

ROAR!



The Summer Health Issue

ISSUE 59 • SUMMER 2020

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 email at info@pouchsupport.org.

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NORTHERN IRELAND

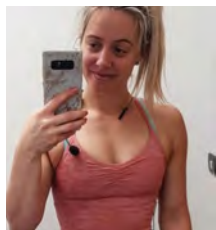
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Please support the Red Lion Group
Registered Charity number 1068124



RED LION

Pouch Support

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: **Red Lion Group Treasurer, Pantiles, Marlow Hill, High Wycombe, HP11 1QL.**



Notes from the editor

It's been one of those years – for you, me and the rest of this unpredictable planet. It really has. Lock-downs, presidential buffoonery, repeated terrorist attacks, Brexit talks (remember those?) – and crucially for us the cancellation of Information Day.

Happily though our pride of Red Lions has continued to grow with a spate of new members and more than 100 registrations for the summer series of talks on Zoom – some of them enthralling; all of them informative – which kept us amused, entertained and proud to be a Lion during a tricky period.

So, yes, we may have missed Information Day but our “Zoom into Summer” series more than made up for it. Then on 2 July we decided to hold a pouch forum on Zoom – an online version of the popular Information Day workshops – with 20 of us in male and female breakout groups sharing an hour of animated discussion about mutual issues, ideas and

problems. I sincerely urge you to book for the next one on Monday, 3 August at 8pm on pouchsupport.org if you haven't already done so.

If there is such a thing as star quality in the medical world, then St Mark's surgeon Janindra Warusavitarne has it in abundance as many of you have found during his talks on Information Day and more recently Zoom. He will soon sprinkle some more of his stardust on us after he was recently appointed a Red Lion Group patron (see page 13). Our other patron, as most of you know, is Professor John Nicholls.

So we have many reasons to be cheerful in this Covid recovery spell and you can enjoy a few more seasonal surprises in this Summer Health Issue of Roar!

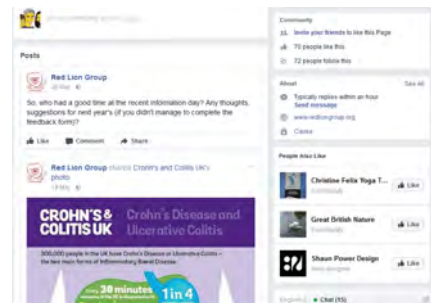
Let's start with Veganism. Lauded by some, criticised by others, former Red Lion Group chairman Andrew Millis's views on pages 15-16 will certainly make you think again, while Red Lion Group notes secre-

tary Theresa Parr reveals a novel way to help cope with pouchitis (page 14) and welcomes a new method of pouch control (page 18).

And if you've decided to take a late summer holiday, you'd do very well to heed Red Lion Group committee member Susan Burrows's travel tips in her vividly written account of a visit to the Arabic state of Oman (see page 6).

But heaven forbid that a health and fitness issue of the magazine should overlook pouches so we have news of the first of a series of videos about the ileo-pouch made by new committee member Michelle Martin on page 13. Watch it on the website or You Tube <https://youtu.be/HHL58oSgWDo>.

Happy summer reading!
CHRISTOPHER BROWNE



Find us on Facebook



www.facebook.com/theredliongroup/

Visit our website

pouchsupport.org

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

For online support, advice and tips on life with a pouch, please visit our Frequently Asked Questions (FAQs) page on the website at:

pouchsupport.org/faqs/

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Why Zoey wears her pouch with pride

Former world champion fitness model Zoey Wright wore a stoma for four years before deciding to have a J-pouch op – and is delighted she went ahead

My J-pouch is now 15 months old, and with each month that passes it's becoming stronger and

I eased myself back into taking exercise and made sure I focused on engaging my core muscles to

Before I had my J-pouch created I was a fitness modelling competitor and, after three long hard years of intense training and dieting with my stoma, I was awarded the highest title recognised by Pure Elite, the fastest-growing fitness federation in Europe!

But I've now decided to take a step back from those appearances on the stage with a new mission in mind. I aim to continue to train at a high level but wish to encourage and inspire people from all walks of life to start their journey in health and fitness.

I must say that as a regular gym-goer I have found the lockdown tough. There have been many ups and down with my mental health but I've found it a great time to reflect on what I want to do next in my career and to see family and friends who don't normally exercise now actually MOVING has given me some great ideas to help them continue to exercise once life returns to normal.

I'm feeling very grateful for my J-pouch, and couldn't be happier with the progress I've made.



Zoey Wright moves from post-op recovery to teaching mode

stronger and so is my confidence in my decision to have the two-stage surgery.

I can now go six or more hours without even thinking about the loo and most nights I sleep right through until the morning, which is something I never thought would be possible. As a personal trainer/fitness instructor I did worry that it would put stress on how I perform in my job but it's been no different to when I had my stoma.

I started taking my instructor-led fitness classes around eight weeks post-takedown—under the guidance of my surgeon Mr Denizil May from the Royal Cornwall Hospital where I had my op.

prevent any post-surgical complications/injuries and it didn't take me too long to bounce back into action!

Since my takedown I've also managed two holidays, one being only 14 weeks post-closure to Tenerife with a friend which was rather boozy! And my J-pouch survived! Then at the start of this year I had a mini-break to Budapest and had no worries then either.

However before having my large intestine removed travelling was out of the question, the thought of flying would make me incredibly anxious and I would have found eating anywhere very tricky. Now I can enjoy all the foods and drinks I like without a second thought.



Wright decision: "The new me!"

Chairman Davies's summer review



We live in extraordinary times and I hope you and your family have been safe and well during the COVID-19 crisis.

Aside from the human cost, the pandemic has left vast swathes of the economy in serious financial trouble and charities are no exception. The National Council for Voluntary Organisations has estimated that at least £4.3bn in income has been lost by UK charities because of COVID-19. Red Lion Group is fortunate in that our expenditure and overheads are comparatively miniscule; we have no premises or assets and we are entirely run by volunteers. So we are much less exposed than many larger charities.

Unfortunately, we had to cancel our flagship Information Day, which was to have taken place on 25 April and we have since cancelled the contingent date, which was to have been in October.

The next Information Day will be held in April 2021, with the exact date to be announced. We will publish the date on our website pouchsupport.org and keep members informed via emails as and when it is confirmed.

Meantime in June we set up a series of weekly presentations on pouch-related issues and delivered by prominent and respected figures via Zoom on the internet. The series has been fascinating and I think we have all been impressed by the ease with which platforms such as Zoom allow us to be able to see slides, listen to presenters and then ask questions for immediate answers, all achieved without leaving the comfort of our own lounge. Your Committee will also be looking into holding monthly coffee mornings on

Zoom for get-togethers and chats, rather like the breakout groups at each of our Information Days. These are extremely popular and much-loved opportunities for pouchees and their friends and families to discuss matters of concern in a mutually supportive, like-minded community. Watch the website for more details.

You will all be saddened to hear of the death of one of our patrons, the TV and radio personality and bowel cancer campaigner Lynn Faulds Wood, who passed away recently after a stroke. Lynn, who



Lynn Faulds Wood

founded the charity Beating Bowel Cancer (BBC), was an FAP sufferer herself and a patient at St Mark's Hospital. She was an enthusiastic supporter of the Red Lion Group and became patron in 2010. Our commiserations have been sent to her

family on behalf of all our members. You can also read Lynn's obituary on page 12 of this issue.

New Patron

I am delighted to announce that Janindra Warusavitarne, lead surgeon and Consultant in Colorectal Surgery at St Mark's for the past 10 years, has agreed to take up the role of patron. Before he came to St Mark's, Janindra was a consultant in Sydney, Australia, where he completed his training and early medical career.

Janindra carries out approximately 30 pouch operations a year which makes him one of the most experienced and talented pouch surgeons in the UK. People tuning in to his recent webinar as part of our "Zoom into Summer" series, will have been intrigued to hear of recent innovations in pouch surgery which are being pioneered by Janindra and an international team of collaborators (you can see a recording of the event on pouchsupport.org).

Janindra has been a loyal supporter of Red Lion Group and many of you will recognise him from his frequent appearances at our annual Information Days. Please join me in welcoming Janindra to the team.

David Davies

Red Lion Group Chairman
dbd60@hotmail.com

IMPORTANT ANNOUNCEMENT

Does the committee have your email address? And if we don't, it's very important that we do as quite a few Red Lion Group members are missing out on key announcements and news items about the group because we don't have your online details. So please make sure you send your email address to info@pouchsupport.org. That way you'll make sure you don't miss out on RLG's key announcements and alerts!

A city tour of sun, spectacle and surprises

Roar!'s chief travel correspondent Susan Burrows decided to satisfy her curiosity and visit an Arab-speaking country for the first time. She wasn't disappointed

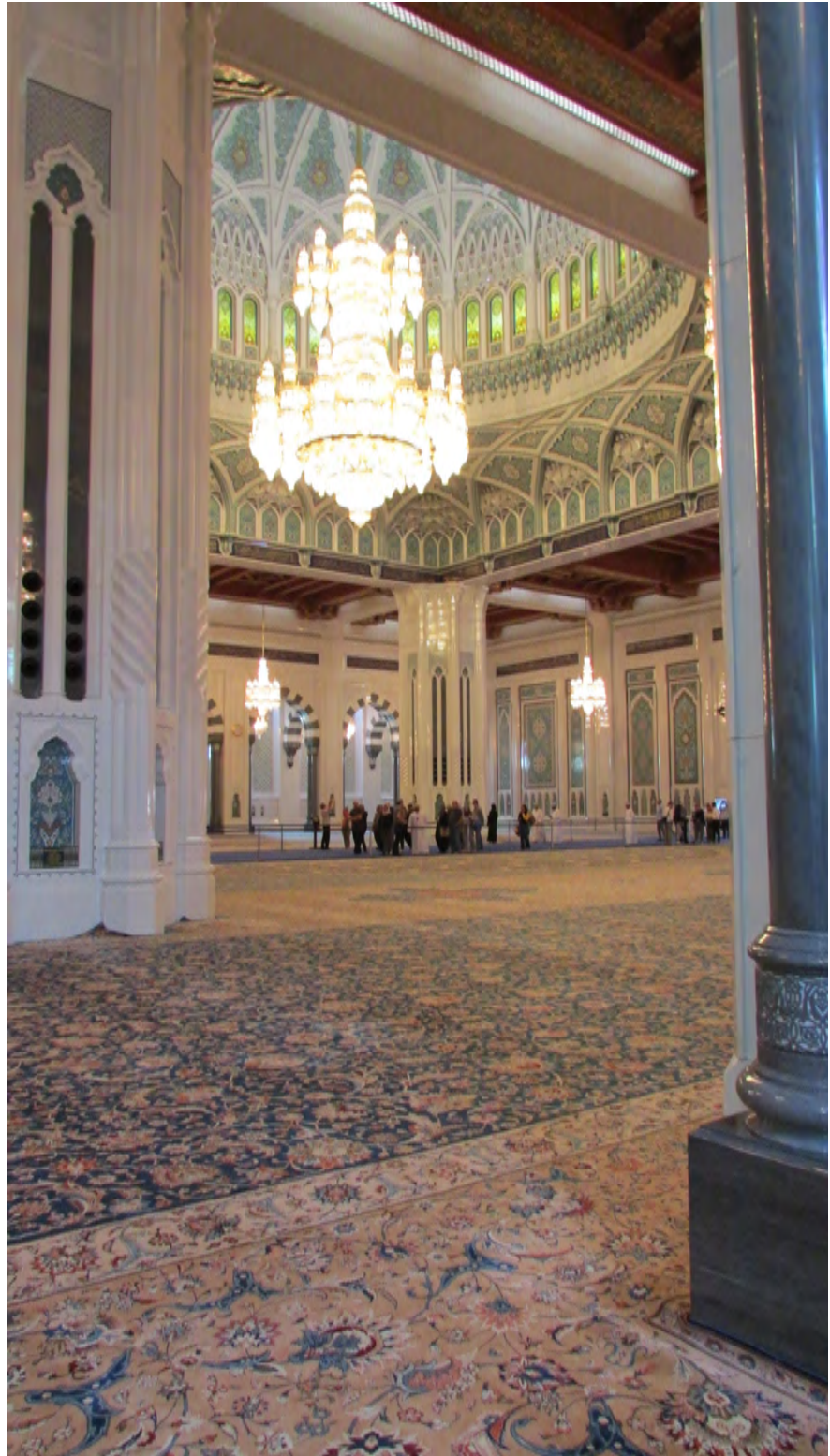


Many of my friends wondered why I wanted to go to Oman. My main answer was curiosity. But also I had never been to an Arab-speaking country before, the seven-and-a-half hour flight was mercifully short of a long-haul one and, of course, there was the winter-warmth factor.

Our party of 20 started the tour in the capital, Muscat, where the most imposing buildings are the Sultan Qaboos Grand Mosque and the Royal Opera House. The mosque was a gift to the nation from the Sultan to mark the 30th year of his reign. Its prayer hall is breathtakingly lavish with a Persian carpet measuring 70m x 60m that took 600 women four years to weave. While the hall's chandelier must be seen to be believed – 14m high and weighing around nine tons – and embedded with 600,000 Swarovski crystals (see photo).

In fact it was in 2001 that the Sultan ordered the building of the famous Opera House to reflect his love of western classical music and the arts. It was officially opened 10 years later with a production of Puccini's *Turandot* starring Placido Domingo.

We travelled in a 4x4 vehicle for two days journeying into the desert for one night and then to the top of Yeru Ebuon, Oman's tallest mountain, where we could see into Wadi Ghul, the second deepest canyon in the world after Arizona's Grand Canyon.



We made our way to the ancient city of Nizwa, which is known for Nizwa Fort, a castle built in the 17th century to defend the city's position on a major trade route. The weekly cattle market, auctioning mainly

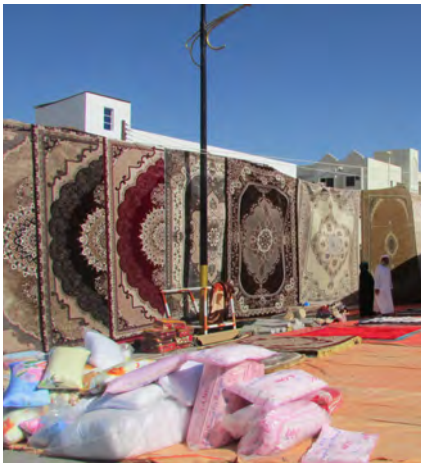
goats, is the largest in Arabia and a sight to behold. Very different from cattle markets in the UK!

We then flew south to Salalah. This is where Sultan Qaboos was born. Here there is another Grand



Mosque and you can also see the famous frankincense trees that produce the incense found in the local markets and all over the world. We watched as groups of camels roamed freely and every morning and evening we could see them making their stately progress along the beach.

There is always some concern about toilets when travelling. As Oman develops its tourist industry I think they recognise the importance of western loos for visitors. I have to say that wherever we stopped there were toilets – both western and eastern.



Extra tissues

We were warned that there would not always be loo paper so we were advised to always carry extra tissues. This is something that I always do when travelling. Extra Imodium is always useful to take with you wherever you are travelling too and even though I have sometimes been told that the water is clean to drink I do not drink it because the

chemicals used to filter it are different to those we use in the UK.

There is also free medical treatment at the point of entry for all Omanis. If more investigations are needed there is a small amount to pay. I was told that if tourists become unwell when travelling in Oman our

travel insurance would pay for treatment in private facilities.

As usual I carried a letter from my consultant outlining my surgery and my subsequent medical condition. I also had with me a travel certificate for people with an ileo-anal pouch. You can obtain this from the IA (Ileostomy and Internal Pouch Association) website www.iasupport.org and it explains in 12 languages exactly what an ileo-anal pouch is and the precautions to take if you become unwell.



Anatomy of Oman

The small coastal Sultanate of Oman lies across the Persian Gulf from Iran and India and just south of the skyscrapers of Dubai. However skyscrapers are forbidden in Oman.

The country, which has a population of just over 5 million, is geographically diverse with arid deserts, fertile plains and mountains. A seasonal monsoon yields green plains and mountains in the south.

The state religion is a less widespread form of Islam known as Ibadism which is only found in Oman, Zanzibar and small areas of Tunisia and Algeria. It places great importance on pacifism, tolerance and leniency and there is a strict religious, moral and legal code.

Omanis are also a very relaxed and polite people so crime is not in their nature. It is a wealthy country and also a safe place to be.

The Omanis revere Sultan Qaboos who ascended to the throne in July, 1970, though sadly died in February this year. He had been educated in the UK and Europe and using the country's oil wealth he began to modernise Oman. In 1970 there were only six miles of surfaced roads. Now all of them are surfaced. There are no potholes; you just need to avoid the camels in some areas.

Sultan Qaboos also introduced free education for all six- to 18-year-olds. English is part of the curriculum and the majority of Omanis speak English. Because the Sultan placed a great deal of importance on education, in the mountains where it is difficult to build schools, 4x4 transport is arranged to bring the children down to the nearest school.

The Sultan moved the country on so much and the Omanis are very proud of their country. Though there is an awareness that the revenue from oil is declining, the government is trying to diversify the economy.

Extraordinary AGM? That's what you get during a pandemic!

How do you hold an AGM when all face-to-face meetings are banned? You use a Zoom webinar of course!



When lockdown threatened to cancel the Red Lion Group AGM – and a stern cautionary letter from the charity commissioners no doubt – we turned to one of the rare delights of Covid-19 – Zoom.

The AGM is normally held on Information Day which was cancelled so we needed to hold it online, within the current financial year and with a quorum (minimum number of members to make it legal) – hence the Extraordinary Annual General Meeting (EAGM) title.

And it was well worth the last-minute-itis!

A steadily increasing membership, new income from Gift Aid,

more than £1,000 in donations from JustGiving and other sources, a successful series of talks on Zoom, the making of an A-Z video on the pouch by new committee member Michelle Martin (see page 10) and the election of a new Red Lion Group patron were among the highlights of 2019-2020 – “and the activities of a fabulous community of people” commented Red Lion Group chair David Davies.

Reporting on 2019, David said Information Day attracted a record number of attendees – 87 – a figure that included seven potential pouchees. As the 2020 event was cancelled, we replaced Information Day with Information Month—a series of five talks on Zoom (see page 10) which David said was a “fantastic achievement that people could enjoy from the comfort of their own sofas”.

He said the Zoom webcasts had been a “terrific resource during a time when we have been unable to

hold meetings” and Red Lion Group now plans to extend the “Zoom into Summer” talks with a series of monthly coffee mornings where members can discuss pouch-related issues.

Over the past 12 months Red Lion Group has forged successful links with other support groups and charities, said David, and we have renewed our pledge to make an annual donation to pouch medical research projects – with £350 from last year and a further £500 this year.

Membership has continued to burgeon, said David, and in the past two to three months there have been more than 100 new registrations for both the Zoom talks and new Red Lion Group memberships.

In his treasurer’s report, Jim Symington reported a “stable bank balance” in the 12 months to 31 December 2019 and a sizeable increase in income over the previous year-2018. For a full summary of the figures see the three slides below:

Income and Expenditure

	2019	2018
Income:		
Subscriptions	£2,125.00	£2,053.00
Donations for RLG	£669.00	£1,102.00
AGM	£808.00	£704.00
Tax recovered on Gift Aid	£383.16	£0.00
CAF/Just Giving	£1,072.78	£0.00
Bank Interest received	£12.14	£4.30
Total Income	£5,070.08	£3,863.30
Expense:		
Printing & Postage Roar	£2,275.41	£1,869.99
Cost AGM & meetings	£1,121.14	£744.52
Printing, Postage & Stationery	£125.59	£38.48
Travel Expenses	£0.00	£121.60
Website fees	£0.00	£1,864.39
Other	£0.00	£298.14
Total Expense	£3,522.14	£4,937.12
Excess of income before donation payment	£1,547.94	–£1,073.82
Donations to Research	£0.00	£0.00
Surplus/deficit after donation payments	£1,547.94	–£1,073.82



BALANCE SHEET AT 31st DECEMBER 2019

RED LION		
Pouch Support	2019	2018
Bank Current account	£386.17	£597.17
Bank Reserve account	£6,170.06	£4,411.12
Total Bank accounts	£6,556.23	£5,008.29
Represented by:		
Accumulated fund balance brought forward		
at 1st January 2019	£5,008.29	£6,082.11
Add surplus	£1,547.94	-£1,073.82
Accumulated fund balance as at 31st December 2019	£6,556.23	£5,008.29

Financial highlights 2019

	2019	2018
Income	£5,070	£3,863
Gift Aid	£383	£0
Sponsorship	£0	£0
Expenditure	£3,522	£4,942
Balance	£1,548	-£1,079
Cash at bank	£6,556	£5,008

- Stable financial picture.
- Some Gift Aid recovered from HMRC.
- Just Giving website brought £972.
- Normal website costs in 2019 after modernisation in 2018.
- Reduced costs this year due to no Info Day.
- Bank reserves will cover more than a year's expenditure.
- Accounts independently verified.

Why everybody's talking about Information Month

Undeterred by a world of 'Closed - until further notice' signs RLG found another way of getting its messages across

Who needs a summer holiday when you can raise your spirits with a series of Zoom talks - and Red Lion Group ones at that.

Instead of the 2020 Information Day which was due to be held

And what a line-up of speakers we had for the May-June event: Professor John Nicholls, founder of the ileoanal pouch and former clinical director of St Mark's Hospital; Dr Yoram Inspector, the eminent psychiatrist and head of the medicinal psychology unit at St Mark's; Janindra Warusavitarne, one of the world's leading gastro surgeons and consultant colorectal surgeon at St Mark's; Zarah Perry-Woodford, a pioneer in patient care and support and the consultant nurse

guru Gary "Gazzer" Bronziet - who first thought of the idea - and ably chaired by Mr Eloquence Himself, David Davies.

In fact the audiences of up to 60 to 70 per sitting (and more than 100 in total) drawn from Red Lion Group, the Kangaroo Club and J-Pouch Group support groups easily matched the audiences of the most popular Information Days of the past 20 years - and there were five of these one-off events, not just one.

The success of the summer talks has led the committee to consider many other Zoom events such as coffee mornings, discussion groups and also workshops similar to the ones we run at Information Day (see David Davies's report on page 5).

At this rate we'll be talking about Information Year let alone Information Month.

• **Don't worry if you missed any - or in some cases all - of the talks, recordings of the Zoom events were posted on the website by Gary Bronziet.**



Now where did I put that book? The St Mark's medical team's - and possibly one of the UK's - quirkiest bookcase shown during the Zoom talk of St Mark's consultant surgeon Janindra Warusavitarne

on Saturday, 25 April, and had to be cancelled due to COVID-19 the Red Lion Group committee came up with something completely different - namely Information Month.

at St Mark's; and Jason Bacon, CEO of the St Mark's Hospital Foundation.

Catchily titled 'Zoom into Summer', the talks were convened and hosted by Red Lion Group's IT

Fascinating facts

UK archaeologists have found what is believed to be the first-ever Shakespeare theatre. Based in London's Whitechapel, it was called the Red Lion after a nearby pub of the same name and dates from 1567. It was also used as a prototype for the more famous Shakespearean Globe Theatre, predecessor of today's Globe on London's Bankside.



An offbeat summer poser!

How many books, movies and TV titles can you think of with 'Roar' in the title? Here are a few to start with:

• *Dinosaur Roar* by Henrietta Strickland and published in 2014 is a children's book about a dragon - and not a lion believe it or not!

• Most of you have probably heard of *The Mouse That Roared*, a 1959 comedy film starring Peter Sellers

• Roar is the name of a 1981 American adventure comedy (aren't they all!) starring Melanie Griffith and Tippi Hedren. However the word 'comedy' is perhaps a little far-fetched. The film was in fact dubbed

the most dangerous movie in history after Melanie Griffith had to have reconstructive surgery on her face after being mauled by a lion.

• A collection of 30 short stories about female empowerment titled *Roar* was published in 2018. The author is the Irish novelist Cecelia Ahern.

• *In the Roar of the Sea* is the name of a book by Sabine Baring-Gould about life on the Cornish coast in the first half of this century. It was published in 1950.

• *The Roar* written by Emma Clayton and published in 2009 is a thought-provoking portrait of London set in the future.

• ROAR is the name of a health and fitness guide by Stacy T. Sims. Published in 2016 it urges readers to "match your food and fitness to your unique female physiology" (see photo, left).

The thoughts of Chairman Davies

David relishes some of the key moments of Dr Yoram Inspector's Zoom Into Summer talk

Yoram looks at healing and the patient journey in a holistic way," says David. "He considers the overall health of the person, especially focusing on their mental health and fostering a positive state of mind. He considers their like experiences, their beliefs and their aspirations as well as their attitude to their medical condition. He forges a strong link between the gut and the mind, giving simple examples like 'butterflies in the stomach' to illustrate that link.

"Indeed he has written an article entitled 'Our guts and brains are in a relationship and it's complicated', a reference to a 2009 romantic movie of the same name. During his talk he illustrated his points with many references to classical art, literature, statues and architecture in a rather unique way."

Says David: "He began with a powerful point—we all have anxiety in our lives and our minds cope with anxiety in very different ways. Indeed, the way in which our minds cope with anxiety might well predict the impacts on the body. Anxiety causes stress and stress has been implicated as a possible causative agent in inflammatory bowel disease (IBD).

"Anxiety stems from uncertainty and a fear of irreversibility, he said,

and these are fundamental elements in the journeys undertaken by pouchees during their surgeries and subsequent care and rehabilitation.

He pointed out that support groups like Red Lion Group help to address this uncertainty by providing a platform for pouchees to talk to one another and to pick up tips and tools to help them cope with the outcomes and realise that they are not alone.

"Being part of a community is a very important part of normalising our condition, he said, and Dr Inspector referred to humane experiments on mice to demonstrate his point and encouraged us all to 'be like the second mouse' (you'll need to watch the video on the Red Lion Group website pouchsupport.org).

"Another key issue for some people who have been seriously ill are the negative feelings of being 'changed' or 'different'. Our revised plumbing can give rise to symptoms such as urgency, incontinence, frequency and pain which can make us feel abnormal. However let us not forget those noisy and smelly farts on the toilet. This produces stress in all of us to a greater or lesser extent and Dr Inspector emphasised the importance of humour in helping to process this stress, rather than internalising and dwelling on the



Dr Yoram Inspector

negativity. He told a joke to illustrate his point:

'Four good friends, all with pouches, are talking one day. The first says he has terrible wind which is very loud and so embarrassing. His friends all shake their heads. The second says he also has terrible wind and his farts are so smelly. His friends all shake their heads. The third says he has awful farts too, but his are both very loud and very smelly. Again his friends all shake their heads. The fourth smiles and says his farts are neither smelly or noisy. His friends look at him with sympathy and say "where's the fun in that?"'

Always try to see the funny side, it really helps, said Dr Inspector.

ED: Pithily put Mr Davies!



Lynn Faulds Wood: Broadcaster, campaigner and Red Lion Group patron



Lynn Faulds Wood and husband John Stapleton mark Dress Spotty Day

Broadcaster, campaigner and Red Lion Group patron Lynn Faulds Wood sadly passed away in April this year after a stroke.

Lynn, who was 72, was one of TV's first consumer champions as founder-presenter of the BBC's *Watchdog*, which she co-presented with her husband John Stapleton.

Lynn later used her investigative skills as a journalist in several other fields – most recently as a pioneer of treatment for bowel cancer after her own experiences with FAP (familial adenomatous polyposis).

During her illness Lynn was treated as a private patient at St Mark's Hospital when it was based in London's City Road. Shortly afterwards she set up her own charity, Beating Bowel Cancer (BBC) (www.bowelcancer.tv) near her home in Twickenham.

She agreed to become a patron of the Red Lion Group [our other patron is Professor John Nicholls] and in a 2010 Information Day talk, "The Pope and I", Lynn told us about her meetings with Pope Pius IV who also had FAP and Prince Charles whom she persuaded to say "bottoms and bowels" on prime-time TV.

Another Lynn-led campaign was "Dress Spotty Day" (see photo, above) an annual event that encourages people to get regular cancer screenings and so "spot" any symptoms of FAP. She also set up the European Cancer Screening Campaign at the European Parliament.

However when in the 2016 New Year's Honours List Lynn was offered an MBE, she turned it down saying "I would love to have an honour if it didn't have the word 'empire' on the end of it. We don't have an empire, in my opinion... Let's drag us into the 21st century."

She leaves a husband, John Stapleton, and son Nick.

Portrait of the ileoanal pouch

RLG committee member Michelle Martin has made a step-by-step guide to the operation many of us have had, are about to have or else are thinking of having



Michelle Martin

New Red Lion Group committee member Michelle Martin has made the first of a series of videos about the pouch featuring her own surgeon Mr Toby Hammond as the presenter.

The idea for the series was prompted by Michelle's experiences of ulcerative colitis and what exactly made her decide to go ahead with J-pouch surgery.



Video presenter: Mr Toby Hammond

Says Michelle: "In 2017 I had an emergency operation to remove my colon due to undiagnosed ulcerated colitis. It was a total shock. Suddenly I was living with a stoma and everything in my life had changed.

"Initially, my main focus was to have my stoma reversed, however over time I got used to it, I felt well for the first time in years and I didn't want any more operations."

However, she wanted to find out more about the other option – having an ileo-anal pouch fitted. "I spent a lot of time talking through my options with my consultant Mr Hammond [Toby Hammond, consultant general and colorectal surgeon at Broomfield Hospital, Essex], but I found that away from the hospital there was limited information that would help me make an informed decision.

"I eventually decided to go ahead with the operation and just over a year later I couldn't be happier," says Michelle.

As she points out: "I know deciding to go ahead with the operation is a difficult decision, and I wanted to help others in a similar situation. I approached Mr Hammond and he was more than happy to support the project, and I hope this will be the first of many videos that will help people living with a J-pouch."

You can watch the video on <https://youtu.be/HH158oSgWDo> or on the Red Lion Group website pouchsupport.org.

Janindra sprinkles his stardust on the Red Lion Group

Please give a warm welcome to the award-winning surgeon and keyhole surgery pioneer Janindra Warusavitarne who has just joined Professor John Nicholls as a patron of the Red Lion Group.

Janindra was elected to the post by the Red Lion Group committee just before the recent AGM.

He studied medicine and took his medical degree at Australia's Newcastle University before moving to Sydney to complete his general surgery training. After a three-year period of research into the genetics of colorectal cancer he was awarded a PhD by the University of Sydney.

His next assignment was closer to home. In 2010, Janindra was asked to join St Mark's Hospital in Harrow

as a consultant colorectal surgeon and was later appointed the hospital's lead surgeon for IBD.

For the past few years he has led the St Mark's team developing and improving laparoscopic – or minimally invasive – surgical techniques that are sometimes referred to as keyhole surgery. It has proved a popular alternative to the traditional open surgery the hospital has built its reputation on.

Apart from his surgical roles, Janindra holds a number of academic posts, has written chapters for or contributed to many academic books, articles and papers and is a renowned speaker at international conferences.

Some of you have undoubtedly



Janindra Warusavitarne

heard or spoken to him during his regular talks and visits to Red Lion Group Information Days and been able to appreciate his warmth and attentiveness when dealing with pouchees' and potential pouchees' personal issues.

Janindra's appointment follows the sad death of the previous patron, Lynn Faulds Wood, the broadcaster and campaigner (see obituary on opposite page).

Welcome to the fold Janindra!

P-word problems? Why not try a little yoghurt

RLG Notes Secretary Theresa Parr finds regular doses of her own home-made yoghurt help keep pouchitis at bay



Just what is it about pouchitis? What causes this painful seemingly incurable condition that many of us have suffered from time to time?

Years of research projects, in-depth case studies and scholarly medical papers have produced very little so far for patients and medical professionals to go on.

One possible remedy many pouches turn to has been probiotics – live bacteria and yeasts that

are good for your digestive system. However the people’s favourite, VSL#3, has recently been partially discredited due to lack of scientific data or testimonials.

Antibiotics are the usual standby as they can give short-term relief and certainly help to allay some of the worst symptoms of pouchitis.

But what about longer-term solutions? Red Lion Group’s Theresa Parr has her own unique method of anti-pouchitis control. “I’ve been lucky and have only had two mild

bouts of pouchitis which was many years ago. I didn’t fall into the prescribing category and, as VSL#3 is very expensive to purchase, I looked at alternatives,” she says.

Her solution? Yoghurt. “For many years I’ve been making home-made yoghurt and, touch wood, it seems to be doing the trick and moreover it’s extremely simple to make,” says Theresa.

Theresa uses a yoghurt maker she bought from the supplier Lakeland (www.lakeland.co.uk) some years ago. The device has an outer unit housing a heating element and



Yoghurt-making equipment

an inner, removable plastic container (see above).

Here then is the Parr formula:

“You put a small portion of your starter culture (plain yoghurt containing a balanced blend of bacteria which consume lactose) in the container, add milk (full fat, semi or skimmed according to your taste or waistline!), give it a good stir and then just ignore it for 10 to 12 hours.

• “If you want thicker yoghurt, then I suggest you strain it*. I tend to use Yeo Valley as my starter yoghurt

but that is just down to personal taste.

“Thereafter, you just use some of your home-made yoghurt to make the next batch and I only resort to shop-bought starter yoghurt if I’ve been away for a few weeks.

“Lakeland now make a new all-singing-and-dancing yoghurt-maker with an adjustable thermostat and a strainer for about £25, while Amazon (www.amazon.co.uk) sell similar for about £18. This can also make Greek-style yoghurt and cream cheese. Fancy!

“I like the fact that yoghurt has no artificial sweeteners, additives or preservatives (and I find I’ve usually eaten it all before it goes off anyway!) and, of course, you can add any extras you like to suit your palette.

“It is also great as a base for salad dressing or with chives on jacket potatoes, etc.

“I do not know the precise strains or levels of active bacteria in yoghurt but my pouch is a lot happier if I eat some on a daily basis.

And Theresa’s secret recipe for success? “I just throw some on my breakfast porridge!”

* Put a clean tea towel over a fine mesh sieve on top of a large bowl (at least 1 litre capacity). Then allow to stand until thin liquid stops draining through the sieve (about 1 hour).



Breakfast treat – cereal topped with yoghurt

Why dieting is not always to die for!

When Andrew Millis, a former RLG chair, was given a startlingly-titled book he says it not only improved his well-being and outlook but made a radical difference to his life with a pouch

I don't know what came over my son recently—maybe he was genuinely worried about my state of health—anyway whatever the reason he gave me a book titled *How Not To Die*.

I'm glad to say I've so far heeded the message of such an arrestingly-titled book and, just as significantly perhaps, eagerly digested its remarkable contents.

Its author, Dr Michael Greger, tells the story of his grandmother who was given multiple heart bypasses to help treat her ongoing cardiac problems. She was wheelchair-bound and had been worryingly written off by her consultants. More crucially she was given just a few months to live.

But Dr Greger's gran then made a bold decision. She opted to go on a whole-food, plant-based diet—and it wasn't long before she was able to walk freely and unsupported once again. The plucky lady lived another 30 years!

So what was the key to her remarkable transformation? Diet, the author tells us, just plain and simple diet. In the book he stresses the key anti-inflammatory and antioxidant benefits of eating plants and fruit and the harmful effects of the toxins found in meat.

I took note and started to switch to a vegetarian diet myself. I also took the trickier step of dropping dairy foods such as milk, butter and cream. Doubly tricky in fact as I have always consumed large volumes of milk – at least two pints a day and I part-attribute this to the severe ulcerative colitis I suffered at the time.

Litres of milk

My UC symptoms started shortly after a spell of working in France, where I would buy litre-sized car-

tons of milk to drink on my walk to work. [Did you know that milk is said to contain up to 400 million pus cells per litre, antibiotics to address udder infections, hormones to maintain lactation and more]. But since then I've been really happy with Alpro soya milk. It contains almost as much protein as cow's milk [3.0mg/100ml compared to 3.4mg/100ml] and has added calcium. Another milk product, Oatly, tastes barely different from dairy milk and so is great in tea, while Flora

the anal sphincter. My output is the ideal "thick porridge" or even stools. It's as if I had had no surgery at all.

I take no medication whatever nor do I need any cream. I am far happier eating in the evening than I used to be, something that would have had me up several times in the night. Now, if I do have an evening dinner rather than lunch, I'm up once in the night then back to sleep again. Toilet odour is much reduced and sometimes it has gone altogether.

Marathon man

I'm convinced a vegan diet will help me keep running into my late years (I had another eight marathons booked this year and I'm 60).

Among the other benefits I've found is that if you want to lose weight on a vegan diet, you will. With vegetables you can eat as much as you like as they are filling and nutritious and don't leave you wanting to snack on pointless calories. I used to have to stop myself from eating when I didn't need to. Now I tell myself to have something to eat to maintain my weight. If you don't want to lose weight, just eat more carbohydrates (e.g. bread, dried fruits etc.). I've had some really big platefuls of food, and my pouch is absolutely fine.

I now find shopping takes a little longer but is more fun. I look at ingredient lists on everything and pick an item up if there is no sign of animal products. Many items also say helpfully "suitable for vegans".

In fact, plenty of foods are vegan-friendly when you wouldn't think it, like McVities digestive biscuits. Most plain chocolate is too. Linda McCartney sausages are also better than the real thing. Reading the labels gives you a good feeling of being ultra-discerning and selective. You'll find there are so many good things to



Andrew Millis: A marathon man with a mission

is fine on bread and in cooking.

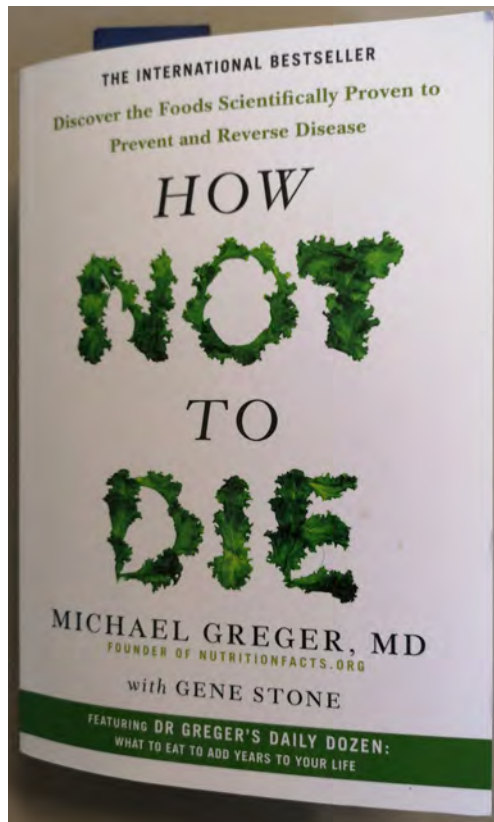
Finally, I dropped anything containing eggs, and although I do occasionally reminisce about my wife's spectacular cakes, the benefits of my new regime are enormous!

My toilet trips have dropped to three to four a day from considerably more and I no longer have the uncomfortable wave pressure on

eat which you might not have chosen before.

It is certainly worth noting how many very credible articles in the media stress the dreadful lives farm animals lead. And that's before we think about the causes of Covid-19. For most people, the only way to cope with that information is to pretend there is no link between those animals heading to the abattoir and the meat on your plate.

There's no doubt that a vegan lifestyle solves that. You become more receptive to those features and articles about farm animals' lives, and your decision to change is all confirmed. And for the very few elements that are less easily absorbed from plant food, there is a supplement called "Veg 1" which is read-



The book that says it all

making the change sooner.

Significant too is the number of top sportspeople who have adopted veganism. It speaks for itself really. Carl Lewis, the elite sprinter of the 1980s and 1990s, tennis players including the Williams sisters, Formula One's Lewis Hamilton, a number of MMA (mixed martial arts) fighters



A typical vegan meal

ily available from The Vegan Society (www.vegansociety.com). No vegan goes back to eating animal products. My only regret is not

and the former British heavyweight boxer David Haye are all confirmed vegans. Research has also linked vegan diets to lower blood pressure and cholesterol and lower rates of heart disease, Type 2 diabetes and some forms of cancer.

The evidence is clear. There's been a strong shift to veganism and it can work for pouch owners too. So what are you waiting for?!

Editor's Note: What an inspirational character you are Andrew – many of you will have read about his exploits as a marathon runner in previous issues of Roar!

You can order *How Not to Die* by Dr Michael Greger and Gene Stone (Macmillan USA) in paperback, audiobook, hardback or Kindle from Amazon.com.



Vegan, vegetarian or plain, old-fashioned foodie? We can all indulge in a few slices of carrot cake

Marathon man Andrew Millis shows us how to make his favourite post-race treat



This is a recipe I have made for my family several times. It's a pretty straightforward piece of baking and when done properly the result is both moist and delicious (though no soggy bottoms here!). Also there's nothing light and fluffy about this specimen!

Here are the key ingredients:

- 50g walnut halves
- 105ml vegetable oil
- 65ml orange juice
- 160g castor sugar (or demerara for more flavour)
- 170g strong plain white flour
- 2tsp baking powder
- 1tsp ground cinnamon
- A pinch of mixed spice
- 105g ground almonds
- 100g sultanas or raisins
- 200g grated carrot (about 4 medium-sized carrots)

Here's how to do it:

Grease and line the base and sides of a 20cm/8in springform cake tin with baking parchment. Then preheat the oven to 180C/fan 160C/gas mark 4.

Toast the walnuts in the oven for 2-3 minutes before setting aside to cool.

Whisk the oil and orange juice together in a bowl, then beat in the sugar, flour, baking powder, cin-

namon, mixed spice and ground almonds.

Add the sultanas, walnuts and carrot flakes. Mix into the batter – it'll seem stiff but the carrot contains a lot of moisture so the batter will soon loosen.

Transfer the mixture to the tin and bake for 45 minutes, or until a skewer inserted into the centre comes out clean.

Leave to cool slightly, then turn out onto a wire rack to cool. When you can't resist it any longer, cut yourself a large piece to enjoy with a cup of tea. Or else serve with Alpro Soya yoghurt.

Why Theresa's positively flushed with success

RLG Notes Secretary Theresa Parr was about to have an op to remove her troublesome pouch until she discovered the Medena catheter. Now she has found an ingenious alternative. Here's her story

Isn't medical technology wonderful? One year the designers in their labs come up with something entirely original and then, in a matter of months it seems, they invent another completely different device to replace it.

Take the catheter. A growing number of us have been using this 12-inch-long plastic tube to improve our pouch control, frequency and general lifestyles for years. Now backroom science has devised another emptying method called the Aquaflush.

One of its early users is Red Lion Group's Theresa Parr who told *Roar!*: "While I was waiting for surgery to have my problem pouch removed, I started using the Medena catheter and, thankfully, good function was restored and the surgery was cancelled.

"However, possibly because of the U-bend issue that affects some of us when going to the loo, using the Medena catheter was effective but not the most comfortable of procedures."

So Theresa decided to book an appointment with her pouch support nurse at St Mark's Hospital. She in turn recommended Theresa try a new emptying method called an Aquaflush anal irrigation system.

"This has a much softer silicone cone than the Medena tube that you insert into your bottom," says Theresa. "Although small sachets of lubrication gel are provided with the packaging I find it much better to use Instillagel which has an anaesthetic ef-

fect and you can also use greater volumes than those provided," she says.

The kit, which can be prescribed by your GP, "comes with optional extension tubes which means it is easier to insert whilst sitting down. Personally, I find it easier to relax my pelvic floor by sitting rather than standing," says Theresa.

"It has been a very interesting time. Thankfully, as well as avoiding surgery, I have been able to retrain my pouch and now only have to use the Aquaflush irrigation system occasionally, usually if I have eaten red meat.

"And, after 20 years with a pouch, my function is better than ever!" adds the delighted pouchee.

"Huge thanks go to Sam Evans and Lisa Allison, the two St Mark's Hospital pouch support nurses who helped me, for their practical advice and, more importantly, their moral support. You are both absolute stars and we are so lucky to have such support at St. Mark's and the Red Lion Group," she says.

EDITOR: The emptying devices we use are down to personal choice. If in doubt speak to the pouch or stomacare nurse that looked after you after you had your pouch fitted.

You can also refer to the article "My catheter conversion" on the Red Lion Group website pouch-support.org.



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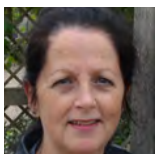
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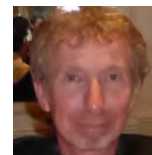
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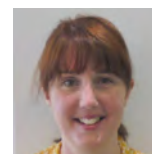
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Join the Red Lion Group

- 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 and More Ideas

Yes, *Roar!* thrives on them for it's ideas that make the magazine 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.

Please email info@pouchsupport.org if your email address or contact details change

That way we can keep your newsletter bursting with life and information and make reading about pouch issues fun and stimulating. Please send your articles, letters and ideas to: **Christopher Browne**
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