

HOT TOPICS



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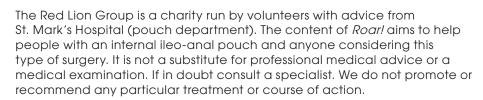
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ON THE COVER...

Cover image shows David Skinner flanked by the Frankfurt Marathon race director Jo Schindler (I) and the winner Benard Biwott from Kenya







o you suffer from stress? I think most of us do but what do we do about it? The answer is usually very little.

So I was both surprised and pleased to see that stress and how to cope with it was a key topic on the agenda of the Kangaroo Club's recent Information Day.

We, the audience, were lucky enough to hear from two stressbusters and as you'll see on page 7 of this issue of Roar! the two speakers not only gave us some sage advice but also showed us several vital techniques to help deal with those niggling all-too-familiar thoughts. They certainly helped to becalm us during the event and helped us to look at our lives in a freer, less cluttered way.

Stressbusters

Someone who's managed to take stressbusting to an of being a member altogether new and higher of the RLG is that we level is RLG pouchee Ben have several sources Barbanel. To help his recovery from major of support to help us surgery, Ben bravely went on a relentless fitness regime helping him to lose weight, improve his lifestyle, sharpen his workplace performance and enrich his life as a married father-of-three. You can read how he did it on page 6.

Another stressbuster is RLG liaison officer David Skinner. David managed to combat the after-effects of severe pneumonia and a spell of serious breathing difficulties to compete in the annual Frankfurt Marathon in October last year. Even more remarkable is that it was his 10th Frankfurt Marathon and he was the first British runner to make it to the magic figure of 10. You can read his remarkable account on pages 12 to 13.

Support network

'One of the joys

beat conditions

like stress'

One of the joys of being a member of the Red Lion Group is that we have several sources of support to help us beat conditions like stress. We have the monthly personal forums on Zoom,

the regular webinars, the RLG website pouchsupport.org, even *Roar!* (!), and finally the ever-popular Facebook site which we've highlighted with a special Q&A article on page 8.

And it's certainly worth joining the site to help you solve any awkward or urgent issues as and when they occur.

Meanwhile enjoy those first green shoots of spring and happy reading!

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



The times they are a'changin – for the better says David Davies

The RLG chair welcomes recent changes in medication and diet but says there are still questions to be asked about weight-loss drugs for pouchees

When I look back to the early days of ileo-anal pouches, I consider it remarkable how little has changed for we pouchees. In the 1994 launch issue of *Roar!* there was an article on diet, with advice for exactly the same problems that are being raised today 31 years later.

However, we now know so much more about diets for pouchees, with experts at St Mark's and elsewhere able to provide detailed advice and insight to help resolve problems such as blockages, vitamin B12 deficiency, low iron, pouchitis and dehydration.

Look for the recording of the webcast "Healthy eating for patients with an internal pouch" by St Mark's lead dietitian Gabriela Poufou on our YouTube channel **Youtube.com/**@pouchsupport. It's a hugely impressive hour-long webinar packed full of dietary information, hints and tips to inform and advise and which can be downloaded and viewed by pouchees throughout the world.



LEFT: David Davies (left) with ultramarathon man and RLG member Tom Plater (see article on pages 6&7 of the Winter 2022-23 issue of Roarl)

'We now know so much more about diets for pouchees'

The various RLG
platforms continue
to be a great way to share
information. There is
Roar! of course, the
monthly pouch forums on
Zoom, the webinars, the
YouTube channel and the
J-pouch support Facebook
page. Solutions to pouch
problems are now readily
accessible on the internet and it is

pouchees themselves who have added to the body of evidence. After all you are the best judge of what works and what doesn't work for your pouch and what we do at RLG is provide the platform for you to share stories, tips and advice so new pouchees can benefit.

Thankyou to everyone who has contributed over the years and who continue to support the charity and contribute to our deepening knowledge of good pouch management.

The latest weight-loss tablets are effective at reducing those extra pounds and also help to manage pouches. Though they have not been officially approved for pouch management, they are available on private prescription via the internet as well as through GPs.

RLG will be keeping a watch over the availability of these drugs and their impact on pouch health. The tablets, which

are known as GLP-1, are available from just two companies at the moment but a staggering 270 plus are currently in development as drug companies race to add them to their portfolios.

The big news of 2024 was the disbanding of the pouch nurse specialist team at St Mark's Hospital. I am demoralised by the loss of this team, who I feel were setting the standards in pouch nursing care and providing excellent pouch nursing support. Two of the team have set up in private practice – pouch twins Petya and Rali Marinova are now practising with their own business and a website where you can contact them (https://www.ipouch-stoma-twins.com/). The twins continue to pursue NHS validation and verification so they might one day be able to receive NHS referrals from all over the country, though this takes time.

However we are advised that the recruitment of pouch nurses at St Mark's is progressing and that the management are keen to have a fully-fledged pouch nurse specialist function in due course. The good news is that at least two of the posts have been filled in the past month. Please note that you will need a formal GP's referral to receive nursing care at St Mark's in future.

Those then are my pouch-related thoughts for spring 2025 and I wish you all the very best for the rest of the year.

David Davies RLG Chairman



How Ben reached his peak at 45!



'I felt the weight

of my success -

literally!'

ABOVE: 'Before' and 'after images of Ben Barbanel

If things go wrong for RLG member and pouchee Ben Barbanel he has an uncanny knack of defying the odds

he incorrigible Ben has done it again!

Regular readers of *Roar!*will have read about the five-year plan he created to help his recovery from surgery after pre-cancerous cells were found in the lining of his rectum (see page 10 of *Roar!*'s Summer 2023 issue).

For by following a set of cleverly devised rules and changes of medication, the Red Lion Group member and pouchee successfully improved his lifestyle, family life and work as a City banker.

Now he has moved several steps further ahead with another, even more rigorous regime which we will call Plan A! Ben's aim? To reach peak fitness in all his activities at the grand 'young' age of 45.

And the father-ofthree's efforts didn't
go unrecognised. He
joined a highperformance gym
in London's
Mayfair and now
features in their
eye-catching, high-viz
App – aptly (sorry!)
named UP (which stands
for Ultimate Performance).

So how did our intrepid colleague hear about UP? He read about it in a fitness magazine called *Men's Health*.

As Ben says: "I often sat in boardroom meetings, glancing around, thinking 'I'm the only fat one here'. As a senior London banker and a father of three, I felt the weight of my success – literally!.

"Something just finally hit me one day when I was reflecting on the trauma of what I had been through — and I thought to myself that being in peak condition can only give me the best chance (but clearly no guarantee) of everything working well going forward, and hopefully living a long and healthy life!

"I found that years of living with ulcerative colitis and long stressful workdays had taken a toll on my body, energy and mood," he says.

However Ben's
efforts on the course
meant he not only lost
all his excess pounds but
also felt happier and fitter. As

he told *Roar!*: "Losing 20kg(!) and regaining my health with UP has completely changed my life. I'm now strong, disciplined and thriving in every area of my life."

Ben's personal trainer at UP, adds: "It's no secret that Ben had complex health issues, but we managed to work through them together. He had a real eagerness to learn and was completely bought into the process at UP. That's just one of the reasons he achieved such great results."

Please turn to page 10 of this issue to find out about another of Ben's unique remedies.

Or if you would like some advice and/or health tips from him, you can contact him at **bb@barbanel.co.uk**.

MAIN A selection of audience and speakers CIRCLE Chair Laura Dunn (3rd from left) introduces one of the speakers

agic bing with an ideal and or offered pow



Stressbusters charm Oxford's pouchees and support staff

The Kangaroo Club, the Oxford equivalent of RLG, recently held its annual information day

had a moment of real joy last October when I joined a group of 40-plus marsupials (sorry people!) at the annual Kangaroo Club Information Day.

This Oxford-based pouch support group always puts on a good show – if 'show' is the operative word here – each year and once again there was an impressive line-up of fluent speakers and a spread of exceptionally palatable food funded by the group's sponsors Salts Healthcare.

And I wasn't the only lion mingling with this good-humoured group. RLG's intrepid chair David Davies drove the 190 miles or so from his York city home to Oxford and added ever more lustre to the event with his pithy and poignant remarks.

For me the day's highlight was two talks about stress – an issue we pouchees sometimes overlook. It was led by two stressbusters – Rachel Hornsey, founder of Mustard Seeds (www.mustardseeds.org.uk), a company whose name typifies the potential we all have to grow and influence others (just like newly-planted seeds!), and Sarah Bagnall, a therapist and life coach (www.sarahbagnall.co. uk), who gave us some sage advice on how to shed our anxieties and relax.

Rachel's theme was 'Understanding the physiology of stress and how stress affects you and your body' - a subject she handled with great aplomb.

In her refreshingly personal talk, Sarah asked the audience to take part in a half-hour 'rest session' showing us how to use basic techniques such as breathing and meditation to monitor and control our thoughts and help prevent any stressful ideas creeping in – a practice she referred to as 'digital de-toxing'.

Her talk certainly had a calming effect on the audience and the unusually relaxed Q&A (question-and-answer) session that followed.

As with all information days, knowledge was to the fore. Ms Kat Baker, consultant colorectal surgeon at Oxford 's two main hospitals and the new Kangaroo Club president, gave a lucid appraisal of how pouch operations have evolved from the mechanics of open surgery to the advances of laparoscopic (keyhole) and robot-assisted surgery.

The topic of pouchitis needs little introduction – and if it does you're very lucky as it probably means you have never had it! As Oxford consultant IBD nurse Lydia White pointed out, the p-word is a very painful and disruptive condition and has been the bane of many a pouchee's life. Yet, surprisingly, many years of research have failed to find a satisfactory cure for it.

What are the causes? How do you prevent it? What are the best remedies? These were the themes of Lydia's talk. Let's hope we do not face too long a wait for a final cure.

On an encouragingly upbeat note two of Oxford's senior specialist nurses, Fran Woodhouse and Simon Turley, paid tribute to the expanding role of today's NHS pouchcare nursing teams and their versatile, hands-on approach to patients, so showing the true value of teamwork in this fast-moving hi-tech age.

Meanwhile a lively band of pouchees and professionals from ia (Ileostomy and Internal Pouch Association), the UK charity and support group, managed to keep us amused and entertained in the lunch-break with a series of eyecatching advice guides and hand-outs about health and well-being.

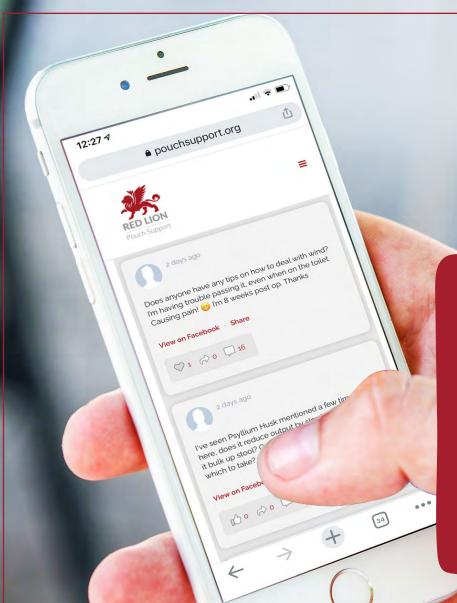
The day's organiser, Laura Dunn, Kangaroo Club chair and founder, told Roar!: "We were absolutely delighted to announce that Kat Baker, consultant colorectal surgeon (and the primary pouch surgeon) at John Radcliffe Hospital, has agreed to take on the presidency of the club, following the 'retirement' of Bruce George, who, at the time of the Information Day, was actually working in New Zealand!

"It was marvellous to have Kat give the keynote talk during the event and we were inspired and astonished by her images of robotic surgery, and the stories of its transformative success. We very much look forward to working with her in the future.

"We feel equally lucky to have the continued support of Simon Turley and Fran Woodhouse, who are key members of the current team of six specialist pouch nurses, supporting pouches and pouch owners in Oxford."

The bonhomie of the day's audience and speakers was infectious – much to the delight of the Kangaroo Club's two resident stresshusters

Chrisopher Browne



Have yo joined the Facebook

During a check-up at St Mark's I mentioned I had excessive gas with excruciating pain for which I was taking a drug called simethicone. I said it had not been a great help and the consultant suggested I try VSL#3 for three months to see if it helps. But it's quite expensive and I cannot get it on prescription. Are there any similar alternatives that have worked for you and which are cheaper?

It's candid, direct and highly personal and RLG's J Pouch Support (UK Specific) Facebook site is an invaluable source of help. So what are you waiting for?

ne of the highlights of the Autumn 2024 issue of *Roar!* was an article about our highly-rated Facebook website – J Pouch Support (UK Specific).

It said that the site's appeal is that "anyone who joins – and you don't have to be an RLG member to do so – can share their highly personal pouch-related issues – either anonymously or by name – with a group of sympathetic, knowledgeable and experienced pouchees" ie you and me.

The article added that users will receive sage advice, useful tips and guidance to aid their treatment and/or recovery from surgery and, crucially, to let them know they are not alone.

Tempted? I'm sure you are and here (to the right) is a classic Q&A taken from the site which mirrors its special appeal.

- Pouch irrigation.
- It didn't make any difference to me, but we are all different.
 - I drink kefir (a fermented milk drink) every day.
- VSL#3 didn't make any difference to me but we are all different.
- VSL#3 is a probiotic and you can also try curd which is a natural probiotic.

So what conclusions can we draw from the conflicting answers? 1. That although none practitioner they have strong views and cor Many ailing, anxious or troubled pouchees receive on our Facebook website.

So if you haven't already done so, it's worth specific) to join the 1,700 fellow users and



u ? ne ? ok set?

- VSL#3 was taken off the NHS list of reimbursed medicines as they did not feel there was enough of a benefit.
- VSL#3 is not the original VSL#3. The original is now Vivomixx.
- I take Vivomixx. It has done wonders for me -bleeding, bloating, pain, diarrhoea, fatigue - all have been vastly improved. I also put weight back on as I had previously lost almost 16 kilos. Also a family member had gluten intolerance and was slowly eating less and less, in terrible pain with wind and bloating etc etc. She took Vivomixx for a couple of weeks and is fine now. She still cannot tolerate gluten, but at least the associated symptoms have mainly gone. Maybe worth trying for a bit.
- I tried VSL#3 but it made no difference. It's worth trying, but bear in mind it doesn't work for everyone.
- Vivomixx is slightly cheaper than VSL#3 and has similar qualities.
- Vivomixx didn't work for me and actually made my pouch very unhappy. It was the same with other prebiotics and probiotics I've tried.

se interesting, varied and sometimes of the respondents is a qualified medical wictions based on their own experiences. 2. have benefited from the feedback they

a logging on to **J Pouch Support (UK**) gain some invaluable help and advice.

David Davies and Chrisopher Browne



Gary Bronziet's year with a difference

Despite several spells of illness and hospital surgery RLG's membership secretary managed his day-to-day and online roles with his customary panache

ell, this year (2024) has been another eventful year, both personally and in my capacity as membership secretary. Our membership has continued on an upward spiral including an increasing number of overseas members. Several of these are regular attendees on our monthly forums, and it's interesting to compare some of the issues as they relate to our respective countries. For example, our USA members are quite envious of the support that is available to us in the UK without charge on the NHS. Our

website activity also continues to increase, and we were very close to hitting 60K views in 2024 and a total of 200K all-time views. We actually hit 200K website views on 31

January 2025. Not surprisingly, our most frequently viewed pages are "Stoma

or J-Pouch?
A life changing decision" and "What is the expected lifespan of a J-Pouch".

Which leads well into my personal story. Exactly forty years after starting my pouch journey in the London Clinic in November 1984, this past November I found myself back there reverting to a stoma. I was very fortunate to have had (courtesy of Prof. John Nicholls) a very long spell (more than 30 years) with a perfect pouch. In later years I began to experience difficulty with incomplete emptying and blockages resulting in a few hospitalisations and eventually an enterocutaneous fistula. In November 2024, the fistula "won the battle" with my pouch and in an emergency situation, the resolution was to give me a loop ileostomy, with my pouch still in situ but de-functioned.

We do hear increasingly on our Facebook group of people experiencing difficulties with their long-term pouches which seem to be as a result of scar tissue from their original surgery causing adhesions and strictures. But

aware of several people with older pouches than mine that are still getting along fine.

do not be too alarmed, as I am

In conclusion I would say, from my experience, that either a stoma or a pouch is far better than living with Ulcerative Colitis, but a stoma may be better than struggling along with a "problem pouch". However, I certainly don't regret my decision to have a pouch back in 1984 – I had many good years with it!

Posts & pages Front Page Home page / Archives Storms or J-Pouch? A life changing decision FORUM Stories What's the lifespan of a J pouch? St. Mark's Oral Rehydration Solution (ORS) Events J Pouch and Vitamin B12 deficiency Dietary advice for J-pouch

`Stoma or

J-Pouch? A

life changing

decision'

Gary Bronziet

Membership Secretary and IT membership@pouchsupport.org

ABOVE: Most viewed pages on the RLG website pouchsupport.org



Hot off the presses: Ben Barbanel's magic formula

Do you suffer from butt-burn?
If you do why not try this unique
Red Lion Group remedy

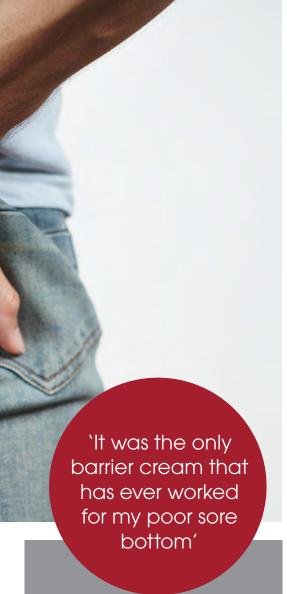
hen the manufacturer of the popular barrier cream, Ilex, suddenly stopped making the product, many RLG pouchees who had relied on it for butt-burn were at a loss. One of them was Ben Barbanel .

"It was the only barrier cream that has ever worked for my poor sore bottom (known in the trade as 'butt-burn') and it was randomly discontinued with no explanation from the manufacturer. I tried contacting them multiple times, but to no avail," says Ben.

So the frustrated pouchee took the initiative, bought the ingredients from a local pharmacy and tried to make it himself – without success. He then contacted a cosmetics manufacturer and tried a more professional route. This too proved problematic.

However while he was researching the US Facebook pouch support website, Ben discovered a pharmacist who had created his own preparation.

Ben made a note of the pharmacist's formula and "with a few special tweaks I'm happily making the barrier cream myself and am delighted to confirm that I finally have a decent replacement – and a happy, comfortable bottom again."



Ben's special formula

Mix together:

two parts of **Cerave healing ointment**

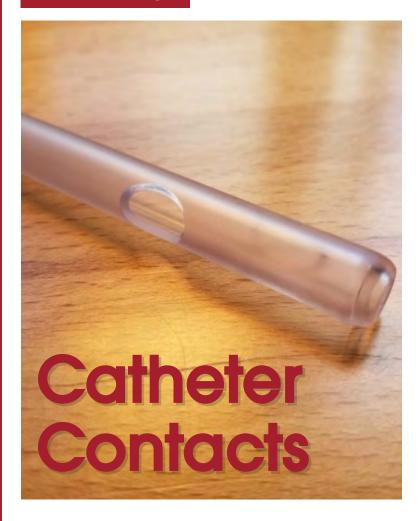
one part of **Convatec stomahesive paste**

and **5g of Orahesive protective powder**

and hey presto you'll have your own source of barrier cream.

For further advice contact Ben on bb@barbanel.co.uk.

HEALTH ADVICE



Using a Medena catheter to help you empty your pouch could help to transform your life. How do you get hold of one?

The main supplier is called **Bullens** (www.bullens.com) and you'll need to get them prescribed (in packs of 3 or 5) by your GP.

When using the catheter you'll also need a 100ml syringe to help irrigate your pouch. You can

obtain these – again with a GP's prescription – from a company called **Coloplast** (www.coloplast.co.uk).

Before you use the catheter, you'll need to learn a few basic techniques. The best way to do this is to ask for guidance from one of the stoma or pouchcare nurses (who probably know you already) at your local hospital or a specialist pouchcare centre like St Mark's Hospital.

Good luck!



Mad! Foolhardy! Dangerous! Some might say. But RLG liaison officer David Skinner didn't let a bout of pneumonia upset his attempt on an unusual record

ou couldn't make it up! Four months before he was due to join his fellow competitors in the Frankfurt Marathon RLG liaison officer David Skinner was lying in intensive care suffering serious breathing difficulties after a bout of severe pneumonia.

But defying doctors' orders and the advice of his friends and relatives, David decided to enter the famous race and, even more remarkably, managed to finish as well. However it may not surprise you to know there was a compelling reason for David's apparent foolhardiness. For the marathon which was held in October last year was David's tenth Frankfurt Marathon.

If he finished he would achieve the accolade of being the first-ever British athlete to do so.

"As I stood before the start line with 10,701 other runners, I knew I was nearly at the end of my 10-year journey.

One that had taken me 26.2 miles around the city of Frankfurt nine times, in an attempt to become the first person from the UK to run 10 Frankfurt marathons and be invited to join the Frankfurt Marathon Club. Save for the Covid years I had been making this pilgrimage since 2012," says David

"My plan was to run slowly enough to finish without any mishaps," he adds. And, mishaps or no mishaps, David's race had a touch of the burlesque too. For his race companion was a runner



called Billericay Bob who, in the finest traditions of marathon running, wore fancy dress.

"At half way, we were moving so slowly that we thought we were probably very near the back of the race. I also noticed that after 16 miles my breathing was reminiscent of when I came out of

hospital and I was more than a little concerned," says David.

"Then unbelievably a motorcyclist pulled up next to us with a cameraman on the pillion and began interviewing us live on German TV. I left the speaking to Bruce, saving my breathing for the running, which was not going At the 18-mile mark a race official known as a 'sweeper' told the intrepid duo that they would have to pull out of the race altogether if they did not increase their pace. However they were granted two time extensions and managed to cover the last 60 yards of the marathon on the famous red carpet.

"I have to say that I have never been so happy to finish last in a marathon – I was placed 10,702nd and the 1,430th person to have run 10 Frankfurt marathons.

"Now my Frankfurt Marathon race number – known as a 'bib' – is 1,430 for the rest of my running career," adds David.



Michelle with

Amy Joy

Baby Joy!

Oh, how the RLG committee miss Michelle Martin, her clever ideas and timely videos.

For our hardworking communications officer recently stood down from the committee after giving birth to a baby girl — Amy Joy. Congratulations Michelle!

During her spell on the committee Michelle produced several medical videos which you can watch on youtube. com@pouchsupport.

In fact two of them – about the workings of J-pouches and advice and tips on how to cope with fistulas – were nominated for the prestigious Smiley Charity Film Awards.

We're pleased to report that mother and baby are doing fine. Thankyou for all your efforts Michelle!



Jim Symington was the RLG Treasurer for five years from 2019 until his retirement on grounds of ill health in 2023. Jim sadly passed away on 11 September 2024 after a brave fight against cancer.

Jim responded to an advert on a charity volunteer recruitment website after we had spent the best part of a year looking for someone to take over the reigns from Peter White. Jim had a long and successful career in senior management and IT behind him and wanted to give something back by helping out a small charity such as RLG. He had an ileostomy following an episode of bowel cancer in his early 50s, so he had an insight into the challenges of living without a large intestine and had a large degree of empathy with the charity objects and the needs of our members. Regarding his financial skills, I remember Jim saying at interview that he wasn't a qualified accountant but he "knew his way round a spreadsheet"; and so it turned out as Jim's comment proved to be our first glimpse of his modesty and understatement.

Jim was a brilliant colleague on Committee, anticipating needs and offering wholehearted support to myself and all of our colleagues. He managed the accounts with great skill and impeccable accuracy and it gave us great confidence to know that the figures were correct and moving in the right direction with Jim. He had a dry sense of humour and was pragmatic and focussed – he would leave a Committee meeting exactly one hour after they had started, whether the agenda was finished or not! He was a charming and compassionate person and I valued his support and sage guidance during his tenure as Treasurer.

Jim lived with his wife Caroline in High Wycombe, but moved to stay near family in the Cotswolds during his final illness. His wife let me know of his passing and commented that the Red Lion Group "meant a good deal to him and he was happy to help while he could".

David Davies

Jim Symington



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.

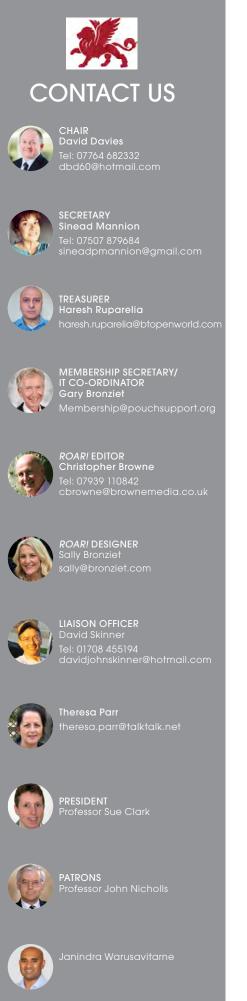
But then if writing articles isn't exactly your

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





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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
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)



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