



# ROAR!

## ISSUE 52 • CHRISTMAS 2016

Newsletter of the Red Lion Group  
St. Mark's Hospital • Watford Road • Harrow • HA1 3UJ



## Regional Reps

HERE IS our current list of regional reps with home telephone numbers — please feel free to contact your local rep and get acquainted.

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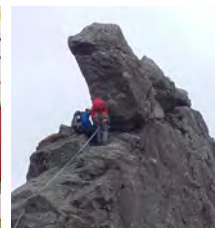
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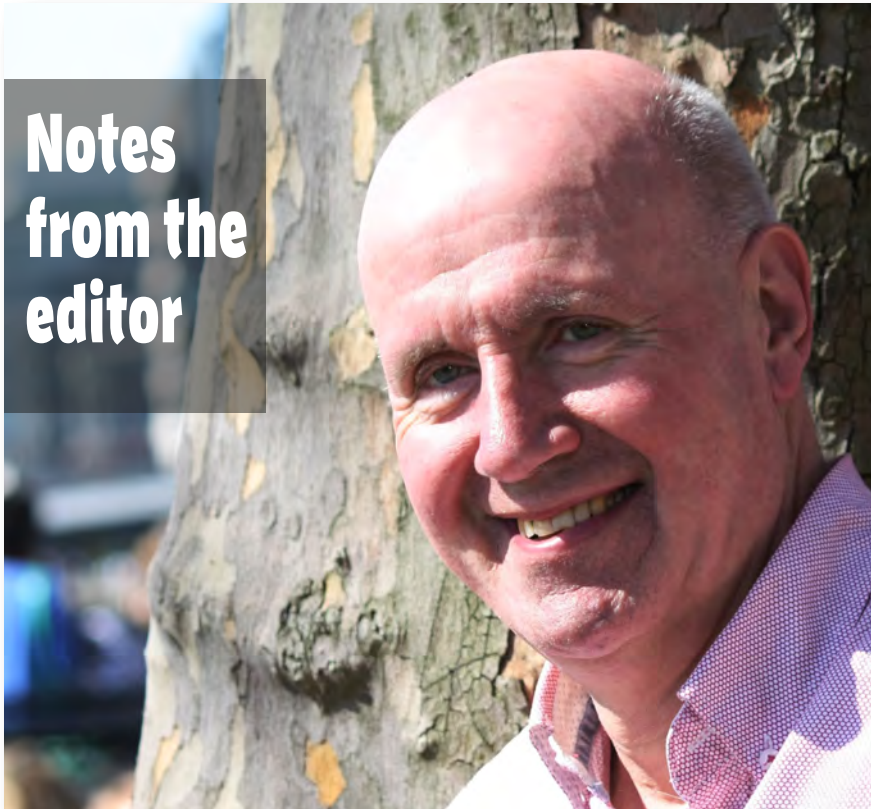
## Please support the Red Lion Group

**Registered Charity number 1068124**



All donations, however small,  
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group will be gratefully received. If you  
would like to send a donation please  
make your cheque payable to The Red  
Lion Group and send it to: **The Red  
Lion Group Treasurer, Paul Mulot,  
103 Whitehill Road, Hitchin, SG4 9HT.**

## Notes from the editor



**W**e thrive on bad news – almost every bulletin we watch or read features a war, an air crash, a fatal accident, the break-up of a marriage, an erring politician, gloomy trade figures or a celebrity misdeemeanour.

After all it's easier to talk about others' misfortunes than to appreciate our own personal sense of well-being. The media too likes to pander to our baser instincts with stories of conflict, tragedy and man's inhumanity to man instead of humour, kindness and human endeavour.

At *Roar!* we try to buck this trend. Yes, we tell you about people's mishaps and problems but we also show how they manage to overcome them and in many cases thrive. So let's call this issue *The Good News Roar!*

One of the highlights of the past six months was a lively face-to-face committee meeting

we launched a membership drive to contact all the NHS and private hospital pouch care departments that are not currently on our database. A sizeable task but a most productive way to increase our membership and expand our role as a support group.

And this is where you come in. I'd be very grateful if you would be good enough to let us know

the name of your local pouch care hospital or any others you know about so that our able membership secretary, Susan Burrows, who is leading the initiative, can check them against the database. It will certainly help our worthy cause. Susan's email address is [sburrows700@gmail.com](mailto:sburrows700@gmail.com).

On the same theme, we would like to hear from those of you who are not yet Gift Aid donors. Some of you already contribute, but if you don't please fill in the form on the back page. This will enable our treasurer, Paul Mulot, to claim back 25% of all subscriptions or donations you make to the group as tax relief from

Revenue and Customs (HMRC). It is a very valuable source of income both for RLG and the research projects we support!

And talking of money. If you need an incentive (though I know you don't really!) to go to the summer Information Day which is on Saturday, 13 May, 2017, Paul has managed to persuade APCOA Parking which manages St Mark's Hospital's main open-air car park to let us park there free on the day. Normally it costs up to £9.40 for eight hours. So a big saving there!

And to echo our Good News *Roar!* theme we have included uplifting articles by two intrepid committee members. Pouch owner Peter Wright writes about his brave attempt to conquer one of the UK's toughest peaks (pages 6 and 7); and Susan Burrows talks about an altogether different kind of challenge – how living with a pouch did not prevent her working as a head teacher of a large primary school and boldly touring such places as South Africa, the Galapagos Islands, Australia, the USA, Singapore and Hong Kong among others.

So happy reading and I wish you all a very peaceful Christmas and a fulfilling New Year!

CHRISTOPHER BROWNE

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**Visit our website**

[redliongroup.org](http://redliongroup.org)

Browse nearly every copy of *Roar!* that has ever been published (including issue 1 from 1994) at [redliongroup.org/roar](http://redliongroup.org/roar)

For online support and advice from other members or to share your views about any aspect of life with a pouch, please visit our online discussion forum at:

[redliongroup.org/talk](http://redliongroup.org/talk)

## The chair's winter report (and what he said to Sir Steve Redgrave)

Season's Greetings to you all from myself and the rest of the committee! I'm sure the festive planning is in full swing and you'll be looking forward to spending quality time with family and loved ones (they might even overlap). Nevertheless I hope you'll have time to read through this latest edition of *Roar!* which is packed with all sorts of interesting and useful items for us "pouchees" and potential "pouchees".

I had the privilege of meeting Sir Steve Redgrave, the Olympic rower and BBC commentator, recently at a conference in Vienna. As many of you know, Sir Steve is one of our two most successful Olympians, having won five gold medals at five successive Olympic Games, only one fewer than the six golds of the Olympic cyclist Sir Chris Hoy. He has achieved his success despite the onset of type II diabetes late in his career and ulcerative colitis which he has suffered on and off for many years. His message, delivered to a packed conference, was that diabetes and ulcerative colitis have had to fit in with his lifestyle and not his lifestyle having to fit around them. And I reflected on what a great message that was for pouchees and potential pouchees.

Sir Steve has benefited from excellent medical care, which he generously acknowledged (and his wife is a GP), but even so his determination to be so successful in a hugely physical sport that demands enormous reserves of physical endurance in spite of diabetes and uc is an inspiration to me and to many others, I'm sure. In some respects we have been unlucky in having to have a proctocolectomy in the first place, but in other respects we are indeed lucky to be reconnected and to live a more normal life compared to others.

In my case it helped me to play rugby, a game I loved, for 12 years post-op and to enjoy many other sports which would otherwise have been more challenging with a stoma. Steve and I reflected on a notorious annual kayak race from Devizes in Wiltshire to Westminster Bridge ([www.dwrace.co.uk](http://www.dwrace.co.uk)), which I finished in 2006 and he failed to finish a few years later! However I didn't mention my time (which at 35 hours was nothing to shout about), but



David (l) and Sir Steve Redgrave

even so it goes to show that having a pouch is no barrier to these sorts of extreme activity. I was mightily glad someone found the key to the toilets at Marlow Lock though!

Your committee met recently on Saturday 19 November – a rare face-to-face meeting rather than the usual teleconference. It was a pleasure to welcome Gary Bronziet and Peter White on to the committee – even though Gary is a Spurs fan! Gary and Peter have spent some 40 years between them of living with a pouch (that would be a pouch each!) and many will recognise them from recent Information Days. Welcome to you both.

Speaking of Information Day, the committee is working hard to prepare the 2017 event, which will take place on 13 May 2017 at St Mark's Hospital. An exciting agenda is as-

sured, so please put the date in your diaries and keep it clear. We look forward to seeing you all again. As the editor Christopher Browne mentioned at the start of the magazine, Paul Mulot has managed to secure FREE PARKING in the hospital car park for those of you planning to drive to the event, so well done Paul.

We are looking to raise more money to support the excellent causes that have been funded by RLG in the past. In particular we

want to ensure that all pouchees and potential pouchees are aware of the excellent support offered by RLG, that they know they are not alone and that there are many of us facing the same sort of challenges (which in my case was a tremendous reassurance) and to continue to fund essential research into pouch-related issues such as pouchitis. Research that may lead to medical progress from which we might one day benefit.

To this end I ask you all to think about ways you might be able to contribute, for example holding a coffee morning with family and friends or doing a sponsored walk, for example. I will be doing a long-distance bicycle ride (the Dunwich Dynamo 2017) for RLG next year and would appreciate your support with a donation, however big or small. More information to follow nearer the time.

I hope you enjoy this edition of *Roar!* Please feed back any comments or suggestions via our editor Christopher Browne at [cbrowne@brownemedia.co.uk](mailto:cbrowne@brownemedia.co.uk) or via the RLG website [www.redliongroup.org](http://www.redliongroup.org) (click on "about us" and then "contact us") or start a discussion on the RLG Facebook page.

Finally, on behalf of the committee, may I wish you all a happy and harmonious Christmas and a healthy and successful New Year!

DAVID DAVIES



## LETTERS TO THE EDITOR

### Perking up my bladder with Botox!

Dear Editor

Has anyone had bladder problems (needing to go to the loo to pass water frequently) since their pouch operation?

I ask because it has happened to me. More specifically I have suffered from nocturia (needing to pass water three to seven times a night) for the past six years. Although I had my final pouch closure 25 years ago.

It took me almost four years to find the cause of this worrying problem. It has meant many spells of tiredness – and even exhaustion – in that period.

And the cause? My consultant believes my bladder's nerve endings were slightly frayed and in some cases weakened during my pouch surgery.

As I sought a remedy for the nocturia, I saw five of the UK's leading urologists and tried at least five different courses of drugs – all to no avail.

Then a few weeks ago I found the answer. Botox, yes, you read it correctly, Botox.... the treatment women (and men) sometimes use to remove lines and wrinkles from their faces to make them look younger and prettier!

My version of the Botox – which incidentally is a medically-approved poison – was injected into my bladder. Slightly uncomfortable, but undeniably worth it. And it means I no longer have to keep getting up in the night! What a merciful release it is too!

I do need to use a catheter to empty my bladder fully just before I go to bed. Though it doesn't apply to everyone who opts for Botox. But I can now sleep regularly without hav-

ing to go to the loo and wake up refreshed, alert and happy. Thanks to my consultant and medical science!

Yours faithfully

Name and address supplied

**Rajesh Kavia, Consultant Urological Surgeon with special interest in bladder dysfunction at London North West NHS Trust and St Mark's Hospital, writes:**

Many patients who have had colorectal operations will have had some issues with their bladder. This can be either a poorly function-



ing one or an overactive bladder. The overactive symptoms are an increased frequency of urination, night-time frequency (nocturia) or the more devastating urgency or urgency incontinence.

It is the last two conditions that are particularly bothersome. A patient's life can be controlled by the constant feeling of wanting to urinate, a condition that is difficult to defer. They sometimes have to plan their journeys around toilet access, face social isolation and, in some cases, suffer depression.

The standard management for this is bladder retraining, pelvic floor exercises and altered drinking habits. Sometimes these work, however as many colorectal patients have had surgery such conservative measures may not help.

Oral medications include the anticholinergics which are successful but can cause side effects such as dry mouth, dry eyes or constipation, or else the latest drug, Mirabegron, which works in a different way.

However if patients fail on the oral medication the next line of treatment will often involve a test called urodynamics. This involves placing catheters (tubes that are inserted into the bladder and bowel to assess if the bladder is stable or not). If unstable, the mainstay of treatment will be Botox injections.

The Botox works by partially paralysing the bladder and altering the perception of the bladder actually filling. The injections are usually given with a dose of 100 units under local anaesthesia using a cystoscope. The procedure lasts about five minutes with average pain scores of

2-3/10. The main side effects are the need to self-catheterise in up to 20% of patients or urinary infections. However the success rates can be impressive with improvements in up to 90% of patients. The treatment needs to be repeated every six to 12 months.

So I recommend that if patients' bladders are controlling them, they seek the help of a friendly urologist to help them get back their control once again.

**• Has anyone else had a frequency or nocturia problem since their pouch operation? If you have please write to The Editor, Roar's Letters Page at [cbrowne@brownemedia.co.uk](mailto:cbrowne@brownemedia.co.uk).**

## It's time to get your 'Just can't wait' card

Dear Chris

I write to recommend something

to Red Lion members that is small and beautifully formed but which is extremely powerful at opening doors (quite literally).

I first heard about this from an old edition of Roar! so I wanted to raise it again as it has been very helpful to me on several occasions. The Bladder and Bowel Foundation ([www.bladderandbowelfoundation.org](http://www.bladderandbowelfoundation.org)) produce a card called "Just can't wait" (see photo above), which can be carried in your pocket, wallet or handbag and which alerts people to the fact you might need to use a toilet quickly.

I don't have to use the card in my normal day, but just now and again it has proved to be invaluable. Once when walking back from a night out

in to a small business and flash the card. Without doubt I wouldn't have got into the toilets without the card.

The card is free but you have to register first at [www.bladderandbowelfoundation.org/forum/register/](http://www.bladderandbowelfoundation.org/forum/register/)

Best wishes

David Davies

(Red Lion Chair)



**Editor: That's a really useful tip David! There are two or three other cards shown when searching on Google, but this is as good as any of them! You can also order one of three types of radar key**

**for access to 9,000 plus UK disabled toilets for a mere £1 - £3 from [www.ageukincontinence.co.uk](http://www.ageukincontinence.co.uk) or by phoning 0800 046 1501.**

## How I nearly conquered one of the UK's toughest peaks

The stark Cuillin Ridge – the crescent-shaped remains of an ancient volcano rising 1,000 metres out of the sea on the Isle of Skye – is one of Britain's toughest mountaineering challenges! Here new Red Lion committee member, PETER WRIGHT, describes his experiences

**M**ost of those who try to master the Cuillin Ridge – a 12km-long ridge with more than 30 peaks and 11 munros (mountains of 3,000ft and more) and dramatic weather changes – at a single attempt fail as it is a technical and mental challenge that combines mountain walking, scrambling and climbing.

However I managed to persuade my friend, walker and climber, James, to give it a go in May this year.

On the first day, after a day and a half of travelling, we climbed 1,000m from Glenbrittle to Loch Coir' a' Ghrunnda and made our camp there. We then ascended

half an hour to the ridge to do its three southern peaks and return before sunset. We travelled as light

had sleeping bags with bivvy bags rather than tents and hydrated and de-hydrated food in sachets.



Peter White (right) and his friend James

as we could, but somehow we were still carrying 15 kilograms each. We

On the second day, we got up late, having over-exerted ourselves the day before. Camping by the Corrie (a hillside hollow) meant we had to do the ascent to the ridge again with our large bags. We decided not to do the TD Gap – a 'very difficult' graded climb – as we had never climbed with large rucksacks before. So we skirted round to avoid it, and had lunch just round the corner, still wearing our helmets.

It was a good job we were too, as rocks fell from climbers farther





*The 'inaccessible' pinnacle*

up the ridge and landed just inches away from us!

As we made our way towards Sgurr Alasdair, a 3,350ft peak, we went wrong! Our poor route-finding led us up a narrow chimney (a rock cleft with vertical sides) leading up the ridge. The chimney got narrower and we couldn't get through with our rucksacks on, then had to manage an awkward overhang wearing our rucksacks. Where would it lead, and would we find ourselves climbing routes we simply weren't prepared for with 500m drops on both sides?

Worst of all we knew we'd gone wrong and the sun was setting, so we decided to make an emergency escape, abseiling down the northern ridge to the scree slope. With a wing and a prayer

we navigated down into Coire Lagan and spent the night there by the loch.

On the third day we woke up cold and uncomfortable. We had lost 500m in height, but decided to go back up to reach An Stac, an exposed and narrow ridge with long drops on both sides. The prize was

the 'Inaccessible Pinnacle', which we climbed from the southern side, abseiling off the northern end. But the previous day had shaken us, and we decided to do just one more section of the ridge, then make our way back to the Glenbrittle campsite – where showers and a tent awaited us.

The following day we departed, having done only half the route, but had returned to tell the tale!

And strangest of all, my pouch had never worked better. I had had to empty my pouch only half the number of times I normally do.

So how was that possible? By strictly planning my food and drink intake, eating a low residue diet, and taking double my usual dose of Lop-eramide – strictly half an hour to an hour before eating.

Having entered the real world again I haven't managed to keep this up, but I know I could if I needed to – and that means I'm not limited by my pouch. I'm planning to make another attempt on the Cuillin Ridge next year!



*A view of the ridge*

## How I held down a demanding job with a pouch

She may have been apprehensive about going back to work as a head teacher, but RLG social secretary Susan Burrows is very glad she did

**I**n April 1992 I returned to work. I was the head teacher of a large primary school in North London and I had been away from work for two terms having had three stages of pouch surgery.

Like most people who have had this surgery I was apprehensive about returning to work. However I felt that I had been on the "hard shoulder" of life for long enough and really wanted to get back onto the main highway again.

It was difficult at first catching up with all that I had missed during my absence, managing the huge fundamental changes that were happening in education, attending the many late evening meetings after long tiring days and above all coping with my pouch and the concern as to whether the stress of my work would affect it.

However I was so pleased to feel well that I think that helped my confidence and little by little my life with a pouch improved. As time went by I proved to myself that I could do more than I expected.

I had a similar experience with my diet. I am definitely a foodie and was very careful with what I ate after surgery but slowly as I gained confidence I introduced new things into my diet and found that my gut could cope with them. There are still a few things that I don't eat but I always try and maintain a healthy diet. I feel that with a pouch I am in charge of my body unlike when I had

ulcerative colitis and it was in charge of my body.

### Have pouch, will travel

I found I could travel with my pouch too. Six months after the third stage of pouch surgery I travelled

Rica, Guatemala, South Africa and many other places. There have been times when I have been concerned about where the next loo would be, but if you look they are everywhere, sometimes not wonderful (always carry some loo paper or tissues).

One good tip: when you are in a large city, do not be afraid to walk into a large hotel and use the loos which are usually just off the main lobby!

I always make sure to book an aisle seat when I am flying, particularly on long haul flights or if I am travelling alone and I go to the loo before boarding in case the seat belt sign prevents movement for a time after takeoff.

I also eat sensibly when overseas – peel fruit, ignore salads and ice in drinks and, if possible, avoid buffets or choose what I eat very carefully when that is all that is available. In fact it is all good advice to anyone with or without a pouch when travelling overseas.

There are two items I always carry with me overseas. They are a letter from my consultant detailing my surgery and a travel certificate that I recently

acquired from the IA for those with an ileoanal pouch. It is in 12 different languages and must be signed by your GP or consultant. It is these two items that really do give me more confidence when I am travelling and the more frequently you travel with a pouch – whether near or far – the more confident you become!

Happy travelling!



to the United States to stay with friends who live in North Carolina. It was an ideal trip to make as a first time overseas visit with a pouch. I travelled to somewhere that I knew and stayed with friends who I felt comfortable with.

Since then I have been to Singapore, Hong Kong, Australia, Peru, Ecuador, The Galapagos Islands, Costa



## Only one in 10 pouches fails, says a key survey

A poll of pouch patients in Italy reveals some surprisingly positive findings and a generally high level of satisfaction

**A**pouch failure rate of 10% was the figure reported in a recent survey of pouch patients.

A total of 185 patients took part in the survey which was carried out in Naples, Italy and published in the December 2016 issue of the International Journal of Colorectal Disease. Each of the patients had suffered from ulcerative colitis before their operations and their pouches were between five and 20 years old.

As the survey points out: "This is a reasonably large sample of long-term data which means that the results are reasonably robust." It adds one rider however that "the outcomes might not be the same in patients who have had procedures for other reasons."

So what does the survey tell us? Though there was a pouch failure rate in around 10% of patients, the figure dropped to around 6% if patients who had been misdiagnosed with Crohn's disease were excluded. The 6-10% failure rate is consistent with other reports from experienced

centres – though this one was in Italy, not the UK – and echoes recent comments made by St Mark's Hospital Consultant Surgeon, Professor Sue Clark.

Heading the main side-effects was chronic pouchitis which, says the survey, was experienced by 29% of patients at some stage during their 20 years; 17% had at least one fistula during that period; 13% had narrowing of the gut; while another 8% experienced pre-pouch ileitis which is inflammation of the ileum or the lower area of the small intestine.

However there were only two significant differences between a five- and a 20-year-old pouch. The first was loo visits. Patients made 0.8 visits to the loo at night in pouches up to five years old which grew to 1.2 visits by 20 years. The second was using drugs such as loperamide and codeine phosphate to slow down the gut.

Approximately 1 in 8 patients had used one of these drugs at five

years rising to 1 in 3 patients at 20 years.

The number of day-time evacuations was slightly increased, from an average of 4.3 times a day at 5 years to an average of 4.8 times at 20 years. Similarly, urgency was experienced by approximately 1 in 14 patients at 5 years, rising to approximately 1 in 10 by 20 years, but the survey reveals this was not statistically significant and indicated that some did better than others in both groups.

Such factors as dietary limitations and work restrictions were similar in both groups over time. While satisfaction for the operation was always high and did not diminish over time.

In general the scores for quality of life "remained high" and most patients "expressed satisfaction and were happy to recommend the procedure to others", which we would interpret as a very positive endorsement overall.

**DAVID DAVIES AND  
CHRISTOPHER BROWNE**



1. Christmas Island, in the Indian Ocean, is a territory of which country?
2. The North Pole, which is said to be Santa Claus's home, is located in which ocean?
3. "And all the bells on earth shall ring on Christmas day in the morning..." is from which Christmas carol?
4. Peter Auty sang "Walking In The Air" in which film?
5. Which Christmas condiment is made from fruit – sometimes referred to as marshworts?
6. Which Christmas slogan was introduced by Clarissa Baldwin of the Dogs Trust in 1978?
7. Which British monarch (born 1865, died 1936) introduced the custom of giving thousands of Christmas puddings to staff?



8. In the UK it is traditionally believed that eating one of these each of the 12 days of Christmas brings happiness the following year: a sausage, mince pie, carrot or turkey drumstick?
9. What is the surname of the family in the 1989 film "National Lampoon's Christmas Vacation"?
10. Who composed the music known as "The Nutcracker Suite" for the Christmas-themed ballet The Nutcracker, premiered in St Petersburg in 1892?
11. Which southern central US state, whose capital city has the same name, was the last to recognise Christmas as an official holiday?
12. In which country is it said that finding a spider's web on Christmas morning brings good luck and so its Christmas trees are decorated with artificial spider webs?
13. Which day of the week was Christmas Day in Year 2000 (in the conventional western calendar)?
14. Charles Dickens is said to have considered the names Little Larry and Puny Pete for which character? (and for a bonus point: in which Dickens novel did the character appear?)
15. Under which Puritan leader did the English parliament pass a law banning Christmas in 1647?
16. Name two former territories of China where Christmas Day is a public holiday – unlike mainland China.
17. Very loosely related to Christmas, the animal uncia uncia is better known by what name?
18. Which traditional Christmas plant was once so revered by early Britons that it had to be cut with a golden sickle?
19. In the song "The Twelve Days Of Christmas", how many swans were a-swimming?
20. What former Egyptian president was born on Christmas Day in 1918?
21. "Driving Home For Christmas" was a 1988 hit single for which singer?
22. Who composed the "Lieutenant Kijé" orchestral suite, for a 1934 film of the same name, including the Troika movement commonly used as Christmas theme music and usually with prominent sleigh bells?
23. Name the colour of the underwear you should wear in Mexico on New Year's Eve to find love and romance the following year: yellow, green, red or brown?
24. Which Latin word meaning "the coming" or "arrival" refers to the approach of Christmas?
25. In which country does Santa have his own personal postcode HOH OHO?
26. In 2004, which national postal system gave away 20 million free scented stickers to make Christmas cards smell like fir trees, cinnamon, gingerbread or honey wax?
27. "Nadolig Llawen" means Merry Christmas in which west European language?
28. "Olive the Other....." is a Christmas book by Vivian Walsh and J Otto Seibold: reindeer, snowman, otter, orangutan?

*Compiled by David Skinner*

**Please send your entry to [cbrowne@brownemedia.co.uk](mailto:cbrowne@brownemedia.co.uk). The winner will receive a £25 Boots gift token**



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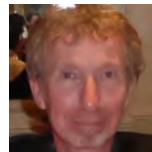
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## Join the Red Lion Group

- Newsletter twice a year with all the latest news, views and events
- Membership is £10 (£5 for hardship cases, and free for under 16s) per annum
- Write to the Membership Secretary (see above) for a membership form

## Write for Roar!

### Ideas, Ideas and More Ideas

Yes, Tim Rogers and I thrive on them for it's ideas that make *Roar!* 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 newsletter bursting with life and in-

formation and make reading about pouch issues fun and stimulating. Please send your articles, letters and ideas to:

**Christopher Browne**  
**Editor Roar!**  
**89 Fulwell Park Avenue**  
**Twickenham TW2 5HG**  
cbrowne@brownemedia.co.uk

Please email  
membership@  
redliongroup.org  
if your email address or  
contact details change





DECEMBER 2016

To: The Treasurer

**THE RED LION GROUP (REGISTERED CHARITY NO 1068124)**

**Please send this form to Paul Mulot, 103 Whitehill Road, Hitchin, Hertfordshire, SG4 9HT, United Kingdom**

I request that ALL subscriptions and donations that I have made to the Red Lion Group for the last four years, and ALL subscriptions and donations I make thereafter, be treated as Gift Aid donations. I confirm that I currently pay, or will pay, an amount of Income Tax and/or Capital Gains Tax that is at least equal to the amount to be claimed and I expect this situation to continue. (Current tax reclaim is 25p in £1 or £2.50 for £10). I am under no commitment to make any further donations and I may cancel this declaration in respect of future declarations at any time.

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**NB If you have previously completed this form it is only necessary to complete again if your tax status or home address has changed or you want to cancel this declaration.**

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