
Magazine of the Red Lion Group
St. Mark's Hospital • Acton Lane • London • NW10 7NS
ROAR
RED LION
Pouch Support
SPRING 2026
#70
70th Edition!

## HOT TOPICS




# IT'S GOOD TO TALK!

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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.

## MONEY TALKS

RLG donates £3,000 to Orestis Argyriou's pouch study (see pages 8-9)



# NOTES FROM THE EDITOR



Please wish *Roar!* a very happy birthday for this is the 70th issue of the magazine. Editing *Roar!* is fun and I hope you enjoy reading - and sometimes writing for - it too!

Happy reading and let's look forward to many more *Roars!*

Christopher Browne
Editor
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## LETTER FROM THE CHAIR

# Happy Birthday, *Roar!*



RLG Chair David Davies leads the celebrations to mark the 70th issue of the magazine

'Three decades of pouch history, community and support — all documented in Roar!'

Welcome to this, the Spring 2026 edition of *Roar!* which also happens to be the 70th edition of this astonishing publication. The first edition was published in Summer 1994 and they have come thick and fast ever since – at least two per year on average.

Almost 50 of these publications have been produced by Christopher Browne, a long-time Committee member and previous Chairman of the Red Lion Group. Over the years Chris has kept the members informed, educated and entertained with insightful and varied content of deep relevance to the pouch community. Chris's dedication provides a continuous series of colour magazines which document the evolution of the pouch operation and pouch-related topics of interest throughout three decades. It is an astonishing catalogue and every single edition is available on the RLG website for you to download at your leisure. Go to **pouchsupport/org/resources** and type in the password: RedLionGroup

This 70th edition is packed with varied and informative content, including the reflections of a pouchee who sings in a choir, the details of a fascinating, pouch-related, clinical project being undertaken by Dr Orestis Argyriou, the virtues of pouch irrigation, M&S knickers for ostomates, an account of the Kangaroo Club Information Day in Oxford, an article on the new weight loss drugs (GLP-1) and their potential value for pouchees. We hope you enjoy this latest edition of *Roar!*.

I reserve a separate mention for a very special person in the charity and for whom there is a glowing tribute in this edition (see page 11) Professor Sue Clark has been our President for 18 years, taking the reins from Professor John Nicholls as long ago as 2008.

She has been our figurehead and ever-supportive President throughout these years and the Trustees are hugely grateful for her guidance and advice on pouch-related surgery, pouch well-being and governance. Sue has recently retired from conducting surgery and this marks a good time for her to pass on the Presidential baton, with our profuse thanks for all her support over the years.

Our new President is Mr Janindra Warusavitarne, who until now was a patron of RLG and who will be known to many of you as one of the colorectal surgeons at St Mark's Hospital and an eminent pouch surgeon in his own right.

Thank you to Sue for all your support over the years and a warm welcome to Janindra!

David Davies
RLG Chairman



LEFT
Suzy Gaughran

# Why I love the sound of music

We Red Lions are an energetic bunch who enjoy our feats of fitness. However RLG member Suzy Gaughran prefers to use her talents for another form of exercise – singing

It all started at an evening course in performing arts at a local adult college. The course I signed up for was for amateur opera singers, learning and then performing two operas a year in the college theatre.

Usually we performed a light operetta such as The Mikado by Gilbert & Sullivan and the other would be a bigger and more momentous grand opera.

The first opera I performed in was The Elixir of Love by Donizetti which is a light-hearted opera with lovely music and great comic turns by some of the characters. I sang in the chorus – I know my limitations and have no desire to sing a principal role.



RIGHT
Partners in rhyme: Suzy and Mike Gaughran in La Traviata



RIGHT
Change of costume: Suzy in her choir's performance of Orpheus

'What started as an act slowly turned into a partnership – and we got married for real just 18 months later!'

When I had been in the company for about six years, a tall, handsome chap walked into the rehearsal room. During the following months as we rehearsed our next show, La Traviata, we enjoyed chatting together. As rehearsals progressed, the director told us that we should all be assigned a character, so that we had something or someone to act with while on stage. Mike, the tall chap, and I were fortuitously paired up as a 'married couple'. The director obviously saw something, and what started as an act slowly turned into a partnership – and we got married for real just 18 months later!

After a few years the company separated from the college, renamed itself Southgate Opera and started performing in a local theatre.

We always sing in English and perform with a proper orchestra and in full costume. It is a wonderful experience, and over the years we have performed to large and enthusiastic audiences.

I have sung in the chorus of more than 45 operas and operettas which is a lot of words and music to learn. There can also be some dancing involved which, because none of us are professional singers or actors, can be an entertaining process. It usually works on stage as long as no one looks too closely at our feet.

For the last two years I have also sung with Bella Cora, a local upper-voice choir. This is a different experience, singing varied types of music including pop (past and recent), jazz, baroque, folk and gospel among others. We have also sung in various languages including one particularly challenging piece in Czech. We have 25 women in the choir, plus our brilliant musical director, and it is such a friendly, supportive group.

I've had my J-pouch for more than five years now. Although I do still have some difficulties and am currently having Vedolizumab infusions every eight weeks to keep things under control, luckily I am able to continue with my singing activities.

I have also regained the 10kg weight I lost during two years of ulcerative colitis and feel strong enough to get out and about with my husband Mike for bike rides and some invigorating walking holidays in places like the Peak District and the Lake District.

This summer Mike and I visited the annual Gilbert & Sullivan Festival at Buxton in the Peak District where we enjoyed seeing many professional performances of the shows that have given us so much pleasure to perform ourselves .

My 25 years of musical activities have brought me entertainment, fun, joy and a great social life – not to mention meeting my husband Mike.

SPEAKERS' CORNER

# Are slimming drugs a winner for pouchees?



How many of us have asked ourselves that question or else joined the growing network of regular jabbers? RLG chair David Davies investigates

How many of you are using or thinking of using the latest batch of slimming aids – more technically known as GLP-1 drugs?

As the moderator (with Gary Bronziet) of the Red Lion Group's (RLG) Facebook site and RLG's monthly forums, David Davies has seen a recent surge of interest from pouchees in GLP-1 drugs.

So what are the facts behind GLP-1 use in pouchees and can some of the flattering statements about these apparently life-enhancing drugs be backed up by hard evidence.

■ To give GLP-1 its full title 'Glucagon-like peptide-1', it is a naturally occurring hormone that helps regulate blood sugar and appetite and is prescribed in the UK for patients with type 2 diabetes and obesity," says David.

'GLP-1 drugs reduce food noise and food consumption, resulting in reduced frequency, urgency and night-time interruptions'

■ It promotes a feeling of fullness which can help with weight management. GLP-1 drugs also reduce food noise and food consumption, resulting in reduced frequency, urgency and night-time interruptions as well as encouraging weight loss.

■ And there is a suggestion of an anti-inflammatory effect, potentially reducing the risk of pouchitis and contributing to good pouch health," says David.

■ Quoting from clinical trials in the USA, David says doctors found a 35 per cent reduction in frequency and less urgency as well as better stool consistency after two weeks of low-dose GLP-1 treatment on eight high-frequency pouchees. In a second US study, doctors examining 43 obese pouchees with a history of recurrent pouchitis found that GLP-1 treatment lowered the risk of recurrent pouchitis from 53 per cent to 26 per cent – a fall of just over 50 per cent.

### So are GLP-1 drugs safe?

"They are generally considered safe. Common side-effects include nausea, vomiting, diarrhoea and constipation. There are also concerns about some long-term effects that people tend to regain weight quickly when they stop taking the drug," says David.

### Are fat jabs UK centric?

The answer is "No". The volatile UK news media seems to have fooled its readers into believing we are the only nation to have caught the fat-jab bug. Not so. The highest number of GLP-1 users is the USA with at least one person in 12 per cent of households taking the drugs, followed by Denmark (9.1 per cent), Germany and Spain 7 per cent and the UK and France 4 per cent.

### Can pouchees get GLP-1 prescribed on the NHS?

The answer is "Not yet". Currently the only prescribed use of GLP-1 is for patients with type 2 diabetes and/or obesity. The majority of UK users purchase GLP-1 via private prescription and under remote medical supervision.

### What does RLG think of the drugs?

RLG supports the use of GLP-1 drugs but only under appropriate medical supervision.

You can read a fuller version of this article on the RLG website at **pouchsupport.org/do-the-new-glp-1-drugs-slimming-drugs-deliver-better-pouch-performance/**

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

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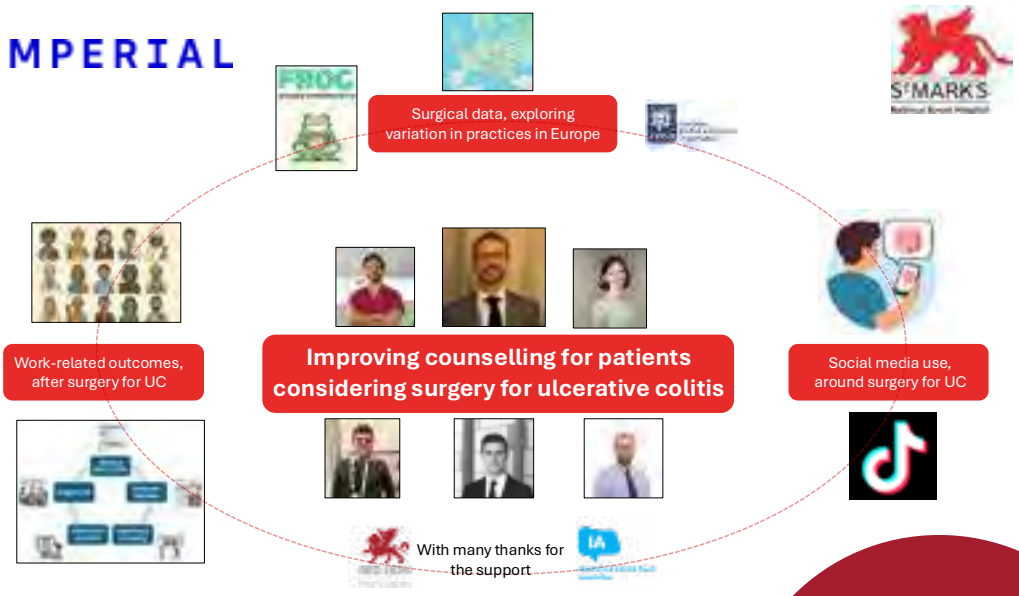
# Welcome to the wonders of work

## How well do we cope after surgery? A new study – the first of its kind – will help to fill in the gaps



Study leader Orestis Argyriou (left) with colorectal surgeon Professor Michel Adams and Orsalia Mangana, Manchester-based IBD/ colorectal surgery fellow pouch study

RIGHT
An overview of
Orestis Argyriou's project




How soon did you go back to work after your pouch op? This is just one of the many topics covered by a PhD research project into pouchees' quality of life post-surgery led by St Mark's Hospital research fellow and trainee surgeon Orestis Argyriou.

"The aim of the thesis is to improve the counselling for patients considering surgery for ulcerative colitis (UC)' and to improve how the medical profession supports people with UC when they are faced with decisions about surgery," said Orestis

"Overall, as with any decision about surgery, the goal is not to push patients towards a particular choice, but to make sure they feel informed, supported, and able to decide what is right for them – based on clear information, realistic expectations and their own priorities.

One area the study found had very limited information was work – whether "returning to work, managing in the workplace, and the impact of surgery on working life," Orestis told *Roar!*.

To confirm this gap in knowledge, Orestis's team – which is supervised by two St Mark's specialists – Kapil Sahnan, consultant robotic IBD surgeon, and Professor Ailsa Hart, consultant IBD gastroenterologist – carried out a review of the published literature on work.

"It showed that work-related outcomes have largely been neglected or have only been explored as a small part of broader quality-of-life questionnaires and without enough detail," said Orestis. So in a series of interviews with patients Orestis's team "learnt much more about what it is really like to work with a pouch and what this can mean for day-to-day working life. We also learned about the importance of employers' and workplaces' attitudes towards acceptance, support and understanding – and identified factors that can make this journey easier," said Orestis.

Another of Orestis's key sources is data collection. One of his projects, catchily titled FROG (it stands for Frequency Rates, mOrbities and timinGs), collects data from surgical interventions for UC from leading hospitals in Europe.

So far the team have signed up 38 active sites from 16 European countries and aim to reach 55 to 60 sites and a total of 2,000 to 3,000 patients – making it one of the world's largest surgical studies – by the end of the study. It's due to be completed by September 2026 and the results published in mid-2027.

One major source used in Orestis's study is TikTok **(see "Why not TikTok your way to good health" in the Autumn 2025 issue of *Roar!*).**

"Social media is one of the fastest-growing ways in which people access and exchange information, and many people diagnosed with ulcerative colitis are already using these platforms as part of everyday life," said Orestis.

> "Work-related outcomes have largely been neglected."

"Social media offers an opportunity to observe conversations and experiences that are not limited by traditional search questions, allowing patients to highlight the issues that matter most to them in their own words."

Orestis's study has been peer-reviewed by several leading professional bodies including the ACPGBI (Association of Coloproctology of Great Britain and Ireland) and ECCO (European Crohn's and Colitis Organisation). The research is also supported by Dr Itai Ghersin, IBD gastroenterology fellow at St Mark's Hospital, Guy Worley, consultant IBD surgeon at Bart's Hospital, and Phil Tozer, consultant IBD surgeon at St Mark's.

In the past 18 months Orestis and his team have given many Europe-wide presentations to hospitals and major institutions on their findings and research and won a number of grants and awards including a recent £3,000 donation from the Red Lion Group (see photo on page 3).

Orestis also gave a lively and thought-provoking talk on Zoom in May this year about his project as part of RLG's 2026 webinar series.

# Kangaroos smarten up their pouches

"A day of expert advice, shared experiences and practical tips for living well with a pouch"



ABOVE: Kangaroo Club president Kat Baker

## The Oxford-based Kangaroo Club's information day was as educational as it was entertaining

The highlights of the Kangaroo Club pouch support group's Information Day in November 2025 were two talks by the nutritionist Clemmie Oliver.

In her first talk 'Diet for your best life with a pouch' Clemmie who specialises in treating patients with IBD gave members many valuable tips on the best diets and nutritional foods for a healthy lifestyle.

Interestingly in her second talk Clemmie told the story of her own experiences as an ulcerative colitis sufferer. For she first suffered UC at the age of nine. Two years later she had an ileostomy and finally at the age of 18 a two-stage J-pouch.

When she left university these experiences prompted Clemmie to set up her own nutrition and lifestyle clinic for people with IBD (**clemmie@nalmclinic.com**).

Other speakers included the Kangaroo Club president and Oxford University Hospitals' consultant colorectal surgeon, Kat Baker. In her talk 'Ileo-anal pouch – Living my best life' she discussed pouch surgery and the alternatives to surgery and how to live your best life with a pouch.

Then Fran Woodhouse and Simon Turley, two of the Oxford University Hospitals' specialist pouchcare nurses, described the challenges facing pouchees post-surgery before answering questions and giving advice to members of the audience.

The day ended, appropriately, with tips about exercise and how to keep fit with a pouch.

Commenting on the event which was sponsored by Salts Healthcare, Kangaroo Club secretary Ruth Cox told *Roar!*: "We had a successful day with a very good turnout and we have had much positive feedback about the event."

"From an ileostomy at age 11 to a J-pouch at 18, my own experience inspired me to help others with IBD live healthier lives."

— Clemmie Oliver

BELOW: Nutritionist Clemmie Oliver





ABOVE: Kangaroo Club chair Laura Dunn

# RLG appoints new president



After 18 years in the post Professor **Sue Clark** has stepped down as president of the Red Lion Group.

We are very grateful to her for her kindness and gems of wisdom during her presidency and we wish her the very best for the future.

As a consultant colorectal surgeon at St Mark's Hospital, Prof Clark has built up an international reputation for her work repairing and/or removing pouches with poor function, a role she held until recently.

Another of her achievements at St Mark's was a two-year spell investigating the genetics of cancer in polyps associated with FAP (familial adenomatous polyposis).

From 2014 to 2019 Professor Clark was dean of the St Mark's Academic Institute and also served as dean and clinical director of the St Mark's Polyposis Register.

She took over the presidency of RLG from Professor John Nicholls in 2008.

Her successor as president is **Janindra Warusavitarne,** St Mark's consultant colorectal surgeon and until now a patron of RLG.





# Flushed with success

## How water can help cure the trickiest of pouch problems

Blockages, frequency, emptying problems. Sound familiar? A growing number of pouchees are using a simple technique that needs little more than a basin of water, a syringe and a catheter to help relieve those awkward moments.

And I am one of them which I wrote about in the Christmas 2008 issue of *Roar*! The most helpful guide to your catheter conversion is a video produced by membership secretary Gary Bronziet at **youtu.be/XIYg-bCyVW**. Check it out and give yourself a few welcome doses of joy!

Another user-friendly device is the Qufora Irrisedo cone system which Red Lion Group (RLG) member Claire highlights in a series of six videos at **pouchsupport.org/pouch-irrigation-and-catheterisation-demystifed**.

Claire had issues with frequency, cramping and poor emptying at night due to strictures below and above the pouch. Then she discovered the Qufora. "It is an absolute game changer. I can go out all day and not worry about pouch problems. I was intimidated by irrigation to start with, but it now takes just 15 minutes at either end of the day," she says.

> "It is an absolute game changer. I can go out all day and not worry about pouch problems" — *Claire"*

And that's not all! A third way to empty when pouch problems threaten is called the Aquaflush anal irrigation system. RLG member Julia told *Roar*!: "This has a much softer silicone cone than the Medena catheter though like the catheter you also insert it into your bottom."

The Aquaflush kit comes with optional extension tubes which makes it easier to insert while sitting down. "I find it easier to relax my pelvic floor by sitting rather than standing. Now I find that after several years with a pouch my function is better than ever," added Julia.

You can get all three devices on prescription. However before trying to use any of them you should heed the advice of a member of the pouchcare team that cared for you after your pouch operation.

**The key suppliers of these devices are Coloplast Charter on 0800 132 787 and Bullen Healthcare on 0800 888 501**

# Leaders of the pack

## The Red Lion Group's online activities are part of a numbers game – and the numbers keep on rising!



LEFT
Gary Bronziet

"With nearly 300,000 website views and members joining us from around the world, our pride of Red Lions has never been stronger."

Our membership and website traffic continue to move ever onwards and upwards and we are now very close to hitting 300,000 views on the Red Lion Group website **www.pouchsupport.org.**

Not to be outdone our other website J Pouch Support (UK specific) Facebook recently welcomed its 2,000th member and continues to keep on growing! Interestingly it has twice as many female as male members!

Our monthly zoom forums have proved an ideal outlet for pouchees and potential pouchees to discuss their personal pouch issues and problems with fellow pouchees. The forums are always well supported with a core audience of "regulars" including a few from the USA.

If you haven't attended one yet, I highly recommend you give it a try – you never know, you might become one of the "regulars".

Another success story is RLG's 2026 webcast series. Two of these have been given by a pair of St Mark's Hospital pouch nurse specialists – **Samantha Evans**, nurse consultant for stoma and pouch care, and **Lisa Allison**, clinical nurse specialist for pouch care.

While **Alexa Duff**, lead clinical psychologist at St Mark's and founder of the Gut-Brain Connection network and website (**wwwgutbrainconnection.co.uk**), gave a fascinating talk on the links between psychology and IBD. More recently **Orestis Argyriou**, a St Mark's research fellow and trainee surgeon, gave an invigorating talk on his PhD research project into pouchees' quality of life post-surgery.

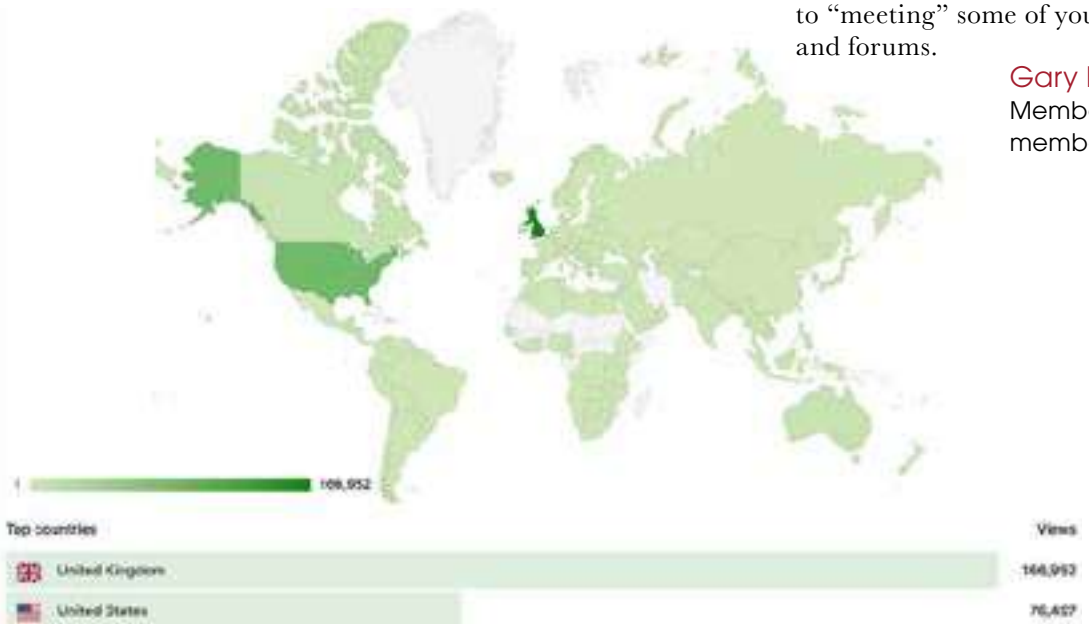
More webcasts are scheduled for 2026. So check **pouchsupport.org/events** for up-to-date information and registration details of these.

To discover how our pride of Red Lions is growing, the map below shows the number of viewers worldwide.

The darker the shade of green the greater the number of views – and as you can see, there are very few places that haven't visited our website at least once!

I hope you are all keeping well and I look forward to "meeting" some of you on upcoming webcasts and forums.

Gary Bronziet
Membership Secretary and IT
membership@pouchsupport.org






ABOVE
Dr Alexa Duff: a lucid webcast speaker

# Knickers!
# *The inside story*



## Do you have a temporary – or even a permanent – ileostomy? If so, here's a neat little way to stay comfortable and follow fashion

Do you have a stoma – or know someone who does? If the answer is "yes", M&S, the high-street superstore, has produced a range of men's and women's knickers just for you!

At the last count, 200,000 people in the UK have a stoma, NHS figures report. And many pouchees who have had two- or three-stage ops have needed to use a stoma-bag for anything from three months to a year or more while their newly-fitted pouch settles down.

So here are a few facts to help you avoid getting your knickers in a twist, if you'll pardon the phrase, and, even better, to stay in fashion.

M&S's new range of cotton-based stoma knickers come in four colours and several different styles (including high-waisted thongs and Brazilian-style knickers!). In fact they are just like any other style of underwear with one key difference – they all have one or more in-built expanding pocket or pockets to hold your stoma-bag or bags and so help prevent accidents or leaks.

The M&S brand was created by an ileostomist and M&S employee called Jiggi Sohi. Jiggi says: "I've been living it large without a large intestine and with a stoma in its place to collect my waste. For years I've known there is a real gap in the market for stoma knickers and I built up the confidence to do something about it."

So if you too have an ileostomy – whether temporary or permanent - isn't it time you joined the stoma set by logging on to www.marksandspencer.com and buying a pack of three for £18.

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**A TRIBUTE**

# Jean Reed's moment of history

## Tribute to an RLG member with one of the world's oldest pouches

One of the world's first pouch patients, Jean Reed, has died – an event that also marks the end of a unique and historic partnership.

For Jean met fellow pouchee Sylvia Panford in the same ward of St Mark's Hospital when they were both recovering from pouch surgery in 1978.

The pouch operation had only just been invented by the surgeons Sir Alan Parks and Professor John Nicholls at the nearby Royal London Hospital where both women had first been admitted after spells of ulcerative colitis.

A few weeks later Sylvia was the ninth patient to have the pouch op and her friend Jean the tenth.

After befriending one another at St Mark's the two pouchees joined the Red Lion Group and have been active members ever since. Sylvia says: "Jean was such a lovely friend. She spoke her mind and we would have discussions but never fell out. She left her bank job and became a social worker. She always stood up for her clients and could be very sharp-tongued in fighting for their rights. Not that I ever experienced that!!

"She loved talking about being a grandmother and eventually a great-grandmother and we always compared notes.

"As the years passed, sadly Jean was unable to walk so I




# 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:

Christopher Browne, Editor
cbrowne@brownemedia.co.uk



always went to see her. She never complained and there were always the lovely phone calls. My daughter and I visited her four times a year when I came to England from my home in Portugal.

"I have wonderful memories of our times together and there was always a lot of chatting of course.

"I will always miss Jean with sadness but remember her with a smile," adds Sylvia.



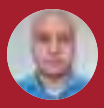
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# RED LION

## 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)

Attend our monthly Zoom forums on the first Monday of the month to discuss personal issues and problems with fellow RLG members

# 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)



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