

# ROAR

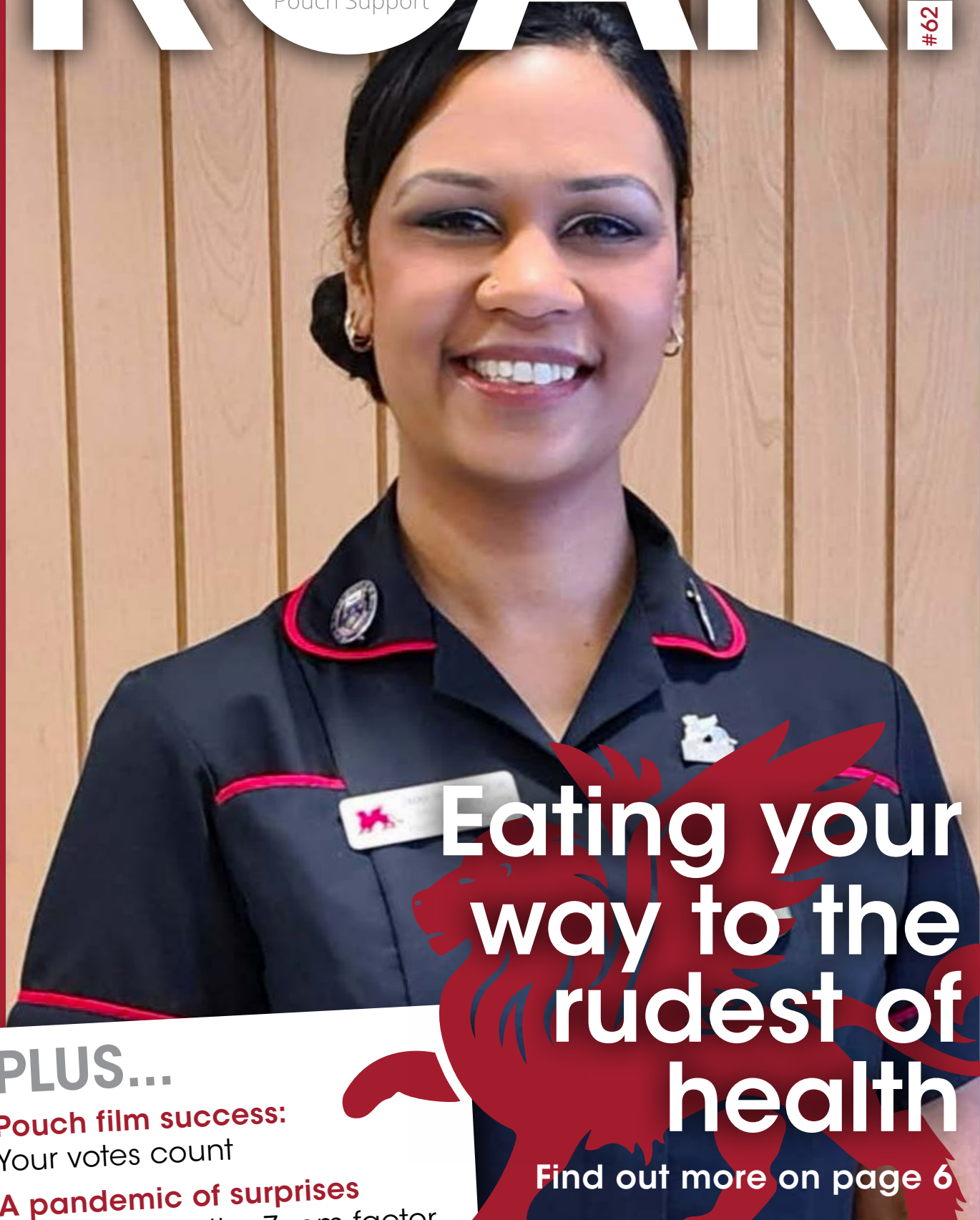


RED LION

Pouch Support

WINTER 2021-22

#62



## Eating your way to the rudest of health

Find out more on page 6

### PLUS...

**Pouch film success:**  
Your votes count

**A pandemic of surprises**  
Covid creates the Zoom factor



## 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**

### BEDFORDSHIRE

Carol George  
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## CONTENTS



3 Notes from the Editor

4 The chairman speaks...

5 Tim Rogers says farewell



6 Eating your way to the rudest of health

10 A layman's guide to living with a stoma

11 How Covid created the Zoom factor

13 Vote now for Michelle's pouch film

14 Kangaroos gather to discuss pouches

15 It's good to talk says chairman Davies

16 Seeing stars on the computer screen

18 RLG donates £5,000 to pouchcare research



19 Contact the Red Lion Group

The Red Lion Group is a charity run by volunteers with advice from St. Mark's Hospital (pouch department). The content of *Roar!* aims to help people with an internal ileo-anal pouch and anyone considering this type of surgery. It is not a substitute for professional medical advice or a medical examination. If in doubt consult a specialist. We do not promote or recommend any particular treatment or course of action.



## RED LION

### Pouch Support

All donations, however small, towards expanding the work of the group will be gratefully received. You can donate online via the donate button on the RLG home page **pouchsupport.org**

**Please support the Red Lion Group**

Registered Charity number 1068124



## NOTES FROM THE EDITOR



I'm proud to be a Red Lion – and with good reason I'd say! For this year seems to have been marked by an almost unending series of successes.

It was the ingenuity of our guru extraordinaire, Gary Bronziet, that led to one of our biggest triumphs. When the Covid outbreak forced us to cancel our major event of 2020, Information Day, Gary cleverly decided to create a series of webcasts on Zoom to replace the traditional line-up of professional speakers.

Titled "Zoom into Summer" it had an almost instant impact with up to 60 followers for each webcast. We zoomed into summer again this year with an equally erudite line-up of speakers (You can read all about it on pages 12-13 and 16-17).

### Reaching out

Another 2021 success stemmed from our decision to link up with the J-Pouch Support (UK specific) Group on Facebook. With more than 1,000

members from the UK and overseas, the group can be accessed on our website and the partnership has significantly broadened our reach.

But back to the Zoom factor for a moment. RLG has been holding monthly Zoom forums – another of Gary's ideas! – in 2020-2021. These replaced the ever-popular male and female Information Day workshops, giving RLG members a forum to talk about personal and health issues that they almost certainly cannot discuss anywhere else! (see article on page 15).

If you've ever faced a 'Can't Wait' moment – and many of us have – you'll appreciate our new smart card which also has a QR link to RLG secretary Theresa Parr's incisive guide to the pouch for GPs. Devised by Gary Bronziet – who else? – the card is now so popular that it won't be long before it features in the Great Loos of Britain Guide. Its impact has also helped raise our membership by more than 80 in 2021.

'The card has helped raise our membership by more than 80 in 2021'

### Global community

Partnership is RLG's second name and led by our charismatic chairman David Davies we have been liaising and exchanging ideas with other support groups in the past year or two which brings the idea of a truly global pouch community ever closer.

And one final accolade for this season of joy, fellowship and goodwill – committee member Michelle Martin's film about the workings of the

J-pouch has been nominated for the prestigious Smiley Film Awards (see page 13) and it is our votes that could get us to the final – and even further perhaps. So please go to the awards website and ask your friends, colleagues and family to do so too at <https://smileymovement.org/single-award/286> and VOTE!

A very happy and healthy Christmas and New Year to you all and enjoy your Winter Roar!

### Christopher Browne

Editor

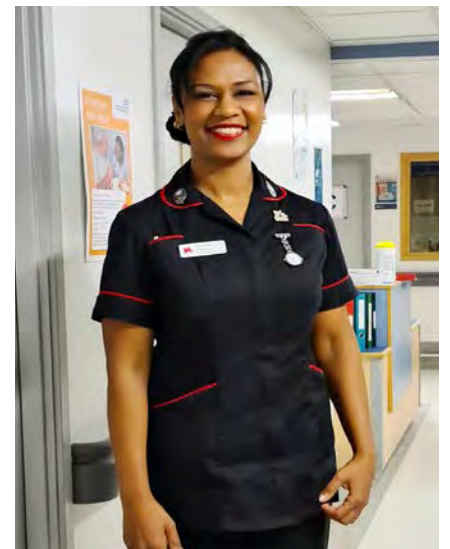
cbrowne@brownmedia.co.uk

## On the cover...

Have you ever been to a one-woman (or man) medical advice clinic? No? Nor had I until I met Zarah Perry-Woodford.

Her official title is Nurse Consultant, Pouch and Stoma Care, at St Mark's Hospital where she heads up a team of three. But she is far more than that. For the past 16 years she has developed and expanded the hospital's ileoanal pouch service and run nurse-led clinics and email and telephone advice lines.

But Zarah's talents don't just end there. Her infectious personality has made her a frequent speaker at international conferences and seminars and her books including "Ileo-Anal Pouch Surgery for Ulcerative Colitis" are respected books of reference.





## LETTER FROM THE CHAIR

# The chairman speaks...

**David Davies** extols the scope and scale of the Red Lion Group website and the global impact of our online forums

### Dear RLG Members,

I was back in the vibrant and historic city of Bristol this summer (see photo, enjoying the Watershed area). I last visited the city some 30 years ago and, indeed, when I was a student I had my pouch surgeries there in 1984 and 1985.

At 36 years, my pouch is one of the oldest, but there are many even more ancient versions out there and at least two members of RLG with 43-year-old pouches.

RLG members have had pouch surgery in many different hospitals throughout the UK and the longevity of some of these pouches reflects the fact that they are durable. This is reflected in the broad geographical range of the RLG membership. I am struck that our stories reflect the fact that pouches are durable and also that operations were undertaken throughout the UK, which is reflected in the broad geographical range of the RLG membership.

We also have an enduring and treasured association with St Mark's Hospital, which pioneered the procedure and is still a centre of excellence for all things pouch-related. Only five per cent of our members now come from the Middlesex area and a further 11 per cent from Greater London, a relatively small percentage that reflects how many other areas (and countries) are involved.


### Global appeal

As well as the UK, we also have members in America, Australia, the Middle East and mainland Europe and this growth and diversification is mainly down to the use of the internet as a platform for our content.

The profusion of pouch-related information now available on our website means that members can download a large amount of content from the comfort of their own home. This information is now available to any member, wherever they are in the world and at any time. We have reached pouches who live many miles away in both high-frequency pouch centres and also areas where they might have no other local pouches to talk to and no local medical pouch-related expertise among GPs and consultants to provide informed and relevant medical advice. The internet is allowing RLG to provide the information and camaraderie to reassure Red Lions that they are not alone, that their challenges are shared by others and that we have tips and practical advice to support them.

### Tireless worker

All this is made possible by the tireless work of Gary Bronziet, the talented IT guru at RLG who presses all the right buttons and organises and drives all our internet offerings and platforms. You might well have seen "Gazzer" at



'Our growth and diversification is mainly down to the use of the internet'

zoom meetings, sorting out issues and ensuring all runs smoothly. His regular updates ensure that pouchsupport.org is right at the top of the Google rankings for anyone searching for "pouch support".

Gary has made possible many of our offerings to members this year.

He has also devised an improved registration system for events, a QR code for the "Just can't wait" membership cards with a link to an information platform for patients and healthcare professionals alike. He has also linked the feed from the highly active J-pouch support (UK specific) Facebook page to the RLG website for ease of reference for our members.

### Ambitious plans

Your Committee has once again worked extremely hard on your behalf in their own time on a voluntary basis to make all these good things possible. We have ambitious plans for 2022, including more webcasts, more forums and more online articles. But as social



**ABOVE:** Bristol fashion: David Davies relaxes in the city's Watershed area

restrictions ease, we are also planning to stage a face-to-face Information Day in the spring. There is no substitute for live interaction and holding an Information Day is such a good chance to meet up with pouchee friends and associates as well as the speakers who present the excellent talks. Keep a look out for more announcements and your chance to register and we look forward to seeing as many of you there as possible.

There is much work to do and we are keen to hear from people to join our Board of Trustees and share the load. If you have time to spare, a passion to support pouchees in the UK and abroad and are prepared to roll up your sleeves, then we would be delighted to hear from you ([info@pouchsupport.org](mailto:info@pouchsupport.org)).

Have a great Christmas break and best wishes for a healthy, happy, Covid-free 2022.

**David Davies**  
RLG Chairman

# Goodbye Tim – it's been a real blast!

Our longest-serving committee member and *Roar!* designer, Tim Rogers, bids us farewell

Former *Roar!* editor and Red Lion Group committee member Tim Rogers who has masterfully laid out the magazine for many years recently stood down from the committee and *Roar!* for work and personal reasons.

And we are all very sad to see him go – a mere 27 years after he and a small group of patients and staff from St Mark's Hospital founded the Red Lion Group in London's Syon Park in 1994.

As Tim said prophetically at the time: "I could not help thinking that this was the beginning of something big." Wise words indeed!

Tim was the first editor of *Roar!* and you can still read about RLG's early activities in the *Roar!* archive on our website [pouchsupport.org](http://pouchsupport.org). And it was Tim who, as a marketing and IT specialist, set up and hosted the forerunner of the current website.

I have worked with Tim on *Roar!* for many years and have always admired his magazine design and IT skills – and I like to think we have managed to keep our readers amused and entertained!

Red Lion chairman David Davies commented: "So farewell Tim. We are very grateful for your hard work, enthusiasm and ideas and wish you and your family all the very best for the future."

I am pleased to say we have found a replacement – and a very good one as you will see from the Summer and Winter 2021 issues of *Roar!* and future issues too. Graphic designer Michele Hall's CV includes such national magazines as *Smash Hits*, *FHM*, *New Woman* and *What Car?*.



Tim Rogers (L) with RLG chairman David Davies



# Eating your way to the rudest of health

Rest and relaxation are vital aids to recovery after major surgery – but then there’s diet, says **Christopher Browne**

**G**lance through any tabloid newspaper or popular weekly magazine and one of the hottest topics you are likely to find is dieting. Most of these diets aim to make you feel good about yourself, slimmer and more svelte-looking (both men and women).

And why not indeed! But dieting is not just a way to lose weight. Your diet and what you choose to eat and drink is a major priority when you are recovering from an operation. Your body needs sustenance, essential minerals, salts and vitamins to help you grow stronger and recover your former health.

Some of us were lucky enough to see RLG’s summer webcast about healthy eating by Gabriela Poufou, lead IBD dietitian at St Mark’s Hospital. It was the best guide to diet and recovery I have ever seen – far more thorough than any newspaper guide. And I’ve got to admit that until recently – apart from taking care to avoid certain foods – I haven’t taken diet as seriously as I should. Neither, I might add, has it seemed to be a top priority in hospitals – apart from St Mark’s and Central Middlesex Hospitals perhaps – GPs’ surgeries and health clinics.

Until now. Pleasingly, this trend is changing. Surgeons, GPs, clinicians, nursing staff, patients and support groups are recognising the importance of diet and healthy eating and as an enthusiastic layman I make no apologies for drawing on the outstanding knowledge and advice Gabriela Poufou gave us in her webcast.

## A canny solution

Let’s start with dehydration. Do you remember how tired and thirsty you felt as the effects of the final closure of your pouch began to wear off. This is because you were dehydrated. The removal of your large bowel meant it could no longer act as a reservoir to reabsorb water and salts.

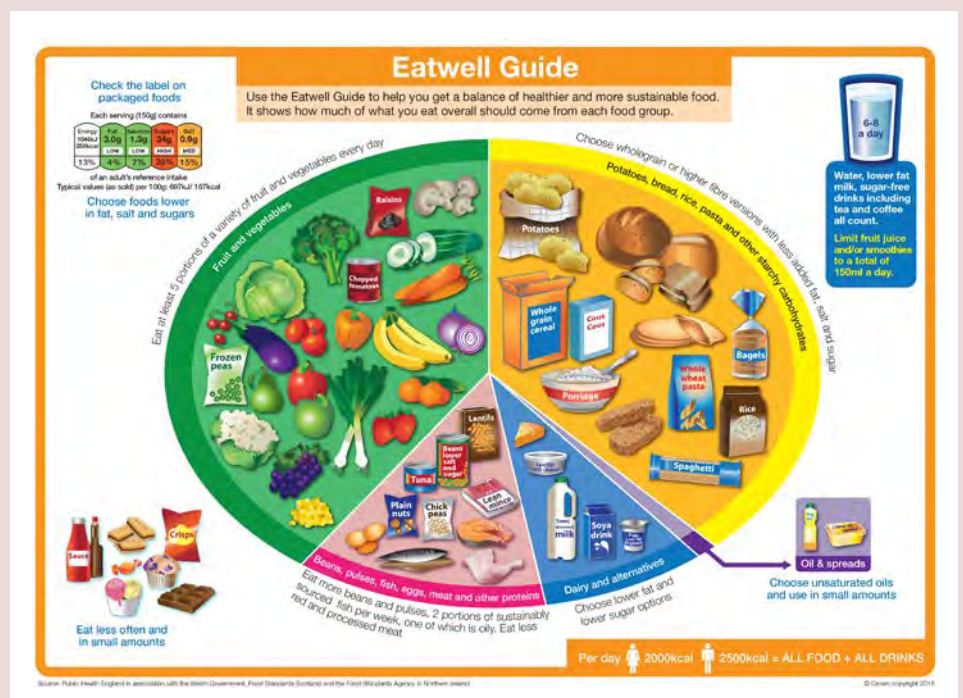
This major change in your bodily functions needs time to settle. So one of the best go-to remedies is St Mark’s Hospital’s electrolyte solution – six teaspoons of glucose powder, a teaspoon of salt and a dessertspoonful of bicarbonate of soda dissolved in a litre of water. Pouchees are advised to drink this solution at regular

intervals during the day (There are other variations too which you can find on Google).

Gabriela Poufou encourages pouchees to continue this regime for at least two months as your body starts to heal after your final pouch closure.

Here are some of the other keys to post-surgical diet and recovery. (Please watch Gabriela’s video for a much fuller and more detailed version).

For the first few weeks dietitians recommend a soft, low-fibre diet, and as you start to recover move on to high protein and energy foods to encourage the wounds from the surgery to heal more quickly, reduce the risk of blockages and help prevent weight loss.



This is the third in our series of specials on health and fitness – just to help keep you on your toes before and after the feasting and excesses of Christmas and the New Year! You can read the first article about Health and Fitness in the Summer 2020 *Roar!* and the second, on Mental Health, in the December 2020 issue.

**Diet and Recovery** is the theme of this, the third article, in our series. It is a very basic guide and should be backed up by expert opinion including the comprehensive webcast by Gabriela Poufou, St Mark's Hospital's lead IBD dietitian ([https://www.youtube.com/watch?v=\\_uHbtfslJR0](https://www.youtube.com/watch?v=_uHbtfslJR0)). Happy reading!

The diet Gabriela Pouchou and specialist dietitians recommend for pouchees after four to six weeks has many of the features of the NHS's excellent Eatwell guide (<https://www.nhs.uk/live-well/eat-well/the-eatwell-guide/>) [see chart below].

The foods recommended for pouchees after four to six weeks are: Proteins – meat, fish, cheese, eggs, milk yogurt and pulses; carbohydrates including cereals, bread, rice, pasta and potato; healthy fats and calcium-rich dairy products – or lactose-free alternatives – including olive oil, milk puddings, yogurts and petit filou (small yogurts), custard and blanchmanges.

### Avoid nuts, seeds and mushrooms

After two months you'll also be able to drink fluids such as water, tea and coffee (in moderation), unsweetened fruit juices and sugar-free squashes. If your loo output is up you may need to continue with an electrolyte mix 30-60 minutes before meals.

During the first few weeks post-surgery (and, in some cases,

permanently) pouchees should avoid nuts, seeds, peas, raw vegetables, mushrooms, sweetcorn, celery, dried fruit and coconut. In time you may be able to reintroduce some of these foods in small amounts.

The dietitians advise pouchees to adopt a “little and often” approach to food and to eat slowly and chew your food well. They also recommend you experiment with the size and timing of your meals and you may find some foods suit you better than others.

So a bit of trial and error won't do you any harm!

In the NHS's Eatwell Guide is a dietary caveat which applies to all of us whether pouchees or otherwise: “Most people in the UK eat and drink too many calories, too much saturated fat, sugar and salt, and not enough fruit, vegetables, oily fish or fibres.” So there!

Whatever approach you take to your post-surgery diet, if you are in any doubt whatsoever about anything please seek advice from your hospital dietitian. He or she will be only too happy to pass on dietary advice and eating tips.

'Adopt a little and often approach to food and eat slowly'





# The Michelle Martin formula



RLG's Communications Manager has a novel way of keeping healthy and looking after her three-year-old pouch

**P**ouchee and RLG committee member Michelle Martin who had her pouch fitted in 2019 says: "I religiously followed what I refer to as the 'beige diet' - avoiding anything with too much fibre including too many vegetables and fruit. After that, I gradually reintroduced fruit and veg and very quickly I was able to enjoy a very healthy and varied diet.

"I have made some adaptations to my diet as I find certain foods do not agree with the pouch. I have therefore limited the amount of red meat I eat, I avoid ice cream and despite my love of sugar and chocolate I have to limit these to a treat. However, I frequently give in to my sugar cravings and regularly regret that decision! I also find I have to limit my alcohol intake to one drink per sitting!

Adds Michelle: "I start my day with porridge and fruit. I have a varied lunch menu including sandwiches, salad, homemade soup, and whenever possible I make my own bread or sourdough. I really enjoy cooking. I make the

majority of my dinners from scratch and most of them are based around vegetables, salad and fish. I am still able to enjoy spicy foods and I love curry or chilli dishes.

"I find the policy of eating a little and often works very well, so I have a reputation for always eating! But I normally only eat small amounts at any one time, and I can't eat a three-course meal as I get full up very quickly. Eating out can be more challenging as I need to ensure the food is of good quality and that minimal oils and fats are used during the cooking process. I also find that to save wastage I generally order starters for my main course.

Michelle recently had her first bout of pouchitis. "It was caught early and is now under control, however I have now introduced probiotics to my diet and take them every morning with homemade natural yoghurt," she said.

"To keep my pouch healthy, I find I must look after my general health. I know my pouch is at its best when I take care of myself ie eat the right foods, exercise, and get enough sleep. When I start to rush around, get stressed, and do not take the time to think about what I am eating, my pouch and my overall health deteriorates.

"My pouch has enabled me to live the life I want, and I am so pleased with the outcome. It can be hard to be good all the time but I truly believe that if I take care of my overall physical and mental health, me and my pouch will have a long and happy life together," said Michelle.

'I have to limit my alcohol intake to one drink per sitting!'



'Two years into a vegan lifestyle I can report my pouch and I are doing very well indeed'



Picture of health: Andrew Millis with fellow vegan and running partner Kate Dunbar

# The vegan approach

RLG's very own marathon man finds a plant-based diet has revolutionised his life with a pouch

**T**he recent rise in the number of people seeking meat-free alternatives has led to the growth of vegetarianism and in some cases veganism in the UK.

The vegan diet is based on plants such as vegetables, grains and fruit and foods made from plants. It also excludes meat, fish, dairy products and eggs.

Veganism is not for everyone but Andrew Millis, our very own marathon man who was RLG vice-chair and a very active member of the committee, is a passionate advocate. Andrew, who has run many marathons for various causes, says: "Two years into a vegan lifestyle I can report my pouch and I are doing very well indeed."

"I can still run half marathons, the odd marathon and park runs and my pouch is working brilliantly. No pouchitis, no medication whatsoever, and a good plate of veg with rice or potatoes leaves me wondering if I have had any surgery at all."

"I have so much energy for activities and to help focus on my work as well as stamina for the cycling and running I enjoy. I do take a vitamin supplement called Veg 1 which is a chewable tablet and tastes like the Haliborange we used to take as kids. It is available from the Vegan Society."

"I don't have any colds or such similar elements and if I was missing out on any nutrition, I think I would have known about it after two years. I had a blood test at my local practice, and my vitamin B12 was well up (> 300ug, compared to minimum 200ug)."



'The book is also a vital read for healthcare professionals'

# Everything you always wanted to know about stomas

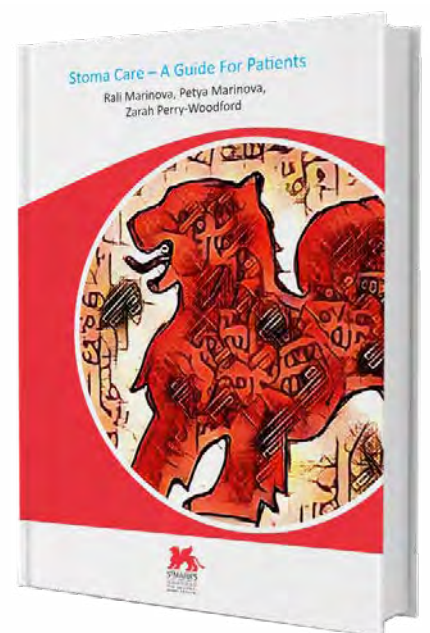
Three members of St Mark's Hospital's pouch and stomach care team have produced a new patients' guide

Writers of popular fiction like to keep their readers guessing by bringing out sequels to their best-selling novels. St Mark's Hospital's three resident authors, Zarah Perry-Woodford and Petya and Rali Marinova, choose to do just the same.

After the success of Zarah's book "Ileo-Anal Pouch Surgery for Ulcerative Colitis - a Guide for Patients" which came out in 2016, the three authors have written a comprehensive guide to living with a stoma titled "Stoma Care - a Guide for Patients".

As readers of Zarah's book which gives pouch patients a stage-by-stage introduction to coping with a pouch before, during and after surgery, the new one is an invaluable A-to-Z for those who have permanent stomas as well as pouches who at some time or another will need to live with a stoma during their surgery whether for three or six months or longer in some cases.

The book is lavishly illustrated with images and diagrams from Rali and Petya Marinova. Apart from graphic images of surgery and surgical procedures, there are sections on diet



ABOVE: The stoma guide

**LEFT:** Petya Marinova, St Mark's pouch nurse specialist, Zarah Perry-Woodford, St Mark's Consultant Nurse, Pouch and Stomacare, and Rali Marinova, St Mark's stoma and pouch nurse specialist

and healthy eating and case studies of patients with stomas.

### **Fear and prejudice**

In his foreword to the book, Janindra Warusavitarne, Lead Surgeon at St Mark's and Patron of the RLG, says: "A stoma can be associated with both fear and prejudice. Much of this is generated by lack of information which can cause undue anxiety for many.

"It is not only the fear of the unknown but also how an individual will be accepted with a stoma. Appropriate information and support is key to ensuring that anyone needing a stoma has the smoothest journey."

As the authors point out: "The aim of this book is to reinforce what you have been told by the surgeon and stoma nurse prior to your surgery, signpost you to independently care for your stoma, make important decisions about your health and become confident in preventing and treating possible stoma complications."

Author Rali Marinova adds: "The book is also a vital read for healthcare professionals as there is detailed and comprehensive information on stoma care."

### **■ What is a stoma?**

A stoma is a surgically created opening into the abdomen which is used to divert the flow of faeces or urine - ie stoma output - into a stoma bag outside the body.

**"Stoma Care - a Guide for Patients"** is published by St Mark's Academic Institute. New St Mark's stoma patients will receive a free copy of the book or you can buy a copy via [www.stmarkshospital.nhs.uk/stoma-care](http://www.stmarkshospital.nhs.uk/stoma-care) for £10 which will help cover the costs of reprinting and distribution.

**VOTE NOW!**

# Michelle's pouch film - she needs your vote!

Our votes for the Red Lion Group's special pouch film could make all the difference to its success

The film "J Pouch Surgery - a life changing decision" made by RLG committee member Michelle Martin has been nominated for the prestigious Smiley Film Awards.

So to help the film make the finals, Michelle needs your vote!

All you have to do is go to:

<https://smileymovement.org/single-award/286> and VOTE!

The film which features Michelle's pouch surgeon Toby Hammond explores the various stages of the pouch operation, recovery time, risks and benefits.

Said Michelle: "This is a fantastic platform to raise awareness of our condition and the more votes we receive the greater our chance of making the finals."

And what an accolade that would be for the Red Lion Group. So get voting NOW!

**SMILEY**  
AWARDS 

The Smiley Film Awards are the world's largest campaign for cause-based films and are a platform for people driving positive change.



**LEFT:** A shot of surgeon Toby Hammond during filming



## MEMBERSHIP REPORT



# How Covid created the Zoom factor

When the pandemic forced RLG to cancel its main event our ingenious membership secretary **Gary Bronziet** found an entirely new way to reach out to members. Here is his report...

One of the casualties of the Covid crisis has been our annual Information Day which is normally hosted at St Mark's Hospital and is the highlight of the Red Lion Group calendar.

In 2020, when it became obvious that an in-person event would not be possible, it struck me that this would be a perfect opportunity to use Zoom technology to replace the day with a series of virtual events. Hence our Zoom into Summer Series that was launched in the summer of 2020.

In fact, the technology was not that new. I had been using equivalent platforms such as WebEx and GoToMeeting for many years in my professional capacity. Then suddenly this virtual meeting technology became mainstream, and "zooming" and dare I say, "You're on MUTE!" also became part of our everyday vocabulary!

In fact, using this virtual platform made the logistics of hosting this event much simpler. No longer did we have to try to coordinate the availability of the potential speakers around one particular Saturday.

Separate events could be scheduled at the convenience of each speaker. The male and female "workshops" that previously ended the day's activities at Information Day were replaced with regular monthly Open Zoom Forums.

One of the key merits of the virtual format has been the accessibility of the events - irrespective of geographical location. We have virtual

attendees from all over the UK including Wales, Scotland and Ireland, from Europe (notably France and Portugal) and we also have some regular attendees from the USA's East and West coasts.

Although we aim to host an in-person

Information Day at the earliest opportunity (hopefully in 2022) we also plan to continue holding our virtual events for the foreseeable future.

**The Red Lion Group website has been significantly improved together with a new easy-to-remember URL**

You have probably noticed that our website was significantly re-vamped a couple of years ago. Thanks to D&AC,

the team who put together the new framework. This has been a major leap forward for us and raised our profile tremendously. The new site at **pouchsupport.org** is at the very top of the Google search results when people are seeking pouch support-related information.

The available resources are continually expanding making our site the "go to" place for pouch-related information and the number of visitors continues to increase - not just from the UK but from around the globe.

Another step was to link our website with the most active Facebook discussion group J-Pouch Support (UK Specific). This group has more than 1,000 members and is very active on a daily basis. Visitors can read the activity on this group directly from the FORUM section of our website. See **<http://pouchsupport.org/forum>** (It is a closed group, so to contribute to the group you need to submit a joining request on Facebook).

**The membership process has been streamlined and our membership continues to grow**

As part of the modernisation, we have also streamlined the membership application process. Visitors can now submit a membership application

'We have attendees from all over the UK, Europe and the USA'

**RIGHT:** Sign of success: RLG's smart card



directly from the website. (See [pouchsupport.org/join](https://pouchsupport.org/join)). We have also registered with a charitable payment portal called CAF (Charity Aid Foundation) which simplifies the fee payment and donation process.

### Can't Wait/Medic Alert card

As many of you know, we recently launched a unique 'Can't Wait' membership card – the only such card designed specifically for pouchees. On one side is a traditional 'Can't Wait to use a Loo' message in several languages, and on the reverse side is a Medic Alert which has an explanation of our condition together with a URL and a QR code that links directly to a more detailed medic alert page on our website (see [pouchsupport.org/medic](https://pouchsupport.org/medic))

Our membership numbers are on the rise, and it is likely that this is very much related to a combination of the steps we have taken as outlined above – specifically the website, the zoom meetings and the membership card. As

a result, in 2021 to date we have added 88 new members.

Whereas the Red Lion Group was originally founded as a St Mark's Hospital-centric support group, our membership has expanded into Europe and further afield.

The RLG committee appreciate your continued support and remind you that the Red Lion Group is run entirely by volunteers. Membership fees cover our expenses (which are minimal) and surplus funds are donated to the St. Mark's Hospital Foundation. We recently made a donation of £5,000 to the Foundation. (See page 17 of this issue and also <https://pouchsupport.org/rlg-donates-5000-for-pouch-related-research/>).

Best Wishes & Seasons Greetings from

**Gary Bronziet**  
Membership Secretary and IT  
[membership@pouchsupport.org](mailto:membership@pouchsupport.org)

# Money matters

RLG treasurer **Jim Symington** reviews the group's finances

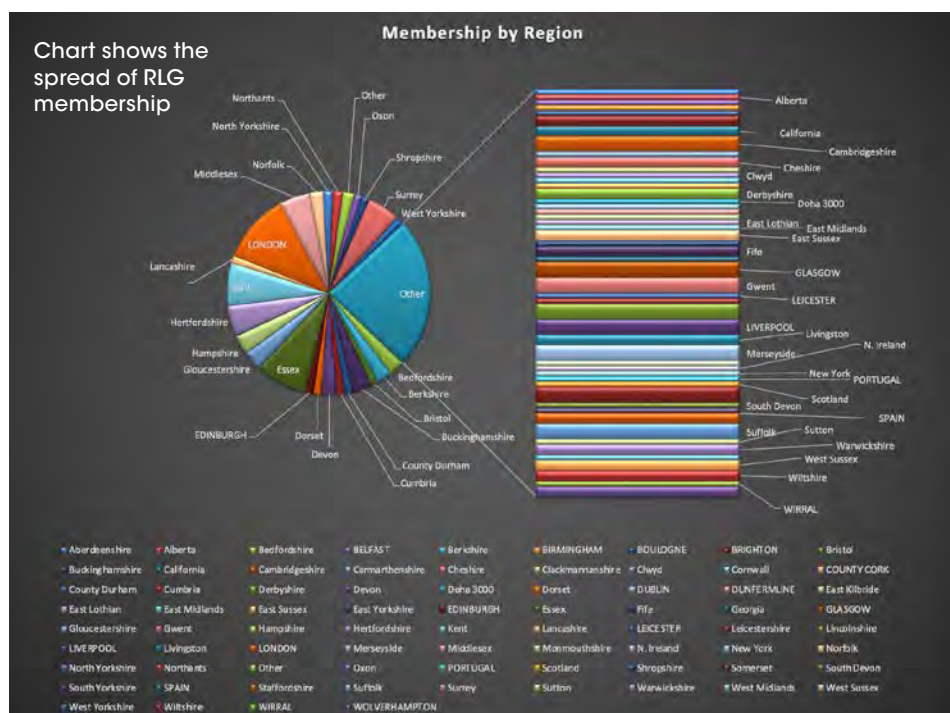
Strong, stable and streamlined are probably the three most apt ways to describe the Red Lion Group's current financial state.

Although when *Roar!* went to press we had not quite reached year-end, donations in 2021 have been higher than in most 12-month periods. These include a £3,000 contribution from a clinical trial company RLG has been involved with and, pleasingly, means we were able to make a £5,000 donation to the St Mark's Hospital Foundation which funds cutting-edge pouch-related research projects (see page 18).

As RLG treasurer Jim Symington points out: "The quality and depth of our service has improved – despite Covid and several lockdowns – due to the use of online delivery."

Very well put Jim and this online output includes a series of very successful webcasts (see page 15) and monthly Zoom forums (see page 15) which like face-to-face workshops enable RLG members to discuss pouch problems and share emotional, physical and health issues.

As Jim says: "We now have robust financial processes in place, exceeding the requirements of a charity of this size." And referring to the previous year (ending 31 December 2020), he said: "Notwithstanding our low budget we also managed to make a £1,000 donation to St Mark's for research in 2020."





# THE OXFORD REPORT



ABOVE: Delegates at the Oxford meeting; INSET: Laura Dunn, founding chairman of the Kangaroo Club

## Kangaroos gather to discuss pouches and other key medical matters

### The Oxford support group celebrates a grand reunion

The Oxford-based Kangaroo Club, a pouch support group similar to RLG, bravely held a 2021 Information Day in October this year.

The event was held in an Oxford hotel, as the John Radcliffe Hospital where the group is based and usually meets was facing Covid restrictions.

The day turned out to be a resounding success, with a series of uplifting talks and an audience of just over 60 patients, relatives and pouchcare professionals.

The two highlights were talks – appropriately titled “the thoughts of the pioneers” – by Professor Derek Jewell, the University of Oxford’s Emeritus Professor of Gastroenterology, and Mr Michael Kettlewell, consultant surgeon and Emeritus Professor of

Green Templeton College, University of Oxford.

The event was organised by Laura Dunn, the Kangaroo Club’s founding chairman, who said: “The overall feedback was so overwhelmingly positive that we shall repeat this [in a hotel] in future. Delegates were delighted to be able to meet in person and ‘not in the hospital’.

“We were also thrilled by the response to the special low-fibre lunch I had requested. The hotel staff thought this was hilarious but were delighted that every morsel was eaten by the attendees and there

‘We were delighted to be able to hold an Information Day in October’

was nothing to clear away – and so no food waste!” said Laura.

She added: “We are delighted to be associated with the Red Lion Group. We have the same general purpose which is to provide support and information (although never advice, as that can only come from

medical practitioners who have knowledge of individual circumstances).

“Our main objective is to run one big Information Day per year and we were delighted to be able to do this in October, having lost the year before to Covid.”

## IT'S GOOD TO TALK

# Fancy a chat with a fellow pouchee?

Why not join one of RLG's monthly forums and talk about your favourite subject – you!

It started out as a one-off experiment with RLG members and fellow pouchees “meeting” over the internet on a zoom videoconference for an hour of informal and relaxed conversation. After all, it's good to talk, isn't it?

The first meeting was a great success with 50 or so attendees talking for almost two hours. So we have carried on with these meetings, which have now become a regular event in the diaries of many RLG members, taking place on the first Monday of every month and set to continue while people still dial in and find it valuable.

Chairman Christopher Browne starts each meeting with the same jovial question – “Anyone got anything they want to talk about?” And away we go, no agenda, no preparation and no preset topics. The hour flashes by and everyone who wants to is given the chance to talk – Chris has developed a sixth sense when someone is wanting to raise a topic.

The topics are hugely varied, from

butt burn creams to dietary tips, from fistulas to frequency, from blockages to dehydration, from Vitamin B12 infusions to probiotics, from GP referrals to loperamide, from noisy toilets to preventing back splash on the loo and from urgency to seepage – nothing is off-limits.

Such topics are what bind us as a group of special people who have undergone an extraordinary re-plumbing of our insides and are different from “normal” people. And it is so good to be able to talk openly and freely in a friendly and supportive environment from the comfort of our own homes when any further social contact has been restricted. We have had potential pouchees joining in, parents of pouchees, partners of pouchees and of course the pouchees themselves, with pouches ranging in

'A group of special people who have had extraordinary re-plumbing'

age from three weeks to 43 years – Jean Reed and Sylvia Panford were the seventh and eighth pouchees at St Mark's some 43 years ago and are regular attendees.

Occasionally we have invited special guests to join in, for example the PhD psychology student Zeina Bushnaq came to talk about her research into pouches and mental health support and to encourage volunteers to complete her survey. Zeina was able to dramatically boost the numbers

taking the survey to provide statistically robust

conclusions to her work and which she will be sharing with us in a webcast to be scheduled early in the New Year.

All these meetings have been enjoyable and informative and will continue into the

New Year. Book yourself in for the next meeting at 7.30pm on Monday 3 January 2022. Pre-registration is essential to receiving the dial-in details.

With thanks to Gary Bronziet for pressing all the right (IT) buttons, Theresa Parr who has often chaired the ladies break-out group, Christopher Browne for his excellent chairmanship and you the members who have dialed in and illuminated the discussions.

See you on 3 January!

**David Davies**  
RLG Chair

## The Big Event

How about this for a family stroll with a difference? RLG has entered the London Bridges Fundraising Walk on Sunday, 22 June next year. You can choose your distance – either 6.5 or 13 miles and you will cross 10 of the capital's spectacular bridges. You can also do this nearer home – by getting sponsorship for you and your family for a more local route. The same event was held this year and was a roaring success!

To pre-register and guarantee your place please send a brief email to the organiser **Ian Tate**: [i.tate@griffininstitute.org.uk](mailto:i.tate@griffininstitute.org.uk)

Save the date!  
26th June

**The London Bridges Walk 2022**

in aid of The Griffin Institute, St. Mark's Hospital Foundation, Hillingdon Hospitals Charity, London North West Healthcare Charity and The Red Lion Group

Watch the RLG website [pouchsupport.org](http://pouchsupport.org) for more information nearer the time.



# Stars of the computer screen

The winter weather may be gloomy, but our recent line-up of speakers has been decidedly buoyant

**O**h the glamour! Oh the glitz! Many of the biggest names in pouchcare signed up for our Zoom into Summer 2021 series of webcasts. And they didn't disappoint!

Talk about an education! I have probably learnt more during those eight webcasts than anything I was supposed to have absorbed at the three

schools I went to.

Yes, just as in 2020, the webcasts were a triumph attracting at least 30 eager followers a time – and a remarkable 50-60 for one of them.

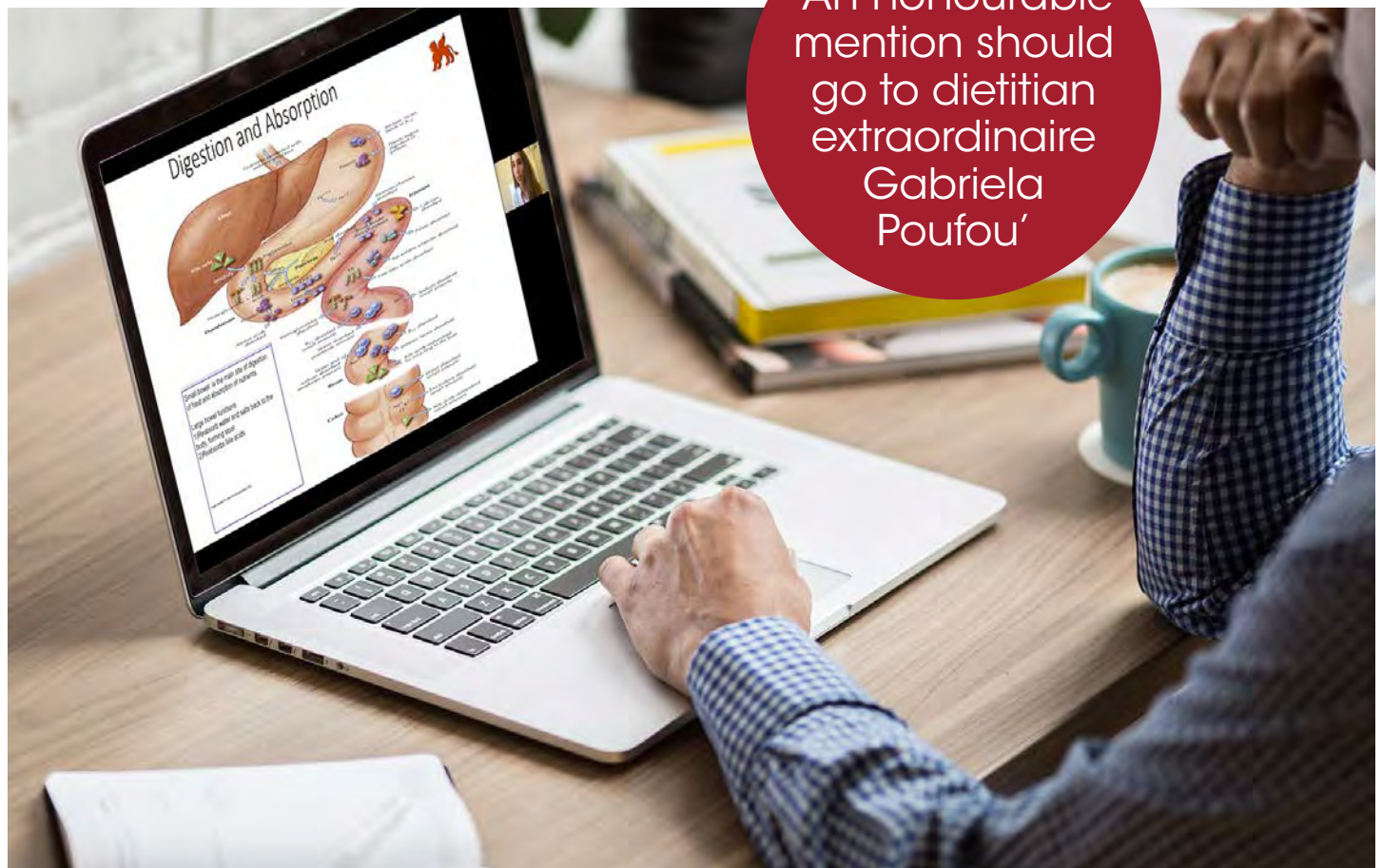
An honourable mention should go to dietitian extraordinaire Gabriela Poufou who gave us the most complete guide to diet and healthy eating (see main

article on pages 6-9) that I've seen in 30-plus years as a pouchee.

Starting with dehydration and ending with the joys of the Mediterranean diet, Gabriela, who is the main IBD dietitian at St Mark's

Hospital, went through the whole gamut of do's and don'ts of diet and digestion for pouchees.

'An honourable mention should go to dietitian extraordinaire Gabriela Poufou'





**Gabriela Poufou**

Lead IBD dietitian at St Mark's Hospital

Watch her fascinating talk and lavishly illustrated charts and diagrams on YouTube

[https://www.youtube.com/watch?v=\\_uHbtfsIJRO](https://www.youtube.com/watch?v=_uHbtfsIJRO)

The webcast by former St Mark's biofeedback specialist Ellie Bradshaw, was equally inspiring but could not have been more different in approach. Titled "Crouch for your pouch – pelvic floor perfection and the importance of emptying", it showed how pouches can retrain themselves to go to the loo properly.

So what then is biofeedback? Like some of the newer pouchcare devices such as the Medena catheter, it's a relatively novel concept in the treatment of people with pouches.

A bit like potty-training for adults, it helps you retrain your brain and use a range of crouching and sitting techniques to help you empty your pouch more easily.

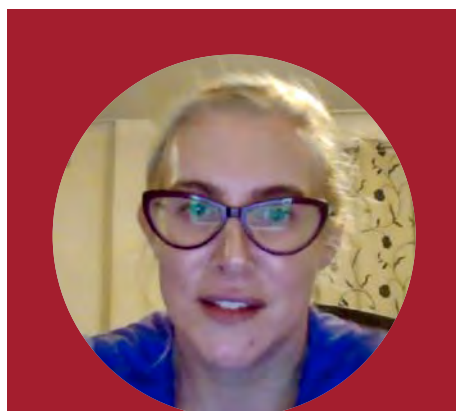
Anyone with a problem pouch would do well to listen to the advice of Professor Ailsa Hart. In her webcast, Prof Hart, who is director of St Mark's IBD unit and a consultant gastroenterologist, spoke lucidly about how to cope with a pouch behaving badly [So where do you start, a cynic might say, although the majority of today's pouches are relatively smooth-

running]. Read her sage advice and comments in the 'Events' section on the RLG website.

Futurologist might be an apt title for Jason Bacon, CEO of the St Mark's Hospital Foundation. After giving an in-depth overview of the merger between St Mark's and CMH hospitals, he predicted some of the likely changes and future events in the pouchcare sector – both locally and nationally – over the next few years. Find out more on his webcast in the website's 'Events' section.

Another overview of the future of St Mark's was given by the hospital's pouch nurse specialist Petya Marinova. In her webcast she described how St Mark's had coped with the pandemic, the move to Central Middlesex Hospital and what St Mark's is doing to improve post-Covid treatment for pouch patients.

On a more historical note, when did pouchcare really begin? You only have to ask Professor John Nicholls, who co-founded the pouch with Sir Alan Parks in 1978 and is a former clinical director of St Mark's Hospital. Prof Nicholls highlighted some of the events leading up to this historic event in his webcast 'Evolution of modern surgery'. It's a fascinating watch and if you haven't seen it check it out in



**Ellie Bradshaw**

IBD specialist at London's Queen Charlotte Hospital



**Janindra Warusavitarne**

St Mark's consultant colorectal surgeon

'Events' on the website.

Janindra Warusavitarne is not just famous for owning the NHS's – and possibly the UK's – quirkiest bookcase (see photo), he's also a consummate surgeon and, luckily for us, a patron of the Red Lion Group. In his webcast "Through the keyhole – latest developments in pouch surgery", Janindra highlighted his speciality, laparoscopic – or keyhole – surgery, and the more recent use of robots in modern pouch surgery. He said the effects of Covid-19 had drastically reduced the number of pouch operations in the past two years.

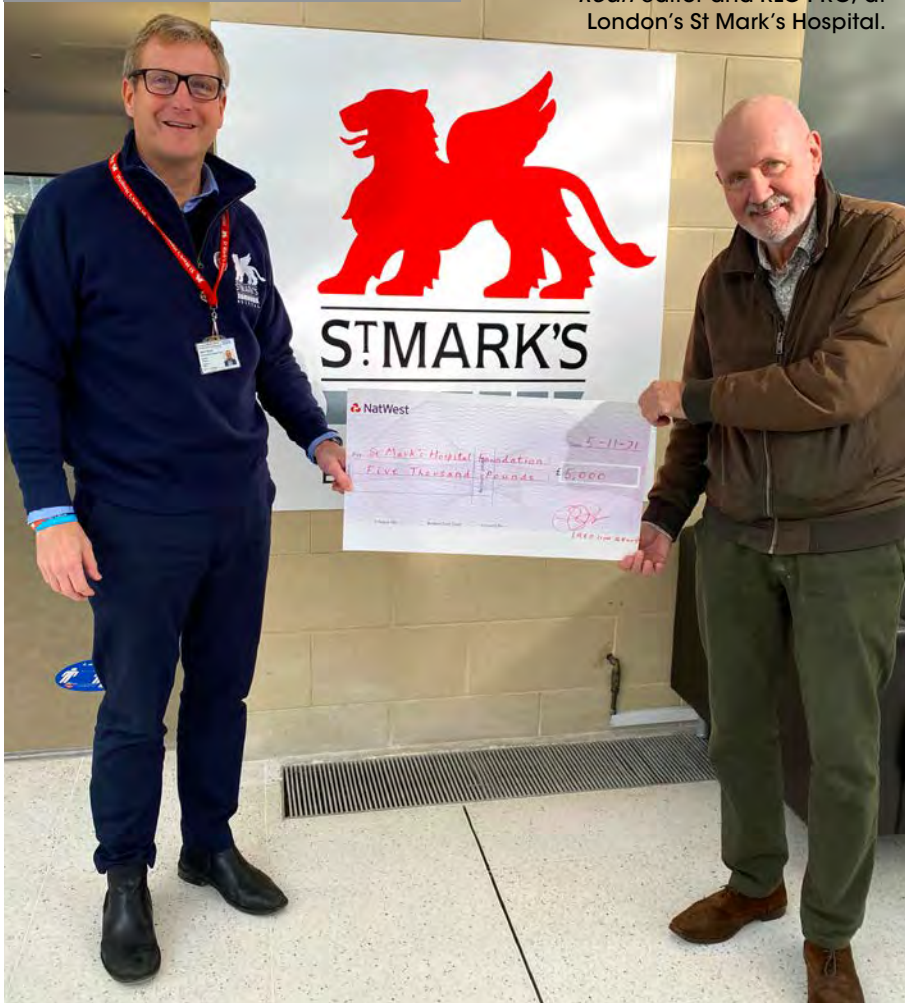
"Keep taking the tablets" is a familiar enough phrase when we're trying to cheer up a poorly friend or relative. However deciding the correct medication for someone with a difficult pouch is a more serious proposition. Ask Uchu Meade, head of pharmacy at St Mark's. In her webcast, Uchu said loperamide and codeine were the two most popular drugs for daily pouch control.

Other drugs such as antibiotics depended on the condition of the patient, and sometimes it was important to decide which drugs to avoid, said Uchu. You can watch her fascinating webcast on the 'Events' section of the website.



## FUNDING RESEARCH

A delighted Jason Bacon (l), CEO of the St Mark's Hospital Foundation, receives a £5,000 donation from Christopher Browne, *Roar!* editor and RLG PRO, at London's St Mark's Hospital.



# RLG donates £5,000 to pouch-related research



ABOVE: A large-scale copy of the Red Lion Group cheque

The money which was raised by the Red Lion Group will help fund vital pouch-related research projects at St Mark's and Central Middlesex Hospitals.

Mr Bacon commented: "We are extremely grateful for the Red Lion Group's very generous donation towards supporting research at St Mark's Hospital. This will help us in our charitable mission to support over 30 research fellows working alongside our specialist consultants and nurse teams."

## RECIPE

# Andrew Millis's vegan lemon drizzle cake

Why not add this to your spread of Christmas treats. Speaking personally, I can't wait!

### Ingredients:

- 100ml Vegetable oil
- 275g Self-raising flour
- 200g Golden castor sugar
- 1 tsp Baking powder
- 1 Lemon - ½ zested and ½ juiced
- 150g Icing sugar

### This is what you do:

- Heat the oven to 180C. Oil a 1lb loaf tin and line with baking parchment;
- Mix flour, sugar, baking powder and lemon zest in a bowl.
- Add the oil, lemon juice and 170ml of cold water and mix until smooth;
- Pour into the tin and bake for 30 minutes or until a skewer comes out clean;
- Remove and transfer to a wire rack to cool;
- For the icing, sieve the icing sugar into a bowl, and add just enough lemon juice to make an Icing thick enough to pour over the loaf.





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# 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.

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

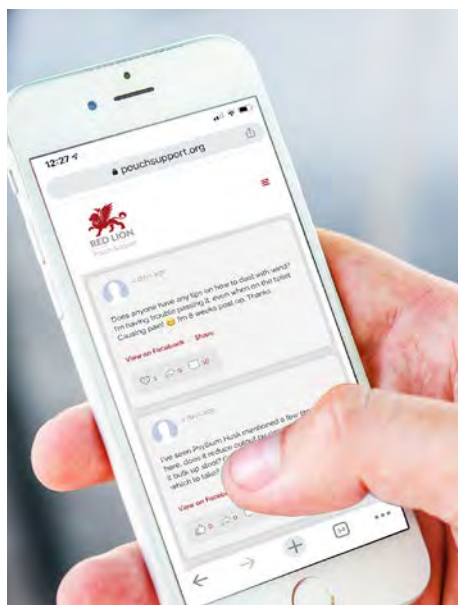
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# VISIT OUR FACEBOOK FORUM

To visit the RLG and J-Pouch Support forum go to [pouchsupport.org/forum](https://pouchsupport.org/forum) or scan the QR code below



SCAN ME



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- 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/](https://pouchsupport.org/faqs/)



# RED LION

## Pouch Support



*Roar!* magazine published twice a year with all the latest news, views and events (Access *Roar!* and the *Roar!* archives on the website [pouchsupport.org](http://pouchsupport.org))

Attend our annual Information Day at St Mark's Hospital in the spring that members can attend at a reduced rate

## Join the Red Lion Group

Membership is £10 (£5 for hardship cases, and free for under 16s) per annum

Free Can't Wait/ Medic Alert card (with QR code linking to medic alert information on Red Lion Group website [pouchsupport.org](http://pouchsupport.org))



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