# ROAR! ISSUE NUMBER



# ISSUE 50 • AUTUMN 2015

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.

### BEDFORDSHIRE

Carol George Sandy 01767 263092

## **BRISTOL/AVON**

David Mair Bristol 0117 922 1906 07719 524 324

# CLEVELAND & NORTH YORKSHIRE

Christine Jackson Saltburn by the Sea 01947 840742 chrisjacks1960@btinternet.com

# ESSEX

Peter Zammit Benfleet 01702 551501

# HERTFORDSHIRE

Susan Burrows St Albans 01727 869709

# NORFOLK

Sandy Hyams King's Lynn 01485 542380

# NORTHERN IRELAND

Sharon Hendron Lisburn 02892 661559

# WILTSHIRE & DORSET

Bernadette Thorn Salisbury 01722 327388

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# **Please support the Red Lion Group**

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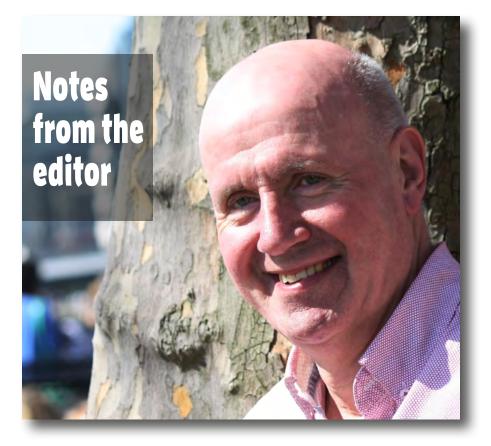


All donations, however small, towards expanding the work of the group will be gratefully received. If you would like to send a donation please make your cheque payable to The Red Lion Group and send it to: **The Red** 

# Lion Group Treasurer, Paul Mulot, 103 Whitehill Road, Hitchin, SG4 9HT.

Page 6 Pills by freeimages.com user Cristian Bender from Brazil Page 7 Cutlery on red plate by yenhoon Page 8 Fight with Water by Joachim Aagaard Nielsen from Denmark Page 9 Pencil by Jean Scheijen from the Netherlands Page 13 Fungus Porcini by Fabio Pusterla from Italy Back cover: Chelsea Flower Show 2015 by Christine Lawton

## Roar! • Issue 50 • Autumn 2015



elcome to the 50th issue of Roar, your newsy, informative and we hope entertaining magazine about pouches and how to look after them.

Tim Rogers and I can't believe where the time's gone since those early days of *Roar!* just over 20 years ago. Though many of you, the members, have changed or moved on, the issues are similar and, of course, the need for a friendly support group is as vital as ever. So here's to the next 50 issues!

After the success of this year's Information Day (see RLG Chair Lisa Allison's report on page 2), we'd like to put on an equally bright and upbeat Information Day in 2016 (Saturday, 21 May). With a little support from you, our members!

I'll start with speakers' topics. Is there a subject that you have been yearning to find out about in the medical, hospital or ileo pouch fields? If so please can you let us know about it and we will do our best to find an expert to speak about it at the 2016 Information Day.

And talking of speakers do you know someone with a unique or unusual tale to tell about their pouch? It could be someone you've met during a spell in hospital. Or else an individual you may have met locally. It may even be YOU. Whatever the situation, the committee would be delighted to hear from you.

Or how about doing a bit of celebrity-spotting. Do you know of a friend or a friend of a friend who knows an actor, musician, entertainer, writer or sportsperson who has had colitis or a pouch. Perhaps you know of one yourself. We've certainly featured a few illustrious speakers in the past, been discussed by a famous opera singer in the Daily Telegraph, and interviewed famous rugby players and footballers (see page 9 of this issue) in *Roar!*.

If any of this applies to you, please don't hesitate to contact Lisa Allison at lisa.allison1@nhs.net or me at cbrowne@brownemedia. co.uk.

Having a "name" speaker at Information Day always helps to attract a larger group of new and existing members!

### A selfless service

Charities have been in the news recently – and not always for the right reasons. A growing number have been using databases to obtain people's personal details and then repeatedly cold-called their "victims" to extract donations. Some innocent individuals have been driven to depression and even despair by such heartless activities.

A recent government report has called for stricter controls to protect people – particularly the old and/or vulnerable – who are pressured into donating to these charities. It has also urged the government to ban some of the worst offenders.

Happily this disturbing trend only applies to a very small minority of charities. Many others like ours are small and voluntary and rely on the goodwill and generosity of individuals.

And speaking of donations, recent changes in the tax laws mean that for the past three years we have been missing out on funds that are rightfully ours. To find out how we can claim this money, read RLG Treasurer Paul Mulot's report on page 9 and, if the article applies to you, fill out the claim form on page 10.

Meanwhile enjoy our 50th issue and very best wishes from the committee for Christmas and the New Year.

Christopher Browne



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



# A Message from Lisa

Lisa Allison, Chair of the Red Lion Group, reports on another successful Information Day and looks to the future.

Velcome to this autumn edition of *Roar!* I hope that you have all enjoyed the summer despite the weather being typically British and very changeable!

I apologise that you are receiving the magazine much later than planned – there have been a lot of changes in the pouch and stomacare teams at St Mark's Hospital over the last few weeks and as result it has taken me a long time to get the transcripts from our Information Day to our very patient editor Chris Browne and webmaster and layout specialist Tim Rogers!

The Red Lion Group held another successful Information Day for 50 people on Saturday 16 May. Due to a very generous donation that the charity received last year as a one-off we were able to offer free admission for the day. The St Mark's Medical Education Centre that usually charges us for use of their rooms also dropped their charges this year so we were very lucky!

There were very informative presentations from St Mark's Hospital's consultant colorectal surgeon Professor Sue Clark, IBD dietician Evi Kyriakidou, pharmacist Bhavisha Shah and biofeedback clinical nurse specialist Ellie Bradshaw (see the reports in this issue).

Workshops to discuss male and female pouch issues were held along with a discussion for family and friends of people with pouches. Those attending the day appeared to get a lot out of mingling over coffee and lunch and sharing their experiences with each other which is what it is all about.

# Would you like to chair the Red Lion Group?

Next year's AGM and Information Day will be held on Saturday 21 May at St Mark's Hospital. I will be standing down as chairperson next year having been in the position since 2012 and am looking for a willing volunteer to take over!

I feel that someone with a pouch should ideally take over the role of chairperson at the helm of the charity.

The role involves chairing four committee meetings a year – three of these are telephone conferences which are usually held on a week-

# Letter to the Editor

### Happiness is J-shaped! Dear Editor

had an ileo-anal pouch operation the old-fashioned way in 2001 and I can safely say that it turned my life around completely.

I am fit and active and can eat anything, including all fruit and vegetables, which I adore, although I never eat ready meals or fast food and never have done so.

I have never had pouchitis or any of the other difficulties I hear about, and I must confess I feel a bit of a fraud because I am unable to advise people what to do in such circumstances, never having experienced them! My body clock has sorted itself out admirably, so much so that I have continued with my lifelong career as a verbatim court shorthand writer and can sit in fitness-to-practise tribunals, as I do currently for the General Dental Council, without worrying about needing a break before the official breaks occur. The other day I sat through a long session of two-and-a-quarter hours without feeling the least bit uncomfortable.

I still go to work two or three days in most weeks, travelling up to the City of London, and transcribing copious amounts of shorthand notes and digital recordings in my office at home. I have to carry lots of day evening and then a face-to-face meeting which we usually hold on a Saturday at St Mark's Hospital or in central London.

There are now nine committee members who are a very friendly and hard-working bunch of people so it is an easy job really! If you are interested or would like to discuss what the role involves please contact me on 0208 235 4126.

Meanwhile enjoy this edition of Roar!



heavy case papers on and off buses and trains too.

I don't think I'm doing too badly, considering I am 69 this year. I certainly do not feel my age.

If you want any advice on coping with a pouch, on the procedure, what you feel afterwards, how things settle down, and tips about how to look after the initial soreness, please get in touch and I'll do my best to help.

Good luck to anyone who is contemplating a pouch or awaiting surgery. I am sure you'll be fine and enjoy a very long life afterwards.

All the very best Christine Lawton (RLG committee member) Roar! • Issue 50 • Autumn 2015

# **Information Day 2015**



# The importance of taking your daily dose

Bhavisha Shah, St Mark's Hospital Specialist Pharmacist, gave her Red Lion Group audience some enlightening advice about drugs and pouches



The familiar debate about which drug works best – Loperamide or codeine phosphate – was one of the themes of Bhavisha Shah's talk at this year's Information Day.

She said that while Loperamide is often favoured as it does not cause drowsiness, both drugs are

recognised aids to slowing down the digestive system during meals.

Loperamide comes in four different forms - tablets, liquids, capsules and, more recently, Loperamide melts. Most hospitals use capsules which patients can open if they so wish so that they can dissolve the powder in water.

Most professionals recommended the capsule and tablet versions, said Bhavisha. Codeine on the other hand is sold in tablet form only.

Loperamide can be taken in doses of up to 16mg four times a day and codeine up to 60mg four times a day. For maximum benefit, the two drugs should be tak-

en 30 to 60 minutes before food, said Bhavisha. They can also be taken just before bed to reduce night-time emptying.

Though both drugs had some side-effects such as abdominal pain and flatulence (Loperamide) and headache and low blood pressure (codeine phosphate), they help reduce contractions in the bowel as food moves through the stomach and allow for greater absorption of food and drink.

### **Pouchitis**

Antibiotics is the main treatment method for pouchitis. The three options are Ciprofloxacin, Metronizadole and Augmentin. While two-week courses are the norm for acute cases, more chronic conditions may need courses lasting several months, said Bhavisha.

Some pouch-owners may need to take a combination of antibiotics and, as she pointed out, taking antibiotics for long periods can cause side-effects and drug resistance.

"It is really important to take the antibiotics on a regular basis i.e. back down and the bacterial level increases back up. This can lead to increased resistance to antibiotics and recurrence of the pouchitis," she said.

Side effects included dizziness and inflammation with Ciproflaxacin, possible nerve damage with Metronizadole and nausea and vomiting with Augmentin.

## **Prescription charges**

Patients can benefit from the Department of Health's prescription prepayment scheme (PPS). This works out at £29.10 for three months which, if you need four or more items in that period, saves money on the £8.20-per-item prescription charge.

The one-year PPS cost of £104 will save you money if you need 14 or more items per year.



twice a day, and 12 hours apart and finish the course even if you have started to feel better and the antibiotic level has reached its maximum level and the bacterial level is at its lowest.

"When you stop the antibiotic too early the antibiotic level goes

You can download a PPS form – or FP95 form – online.

Or you can obtain one from community pharmacies or your own GP's surgery.

You can read the full version of Bhavisha Shah's talk at www.redliongroup.org.

# The benefits of a healthy diet

Pouch-owners need to maintain their energy levels and eat sensibly to aid recovery from surgery advised St Mark's IBD Dietician, Evi Kyriakou, at Information Day



Pouch-owners should have a varied and balanced diet to help replace the key nutritional elements that are removed when the pouch is first formed, Evi told RLG members.

During that early post-operative period when pouch-owners are still recovering from surgery, they should eat high energy and protein foods including energy snacks and drinks such as smoothies and milky drinks. One essential drink during this crucial period is the specially produced St Mark's electrolyte mix, said Evi.

Then as the pouch adapts to daily life, it is very important to follow a varied diet based on the following:

- Carbohydrates such as bread, pasta, cereal, potatoes and grains for energy
- Proteins such as nuts, eggs, meats, pulses, seeds, lentils and meats for growth and repair
- Small quantities of fats
- Fruit and vegetables to provide fibre, vitamins, minerals and antioxidants. Aim for five portions a day
- Milk and dairy products for calcium – to strengthen bones and teeth – vitamins and minerals, although dairy products can be a problem for one in five patients
- Bananas, rice, bread, potatoes, tapioca and pasta thicken the stool and reduce stool output. Evi also advised pouch-owners to introduce one new food at a time.

She said: "Eating patterns can affect pouch function.

"With the busy lifestyles that we all lead, people often find that they are skipping meals regularly. Erratic eating can often lead to an erratic bowel habit.

"Try and ensure that you eat at regular intervals throughout the day."

She said pouchees should try to avoid eating late meals to avoid needing to empty the pouch at night. Keeping a diary can help identify what works best for individuals.

Evi said pouch-owners should eat slowly and chew their foods thoroughly; try to drink 1.5 to 2 litres of fluids a day; take extra salt during high output episodes; and maintain a healthy weight during the recovery period.

You can read the complete version of Evi Kyriakidou's talk on the Red Lion website www.redliongroup.org.



# Why it's best to crouch if you have a pouch

Ellie Bradshaw, St Mark's Clinical Nurse Specialist for Biofeedback, has some valuable tips for RLG members



Scientific-sounding it may be, but biofeedback is a relatively simple, straightforward and practical way to help solve emptying problems, Ellie Bradshaw told her Information Day audience.

For biofeedback retrains the bowel and muscles, using practical techniques to control and help cope with constipation, evacuatory disorders and faecal incontinence.

Those who suffer from emptying problems – or to give them their official title "evacuatory dysfunction" – know the signs only too well. Two of the most common are straining when you go to the loo and experiencing feelings of never being fully empty and thus needing to go frequently.

However, simply plonking yourself down on the toilet and hoping nature will do the rest is not the answer, said Ellie. To make the whole process easier, pouch-owners should squat or crouch over the loo bowl. This enables the pouch and anus to operate in a straight line, avoiding complications and helping to prevent potential blockages.

Another method that has been gaining favour is the Medina catheter. By inserting the catheter into the pouch, aided by one or more syringefuls of water, a growing number of pouch-owners have experienced greatly improved evacuation. Not dissimilar is the Qufora system – a warm water enema that helps to irrigate and empty the pouch, said Ellie.

Other techniques include urge deferral (ignoring the urge to go and

thus building up the time you hold on) which helps to increase the elasticity of the pouch.

While, for those with incontinence problems, pelvic floor exercises and sphincter training are two keys to better control.

One of the best ways to control pouch frequency, she said, was to take medications such as Loperamide, codeine phosphate and Choleystyramine as they help to thicken the stool and slow gastric motility. While pouch-owners who suffer from night-time leakage can use a device called an anal plug made by Coloplast. This can also help with wind problems and follow-through at night, said Ellie.

Pouch-owners can find out more about these techniques at the St Mark's Hospital biofeedback service. Contact the Lead Nurse for Bowel Control, Brigitte Collins at brigitte.collins@nhs.net. See the full version of Ellie Bradshaw's talk at www.redliongroup.org.



# Why it doesn't always hurt to lie when you have a pouch

Sometimes we face situations where we have to be a little sparing with the truth with friends and colleagues, as Premier League footballer Darren Fletcher discovered

owever honest and upstanding we pouch-owners may like to see ourselves, there are moments when a little bit of, how shall we put it, economy with the facts is the best way to get on with our daily lives.

Take the story of West Bromwich Albion and former Manchester United midfielder Darren Fletcher. He first noticed he had ulcerative colitis in 2008 but carried on playing Premiership football and was even selected for Scotland during his illness.

Darren's one remedy was to take medication to help control these tricky spells. Sometimes it meant lying to his teammates about why he wasn't playing at his peak. "I found it very difficult making up stories; reasons why I wasn't at training, why I was looking ill and why I was rushing off to the bathroom...Basically lying to people's faces," he told *The Independent* newspaper recently.

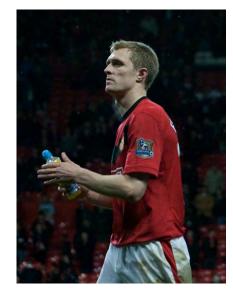
"I stayed silent until around 2011 to 2012 because it's not something you generally talk about, the symptoms of ulcerative colitis. My close family and friends knew, but nobody else knew at the club," said the 30-year-old international who has played for Scotland 62 times. Part of Darren's problem was that as a professional footballer who had captained his country he felt invincible. He also believed his condition would eventually get better.

"I was going to the toilet anywhere between 10 and 30 times a day without much time to get there, losing a lot of blood in the process as well," he said. As Darren's condition worsened he had to seek specialist medical help and at the end of 2011, took an extended break from the game, eventually having colon surgery in January 2013.

After second and third operations later in the year, the midfielder returned to play for Manchester United in December 2013. Then just over a year later, in January 2015, he moved on a free transfer to West Brom, and has had an impressive season with the Premier League side since then.

Fletcher joined up with Lewis Moody, the former England and British Lions rugby player who has suffered from uc for years (as featured in the Christmas 2012 *Roar!*) to launch a United for Colitis dinner for NACC, the Crohn's and Colitis UK, charity.

Now that he has "come out" about his illness, Darren says his



teammates are happy to joke about it. "They've almost been a bit like 'oh right, OK; you're not dying are you? So get on with it," he told *The Independent*.

"Once I started talking about it (uc] and making it public knowledge it was such a relief. It was the best thing I did," said Darren, who is the father of seven-year-old twin boys.

"The surgery was a success, I'm better now and I'm living a normal life...Though there are no guarantees with surgery, it has enabled me to be back playing and feeling great."

# Have you filled out a gift aid form yet?

When you last renewed your membership of the Red Lion Group, did you complete a gift aid form? If you didn't, it's very important that you do so now, as Paul Mulot, our new treasurer, explains

or the past three years the Red Lion Group (RLG) has been unable to claim for valuable gift aid money. This is because Revenue and Customs (HMRC) have changed the claim-making rules and made it very tricky for charities to claim the money to which they – and we of course – are entitled.

The good news is we have now re-registered with the HMRC. So we can now claim this money as before. Even better we can claim for the three missing years as well as this one. So, if you recently renewed your membership and didn't fill in the form – or if you still need to renew your membership – please complete the one on the next page, so we can claim the money that is rightfully ours.

Remember, it will not cost you anything at all and it will enable us to claim back 25% of every £1 you give us - that works out at or £2.50 for every £10 we receive.

Thank you very much for your cooperation. You will find the Gift Aid Form overleaf.





(NOVEMBER 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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# Why you should visit Riga and why I won't eat Weetabix again

Andrew Millis, Red Lion vice-chair and our very own marathon man, didn't let a few digestive problems put him off the architecture and scenery of the Latvian capital

As I hadn't run a marathon in Spain before, I opted to race in Barcelona – my 21st marathon – in March this year. However my first mistake was to book a flight with Ryanair, as the saving I made from using BA from Heathrow was too great to dismiss. Ryanair means

hand luggage only so no room for a 750g box of Shreddies, my favourite carbo-loading food.

On the Friday evening, with the marathon on Sunday, I scoured the local supermarkets for cereal, but apart from the sugary stuff the kids eat, the best I could find was Weetabix. Then on the day before the race and between tours round the city, I ate the whole box of 24 biscuits. I also ate quite a lot of fruit from Barcelona's fabulous market. That evening, I started to feel uncomfortable, and during the night (before the race), I made incessant trips to





the toilet, where all that I had eaten came pouring out.

With this worry in my mind, I boldly set off for the start on the Sunday morning, and enjoyed that great feeling of being ready to go. But after about 19 miles I endured frequent cramping, which is only to have been expected as I had lost all my electrolytes. I struggled on, but I lost the chance of a good time (I finished a few seconds under three hours).

Fast forward a month, but this time at home. I carbo-loaded on cereal during the Saturday before taking the train to the venue for the start of the London marathon. Again, unluckily, I had had a bad night, with loads of toilet trips and a major empty out. Well before the end of the race, I suffered once again terrible cramping in my legs, and it was only while I was struggling on in the last few miles that I considered what was the common factor between the London and Barcelona marathons - while a marathon I had run in Bratislava, in between, had been considerably better. It was bloody Weetabix!

These are the only two occasions I have eaten the cereal. My wife was very amused that I should "wonder" why I had a problem having eaten so much of it. But I can eat a whole box of Shreddies without any problem! Everyone who visited the house that day had to answer my wife's survey of how many Weetabix they could eat. Invariably it was some number like two (although the adverts used to boast three or sometimes four), which was very small compared to what I had eaten.

She'd then say: "Only my husband ...". But running a marathon uses up something like 3,000 calories, and thanks to a pouch to consider, I have no breakfast. So the 3,000 calories have to be taken on the previous day.

So the next marathon (I've gone a bit over the top this year, arranging 13 marathons to run) was Riga, the capital of Latvia. No one I knew had ever been there, and the only people who had heard of the place were those who enjoy the scoring at the end of the Eurovision Song Contest! After making another mistake by flying with Ryanair again (you can also go with an airline called Baltic Air from Gatwick), my first impressions were great.

Even the road from the airport to the city was lined with trees and parks, and the bus was easy to find and cheap to use. Finding my hotel was also a doddle. Cutting through the middle of the city, is not just a lovely park, but beautiful landscaped gardens, with endless flowers, ornamental ponds and bridges. The hotel staff couldn't do enough to help, nothing was any trouble. I could eat as much pasta as I wanted in the restaurants in the vicinity, very reasonably priced and very nicely served.

Riga is a very fine old city with loads of things to see and discover. Some very fine cathedrals, church towers to climb, Europe's largest indoor market housed in four old Zeppelin hangars, and boat trips.

Even the railway station is worth a trip, and you can watch the train bound for Moscow pull out. The Rigans are proud of their local chocolate manufacturer, and there are dedicated shops full of enticing bars of chocolate. I didn't see any grotty parts and I did run over 26 miles round it (there are some old buildings which need a clean though).

I enjoyed return flights and three nights in a very good four-star hotel for £320. It is the nicest place I have ever been to that no one has ever heard of. I really recommend it. Lovely place.

# Key events in 2015

### **Generous donation**

Due to a very generous donation from the estate of Dawn Marie Carter we were able to donate £10,000 to St Mark's Hospital last year. The money went straight into the pouch research fund which Professor Sue Clark oversees. Part of the donation went towards the research undertaken by St Mark's pouch research fellow Yih Harn Siaw. The results of this work are still being written up but once they are available an overview will be published in *Roar*!.

The pouch research fellow post is now vacant after Dr Siaw took up a new position at another hospital but it is hoped that this vacancy will be filled this autumn so that important research into pouches can continue.

### Chairman's dinner

St Mark's Hospital Foundation is the charitable arm of the hospital and supports the work that is done there. Money raised by the charity helps pay for vital research, education and training at the hospital.

Back in October of last year, our chairperson Lisa Allison was invited as a representative of the Red Lion Group to attend the 2014 Chairman's Dinner. This was as a thank you to the group for its longstanding support of pouch research at St Mark's.

The dinner was held at the magnificent Victoria and Albert Museum's Raphael Gallery. There were presentations from Michael Liebreich, Chairman of the Foundation, and patients telling their stories of how the hospital gave them hope which was the theme for the evening,

### **Insurance news**

Leisure and Lifestyle Insurance Services who until recently offered Red Lion Group members travel insurance are now only able to provide cover for existing policyholders.

Jean from the Living With A Stoma website www.livingwithastoma. co.uk has very kindly been in touch to say that Motability offer travel insurance to those with pre-existing medical conditions and you do not have to be a member.

Motability offer annual European travel insurance through Unique and the policy is with All-Clear which Jean says is a well known travel insurance company. Go to www.allcleartravel.co.uk or phone 01708 339026. The Red Lion Group accepts no liability in respect of the sale of this or any other travel insurance product nor do they have a financial interest in the sale of such products.

### Gut reaction

Gut: The inside story of our body's most underrated organ is the title of a new book by Giulia Enders, a Mannheim-based German doctoral student.

The book, which is intriguingly referred to as "Charming Bowels" by the Germans, is a celebration of our gastrointestinal tract and the way it behaves – from those all-toofamiliar bowel movements to blockages and constipation.

Published by Scribe publishers earlier this year, the book has sold 1.3m copies worldwide. It costs £14.99 and can be ordered online or from all good bookshops.

### **Christmas donation**

The Red Lion Group was very pleased to accept a £100 donation from Northfold Community Primary School in Thornton-Cleveleys, Lancashire back in February.

The money was raised from Christmas concert collections.

# How to enjoy mushrooms – without any of the usual side-effects!

By Red Lion committee member and food lover Theresa Parr

### Mushroom ketchup

ave you tried Geo Watkins mushroom ketchup? You can find it in most large supermarkets and it is delicious with dishes like spaghetti Bolognese, giving a rich

mushroomy flavour withoutanyunpleasant digestion problems.Italsoaddsreal depth to gravy.

Meanwhile here is how to make your own mushroom powder – courtesy of Heston Blumenthal and Sainsbury's Recipe collection: You need 10 grams of dried Chinese mushrooms and/or 10g of dried porcini mushrooms.

Pre-heat your oven to 150°C/gas mark 2 and roast the dried mushrooms on a baking tray for 5 min-



utes. Leave to cool. Blitz the mushrooms in a food processor or put them in a sealable freezer bag and crush



thoroughly with a rolling pin.

Pass through a fine sieve and keep in an airtight container until ready to use.

You will find mushroom powder has a very strong mushroomy flavour and is a delightful addition to creamy soups. It can also be added to various other dishes and lasts up to five months in an airtight container.

# Colon, semi-colon and then no colon

When Red Lion member Laura Quigley went into hospital for an op, her sense of humour manged to get the better of her

Before being diagnosed with ulcerative colitis (uc) I had done very well at staying out of hospital. Until two years ago I had only ever been in hospital as a visitor or an outpatient.

In truth, hospitals used to scare me a little. Caring for the sick is a serious business so in turn hospitals are serious places. No place for fun.... Right?

Then in July 2013, at the height of a severe flare-up of my uc, I went into my local hospital for a colonoscopy and came around from the sedation to hear my gastro consultant uttering the words: "We're going to have to keep you in."

The time had arrived to experience hospital as an in-patient and this would turn out to be the first of four admissions over the next 18 months.

In November 2013, after more than a year of worsening uc symptoms, the decision was made to go ahead with surgery to remove my colon. I knew from the outset that I wanted to go through with j-pouch surgery (my sister also has a pouch as a result of uc!) and on the advice of my fantastic surgeon, it was decided that I would have a three-stage procedure.

My first experiences as an in-patient left me with a new appreciation of how much hard work is put in every day by all the staff working on the hospital wards; from the consultants, to the nurses and finally to the catering assistants who provide the infamous hospital food.

As I had thought, serious work was indeed being done but with a compassion that allowed for moments of humour. "If you don't laugh you'll cry," was a phrase I overheard more than once.

Then, during the seven months between my first and second operations, I had an idea – to design a t-shirt that I hoped would be somewhat amusing to the staff that would see me on the ward following my second surgery – which was in fact he creation of my J-Pouch.



The t-shirt I had printed is in the picture shown above, and bears the words: COLON and the year I was born; SEMI-COLON and the year of my first surgery (which left me with my rectum); and NO COLON and the year of my second surgery.

Then fifteen days after my second surgery I pulled the t-shirt from the bottom of my hospital bag and put in on for the first time. As I'd

hoped, it succeeded in raising a smile from many of the hospital staff. On seeing it for the first time, my surgeon did a double take and commented: "I like your shirt." I then turned to show him the back, where the phrase NO COLON STILL ROLLIN' is printed.

It was one (very different) way of saying thank-you to all the people who had been involved in my treatment! The somewhat subtle nature of the message is what most people seemed to smile about and comment on. You get the joke if you are familiar with the surgeries I (and other pouchholders) have been through. So it works pretty well in a hospital setting!

For people not in know about all things colonic, it sparked off conversations about what it meant, which is all the better for raising awareness while not wearing a shirt with a more blunt message such as: "I survived having my colon removed".

Following my final (reversal) surgery in November 2014, the t-shirt made a reappearance on the same ward I had stayed on five months previously. To my surprise many of the nurses remembered it! A dietician I had seen as an outpatient (who had never met me on the ward) told me she had heard about my shirt from another member of staff. Word had spread! I wasn't expecting that.

It is now seven months since the completion of my surgeries and my health is the best it's been in over three years. As I continue to get used to life with a J-Pouch I am "No Colon Still Rollin'."

# **Contact the Red Lion Group**

# **CHAIR**

Lisa Allison **Clinical Nurse Specialist** St Mark's Hospital Watford Road Harrow HA13UJ Tel: 020 8235 4126 lisa.allison1@nhs.net

## **VICE-CHAIR**

Andrew Millis 142 Tavistock Road, Fleet GU514HG Tel: 01252 623674 Andrew.millis@btinternet.com

# SECRETARY

Sarah Bowes-Phipps 84 Centaurus Square Curo Park Frogmore St Albans AL2 2FH Tel: 01727 875156 sarah.bowes@live.co.uk

# **NOTES SECRETARY**

Christine Lawton 19 Nathans Road North Wembley HA0 3RY Tel: 020 8904 7851 ChristineLawton@aol.com

# TREASURER

Paul Mulot 103 Whitehill Road Hitchin SG49HT Tel: 01462 637242 p.mulot@ntlworld.com

# **MEMBERSHIP SECRETARY**

Susan Burrows 7 Hopground Close St Albans Herts AL15TA Tel: 01727 869709 susanmb46@gmail.com

### **NEWSLETTER EDITORS** CONTENT

**Christopher Browne** 89 Fulwell Park Avenue 🕷 Twickenham TW2 5HG Tel: 020 8894 1598 cbrowne@brownemedia.co.uk

# LAYOUT

**Tim Rogers** 30 Amberley Gardens Epsom KT19 oNH Tel: 020 8393 6968 roar@redliongroup.org

## LIAISON OFFICER

David Skinner 23 Halcyon Way Hornchurch Essex RM11 3ND Tel: 01708 455194



davidjohnskinner@hotmail.com

# **CLINICAL NURSE SPECIALIST**

Zarah Perry-Woodford St Mark's Hospital Northwick Park Watford Road Harrow HA13UJ Tel (work): 020 8235 4126 zarah.perry-woodford@nhs.net

# 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-



Theresa Parr 57 Kings Avenue Chippenham Wilts SN14 oUJ Tel: 01249 463612





theresa.parr@talktalk.net

## PRESIDENT



Sue Clark

# PATRONS



Professor John Nicholls



Lynn Faulds Wood

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

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

**Christopher Browne** Roarl 89 Fulwell Park Avenue Twickenham TW25HG cbrowne@brownemedia.co.uk











