pouch nurse specialist **Lisa Allison** gives a professional overview.

Several years ago the editor Christopher Browne wrote an article for Roar (which was also put on the website) about his experiences of using a medina catheter to help empty his pouch. Ever since he has received many questions about catheters from other people with pouches and I thought it would be good for me to clarify a few things about using them.

A catheter is a plastic tube which can be inserted into the pouch via the anus to empty the pouch. The 'medina' catheter was made primarily for use with Kock pouches or continent ileostomies. There are currently no other suitable catheters being manufactured and easily available in this country therefore the medina has been adopted for use with ileoanal pouches. For prescription purposes the catheter is known as an 'ileostomy' catheter but I will use the term medina in this article as it is easier. I apologise for using the term patient but again, it is easier!

Emptying techniques

Some patients who have 'W' or 'S' shaped pouches that were made in the early years of pouch formation have commonly had to use a catheter in order to be able to empty properly. Emptying spontaneously is less of a problem for those with 'J' shaped pouches which are the preferred versions today. Some patients may find that unfortunately they have a problem with emptying their pouch following closure of their ileostomy and in these instances would consider using a medina catheter. The pouch can take 6 to 12 months to settle down and over time emptying can get easier as the best emptying techniques for the patient are sought.

Patients who have had no emptying problems previously can sometimes find that they are having more of a struggle as time goes by and are gradually needing to spend more time on the toilet. In some cases a diagnosis of pouchitis can result in incomplete emptying but this is usually accompanied by frequency, urgency, possible bleeding, abdominal pain, fever and generally feeling unwell. Incomplete emptying on its own could also indicate that the join between the pouch and the anus (the anastomosis) has narrowed down as scar tissue has built up.

Emptying problems can also be due to a functional problem with the pouch for which there is no known cause. Anyone who has developed emptying problems with their pouch should seek advice from their doctor or pouch nurse specialist as investigations will need to be done to assess what the problem is.

Medina catheter

For those who have been recommended to use a medina catheter here is some information that might be helpful:

A medina is a hollow plastic flexible tube that is 30cm long and has two eyelets or small holes at one end. In order to use the catheter it is best to use a lubricating gel to make insertion easier. This can be something such as Aquagel or KY Jelly which just lubricate or if the anal area is very sore it might be better to seek some lubricating gel with local anaesthetic in it. This can be obtained on prescription from your GP in the form of Instillagel or else St Mark's Hospital's pharmacy manufacture a stronger version which also needs to be prescribed. Depending on the consistency of the stool a bladder syringe might be needed to flush the catheter/pouch. These also need to be ordered on prescription (see details of how to order at the end).

When showing the patient how to use the catheter in hospital we always start off with the patient lying on their side but normally it is best to insert the catheter whilst over the toilet. A small amount of lubricating gel should be placed around the anal area and on the end of the catheter – coating the eyelets. If using a syringe this should be filled with 20-30mls of warm tap water. It is best to hold the medina 3 to 4 inches from the eyelet end. The catheter should be gently inserted into the anus until your fingers touch your bottom, you will feel the catheter 'give' as it goes into the pouch and air may be expelled. The other end of the catheter should be aimed towards the toilet bowl to allow stool to drain.

The syringe can be attached to the other end of the catheter and some water flushed into the pouch to aid drainage if the stool is of a thick consistency. It may be that this process needs to be repeated a few times. Some patients find that rotating the catheter, coughing, massaging their abdomen or wiggling their hips can help ensure the pouch is empty. Patients can sometimes empty their pouches more effectively if they insert the tube most of the way up into the pouch, leaving at least three to four inches (but no less) of the tube exposed.

Then gently remove the catheter. Rotating it as you pull it out or flushing it with some more water if using a syringe can often help ease the process. Occasionally the catheter can get stuck as it is pulled out, try to relax, wait a minute or two and then try to remove again

Multiple use

When using the catheter it is generally best for the patient to adopt a crouching position as this allows him or her to move the catheter up or down more easily than in a sitting position. Patients who sit over the toilet may find problems with the outer end of the catheter trailing too near the water in the bowl.

After use, the catheter can be washed in warm, soapy water, dried with toilet paper or paper towel and then put back into the plastic sleeve it came in.

The catheter can be used multiple times and will not disintegrate! The main thing that happens is that the plastic discolours over time. As medinas come in packs of five, it will be some time before another prescription is needed. In each pack there is an extender so that the catheter can be cut in half for easy carriage when out and about and then joined back together for use.

The syringes supplied in the community are 100ml which is larger than needed but unfortunately this is all that is currently available on prescription. The syringes are designated for single use in hospital but can safely be used multiple times at home. If possible it is best to separate the syringe and plunger sections to enable them to dry out properly and last longer. Both syringes and medina catheters can be discarded in the normal domestic waste once they have worn out and new ones need to be used.

Using the catheter for the first time can be quite daunting, so this is one of the reasons it is best used initially with a healthcare professional present. It is also likely to be a bit messy but this will improve the more that you use it. It is quite common to experience some bleeding whilst using, and after using the catheter. This is because despite the catheter being quite soft and flexible it causes trauma to the anal area and lining of the pouch.

The number of times that the medina needs to be used each day depends on the patient and their situation. If pouch emptying is a real problem and nothing empties spontaneously when sitting on the toilet then the catheter will need to be used a few times each day to achieve complete emptying. If night-time leakage is a problem and it is established that this is because of incomplete emptying then using the catheter before going to bed might be adequate. It is vital that you speak to your nurse specialist to discuss the routine best suited to your individual condition before attempting catheterisation.

Wellspect Healthcare (formerly AstraTech) are the manufacturer of 'ileostomy' catheters. The code for prescriptions is 68735 and the telephone number of the company is (01453) 791763. 100ml bladder syringes are manufactured by Bunzl – the code for prescriptions is DB300605.

I would just like to reiterate that medinas should not be used without the advice of a healthcare professional. If you have any questions please do not hesitate to contact me on nwlh-tr.internalpouchcare@nhs.net or chair@redliongroup.org or 020 8235 4126.

A prescription for clarity

How many of us have been prescribed a drug we have never heard of? Quite a number I suspect. And, apart from their Latin-sounding names, how many of us know how safe or effective these particular drugs are?

Those were just two of the key topics raised by St Mark's Hospital pharmacist Rasha Salama (pictured) in her talk "Drugs and Safety" at the 13 May Information Day.

Did you know, for instance, that the best and safest drug for pregnant women with acute diarrhoea is Loperamide. While the penicillin-based Co-amoxiclav is the antibiotic of choice for expectant mothers who are suffering from infections, though Metronidazole can also be used "if clinically required", said Rasha.

Once again, Loperamide and Co-amoxiclav are recommended for mothers who are breast-feeding, while Codeine "can cause drowsiness in the infant, especially during the first week of breast-feeding," said the St Mark's pharmacist.

However there is limited data about drug safety during pregnancy and breastfeeding and although there is evidence from animal studies and reports to the National Technical Information Service (NTIS), it is difficult to apply it to humans.

Rasha recommended that anyone who needed medication should discuss their individual circumstances with their GP.

The main treatment option for those of us who suffer from pouchitis is antibiotics, said Rasha. In acute cases, treatment usually lasted for several weeks while more resistant outbreaks could go on for several months. Sometimes a combination of one or more antibiotics could help cope with a bout of pouchitis, she said.

Anyone suffering from pouchitis should take their antibiotics regularly and always complete their courses of treatment to make sure they reap the full benefits, said Rasha.

An alternative approach was to use Probiotics VSL which contains eight different strains of bacteria. "It may be useful for maintaining remission in more chronic cases and could be used as an alternative to long-term antibiotics," she said.

Meanwhile, pouch-holders who want to reduce their bowel movements, frequency and volume could take up to 16mg of Loperamide (generally more favourable than Codeine as it does not cause drowsiness) and 30-60mg of Codeine four times a day, said Rasha. Both drugs should be taken 30 minutes to an hour before eating to allow them to work properly, added the St Mark's pharmacist.

Why your pouch nurse is both a listener and go-between

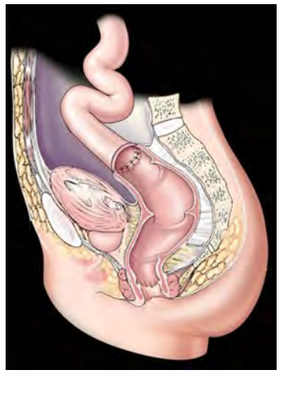
If you are having problems with your pouch or are considering having surgery, who can you turn to? Look no further than your pouch nurse, said **Lisa Allison**, RLG chair and St Mark's clinical pouch nurse specialist, in her talk "Pouch complications and the role of the pouch nurse".

For your pouch nurse acts as a listener, adviser, interpreter and go-between. She – or he – also has the know-how and expertise to:

1. Listen to your individual problems or needs and give you the reassurance of knowing you have a long-term point-of-contact by phone or email;
2. Give you realistic expectations of how your pouch functions and how it will affect your lifestyle;
3. Give you a full understanding of the process of pouch surgery and after-care as well as the best ways to cope with a stoma;
4. Assess your individual needs as a pouch-owner;
5. Explain the various stages that follow a pouch operation.

The main methods of referral for patients who need hospital treatment, advice or possibly further surgery are a GP's letter, your hospital consultant or a pouch support group like the Red Lion Group, said Lisa.

Pouch-holders could then turn to their pouch nurse if they had such problems as emptying difficulties, soreness, itching or burning, leakage, frequency, fatigue and, of course, pouchitis.



The nurse would then suggest, or help to arrange, an initial investigation such as a blood test, an abdominal examination or a pouchoscopy. Further investigation might then be needed such as an MRI scan, a pouchogram or a small bowel follow-through.

In conclusion, the success or failure of a pouch tends to be subjective, said Lisa. We all face varying circumstances and have different outlooks on life. While some people can withstand problems with an element of stoicism, others are less resilient.

She said recent studies revealed that a third of patients are pleased with their pouch and its function, a third can "manage their pouch and may need medical/surgical intervention but deem their pouch overall better than a permanent stoma" and a third have "problematic" pouches and consider opting for a permanent stoma.

A quirky little quiz

Why not test your general knowledge skills with this late summer teaser by Red Lion Group liaison officer **David Skinner**. The reader scoring the most points will win a £25 book token. So what are you waiting for?!

1. Name 10 countries with only four letters in their name? (You score one point for each)

2. Name five London Underground stations that begin with the letter 'U' (one point for each)

3. Which is the oldest club in the England football league?

4. Who is the president of football's international governing body FIFA ?

5. Name the only actor (the term includes actresses) to have won four Academy Awards or Oscars?

6. The Jets and the Sharks are the names of two gangs in which famous musical?

7. What is the popular name for space in the Star Trek series?

8. Name Wallace and Gromit's first feature film.

9. What was Margaret Thatcher's full maiden name?

10. What type of musical instrument is a moog?

11. Which band did Rod Stewart front in the 1960s?

12. Name the biggest-selling female recording artist ever?

13. The Sally Lunn teacake is named after a baker in which English city?

14. What is the name of a champagne bottle that holds the equivalent of 16 standard bottles?

15. Name the shelf of muscle that lies beneath the ribcage?

16. Barwick Green is the theme tune of which radio programme?

17. Rigsby was the central character in which 1970s sitcom?

18. Magwitch is the name of a character in which Charles Dickens novel?

Treasurer's report

In this her final treasurer's report, Marjorie Watts thanked Brian Withers for auditing the 2012 accounts.

Subscription income in 2012 was £24 less than in 2011 due to a small reduction in membership – 247 compared with 252 at the end of 2011. She gave special thanks to the 163 members who pay their subscriptions by standing order as it enables us to claim gift aid.

Although donations were lower this year than last, Marjorie thanked all those who gave us financial support in 2012.

Income from interest continues to be low due to the low interest rates and also the smaller sum of money on deposit this year. The Gift Aid we received in 2012 was £561.55 compared with £618 in 2011. Marjorie encouraged all members who are taxpayers to complete gift aid forms if they haven't already done so as it helps the Red Lion Group's coffers and doesn't cost any money.

The income from the registration and raffle at the 2012 AGM and Information Day was higher than last year – mainly because of the increase in the registration cost.

One of 2012's highlights was the fund-raising efforts of Red Lion member Jane Dalzell and her friend Jan Miller who ran the Great North Run in aid of the Red Lion Group in September. The pair managed to net a significant £737 and counting (the donations continued after the event). Marjorie gave a fulsome thank-you to the doughty pair for their outstanding contribution.

The AGM and committee meeting costs for 2012 were higher than last year mainly because of the cost of the buffet lunch. We managed to halve the £535 room hire fee we paid St Mark's Hospital in 2011 as they agreed to charge us a half-day fee of £262.50 instead of a full one. Apart from the AGM, two other face-to-face committee meetings were held plus four telephone meetings, said Marjorie.

The cost of printing and posting *Roar!* reflected the higher pagination of the two magazines – 12 and 18 pages – compared with two magazines of 8 and 12 pages in 2011. Postage and stationery in general were higher this year mainly due to the rising cost of postage. Letters to the RLG membership continue to be sent by Viapost, which is a time- and money-saving system.

The excess of income over expenditure for 2012 was £1,583.37 and the committee donated £2,500 to St Mark's Foundation for use by Sue Clark in pouch research.

Another £500 was donated to a Masters degree in pouch failure successfully completed by Zarah Perry-Woodford, St Mark's clinical pouch nurse specialist.

A 2012 deficit of £1,416.63 after donations, together with the balance brought forward at the start of 2012, resulted in a final balance of £5,619.66.

Marjorie wished Preash Lad, her successor as treasurer, the very best and encouraged members to give him all their support.

19. Name the Andrew Lloyd Webber musical released in 2004 that was adapted from a novel by Wilkie Collins.

20. In computing what does the 'U' stand for in USB?

21. Which English sovereign was known as the Merry Monarch?

22. From which language is the name "chutney" derived?

23. What is the name given to a young dragonfly?

24. What did wainwrights make in the Middle Ages?

25. On which river does the city of Middlesbrough stand?

26. What is the fifth letter in the Greek alphabet?

27. In astronomy what are white dwarfs and red giants?

28. Who was leader of UKIP before Nigel Farage?

29. In which city is the World Health Organisation (WHO) based?

30. What type of animal lives in a lodge?

31. The painter Henri Matisse, the revolutionary leader Che Guevara, the comedian John Cleese and the compere Jerry Springer are all university graduates in which subject?

32. Which famous figure recently announced his resignation in Latin?

33. Which snooker player is known as The Rocket?

34. Sesame Street is a fictional location in which city?

35. Which famous English author was originally known as Eric Blair?

36. How many capital cities can you name that begin and end with the same letter?

37. What does the name 'Q' stand for in Ian Fleming's James Bond books and films?

38. Which band is named after a South African football team?

39. Who wrote the 1998 novel About A Boy which was later made into a film?

40. What type of food is shitake?

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

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