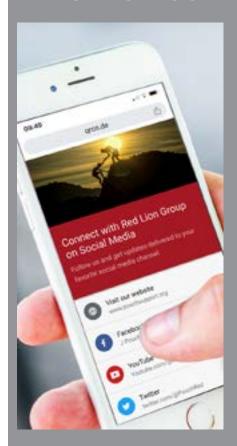


HOT TOPICS



IT'S GOOD TO TALK!

To visit any of the RLG social channels, simply scan the QR code below

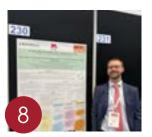




CONTENTS

- Notes from the Editor
- Chairman's autumn report
- Bruce achieves 'impossible' dream
- TikTok your way to good health
- 10 Wildlife-watching by train
- 12 Wisdom on the web
- 14 Riddle of the Red Lions







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.

ON THE COVER...

man Bruce Willoughby flanked by Clifton Suspension Bridge







id you know that Fred Astaire wore a stoma bag even when he was performing his extraordinary gyrations as a dancer.

The great actor-dancer had an ileostomy fitted in 1958 after a long spell of ulcerative colitis (UC). It makes you think: Would he have opted for a pouch if it had been invented by then?

You never know, he might even have joined the Red Lion Group and what an experience that might have been.

the imagination of Interestingly, people an architect." with ileostomies - ie stoma bags – are not as embarrassed about talking about them or showing them off in public – whether swimming, working out at the gym or performing on stage - as they used to be. One or two individuals even seem to wear their bags with pride!

Life-changing decision

To find out more about stoma bags and pouches (and I'm not trying to put people off the idea of the latter) log on to YouTube on the RLG website www.pouchsupport.org and view St Mark's Hospital's consultant surgeon Janindra Warusavitarne's recent webinar 'I-pouch or Stoma – a lifechanging decision.'

Let's face it, the ileo-pouch is such an original invention that it could only have been devised by a surgeon with the skills of an engineer, the finesse of a watchmaker and the imagination of an architect like Sir Alan Parks in 1976 ably supported by his registrar Mr John Nicholls who later became emeritus consultant surgeon and clinical director of St Mark's Hospital and professor of colorectal surgery at Imperial College London. He is currently a patron of the Red Lion Group.

> So the idea of a degree in pouchcare (or a BSc in

Pouchology to give it scientific rigour) is not as far-fetched as it may seem (see the article on pages 12-13). And interestingly the son of the first patient to have a pouch operation is a member of the RLG committee and there are several

other RLG members who've had their pouches for 43-plus years.

Highlight

"The ileo-pouch is

an invention requiring

the skills of an

engineer, the finesse

of a watchmaker and

However the highlight of this autumn issue of *Roar!* is a revolutionary new study about the power and influence of TikTok led by St Mark's Hospital research fellow Orestis Argyriou. You can find out more on pages 8-9.

And a final flourish by Chairman Davies on pages 4-5 as he welcomes a change of charitable status for the Red Lion Group.

A warm, happy and enriching autumn to all Roar! readers!

Christopher Browne

Editor

cbrowne@brownemedia.co.uk



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



RLG keeps counting the hits



Chairman Davies finds many reasons to be cheerful including the Red Lion Group's new status as a charity. Read on to find out more

n the Spring 2025 *Roar!* I said that "...very little has changed for we pouchees..." and I've reflected on that statement along with fellow pouchees on the Red Lion Group committee and during our monthly zoom forums.

And my conclusions?

The pouch world is, in fact, evolving all the time with issues and trends emerging in patient perceptions, patient care, surgical advancements and refinements to pouch management. RLG keeps you – our members – engaged and informed on these trends and indeed we help to maintain a healthy dialogue (forgive the pun) between patients and healthcare professionals. And we would love to hear from you if you have thoughts on what more we can be doing to support pouchees and potential pouchees – please drop us a line at any time at

info@pouchsupport.org.

Perhaps the most significant recent development is the pouch accreditation scheme introduced by the Association

of Coloproctologists in Great Britain and Ireland (ACPGBI). This is a list of some 20 or so centres (or regions) that have submitted the documentation to become "centres of excellence" in pouch surgery and medical care. Research suggests that patient outcomes are likely to be better at these experienced centres than at inexperienced centres. ACPGBI are now undertaking a raft of audits to verify the accreditation at the various centres.

Ultimately people who might be eligible for a pouch and others who are having issues with their pouches will be able to identify their nearest "centre of excellence" and advise their GPs and health professionals where they need to be referred.

RLG delivers a great deal of our content via online platforms. Membership secretary Gary Bronziet has reported recently on our achievement of the 250,000th "hit" on our website since it was set up and the Facebook group has just (as I write) exceeded 1,900 members and the numbers keep on rising relentlessly. We have hosted four webinars to date in 2025 (see article on page 8-9), with experts talking to us about topics as wide-ranging as peak physical fitness (Ben Barbanel), nutritional advice for pouchees (Clemmie Oliver), the latest advances in pouch surgery and pouchcare (Guy Worley) and the difficult decision of choosing between a pouch or a stoma (Janindra Warusavitarne). The recordings are all available online, but you have to be in the webinar to ask your own questions and indeed the attendance for these events has never been higher. On at least two occasions we were concerned that we would exceed the 100 limit for delegates joining these webinars.



We work closely with the research teams at St Mark's Hospital and I am delighted that so many of you have stepped up and volunteered to take part in these projects which have ranged from management of dysplasia (pre-cancerous cells) to sexual dysfunction and from fistulas to the impact of pouch surgery on work. To all those who agreed to take part in these studies we extend a sincere and heartfelt thank you on behalf of the research staff for helping to making these projects so successful. One such researcher, Orestis Argyriou, a research fellow in IBD and colorectal surgery and a trainee colorectal surgeon at St Mark's, writes in this edition of *Roar!* about some fascinating work he and his team have conducted in which they have analysed the content posted on TikTok by patients with Crohn's disease and ulcerative colitis (UC) and drawn some amazing conclusions on the power of social media to influence attitudes. This could have implications for future education programmes delivered through social media.

We are also watching closely on your behalf a growing body of anecdotal evidence (supplemented with one medical publication) that is claiming very positive effects for the new weight loss drugs (collectively known as GLP-1s) in pouchees.

As if all this was not enough, the RLG Trustees took the brave decision in 2022 to migrate the charity to a Charitable Incorporated Organisation (CIO for short). There were very good reasons for this – not least the protection for the Trustees from personal liability in the unlikely event that the charity was subject to litigation. We obtained approval for this at the 2022 AGM and reaffirmed it at the 2024 AGM. I can now announce

that we achieved CIO status on 14 August and we will be migrating to the new charity over the coming months.

I have written an article for the website to explain more about this, but please be reassured that you will see very little change.

Lastly, in response to many questions and enquiries, let me share that St Mark's now has two excellent and experienced pouchcare nurse specialists in Lisa Allison and Samantha Evans who return to the team and bring top-notch pouch expertise. They have a large backlog to work through so please be patient if you are one of those waiting on responses. Lisa will be familiar to many as she was the RLG chair before me and is a pouch nurse expert who was recruited back to St Mark's from London's Royal Free Hospital. Sam is also a highly experienced pouch nurse specialist and has also delivered presentations at RLG Information Days in the past. We extend a warm welcome to these first-class professionals and look forward to working with them on your behalf in the future.

I hope you enjoy this latest edition of *Roar!* and please don't forget to drop us a line at **info@pouchsupport.org** with suggestions, comments and feedback.

David Davies RLG Chairman

How Bruce achieved his impossible dream



hen I told a friend I had a foolhardy dream to run an ultra-marathon he said: "What's stopping you?" So I made a list of all the obvious no-nos and improbables including sharing rooms and toilets with fellow competitors, lack of loos on the route, poor nutrition knowledge and hydration problems.

However my fantasy of achieving the seemingly impossible was re-kindled when a running friend completed the 1,000 miles from Land's End to John O'Groats and returned triumphant.

Then suddenly my earlier misgivings started to nag me again. I am a GP and had a pouch op in my 20s and for a long time the thought of running was too much due to the jigging about that can make you want to go to the loo. This sometimes made it easier to not do the things I wanted to do.

Despite that I had started to go for a few short runs gradually increasing the distances until in 2023 I ran the London Marathon. I then started to train more seriously and ran a 30-mile and then a 35-mile ultra-marathon which began to give me hope.

Then, as luck would have it, I had a problem with my knee and needed surgery. This reduced my preparation time from 18 to six months and forced me to cycle to help build up my fitness.

The big day arrived on 31 May this year and the 22 runners taking part in the event catchily-titled "Run Britannia" met up at the start near the very tip of Land's End.

The event itself turned out to be as much a physical challenge as a scenic adventure. During the first few days we were buoyed with excitement as we negotiated the stunning 630-mile South West Coast Path, followed by Somerset's spectacular Cheddar Gorge and finally ending that first week crossing Bristol's Clifton Suspension Bridge (see cover).

I was managing by eating low residue carbohydrate foods during the day

and keeping myself hydrated, and then moving on to high protein and high carbohydrate drinks and meals in the evening.

However by the end of the second week as we crossed into Wales and the Offa's Dyke Path national trail, I faced a new challenge – aching shins and swollen ankles, popularly known as shin splints, which the event's physio taped up to enable me to continue.

In the third week our doughty crew reached the North West of England via the Runcorn Bridge, through St Helens and Preston, along Morecambe Bay to the Lake District. My shins were still suffering but, pain or no pain, it didn't dull the excitement of crossing into Scotland at Gretna Green.

It was an emotional moment, celebrated with bagpipes and a hearty Scottish breakfast. I couldn't believe we'd come so far, but we were still only halfway to John O'Groats.

Then reaching Glasgow, following the meandering River Clyde, in week four





Why not THE ROAR! REPORT TIKTOK your way to good health



TikTok offers a

into people's

The social media platform has given a team led by St Mark's Hospital research fellow Orestis Argyriou many useful insights,

ideas and tips about ulcerative colitis, Crohn's disease and pouch surgery

veryone's talking about TikTok.... Well, quite a few of us are anyway. So what exactly is it? It's an app for users to either make, watch or show videos up to 15 seconds long. And thus a very clever and catchy way to get your message across on social media.

Just ask Orestis Argyriou, a research fellow and trainee surgeon at St Mark's Hospital, who is leading a study as part of his PhD research into what pouchees say on TicToc. "It is a platform where open and often very honest conversations take place particularly among young people," says Orestis.

"Since ulcerative colitis (UC) often presents at a young age, and surgery may become necessary for many patients, TikTok offers a unique window into people's experiences," he adds.

The study has already had national and global recognition. Orestis gave presentations at the ACPGBI (Associaton of Coloproctology of Great Britain and Ireland) annual conference in Harrogate in July this year and the ESCP (European Society of Coloproctology) annual conference in Paris in September.

The full results will be published in a scientific journal.

"The majority of videos contained rich, first-hand information," he says.

Among the key themes shown in the study were:

- **Patients** experiences" explained their surgical journeys step-by-step, with illustrations of their diseases, the anatomy and mechanics of a J-pouch, and practical details of what happens around an operation;
- Many described living with a stoma or pouch, offering practical tips on diet, eating habits, toilet access, quality of life, weight changes and coping with complications;
- A large number of videos focused on breaking down stigma and promoting acceptance, while others highlighted challenges such as complications or the emotional impact of surgery.

As Orestis points out: "These themes reflect priorities and concerns that are not always captured in clinical settings, highlighting potential gaps in the information provided."

The study applied a similar approach to Crohn's disease surgery, analysing TikTok videos from patients who have had surgery. "Patients shared detailed accounts of operations, recovery and long-term adjustments," he says.

"These studies show that TikTok and other social media platforms unique window provide powerful insight into what matters most to patients, helping to improve communication and support around surgery for IBD."

> Orestis' work is jointly supervised by both a surgeon and a gastroenterologist — Mr Kapil Sahnan, consultant robotic IBD surgeon, and Professor Ailsa Hart, consultant IBD gastroenterologist "ensuring balanced expertise and direction," he says.

As further back-up, Orestis has been working closely with Dr Itai Ghersin, a gastroenterology research fellow specialising in ileoanal pouch conditions. Other members of his team who are regularly consulted and provide feedback are consultant IBD surgeons Mr Phil Tozer and Mr Guy Worley, as well as consultant gastroenterologists, pouch specialist nurses, occupational health experts, qualitative researchers, and, most importantly, patients.

Finally, building on a strong tradition of encouraging early involvement in research, the team is supported by Imperial College London medical students Christianna Petmeza and Chirag Goyal "and so inspiring future doctors to focus on bowel-related medicine and research," adds Orestis.



he first surprise that greeted my husband Chris and me when we landed in Namibia was that they'd just had their first rain for eight years (and we Brits complain when we have to wait a month for a few drops to water the flowerbeds!).

And there was a lot of rain too with extensive flooding. And it was such fun to watch the children playing in the water, but very strange to think they'd never seen rain before.

Actually our trip was something I'd dreamt about for years as Namibia was where Chris had once worked for several years. But I'd had a slow recovery from pouch surgery and we knew parts of Namibia's infrastructure such as its roads and general amenities were limited.

Then one day I saw a couple of adverts for Rovos Rail, a luxury safari service that covers southern Africa and parts of the north too. So our prayers were answered.

On the first day we were welcomed on board the safari train with a red carpet and champagne. "Oh I could get used to this," I chuckled merrily to Chris. It turned out every time we boarded the train, even if it was after only a couple of hours, we were welcomed with champagne!

The first day of our 15-day trip was a visit to a cheetah conservation project with a very holistic approach to looking after the animals. One of the country's main issues is farmers killing cheetahs to protect their livestock so this project has a big programme supplying guard-dogs to farmers which has greatly

helped to preserve cheetah numbers. To find out more log on to **cheetah.org**.

Then it was on to Etosha National Park for some big game watching. I used to live near Marwell Zoo, a conservation zoo just outside Winchester, and spent many weekends looking at the animals. But nothing quite prepared me for the impact of seeing them in the wild. The giraffes no longer look awkward but just perfectly adapted to their environment and the bull elephants are huge!

Our next highlight (literally!) was to climb Big Daddy, the world's tallest sand dune. Coming down this giant mound was far easier than clambering up it as the sand was very soft, so I skidded down on my bottom. Very elegant! That evening, the guides took us out to see the sun setting and the



Namibia: facts and figures

With a population of 3.1 million, Namibia is a republic in southern Africa and one of the most sparsely populated countries in the world. Its name derives from the Namib desert, which is the oldest desert in the world. Namibia's capital and largest city is Windhoek and its main industries are agriculture, tourism and the mining industry.

TOP: More champagne please..... on second thoughts!

MIDDLE: A Namibian cheetah - see cheetah. org

BOTTOM LEFT: Victoria Falls: known as the "largest curtain of falling water in the world"

BOTTOM RIGHT: A small herd of zebras



stars coming out over the desert. The extra surprise was that they had set up a temporary restaurant for us in the desert.

Travelling by train was such a treat. You could just watch the scenery and the animals as you whiled away the hours eating and drinking. It's quite bizarre to be tucking into eggs on toast as an ostrich comes running past. Though being followed by vultures was a bit disconcerting.

Surprisingly, despite the extreme heat, we had no issues with dehydration. We took lots of e-mix (the electrolyte solution recommended by St Mark's Hospital). If anything I probably coped better than a lot of the other passengers in our group. I also started drinking e-mix early in the day.

Among our many stop-offs, we visited some of the diamond mines where Chris used to work including the Big Hole in Kimberley in Namibia's Northern Cape which reaches a depth of 1,097 metres and has only recently been closed.

We rounded off the trip with a few days in Victoria Falls which lie on the Zambesi River. The water level was extremely high so, from the ground, the view was limited due to the spray but the sound was incredible. We then had a gorgeous sunset river cruise up the Zambesi and saw lots of hippos but made sure we kept our distance as they can be dangerous.

We just had to finish our safari with a round of golf. We also discovered that warthogs have the right of way on golf Theresa's top tip:

If you are going to take pain medication to Africa that contains codeine then do make sure you carry a copy of your prescription with you as it is a controlled drug in a lot of African countries.

courses! So for most of the round our caddy was close by and very attentive. Then on one hole he decided to stand at the far end of the green. I thought he'd lost interest in my golf then Chris started laughing and pointed to the sign behind me as I putted, 'Beware of the crocodiles!'.

It was a fantastic end to a fantastic holiday! In fact we enjoyed it so much that we've got another safari booked for next year. A degree in pouchcare? It could just happen

Just ask one of our eminent speakers in RLG's 2025 series of webcasts what they think about the idea and you might be surprised by their responses

ow would you like to add a Degree in Pouchcare to the list of achievements on your CV? It's not as far-fetched as it might seem as the range of surgical inventions and medical cures continues to grow.

You only have to mention the word "pouch" to any of today's specialists and consultants and you might be surprised by the sheer breadth of their knowledge and the sharpness of their insights. So ideal candidates for a pouchcare degree you might say.

Among those to be awarded "firsts" might be that dynamic duo – RLG's patron Janindra Warusavitarne, St Mark's Hospital's lead consultant colorectal surgeon, and his multitalented pouch patient and RLG member Ben Barbanel.

Though they spoke together in the 2024 series of webcasts, in this year's 2025 line-up they performed individually.

We'll start with Ben. Anyone who is keen to improve their fitness – sometimes against the odds – will have relished his honest and forthright webinar which he gave literally off-the-cuff.

The most remarkable stat in Ben's story is that he lost 23 kilos in almost as many weeks. "I was middle-aged and overweight," he says. So what did he do? He devised a fitness plan called "the Triangle".

The first prong is walking. Ben does 20,000 steps a day – without fail he says – thanks to a treadmill built into his desk which he uses for his day job as a City banker and for meetings and conferences. For his second prong, Ben joined a high-performance gym (See page 6 of the Spring 2025 *Roar!* working out with a personal trainer, lifting weights and performing cardio exercises.

Nutritionist and fellow webcaster Clemmie Oliver would certainly agree.

> In her talk, catchilytitled "Recipes for success", the nutritionist revealed that she too has a J-pouch. Which means she knows only too intimately the many issues we pouchees face.

Clemmie first had ulcerative colitis aged nine, an ileostomy two years later and finally a two-stage J-pouch when she was 18. After university Clemmie set up her own nutrition and lifestyle clinic for people with IBD.

Among the top tips in her talk was to make sure we pouchees always chew



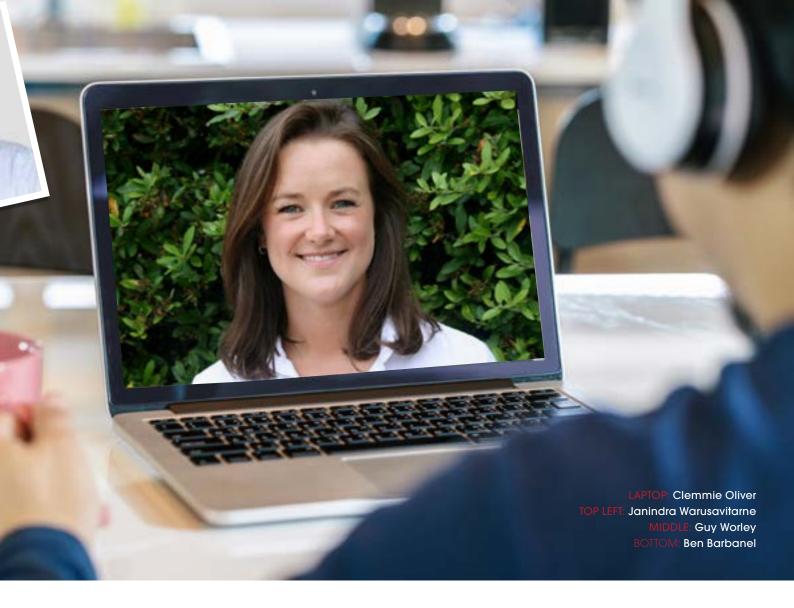
"Chew your food

using your teeth

like a free blender -

it's a game-changer

to prevent bloating'



our food "using your teeth like a free blender". It not only gives us more nutrients "but is a game-changer to prevent bloating", she said.

Another of Clemmie's tips was to eat foods from the Mediterranean Diet – a mainly plant-based regime that includes fish and poultry, a limited amount of dairy foods, seasonal fruit and vegetables, unsalted nuts, seeds, legumes and olive oil. "A good diet can also help to reduce the risk of pouchitis," said Clemmie.

Finally she urged all pouchees to avoid 'trigger' foods and drinks, specially during the first six to 12 months post-op when the pouch is settling. Two of the most common are caffeinated drinks like coffee and spicy foods. Sage advice and you can contact her for advice at

clemmie@nalmclinic.com.

But back to degrees for a moment. One webcaster we should consider for a doctorate in pouchcare (perhaps we should call it Doctor of Pouchology) is Guy Worley. Guy, a former surgical research fellow of St Mark's, already has a doctorate in the study of ulcerative colitis.

After many dedicated years of research into the surgical management of UC and ileal pouch dysfunction, Guy is now a consultant colorectal surgeon at the renowned Royal London Hospital.

In his talk Guy gave a fascinating account of the early pre-pouch days of ileo-anal surgery. He also gave a slide-assisted account of the techniques and intricacies of modern pouch surgery.

He said the three key factors for pouchees to remain healthy were to always contact your surgical and medical teams if something goes wrong; to make sure you always go to the loo when you feel the urge; and, finally, to be happy! Sage advice indeed. St Mark's lead colorectal surgeon, Janindra Warusavitarne, needs little introduction. The St Mark's surgeon who is also a patron of the Red Lion Group discussed the pros and cons of pouch surgery in his talk titled 'J-pouch or Stoma? A life-changing decision'.

Both Janindra and Guy praised the indispensible role pouch nurses play in helping patients recover from surgery. "A lot goes on behind the scenes – unbeknown to both staff and relatives – to help people," said Janindra. Another recent trend, he said, was more people were willing to have an ileostomy as the stigma of wearing a bag was less than it used to be.

You can hear recordings of all these webcasts on the YouTube section of the RLG website **www.pouchsupport.org.**



Led astray by another pride of Red Lions

"we had

over 20k views

in one day!"



Even membersip secretary and IT guru **Gary Bronziet** was baffled when there was a sudden surge in website visitors recently. Read on to find out why

t's been quite an eventful few months since my last report In the Spring issue of Roar!. In August I celebrated a landmark 70th birthday.

Celebrations included a short cruise with my family including two recently arrived granddaughters, followed by a first safari in Kenya with my wife Jacqueline – which definitely exceeded expectations.

The period was marred by the passing of my mother at the age of 96. She had a colostomy (following rectal cancer) about 30 years ago (performed by Professor John Nicholls at St. Mark's Hospital) and she coped remarkably well with it, managing independently until her last days.

last days.

On the RLG front, we

continue to grow our

membership and online reach. Our target of reaching 250k views this year was hit earlier than expected, when our website

www.pouchsupport.org was confused with a completely unrelated Red

Lion Group that was in the news – in fact we had over 20k views in one day. It does distort

our stats slightly but now we can set our sights on hitting 300k.

As you will have read in the chairman's report on pages 4-5, the Red Lion Group structure has been converted to a CIO (Charity Incorporated Organisation). The only affect this will have on membership is a change of bank details. Members that currently pay by Standing Order will need to cancel existing Standing Orders and start new ones using the new bank details.

The details will be provided to all members affected. Alternatively, you may prefer to switch to paying via CAF. This is our online payment platform which allows you to make single or recurring payments. It has the added benefit that CAF automatically processes the Gift Aid for us, where applicable. Again, the CAF payment details will be provided.



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

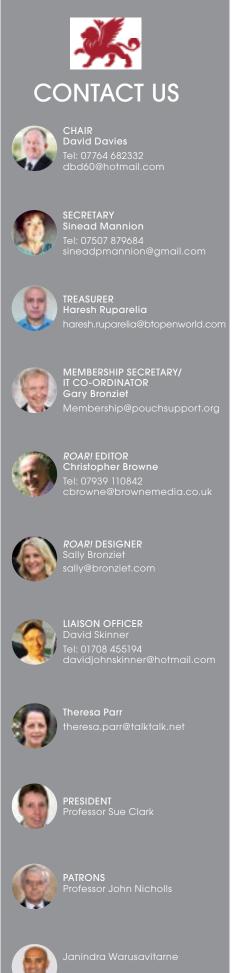
favourite pastime, we are always looking for cartoons, jokes, crosswords and competition ideas too.

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





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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)
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