



ROAR!

ISSUE 46 • CHRISTMAS 2012

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

Lewis Moody on coping with colitis — see page 8

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, Mrs Marjorie Watts, 11 Meadow Way, Upminster, Essex, RM14 3AA**

Front cover: Former England rugby captain Lewis Moody

Back cover: *Gloriana in Butler's Wharf* by Christine Lawton



Let's play a game of spot the semi-colon. I'd like you to try and guess how many of the super-fit athletes we saw compete in the recent London Olympics have either uc or FAP? I'm going to make a very unscientific guess and say 200 to 300. What do you think? I'd love to hear your ideas and views at cbrowne@brownmedia.co.uk.

Some of you may have watched the great Olympic rower Sir Steven Redgrave who won five gold medals while suffering from both uc and diabetes. A heroic sportsman and an example to all of us. Two other famous sports stars who recently "came out" about their struggles with uc are the Manchester United and Scotland midfielder Darren Fletcher and the former England rugby captain Lewis "Mad Dog" Moody.

The Man U supporters among us (although, as an earnest Liverpool follower, I can't believe there are any!) will know how Fletcher had to stop playing for 10 months due to spells of ulcerative colitis. Though he is now training again and recently rejoined the Scottish football squad. And, for the rugby-fanciers among us, we've included a piece about the ordeal of Lewis Moody.

You'll find some of the other stories in this issue reflect the indomitable will that helps people overcome obstacles in their lives and livelihoods. Read about our own Marathon Man, Andrew Millis, and his experiences in Helsinki and the two Jans from Cumbria who managed to finish the Great North Run, the world's most famous half marathon, in just over three hours.

On a more personal note, some of you will have read the moving story of Roz Prescott who had a serious attack of uc just after giving birth to her first

baby. Roz very kindly agreed to talk to us at the May Information Day and you can read her refreshingly honest and moving account here as well.

Childbirth cheer

Talking of which, pregnancy and childbirth have been much-discussed topics at St Mark's and many

other intestinal centres for some time. One recent survey claimed that women have a 50 per cent less-than-normal chance of having a baby after a pouch operation. But the figure is certainly not conclusive, and there haven't yet been any official statistics on pouch operations and childbirth.

Some more reassuring news on the subject came from St Mark's colorectal consultant Janindra Waruavitame at the May Information Day. In his talk, Janindra said women who have keyhole surgery have a greater chance of giving birth than those who have open pouch operations.

Janindra's evidence was based on a poll of 100 patients in Belgian and Dutch hospitals. He also gave us some fascinating insights into the pros and cons of keyhole – or laparoscopic to use

its official title – surgery and you can read his findings in this issue of *Roar!*

The rest of Information Day was an unqualified success too. Our two dynamic ideas people, Zarah Perry-Woodford and Sarah Bowes-Phipps, wanted a more social, hands-on approach than before...and it worked, dear readers, it worked!

Starting at midday with a lavish spread of soups, sandwiches and devilish cakes, we all got to know each other before the various talks and workshops began. The committee wore scarlet Red Lion-logo'd T-shirts (as you do), the sun shone (as it always seems to on Info Days) and at least 80 members, partners, friends, families and health-care professionals turned up.

Then just to add a bit of pizza-zz (sorry pun purists!) to the day, a group of us ended the day with an entertaining hour or two at the Harrow branch of Pizza Express.

You can read all about it, including reports on the speakers and the highlights of the day, on the next few pages.

Wonders of the web

We've been improving and updating the website. So do log on to www.redliongroup.org and send us your ideas for articles and content. Have a wonderful end-of-season and I look forward to seeing many of you at the next Information Day.

Christopher Browne

Did you know...

St Mark's was founded in 1835 by Frederick Salmon in a small room at Number 11 Aldersgate Street, near Smithfield Market in central London. The tiny hospital had just seven beds and operations were carried out on butchers' tables from Smithfield.

It was known as 'The Infirmary for the Relief of the Poor Afflicted with Fistula and other Diseases of the Rectum' and treated 130 patients in its first year. One of the first patients was the novelist Charles Dickens who had a fistula due to long spells of sitting at his desk and 'doing too much writing'.

Three years later patient numbers trebled, and the hospital moved to larger premises in London's Charterhouse Square, later transferring to City Road where it was opened on 25 April 1854 – St Mark's Day.



St. Mark's patient Charles Dickens: "Too much writing" caused fistula.

How Roz overcame the fear factor

The daughter-in-law of former deputy prime minister John Prescott tells how her problems and suffering helped give her the zest to campaign for openness and honesty about colon problems

The doubts, worries and fears many of us have known during spells of ulcerative colitis (uc) and FAP were vividly described by BBC producer Roz Prescott at this year's Information Day.

In a refreshingly personal and honest talk, Roz referred to the often life-changing effects these illnesses can have on our families, careers, daily activities and, of course, ourselves.

The London-based broadcaster and colitis campaigner said that when she was first diagnosed with uc, she was totally unprepared for the frequency, insomnia, pain and loss of appetite the condition could create. And her first bout occurred soon after she had been promoted at work.

"I wanted to prove myself, so I was working 24 hours a day, seven days a week," said Roz. She and her husband, David, were also moving house and canvassing at weekends as he was a candidate for a parliamentary seat.

Roz said her only real pleasure was the "big glass of red wine" she enjoyed to help her relax in the evenings.

After a long spell of uc, Roz was told by her GP to take six months off work while her symptoms were treated. Suddenly the emotional effects of her illness took hold. She began to lose her confidence and also suffered long spells of loneliness with no one to discuss her problems with. "A lot of the time I did not even want to talk about [my difficulties] with my husband," she said.

Then soon after Roz went back to

work, she discovered she was pregnant and, after an incident-free nine months, gave birth to a baby girl – much to her and David's delight, she said.

However, a week later Roz had another, more serious outbreak of uc. She was admitted to hospital where her medical team told her she would have to have an operation to remove her colon.



It was one of the most poignant moments in her life, she said. After telling her consultant she hated the very idea of surgery and pouches, he said: 'Look, no colon, no colitis. You have suffered intensely for the last year or so and you will not have this again.' The message managed to get through.

After the operation, it took Roz a while to get used to her stoma – "then I started to feel good again and it was great not to have to go to the toilet all the time, and be sick all the time, and be careful of what I had to eat all the time...I could eat just anything

which was great".

Twelve months later Roz had her stoma closed and a pouch fitted. "I thought my husband would take one look at me and run for the hills, but he was fantastic in every way. He deserves an award," she said.

Not long afterwards, Roz was asked to be an ambassador for Crohn's and Colitis UK. "There was a point when I did not want to discuss with anyone my personal business and how I felt, but people have helped me, my family helped me and because other people helped me, I wanted to talk, I wanted to raise funds and I wanted to communicate," she said.

"There are so many other things I want to do now to help make people aware of this disease, to get it noticed by the Government as well, I guess. You hear about diabetes, you hear about cancer a lot, there is a lot of funding, a lot of support. Well, we need to hear a lot more about IBD. That is why I accepted to become an ambassador.

Roz's family, including her father-in-law John Prescott the former Labour deputy prime minister, have since agreed to become ambassadors. "I was hugely honoured...we are a family of ambassadors. I am always dragging John Prescott to various meetings.

"He is absolutely fantastic because he has seen first-hand what I have been through and he was a great support. Both my in-laws have been, and of course my parents. Without them, I definitely would not be here today," she said.

New committee officers

We have a new chair! Lisa Allison, whom many of you know in her day job as a St Mark's clinical nurse specialist, agreed to take on the role at this year's Information Day. We also welcomed Red Lion Group member Susan Burrows to the committee as our new membership secretary.

RLG member Preash Lad (lad_11@hotmail.com) has been co-opted onto the committee as successor to treasurer Marjorie Watts (marjwatts@gmail.com). "Marje" will continue in the

post until early next year. We are very grateful to Marje for her dedication and hard work as treasurer.

We'll miss her timely advice and pithy comments at committee meetings and her hands-on approach to everything she does from helping to organise Information Day, welcoming new members and supervising the database.

We'll also miss the ever-cheerful Andy Watts who was a more-than-able helper and advisor at Information Day.



Lisa Allison

LETTERS

Hi

I'm writing to hopefully help other Red Lion readers see a little light at the end of what can sometimes be a very long and dark tunnel.

Just after I had my two children, I had my colon removed in December 1997 when I was aged 28 due to ulcerative colitis, and in the next couple of years I had my pouch formed and stoma removed. Things didn't go exactly to plan, with infection setting in, so it was back to the theatre again that same night for a temporary stoma.

A few months later, when my health had improved, I had my pouch linked up again. Then in 2000, I realised I was becoming a little depressed

In 2004 I retrained as a special needs classroom assistant and returned to work. Independently of this I was also asked to teach a beginners line dance class in the evenings. This soon grew and I now teach two nights a week with classes ranging from beginners to intermediate level. Being blessed with another chance in life, thanks to my wonderful surgeon Mr Roy Maxwell and his team at the Royal Victoria Hospital, Belfast, I decided that I would like to give a little something back.

So each year my line dance clubs – Brookmount Dance Ranch and Belsize Kickers – elect a local charity to donate money to. One of the first was the Royal Victoria Hospital

ever-supportive husband, Charlie, for gaining sponsorship for cycling 100 miles around Lough Neagh!

Every year the generosity of club members, their friends and families amazes me. This latest effort brought our fundraising total to £15,910! Their support has helped change the lives of many people in Northern Ireland.

I know we all suffer with this horrible disease, some a lot more than others. And we're often not understood by those who haven't experienced its cruelty. Sometimes there is little we can do to control this. But what we can control is how we deal with it.

Sharon Hendron

Lisburn, Northern Ireland



Members of Brookmount Dance Ranch and Belsize Kickers presenting a cheque for £2,800 to the Children's Heartbeat Trust

so I joined a local line dance class. I soon found that this really lifted my moods and the physical exercise was good for the recovery.

Yes, I had my fair share of problems e.g. the dreaded pouchitis on countless occasions, with reactive arthritis; numerous bowel obstructions where I had to fast for 48 hours at a time in order to 'rest' my bowel and to let it unravel; and a complete hysterectomy in 2003 when the pouch pressing on my womb, and adhesions surrounding it, caused too much pain. But generally I came to rely on my line dancing to keep me healthy in both mind and body.

Colo-Rectal Fund. Our nominated charity for 2011-2012 was the Children's Heartbeat Trust which provides practical and emotional support to parents and families of children with heart disease in Northern Ireland. We were thrilled to present them with a cheque for £2,800 which we raised with proceeds from line dance party nights, demonstrations, a collection of 20ps, a hosted birthday party and a Cash Not Cards appeal.

A special thank you must go to one of my dancers, Ross McNeill, who suffered meningitis as a child which has left him with speech, hearing and balance problems, and my

Dear Editor

A very successful Information Day on 12 May. One (of many) great satisfactions for me, triggered no doubt by the availability of the excellent food, was to hear in the toilets that I am not the only pouch owner to make a loud reverberating noise when I empty my pouch. Maybe it's the soft tissue that vibrates. Maybe it is the fluid output mixed in with plenty of gas that causes the noise.

I have seldom been able to discuss this with people before, so it was good to hear proof I'm not alone. Some find it very embarrassing. It is possible to feel proud that we have had so much surgery, removing seemingly irreplaceable parts, and yet we can still use the toilet normally.

Does anyone have any techniques to 'quieten' the noise? The only technique I have is to use plenty of toilet paper and hold it against the orifice to act as a baffle. But it is not very pleasant, and it can serve to re-direct the output in an unwanted direction.

Once I was in a pub and went to the toilet. I could hear from the trap a number of drinkers at the urinals. On hearing my noise, they burst out laughing. One said, in the direction of the trap: 'F***ing hell, mate, you got a problem there'. They went quiet (probably embarrassed) when I replied 'considering I have no large intestines or rectum, it's working very well, thanks'.

I was in the toilet at home when my son brought home for the first time his new girlfriend. As they walked past

the toilet into the kitchen, I had to do all I could to muffle my output.

But it isn't always a problem. It can be a useful tool. I was once in a toilet at work when I heard in the trap next to me someone using his mobile phone and talking about his department's profit and loss account. I summoned up all my inner strength for a fast expulsion of the contents of my pouch, with as much resonance as I could muster. I could be certain my neighbour with his accountant on the phone would be able to hear every tone. And yes, it worked! Within a few seconds, my neighbour made an awkward finish to his call. Hopefully that will stop him and his disgusting practice of using his mobile phone in the toilet.

Name and address supplied.

Here are two replies to the continence pads letter in the last issue of Roar!

Dear Editor

I was very interested to read the letter *How to avoid the football effect* about difficulties with continence pads in the Spring 2012 *Roar!* as I was in the same position as the writer a few years ago.

I am now writing to say that I think I may be able to help. Most pads are both male and female and are made in many different styles and sizes. So,

a month to find the right pads for me. Some were too big, while others were too small. Some of them were not wide enough in the crutch and there was also an elasticated-style strip that if you do have a heavy leak problem, slows down the sideways ooze. Finally, I had to decide whether I needed to wear a different pad at night as I did with my last supplier.

This, dear reader, is how I solved my pad problem.

I had a very understanding GP who referred me to my local hospital's continence care nurse. She called to see me within a few days with a range of pads to show me, arranging for size samples to be sent to me to try out for a week or two. When I had tested the samples for a couple of weeks, and decided which suited me best, she placed my first order for me.

At the start I would have four deliveries a year and four pads a day, that's now changed to three deliveries a year and three pads a day. These orders are sent by the manufacturer, and the account is settled by the area health authority who change their supplier every few years, hence my problem last year.

There are two main suppliers, Tena and Attends. You can view the ranges on their websites www.tenadirect.co.uk and www.attendslifestyles.co.uk. You can

a comprehensive range of pads which I have to buy myself as my local area health NHS trust, Hertfordshire, has gone back to Attends. The Trust also has a continence care support office which is open three days a week, and my local council supplies and collects bags called Tiger Sacks for soiled pads to be disposed of safely.

I understand that some area health NHS trusts do not work the same way as Hertfordshire, while other areas issue vouchers that work like a prescription, so that you can get your order from your chemist.

I do hope that this will be of help to you. Your letter brought back memories of those horrible days and nights when my bag and stoma kept parting company – and my poor stoma nurse was getting more and more stressed trying to find something to keep them together. So how I'd have got on over these years without Professor John Nicholls (Sue Clark's predecessor at St Mark's) and my pouch, I dread to think.

Bill Shepherd

Red Lion Group member

Dear Editor

I was so so pleased to read your article as I thought I was the only one this happened to!!!! It's not something you can talk about with anyone and, being a widow, I do not even have a partner to share it with.

The leakage tends to be spasmodic – I have never figured out why but, yes, it happens to me quite a lot – I usually wake to the feeling of 'ugh – oh no, it's happened again!' So I wear pads. I use Always extra long, which mop up some, but never all, of the accident. Some nights it means a complete change of sheets and sometimes even the duvet as well. Apart from the inconvenience and lack of sleep (!!!) I can deal with this at home.

My biggest problem is going away to stay with someone. Every winter I spend four weeks in New Zealand visiting my daughter. I cannot bring myself to tell her what might happen so I wear extra pants, extra pads and even extra security with flannels shoved down there! Then there is the problem of what to do with the soiled articles... and the smell? Hidden away in lots of plastic bags and then deposited in a public toilet as soon as I can, but it does ruin my holidays!!! Every night



without a load of samples and good help and advice, it's unlikely that you will get the one that suits you best.

Let me explain. I've been using pads for about six years now, and about this time last year I was given a new supplier. However it took more than

also buy online or by phone. Attends does an endless roll (it's actually about 30 feet long) called Coldex which costs £5.20 (if you are VAT exempt) and you can cut it to the length you want. I use this as it is easier to carry and slip in to protect the main pad. Tena provides

is a will it/won't it happen tonight.

Any tips you could share would be gratefully received, and, most of all, thanks for writing the article! I would be interested in how many others this happens to, and how they cope.

Best regards

Marilyn Hargraves

Red Lion Group member

Dear Editor

After reading the Letters in issue 45 of *Roar!* I feel lucky to have had such a successful pouch for the last 21 years. This also means my hysterectomy experience may not be the same as that

of the poor lady who wishes to hear from people who've had one (see the letter "Can anyone help?").

I had the hysterectomy five years after my pouch op. I was also low on iron and had a total hysterectomy (ovaries as well). The fact of having a pouch did not seem to make any difference to my surgeon – as no extra precautions were taken. I assume this was because I was no different to anyone else apart from having less in my abdomen than most!

The op was successful. He reopened the bottom of the colostomy scar. I can't remember the name of the

surgeon (even though I'll never forget the name of Professor John Nicholls, former clinical director and colorectal surgeon at St Mark's Hospital). It was performed at my local hospital, Queen Mary's Hospital, Sidcup.

I hope this may offer a glimmer of hope to the lady who wrote the letter. Wishing her all the best!

PS I meant to say that during my hysterectomy the surgeon didn't touch the pouch so it is just the same as before. I wonder why they say they will have to remove this lady's pouch?

Sandra Darvill

Red Lion Group member

Treasurer's report

The following report was presented at the Red Lion Group Annual General Meeting on 12 May 2012

Hello sorry I am not able to be with you this year to present this Treasurer's Report, and thanks to one of my committee colleagues for reading this to you.

I would like to thank Brian Withers for auditing the accounts again this year, it is so much appreciated.

I also thank John White, the previous Treasurer, for his continued help, it is so good to know he is at the end of the telephone.

Now I hope you have a copy of the accounts for the year ended 31st December 2011, so you can join us in looking through them.

Income

Subscription income in 2011 was £216 less than in 2010, caused by a small reduction in membership which was 252 compared with 276 at the end of 2010.

Thank you to the 160 members who pay by standing order, this continues to be most helpful, and I would like other members to do the same.

Donations were lower this year but we would like to thank everyone else who has been able to support the work of the Red Lion Group in this way.

The proceeds from the sale of Red Lion merchandise were very low as there was little for sale.

Income from interest is still very low due to the continued low rates during 2011. The Gift Aid received for 2011 was £618.90 compared with £690 for 2010 (as shown by the extra £77 for the 2010 period). I would like

to encourage you to complete a Gift Aid form, if you are a UK tax payer and if you have not already done so. This will benefit the Red Lion Group and does not cost you anything.

The Information Day and AGM registration and raffle income in 2011 was a decrease on the previous year due to a reduction in attendance.

In September 2011 Jane Dalzell the aunt of one of our members was generous enough to run in the Great



North Run in aid of the RLG and raised more than £511. Thank you so much Jane.

Expenditure

The cost of the AGM and Meetings shows an increase for 2011 due mainly to the cost of £535 for hiring rooms for the AGM and Information Day at St Mark's, previously these facilities having been made available free of charge. Apart from the AGM one other face to face Committee Meeting was held in August and Telephone Committee Meetings were held in March, June, September and December.

The cost of printing and postage of *Roar* reflects the cost of the two magazines produced in 2011 of 8 and 12 pages compared with one magazine in 2010 of 16 pages.

General postage and stationery shows an increase on last year. Letters are now sent by Viapost (a time and money saving system), they are not included with *Roar* and of course the rising costs of postage all combines to effect this increase.

No cost for this year's website www.redliongroup.org.

The Excess of Income over Expenditure for 2011 was £2,177.60 and your Committee has donated £5,000 to St Mark's Foundation for use in pouch research. £3,000 allocated to Jon Landy's Longitudinal Study and £2,000 for research of Miss Clark's choice.

The year's deficit of £2,822.40 after donation payment, together with the balance brought forward at the start of 2011, results in a final balance of £7,036.29.

Thank you for your attention if you have any questions I hope other committee members will be able to answer them. Otherwise please email me at treasurer@redliongroup.org

I have advised the Committee of my decision to stand down as Treasurer now but no later than 2013 AGM. Therefore, please think about stepping forward and playing your part in this group. I will be very happy to show anyone how I have managed this role for the past 8 years.

Marjorie Watts

Treasurer

How former England rugby skipper “Mad Dog” Moody coped with colitis

Lewis Moody discovered talking was the best remedy for bouts of uc – as this edited version of an interview on the BBC’s *Hardtalk* reveals

The former England rugby captain Lewis Moody was used to some tough battles on the pitch but none were to prove harder than coping with a bowel disease.

When symptoms of the condition

though this was a daily routine,” he told the *Hardtalk* programme.

Moody, known affectionately by team-mates and fans as “Mad Dog”, retired from rugby in March this year after a major shoulder injury.



first appeared, the rugby star put off going to the doctor for four weeks. Then once he was diagnosed he feared it would wreck his rugby career.

So he hid it from his team-mates – but the frequent need to visit the toilet was not always an easy thing to conceal. “That was really tough to be fair. I don’t know anyone that openly talks about their toilet habits.

“For a young man – I was 25 at the time – all of a sudden you are going to the loo 20 or 30 times a day. You are losing a relentless amount of blood and being a classic bloke I left it a month before I went to see the doctor even

He now supports the work of the charity Crohn’s and Colitis UK and urges other sufferers to get treatment quickly and to try to lift the taboo surrounding the subject.

He said: “It was very debilitating and humiliating as a young man because you expect it to be an old person’s disease but it is the complete opposite I have learnt since that most people are diagnosed under the age of 30.”

Communications gap

“For me not having any information was the hardest thing and trying

to hide it from my team-mates. I had such an array of injuries I didn’t want there to be another reason for the guys to say ‘well we are not going to be able to pick Lewis because he will never make it to the start of the game because he might have to run off to the loo’,” he said.

Covering the short distance from his home to the training ground could be a battle in itself. “I was struggling to leave the house sometimes. I only lived four minutes away from the training ground and sometimes I would have to plan my route so that I could stop three or four times en route just to go to the loo.

“Some of the poor people in the establishments on the way probably wondered what on earth was going on as I pulled in every morning,” said the former England captain.

Lewis was repeatedly injured during his 15-year career which led to an over-exposure to anti-inflammatories, antibiotics and painkillers. In his autobiography, he says the pressures of playing at the top and his proneness to injury may have contributed to his uc.

He now takes tablets daily and has a special diet and says being more open about his condition eventually made it easier to cope with. “I have to admit it was a couple of years until I told my good mates and they probably knew anyway because it was obvious. I had lost weight. I was gaunt.

“But it became much easier when I did tell the guys... That was one of the learning curves for me with the disease. The more I spoke about it, the easier it became.”



Question time

Here is a selection of the questions you put to Sue Clark, St Mark's consultant gastroenterology surgeon and Red Lion president, and Sue's answers

New pouches for old

If a pouch fails, can you have another fitted and what other options are there?

You can do. It depends on the reason it has failed. There are a whole load of factors. We can redo pouches sometimes. Sometimes it [the operation] is successful. Sometimes it is not.

Running on iron

If you have an iron deficiency and take iron pills and they have the effect of making you go even more, are there any alternatives?



Yes, but it is much better to do it with iron pills, if you can. Some people think Fibregal helps when you take iron tablets. Some people need only a very low dose, like one iron tablet every other day or something like that. There are also various different preparations it is worth trying, rather than just one kind of tablet. It is possible to give iron infusions but they have their own risks and we try to avoid that if we can.

I would like to make a comment on that, if I can. A lot of oral iron tablets are poorly tolerated and cause an awful lot of troublesome symptoms. Generally in inflammatory bowel disease patients, we are trying to move now to taking iron intravenously. We can do it very quickly. We have a little clinic set up on a Tuesday evening. Once a month, the patients come along in 10 to 15 minute slots. The safety profile of the latest medication is pretty good.

There is some good evidence that it gets the iron store beefed up a bit more and is a bit more robust without having the side-effects of tablets.

Do you have to belong to St Mark's?

You do for that, yes, or to be a member of our patient body, as it were.

Diet? It's all about the bacteria really

Has there been much recent research into diet?

Sue Clark said that while there had been no real work done on diet,



Sue Clarke

Just as everyone has their own individual DNA or genetic fingerprint, we all have a bacterial fingerprint. Here too everyone is different.

"The things that are good for you, fruit and vegetables, are good for your colon and as you no longer have a colon or rectum, you do not need them and they tend to increase the pouch's output. Therefore we advise you against having lots of fruit and vegetables.

"...for most blokes, it is marvellous because they can have their own white bread and their white cereals and they do not have to eat their greens. But actually it is a struggle for people who are vegetarian or who actually like eating lots of salads and vegetables.

"Bacteria are interesting because of the way pouches behave and their problems are actually related to bacteria which is very related to food too," added Sue Clark.



Keep taking the tablets

Drugs are an ideal delaying tactic for colon surgery. So which ones should we take and when? St Mark's gastroenterologist Ailsa Hart has the answers

Antibiotics, steroids and other recommended drugs will always help uc sufferers in the short term. However in the long term, surgery is usually the answer, Ailsa Hart told Red Lion members and other delegates at the 2012 Information Day.

"Acute severe ulcerative colitis (uc) is exactly what it says. It happens very quickly and it is awful, it is a horrid disease," she said. "Fifteen per cent of people [who have uc] will have an acute severe attack and will need to come into hospital at some point, and 20 per cent of first attacks are acute or severe in nature," said Ailsa.

So what can St Mark's offer the patient who has a milder version of uc, FAP or Crohn's Disease? The answer is to attend daily IBD clinics as well as young people's – or transition – clinics that help young sufferers transfer from a paediatric to an adult setting.

The St Mark's IBD clinic's team is led by IBD specialist nurse Marian O'Connor who won the Nurse of the Year award in the prestigious Gastrointestinal Nursing – or GI 2012 – awards.

So how do St Mark's and other specialist hospitals deal with more severe cases of ulcerative colitis? About two-thirds to three-quarters of sufferers respond well to drugs and antibiotics, managing to "get the sting

out of that acute, horrible attack, and getting it slightly more controlled so that surgery can be more safely done at a later stage," said Ailsa.

Others do not respond to those first five days of steroids. So what then? "As a physician, you have two drugs to think about. One is cyclosporine and the other is infliximab," said Ailsa.

Around half of patients who re-

If a patient doesn't react to steroids, they can choose either cyclosporine or infliximab, and if these two drugs don't work, they can opt to have surgery.

Each patient has an individual 'seesaw', said Ailsa, which tends to tip at a crucial moment in their lives. "Some people, in their heart of hearts, have tried a lot of those medical drugs

and are ready for surgery... they sort of feel prepared, psychologically as well as anything else, that this is the route they want to go down," she said.

Others do not wish to have any more side effects [from the drugs] and think: 'OK, now my seesaw has tipped and I want the surgical option sooner'. "They know what is involved and they knowabout what it means to have a pouch...the risks and the likely outcomes of longer-term follow-up," she said.

So what is the best option for pouchitis sufferers and patients with medically problematic pouches? Antibiotics are the key way to deal with these, said Ailsa.

Another option was probiotics – or types of bacteria that fight other bacteria in the gut – while St Mark's has also been experimenting with faecal transplants in patients, she said. However their effectiveness has yet to be proved, said Ailsa.



spond well to cyclosporine or infliximab will avoid a pouch or ileostomy operation for around three years. If a sufferer is at a stage when their colon is crucial to their career and circumstances, the drugs can be an ideal option and postpone an operation to a more suitable time, she said.

Dynamic duo raise almost £750 for RLG

Jane Dalziell and Jan Miller – or the two Jans as they are known – from Cumbria competed in the Bupa Great North Run, from Newcastle to South Shields in North East UK on 16 September this year.

The intrepid duo came in together in three hours and seven minutes – a pretty impressive time by anyone's standards, raising £737.30 for the Red Lion Group.

Jan said after the race: "There was a light shower of rain at the beginning.

However it cleared up and the general conditions were good. We decided to finish the race together, however we were a little disappointed not to run it in under three hours."

It was a repeat performance for 68-year-old Jane as she raised £511 for the Red Lion Group after finishing the 13.1 mile race, the world's most famous half-marathon, last year.

Congratulations to both of you. We very much appreciate your efforts and very kind donations to the group.



Jan Miller (left) and Jane Dalziell before the race

Peeping through the keyhole

Women are more likely to give birth after keyhole surgery than after an open operation. That is the startling revelation of Janindra Waruavitarne, St Mark's consultant colorectal surgeon

A recent poll of 100 women shows that those who have laparoscopic surgery have a higher chance of getting pregnant than those who opt for more traditional-style operations, Janindra told 65 delegates and patients at the 2012 Information Day.

The evidence was “really hot off the press”, he said, and based on surgical tests made on patients in hospitals in the Netherlands and Belgium.

While it lowers a woman's fertility and chances of getting pregnant, open surgery reduces it further. This is due to adhesions around the fallopian tubes which affect the free floating of the ovaries, Janindra pointed out.

The reason for the higher fertility rate after keyhole or laparoscopic surgery was “purely because with laparoscopic surgery you do not form [the same] adhesions and the fallopian tubes and ovaries can remain free floating,” he said.

Encouraging news indeed. Another benefit of keyhole surgery, said Janindra, is that patients do not suffer so much after their operations.

The pain is far less in the short term because the surgical cuts are small “and you can usually go home somewhere between five to six days after the surgery”, said Janindra.

Sometimes patients could even leave hospital after only three days as they have enough time to get used to their stomas and pain is “not a huge issue”, he said.

Fewer patients find their bowel stops working and then suffer vomiting too. “It is not to say it does not happen but when you take a large group of patients, it is much less. Those are definite advantages. The recovery is much faster, there is much less pain relief used and the bowel function returns quicker as well,” said Janindra.

It is size that is the main difference between keyhole surgery and the more traditional open version, said Janindra. “We are working to a very small incision” and surgeons need to put gas inside the stomach so they can see the colon from inside, he said.

Surgical teams needed a “lot of instruments” as well as telescopes and cameras and the operation is fed back to a television screen and “numerous different television screens so we can see various parts of the body,” said the St Mark's consultant.

on men – who have narrower pelvises than women, said Janindra.

One snag that can occur during keyhole surgery, he said, is when the pouch is joined to the anus and the vagina gets caught between the two, causing a fistula in the vagina. Although when surgeons need to separate the fistula “they will get a clear view which will help to minimise the problem”, said Janindra.

Keyhole surgery also takes longer than open operations. A one-stage pouch using laparoscopic surgery takes



Surgeons then made a series of ports – or small reservoir areas – in different locations, placing a camera in one of them. Then they perform the operation to remove the colon. “In a sense we are doing the same operation as the old [method], but we are doing it through a different approach,” he said with a much smaller incision – “about three centimetres” – than in the open surgery method.

Laparoscopic surgeons also say they get a much better view of the pelvis which is essential when operating

five to six hours – “a lot longer” than an open operation, he said.

While using keyhole surgery for a three-stage pouch, it takes two-and-a-half hours to remove the colon and about three-and-a-half hours for the second stage. Janindra didn't mention the third or closure stage but we can assume it would be longer than traditional open surgery.

“We get a little faster as time goes on but in general it [laparoscopic surgery] is not like an hour-long operation,” he said.

How marathon running affects my pouch

Red Lion vice chairman Andrew Millis reveals how he manages his health when competing in marathons

I have a ridiculous hobby of running marathons. I don't have a lot of support from my family (more accurately, I don't have any support from my family) and one of the reasons is because my wife believes that after I have been out for a long run, I spend a lot more time in the toilet (or even more time in the toilet). While I play it down and deny it, she's right – I do have a very noticeable flare-up of my pouchitis after running. This leads to more weight loss that I struggle to put back on.

So when I say one or two evenings a week: "I am just going out for a quiet jog round the block," she'll say: "That'll do you good!" thinking I'll spend the rest of the evening in the toilet. The "block" can be an eight mile loop of my local town, Fleet in Surrey, but "going for a quiet jog" seems the best thing to say.

Keen to understand these flare-ups a little better, I consulted Zahrah Perry-Woodford, St Mark's clinical nurse specialist, who said that my ongoing pouchitis is caused by my immune system being unable to accept the normal levels of bacteria in the pouch and attacking it in a similar way it did when I had ulcerative pouchitis. But why is it so much worse after running? Is it likely to be due to a weakened body?

After talking this over with a friend of mine who is a senior paramedic, he sent me an article which provided quite a lot of information. It described research that followed a number of marathon runners from their 20s until middle age, and studied the effect on their bodies. The article divided the impact of marathon running into five categories: bone, muscle, cardiac

fitness, immune system and mental well-being. The bone section found "no lasting evidence of structural change following a marathon". The muscle section also had no concerns, as long as the runner was able to warm up and warm down, with stretching,

that immediately after running, the immune system is in high gear, for whatever reason, ... suggesting a stronger immune system as a result of exercise". I have concluded it is this which causes a flare up of pouchitis, if a similar condition caused the ulcerative

colitis in the first place – although the only running I did when I had uc was short dashes to the toilet!

The report said about the 15 marathon runners that were monitored for 29 years: "A lifetime of regular physical activity is associated with desirable physical and mental health.". I'll drink to that.

To continue my research, on 16 August this year I flew out to Finland, to take part in the Helsinki Marathon on the 18th. I have never been to Helsinki, and am happy that I did. It's not quite as stunning as Stockholm, but it is nevertheless a clean, quietly welcoming, peaceful place to go. There is very little graffiti, and while everyone looks very conventional, I did of course see some lads with their caps on

back to front and some

girls I wouldn't have wanted my son to bring home. Everyone seems very law-abiding, and drives very considerately.

There are some lovely buildings, particularly the magnificent cathedral which dominates the skyline from the harbour. There is a very small underground system, a good bus and tram network with easy maps, cheap tickets, and a fine central railway station which has only four or five platforms (compare that capacity with



Andrew Millis mid-race

before and after running. In the section of cardiac fitness, it noted: "Risk of sudden cardiac death in runners with potentially lethal cardiac disease was only 1 in 50,000. It is as little as 1/100th the annual overall risk associated with living, either with or without heart disease.".

It is the immune system section that is the most telling. It says: "The immune system is put on overtime due to running" and "it would seem

London's). There is a regular market in the main harbour, where several stalls were frying huge salmon and serving meals accompanied by new potatoes and vegetables. I had a good meal for €10 (£8) which I found good value, and there was a lot of fish. The other highlight while I was there was a 1½ hour boat trip, which I enjoyed immensely.

The marathon started, unusually, at 3 o'clock on Saturday afternoon.

I thought this might be an advantage, compared to almost all other marathons which start on Sunday morning. A pouch owner definitely has to start a morning marathon without any breakfast. But an afternoon marathon might allow me to have some breakfast and get rid of it before the start. WRONG! I needed the toilet twice during the run. The second time I was a bit, dare I say, desperate, and although there were plenty of marshals around, none of them seemed to understand "Toilet? Where? How far?". Of course, if you were buying something from them, the local people could speak English fluently (in Helsinki, signs and menus were in four languages, Finnish, Swedish, English and Russian, in that order).

Considering Helsinki is only a couple of hours drive from the Arctic Circle, and in winter the sea in the harbour freezes two foot thick (the harbour cruise points out their fleet of ice breakers), I didn't expect 26C that afternoon. It was a freak heat wave that I didn't want. Although the forecast was rain that afternoon, we never had any. I craved for some cooling rain. One bridge we crossed was a long bridge which had traffic on it separated from runners only by cones, and the sun was beating down on the concrete and felt like cooking us. I walked across that bridge. In fact that was after about 19 miles, and I had hit "the wall" (muscles ran out of



Milling crowds of marathon runners

glycogen) pretty hard. I did a lot of walking after that. There were plenty of stalls offering drinks and one was trying to peddle large pickled gherkins! I saw one on the ground and it looked like some massive slug. What is so beneficial about gherkins that you need them when running marathons? No idea.

Two miles from the finish I was walking with someone with whom I managed half a conversation, though what nationality he was, I didn't know. He had some sort of foot problem. I said "You run, I run" and with that we encouraged ourselves along. The finish was in their Olympic Stadium and I passed the line in 3 hours 40 minutes from the start, which was a bit disappointing but considering

how many other runners were throwing up after finishing, probably from heat exhaustion maybe I didn't do too badly. My watch said 26.5 miles. As for monitoring the effects on my pouch, I was too distracted by my wrecked legs. I only had a quarter mile to walk back to the hotel (whose location was very carefully chosen!). Thanks to my union flag vest and shorts, I heard a "Well done team GB" as I walked home – that was nice. Someone else said "Thanks for doing the Olympics!".

The full article can be seen at sportsmed.info/articles/marathonrunning.html



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