

*World Champion Fitness Model  
Zoey Wright is swapping her stoma  
bag for a J-pouch – see page 5*

# ROAR!

ISSUE 56 • CHRISTMAS 2018

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.

If you would like to be a regional rep, please contact David Skinner on 01708 455194 or by email at [info@pouchsupport.org](mailto:info@pouchsupport.org).

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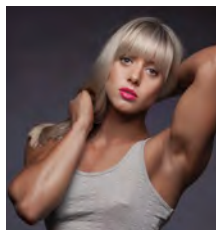
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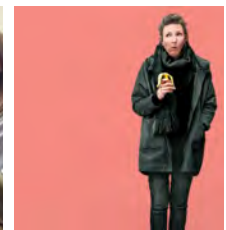
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**Please support the Red Lion Group**  
**Registered Charity number 1068124**



All donations, however small, towards expanding the work of the 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 Acting Red Lion Group Treasurer, 34 Everton Road, Potton, Sandy, SG19 2PA.**

Cover photo: Fitness model Zoey Wright (see story on Page 5)



## Notes from the editor



**G**adzooks! It's that time of year again! Though I've a slight sense of déjà vu for I was lucky enough to visit Bethlehem, the Garden of Gethsemane and its 2,000-year-old olive tree, the seven hills of Jerusalem and the Jordan Valley in October this year. It means I'll be singing my Christmas carols with a little more gusto this year!

Talking of memorable moments, 2019 marks the 25th anniversary of the Red Lion Group. One of the founder-members was Tim Rogers, who designs *Roar!*. Tim was also the first editor of your favourite magazine and in this issue you can read his illuminating report on Red Lion Group's first get-together in London's Syon Park in 1994 (I joined a year later and became Tim's deputy). You'll also be able to hear Tim and our first chair, Dr Martin Peters, speak at Information Day on 27 April. So do make sure you come along and join in the celebrations!

Red Lion members seem to have an uncanny knack for story-telling. In this December *Roar!*, committee members, Sarah Bowes-Phipps (secretary) and Peter White (acting treasurer), have written candid accounts of the medical and surgical dilemmas they have both faced and, more impressively, overcome. But then isn't that what we're really all about – supporting our fellow pou-

chees and passing on our personal experiences.

Another moving story I've included in this issue is the extraordinary exploits of a Cornwall-based fitness model who became a world champion while performing on stage wearing a bikini and a stoma-bag! Remember you read it here first – or second after the *Daily Mail*!

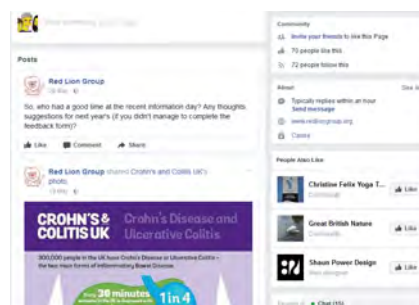
One of the features of the past six months has been your generous comments about the website redesign (pouchcare.org). It means we now have four key sources of news and information – the website, *Roar!*, our Facebook page (tagline: @theredliongroup) and a very lively Twitter account (Redlionpouchsupport – tagline: @pouchred). You can access our social media links by clicking on the logos on the lefthand side of the website. We even have our own social media specialist, Red Lion Group member Tracey Jackson, who has been giving us some useful tips about joining the Twitterati! If you have any comments to make on the sites please contact the committee on [info@pouchsupport.org](mailto:info@pouchsupport.org).

As the end-of-year festivities unfold, the committee wishes you a very Happy Christmas and New Year. We have even included a Christmas Quiz in this bumper issue to help you entertain your family and friends!

See you in 2019!

## AGM reminder

The Red Lion Group AGM will be held at Information Day on 27 April, 2019. The meeting will be the first item on the agenda before the main talks and workshops. If you have any issues, comments or committee nominations you would like to put forward please raise them with the committee and the rest of the group on the day.



## Find us on Facebook



[www.facebook.com/theredliongroup/](https://www.facebook.com/theredliongroup/)

## Visit our website

[pouchsupport.org](https://pouchsupport.org)

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

For online support, advice and tips on life with a pouch, please visit our Frequently Asked Questions (FAQs) page on the website at:

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

## All this for the price of a cup of coffee...

Chair David Davies pinpoints the value – as well as some of the perks – of membership of the Red Lion Group

**W**elcome to the latest issue of *Roar!*, the magazine for Red Lion Group members and one of the flagships of our services to members.

As we approach 2019, it's a good time to reflect on another busy year and your committee has once again been beaver away to achieve our vision for you, which is to provide patient-centred support and advice for pouchees, potential pouchees, and their families and friends throughout the UK and, in a few cases, overseas.

We do this by providing a forum for discussing and sharing information about pouch-related issues. Red Lion Group members receive two editions of *Roar!* each year, the opportunity to attend an informative, entertaining, enlightening Information Day (please note the date for next year: Saturday **27 April, 2019**), access to a super new website ([www.redliongroup.org](http://www.redliongroup.org) or [pouchsupport.org](http://pouchsupport.org)) and the chance to interact with committee and members via Facebook and Twitter. And all this for the price of a couple of cups of coffee per year!

A highlight of the year was the information Day in May and more than 80 members, relatives and friends enjoyed a rip-roaring agenda of formal talks, interactive sessions and three round-table discussion groups (one for men, one for women and one for relatives and friends).

Once again, the feedback scores were extremely high across the board. We were encouraged also by the many compliments we received on the day and afterwards from members. Profuse and comprehensive coverage of Information Day was included in the summer edition of *Roar!* so I won't reiterate the whole agenda.

However, I wanted to highlight the seven people who had had "phase I" of their surgery and wanted help in making the decision on whether or not to opt for a pouch or a permanent ileostomy.

One of the comments that resonated strongly with our newcomers was that they often hear bad things about living with the pouch on social media and at events like our Information Day. What they were looking for was a balanced view. As we all know, the outcomes from this surgery can be mixed and vary from person to person. And we probably all know people who are coping better with their pouches than others.

But there are also many people who achieve improvements in their quality of life compared with having a permanent ileostomy and it highlights the need to give a bal-



anced view. It's a bit like the Brexit debate; all people really want to know are the facts so they can make an informed decision. Did I really mention Brexit?!

One of the presentations on the day was around problems with the pouch. It occurred to me during an extensive question and answer session, prompted by the presentation, that we should have included problems with a permanent ileostomy in the same session. That is what many prospective pouchees want to know and I think we owe them a duty of care to present a more rounded picture of the options available to them.

I was also privileged to attend the Kangaroo Club (KC) information day at John Radcliffe Hospital in

Oxford along with Red Lion Group's membership secretary Susan Burrows in September. During a terrific event we heard three very interesting personal journeys from KC committee members which resonated strongly with the audience and is something we might well copy for our own Information Day.

The three speakers had very different experiences; one with a good outcome and very happy, one with multiple problems with their pouch but overall very happy and finally a woman who had had her pouch removed due to persistent problems. She now has an ileostomy, but is also very happy. It is widely publicised that approximately 10 per cent of pouches are removed due to persistent problems but that still leaves 90 per cent in place, many of which are working very well for their owners.

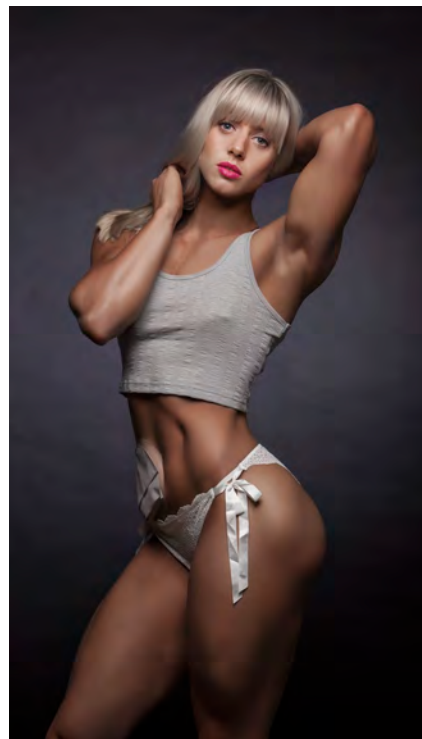
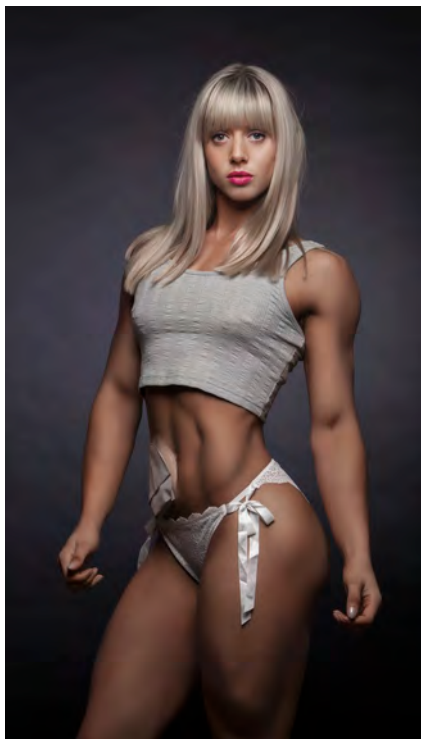
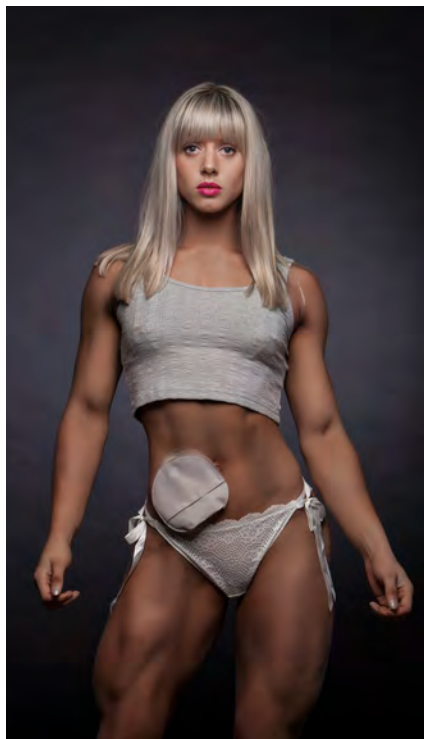
I also had the chance to meet up with my surgeon, Professor Neil "Morty" Mortensen, who operated on me more than 33 years ago. He gave an excellent, unprompted and unrehearsed speech about the early days of the pouch operation and admitted that the surgeons didn't really know what the outcomes would be in those days, but they had a shared conviction that people should have an alternative to living with a stoma. Thirty-four years on I know there are many of us out there who are mightily grateful for their pioneering endeavours.

And finally, the mathematicians among you will have calculated that I was in hospital in 1984/5; the same era that was celebrated at the Rewind music festival. So I end this column with a question for you all – who can think of a 1980s pop song that sums up the life of a pouchee? My favourites would be "Time After Time" (Cyndi Lauper), "Down Under" (Men At Work) and of course "Push It" by Salt-N-Pepa:).

Have a super Christmas break and the committee and I look forward to seeing you at Information Day on 27 April 2019.

## Why world champion Zoey is swapping her stoma-bag for a J-pouch

A Cornish body fitness expert who suffered a long spell of ulcerative colitis opted to wear a stoma-bag instead of a J-pouch – and then changed her mind



**B**ody image and general appearance are two key reasons why most of us choose to have an ileoanal pouch after a long spell of ulcerative colitis (UC) or FAP. So, anyone who relies on their looks and showing off their body to large audiences for a living is unlikely to want to wear a stoma-bag.

Unless they are Cornwall-based Zoey Wright. Zoey beat a host of international performers to become World Champion Fitness Model at the Pure Elite World Championships in the UK recently. Even more remarkably she was wearing a stoma-bag throughout the competition.

Brave 26-year-old Zoey had been a UC sufferer for six years which meant repeated visits to her doctor and spells in and out of hospital. However, when she faced the prospect of surgery and a longer stay in hospital to improve her condition, she opted to have an ileostomy instead of a J-pouch. "I thought it would be temporary as I certainly didn't want to wear a stoma-bag for the rest of my life," she told Roar!.

"However, after two years of relapses and hospital treatment, I decided I would almost certainly need to have a permanent ileostomy. Although I discussed the idea of having a J-pouch with my surgeon, I didn't feel I was ready for it and I didn't know if it would work better for me than an ileostomy" she said.

Twelve months later after a serious pelvic blockage, Zoey had to have an emergency operation at her local hospital, the Royal Cornwall Hospital, in Truro. "I then competed in my first show wearing a stoma-bag and felt better than I had felt since the illness began," she said.

Zoey, who lives in Falmouth, Cornwall, then followed a strict fitness regime with frequent sessions in the gym and regular weight-training. "My sense of well-being was also helped immeasurably by the support of my boyfriend Conor who has been my rock since the illness began and has helped me through all the difficult periods."

Her hard work paid off. In 2016, the year before she was crowned

world champion, she was voted runner-up in the Pure Elite Body Fitness World Championships in the UK.

However, it is her recent victory that has been the real life-changer for Zoey. She was recently voted the face of USN, the international sports nutrition brand. She also plans to compete as a professional weightlifter!

She says probably the biggest decision she faced since her illness began was whether to have a J-pouch fitted. Her response was an unequivocal "yes".

"I spoke to my surgeon and said I had changed my mind about having the J-pouch surgery and I am so happy to have this opportunity to have a J-pouch after all," she said.

The Cornish fitness model is now due to have the first part of a two-stage operation in the next month or so. "With every setback there's a comeback," she said optimistically.

You can read regular bulletins about Zoey's progress on [www.zoeywright.com](http://www.zoeywright.com) and [www.instagram.com/zoeywrightfitness](http://www.instagram.com/zoeywrightfitness).



## How David won his musical marathon

**T**he sheer scale and variety of pursuits that poussees enjoy and take part in shows that having an ileal pouch need not be a barrier to even the most ambitious ideas and activities.

Running marathons, competing in triathlons, climbing mountains, kayaking wild seas and, yes, hoovering the stairs are all activities undertaken by poussees from time to time and I'm always delighted to read of how they coped with their endeavours. However, I think most of us would agree that we need to plan thoroughly for such events and activities, to ensure suitable diet and toilet facilities are available – just in case.

This summer I faced a marathon with a difference, an event that would test my continence to the limit and take contingent planning to new levels. I went to a pop music summer festival in Henley-on-Thames. It was not for the faint-hearted or even some of those with large intestines. This was a three-day event in open fields with abundant booze, fast food that was lamentably lacking in natural fibre content (no one had even heard of psyllium husks), a great big stage, lots of flashing lights and dedicated toilet areas containing row upon row of monochrome portaloos.

I packed my Imodium, some spare toilet paper, a small pot of E45, a spare pair of pants, my "just can't wait" card and a rehearsed line to excuse my jumping the queue. Actually, this last bit is a real challenge. "Do you mind if I jump in, I have no large intestine or rectum" is not going to mean much to many people, let alone a drunk Abba fan who is also desperate having queued for 20 minutes for a wee.

But I need not have worried. One of the features of the Rewind festival, championing the music of the 1980s, was the profusion of middle- and older-aged people in the crowd and the consequent widespread use of camping chairs. One regular

festivalgoer commented they had never seen such an array of camping chairs. Which was nice because if you're anything like me then you'll know that standing up and drinking copious pints of beer is a challenging combination for a pousse.

But sitting down and drinking copious pints of beer is a different and altogether more comfortable proposition. In addition, the toilet facilities on the site were absolutely excellent. Don't get me wrong, there was a queue, but never more than 20 people and it went down quickly because of the row upon row of toilets. The organisers had done an



David Davies: Music to my ears

excellent job of predicting demand (I wonder what their assumptions were!).

And, finally, the true unsung heroes...not Marc Almond, not Kim Wilde, not Kool and the Gang. No, they were the team of toilet attendants replenishing the loo paper on a continuous rolling rota (forgive the pun) and ensuring I never had one of those awful moments when I'm halfway through and realise there's no paper.

The toilet attendants politely declined to be photographed for *Roar!*, I can't think why, but rest assured dear readers that I passed on our gratitude for their endeavours.

## Letter to the Editor

Tricks of the trade

Dear Christopher

I thought I would pass on a few ideas about St Mark's Hospital's E-mix solution (see Summer 2018 *Roar!*, page 6). I regularly drink 2-3 litres a day and since I have been taking it I have learnt a few tricks.

First, St Mark's electrolyte rehydration ingredients – glucose monohydrate, sodium chloride and sodium bicarbonate – are now available in ready-to-use form. This is slightly different from the traditional approach as they are powdered which means they can be absorbed slightly more quickly than before.

My reasons for changing to the newer version are that I am now frailer than I was and the law says carers can only mix solutions such as the powdered E-mix that have been prescribed by a doctor. Also, I have found it difficult to obtain glucose as my local pharmacy says it is used by drug addicts to cut their drugs. This means that E-mix users need to order it specially, or else buy it online so that it can be delivered instead of having to make two trips to your local pharmacy.

I have also given up using a jug as I kept knocking it over and use two 1 litre bottles which you just need to shake to mix up the ingredients. My favourite E-mix is made with carbonated water. However, you have to watch out for the wind!

As E-mix is heavy to carry around, when I go out socially I take rehydration salts with me and whenever I have a coffee I ask for a glass of water and a spoon.

I really hope these little tips help other members of the Red Lion Group.

Janice Nicholls

Herne Bay

**Ed: Thanks for the useful advice Janice – I'm looking forward to my next tippie!**

## Infertile? Me? You can forget it said the defiant young pouchee. And she was right

How Red Lion Group secretary Sarah Bowes-Phipps won over medical opinion, pouch complications, numerous fistulas and tricky IVF treatments to have three bonny babies

**W**ill the operation affect my fertility?" is not a question most 21-year-olds tend to worry about but back in the early 2000s it was playing on my mind as I pondered my decision to go for reversal surgery and the creation of an ileo-anal pouch. Sadly I was misinformed (by my then surgeon) and reassured that I should have no concerns about my future in that regard.

Fast forward eight years, numerous blood tests, scans and X-rays and my worst fears were confirmed. Both Fallopian tubes were completely blocked due to adhesions (a common complication from open surgery for pouch creation). Nothing short of a miracle would allow me to conceive naturally. I felt cheated and deceived to be honest.

IVF, as most people now know, is no walk in the park. Odds are against you, both with the postcode lottery in terms of accessing NHS-funded IVF in the first place, and then the low success rates if you are successful in securing funding. Something about my years and years of battling inflammatory bowel disease and the numerous life and death scenarios I have overcome (an article for another time!) has resulted in me having a somewhat dogged determination in my approach to the majority of challenging obstacles life throws at me. Infertility was not going to win this time.

So what happened next? After myriad tests, the gynaecologist then makes the decision whether to refer the couple to an IVF clinic. We (my husband Steve and I) opted for Hammersmith Hospital having done some research on success rates and their experience with

women presenting complicated medical conditions. Progress went slowly but well. The consultant at Hammersmith seemed optimistic. We attended our final appointment before commencement of IVF was due to start and knew straight away that something was wrong. The nice young fellow we had seen the previous three times was replaced by a female consultant, clearly his senior whose manner suggested good news was not coming our way. "We've reviewed your file", "I'm afraid to tell you...". That was it. The



*Happy family: Sarah Bowes-Phipps (right) with her husband Steve (left), Watford General Hospital consultant Miss Marcellina Coker (centre), and the family's three children*

IVF had been vetoed by the powers above. My particular issues, around pouch fistulas and the perceived likelihood of infection or bowel perforation at egg collection, was deemed too risky. We were handed a pamphlet on 'Egg Donation' and sent on our way.

I sobbed throughout the long journey home. Cheated and deceived again.

Where do we go from here? Private IVF costs thousands of pounds with no guarantee of success, not to mention the extreme stress related to the whole process added to that. And maybe they were right – was I putting my life at risk?

I sat at home, nursing my sorrows, pondering my existence to be frank when my mobile phone rang. "Mrs Bowes-Phipps? It's Heidi from The Lister Fertility Clinic".

When I tell people that we 'won' IVF they look at me like I'm one of those weird people who like to make up fantastical stories for attention. But I'm not, I assure you. We really did, and fate came into play in that we found out the exact same day we were rejected by the NHS.

Each year, The Lister, a private fertility clinic based in Chelsea, works with a charity called the Fertility Network to offer couples the chance to win one of a number of free IVF rounds, the number corresponding with the Lister's birthday. I really hadn't thought much about it when I sent my application in a month or so before. "Have you read through all my medical problems?", I queried frantically, "My IBD, the fistulas?". Heidi reassured me that all was in hand and that the best thing was to come in and meet the Consultant so that everything could be discussed in more detail.

The Lister IVF Clinic is impressive. Part of the Lister Hospital, it is home to many of the stars seeking fertility treatment, beautifully located on the banks of the Thames in the heart of Chelsea. We met with Dr James Nicopoullos, possibly one of the nicest doctors I have met (and I have met a fair few). I was not



a simple case. There were ethical implications in providing me with private IVF.

If something did go wrong at egg collection, most likely bowel perforation or infection, it would then be the NHS footing the bill to care for me. Not to mention the risk to me generally.

Letters went back and forth between James and my Pouch doctor, Professor Sue Clark at St Mark's Hospital. A 'mortality rate' was requested and calculated at 1/250 and I was required to sign a disclaimer which I duly did without hesitation.

At this point I began a long-term course of antibiotics to help reduce the ongoing infections caused by my fistulas. A final review was held and the green light was given. We could start our IVF journey at long last.

The IVF process is long and slow. Treks down to Chelsea almost every other day for weeks on end, constant scans and blood tests, self-administered injections and so on. Finally the egg collection day came. I was given a lovely private room, to wait in and later for recovery, and killed some time ogling over the dining menu whilst we waited! I was taken down to theatre where I was given general anaesthesia whilst the egg collection procedure took place.

When I came round, back in my room, I grabbed for my hand. James had promised to write the number of eggs collected on my hand bandage. Seven. Not a blow-me-away number but not shabby either. I had battled the risks and got through.

Later, James updated me that there had been no issues with the procedure but he made the judgement call to only access one ovary as the other was covered in adhesions

and he did not want to take any unnecessary risks.

And now the dreaded wait to learn if any of the seven eggs successfully fertilised and were viable. We were pushing the wait to Day Five, blastocyst (a key stage in the forming of an embryo) transfer, as statistics had shown that these blastocysts provided the highest success rates. This was a riskier approach though as there is also the option to transfer embryos on Day Three – we were banking on our embryos surviving for another two days and could potentially lose them all without

next morning headed off bright and early back to Chelsea, a very familiar journey now. By this point the fertility drugs had really started to take their toll on my body. I had painful abscesses under my armpits, was in general pain all over and felt tired and very stressed. The transfer process was pain free, no worse than a smear, and was completed in less than 15 minutes. The next hurdle was the 'two-week wait'. I had been following IVF forums religiously and was prepared to try out some weird and whacky things to make sure this transfer worked – eating

Brazil nuts, cutting out cocoa, lying on the sofa with my legs up for hours on end etc. Unfortunately none of this helped, I started to get spots of blood (bleeding between periods) about a week in, the test day came and the result was negative, confirming our fears.

So now what? We could pay £200 to transfer the remaining frozen embryos to the Oxford Radcliffe IVF Unit, an NHS clinic we had sought a second opinion from after the rejection by Hammersmith. Oxford were happy to offer us a free frozen embryo transfer now that the egg collection was no longer an issue. But could we cope with the inevitable agonising wait and slow process?

We talked at length and decided to bite the bullet, and fund the FET ourselves via the Lister again. We were impressed by their approach and undeterred by our lack of success so far.

The FET cycle, for me, seemed to have much less of an impact on my body than the fresh cycle. There were still many scans, injections etc. but it felt more natural in comparison and when transfer day arrived, I was feeling much happier and healthier. From the failure of the



And then there were three... Georgina (left), Lawrence and Albert Bowes-Phipps

ever even getting to transfer stage.

We received the call. Four eggs had fertilised and all looked capable of reaching blastocyst stage. They were also of a very high grade. The embryologist seemed rather excited. The highest-grade embryo was chosen to be transferred as part of this fresh cycle and the remaining three were frozen for future FET (Frozen Embryo Transfer).

I was told to take a Trigger Shot (a hormone medication injection) the evening before transfer and the



fresh cycle to transfer day for the FET was a period of around two months. The time passed quickly. We arrived home after this next transfer and I don't know whether it was the glorious weather or me just feeling better, but I had a real sense that this could end in a positive result.

Unlike last time, I went straight back to work (no lying on the sofa for me). I also ate what I liked and tried to distract myself. I basically worked on the premise that that was how the majority of the female population acted before finding out they were pregnant. The dreaded two-week wait dragged on.

On test day I woke up very early, 5am or thereabouts I think. I sneaked into the bathroom on my own to test. I wanted to shoulder the disappointment alone first, crazy as that seems. But there they were, TWO LINES! We had finally done it. An early scan at six weeks confirmed the pregnancy and that the embryo was in the right place and even had a heartbeat (possibly the most amazing thing we had ever heard at that point).

My pregnancy continued problem-free, with no particular adverse effects on my pouch aside from a slight increase in frequency of visits to the toilet and trapped air but nothing much to complain about in the scheme of things. We opted for a caesarean section having researched the pros and cons of vaginal delivery with an ileoanal pouch and the potential impact on control afterwards. My consultant at Watford General Hospital, Miss Marcellina Coker, was diligent and reassured me whenever I had concerns.

My waters broke in the middle of the night almost two weeks before my due date. Into hospital we went and 12 hours later our lovely little Albert arrived (I say little, all 10lb 1.5oz of him!). I bounced back from the operation very quickly and found motherhood an absolute joy. I didn't need any medications for my IBD aside from Loperamide so was able to breastfeed and actually found it helped with pouch function so rarely took any anti-diarrheals anyway. This period of my life was just such a happy one in comparison to all the hardship that had come before it, that it wasn't very long before I started thinking about the two em-

bryos left in the freezer. Should we give it a go? Why not?!

So we went back to the Lister two more times. Both FETs were successful and we managed to complete our beautiful family with the addition of Lawrence (born 21 months after Albert) and Georgina (born 27 months after Lawrence). We are a tad tired these days and, having braved three C-sections, my body has certainly had enough of carrying babies! We have used up all our frozen embryos so it was an easy decision to decide that three children was where we would stop.

The kids are very close in age, at one point we had three under 5(!) and that is a lot of nappies. They keep us on our toes and to be honest distract me from the day-to-day issues that come with having a pouch. Each evening I creep into the children's rooms and tuck them in and kiss their foreheads and know that it has all been worth it – our little miracles we were told we would never have.

**Janindra Warusavitarne, Consultant Colorectal Surgeon and Lead for IBD Surgery at St Mark's Hospital, comments:** "This is a fantastic and emotion-provoking article on some of the fertility issues related to ileoanal pouch formation. Sarah has brought to life a real journey she went through in order to create her perfect family. Fertility is certainly a topic that is always discussed, and many patients ask me about the ability to conceive after pouch surgery.

"It is true that in the days of open surgery the ability to get pregnant was reduced and IVF had to be the only option for many women. As keyhole surgery evolved, it became apparent that the adhesions around the ovary which was the major reason for the inability to get pregnant was no longer an issue and it has been shown that reduction in pregnancy rates is no longer an issue. I think this is good news for those who are contemplating internal pouch surgery."

**Lisa Allison, Clinical Nurse Specialist for Pouchcare at St Mark's Hospital, says:** "It is brave of Sarah to tell us all of her journey with Steve through the IVF pro-

cess but heart-warming that this tumultuous journey has resulted in three beautiful children. Female patients often ask what we advise with regards to timing of pouch surgery and trying to conceive.

"When patients have acute ulcerative colitis and are advised that surgery is the best treatment option they will undergo what is known as a subtotal colectomy and the formation of end ileostomy. The colon is removed but the rectum is left in place. This is abdominal surgery as opposed to pelvic surgery so adhesions are less likely to form around the Fallopian tubes thereby potentially affecting a woman's ability to get pregnant (known as fecundity). Once patients have recovered from surgery and are feeling generally better they may choose to conceive whilst they have an ileostomy. Having a stoma whilst pregnant can be a bit awkward with changing the appliance as the baby grows but it is manageable.

"The next stage of surgery (if necessary) is to remove the rectum and form an ileoanal pouch which is positioned in the pelvis where the rectum was. It is this stage of surgery that can cause adhesions to form around the Fallopian tubes but, as mentioned above, less so with laparoscopic techniques.

"Patients are advised to get into a good routine with their pouch and establish what their 'normal' function is before they embark on pregnancy as hormonal changes and increased activity in the pelvis as the baby grows can alter pouch function. It is suggested that couples try to conceive naturally for a year and if they encounter problems to speak to their GP to discuss being referred for fertility tests.

"With regards to delivery of the baby it is advisable to have a caesarean section so that the anal sphincter is not compromised and therefore affect pouch function. Depending on the medical history of the patient it can be beneficial to have a Colorectal Surgeon present at the delivery should there be any complications with the pouch. This can be discussed with the obstetrician at initial consultations."

## How to take the sting from your skin

With our limited reservoirs for storing food and liquids, dehydration and dry skin are common problems for many pouchees. Acting treasurer Peter White reports

I always know the cold weather has arrived when my skin becomes more susceptible to injury. As many of us know, having an ileoanal pouch means losing out on some of the fluid absorption the large bowel or colon would normally perform. That means being prone to dehydration – and part of that condition is dry skin. For me, part of living without a colon means managing my skin.

So here are some of the key ways to deal with the problem:

### Skin elasticity

Cold and wet can make skin less elastic, and that has two impacts. First, it can split – leaving painful cracks which sometimes do and sometimes don't result in minor bleeding; either way it hurts. Second, it leaves the hands more susceptible to damage, and this is the problem I really have to watch out for.

### Cracking skin

Avoiding cracking isn't rocket science, but does require some attention. It's quite common for women to carry moisturising hand cream, but not many men carry a handbag! Of course, there are relatively discreet ways to carry hand cream – in the car, in a work-bag, at your work desk and at home – and these cover most eventualities. In my experience women are also more than happy to share their hand cream with a man brave enough to ask!

### Avoiding skin damage

Avoiding skin damage takes more thought. For me gardening, DIY, water sports and mountaineering, each come with potential risks to the skin, and particularly the hands. Gloves are a really good way to manage these risks, and there are loads of different types available these days.

For gardening and DIY leather gloves are well worth using. I recently took some skin off one of my knuckles trying to remove some wire mesh; it could have happened to anyone, but I suspect the injury was worse for me as my skin is less elastic than many people's. For water sports I wear neoprene (wetsuit material) gloves summer and winter, which cost around £5 and absorb all the abrasion.

For mountaineering I often wear waterproof gloves

and socks to reduce blisters and the effects of rubbing, and preventing the skin becoming saturated for prolonged periods.

There are now a lot of waterproof gloves and some socks available for running, cycling, walking and other sports. If you can find them though, it's well worth getting gloves which are smartphone compatible, especially in winter.

### Repairing skin damage

The body is of course extremely good at repairing itself. But constant wetness can hinder that process and result in unnecessary bleeding. With a pouch, going to the loo, and washing hands, are more frequent. So how do we keep hand injuries dry?

I have tried most varieties of

plasters. Many are useless when wet. Even those that are waterproof are little use on moving parts (such as knuckles and other joints); inevitably they don't stay on (or stay waterproof) for very long.

Something I use a lot is Germolene NewSkin. Applied instead of a plaster on minor skin wounds, it's basically like pasting UHU glue onto the injured part using a small spatula contained in the lid.

Within a few minutes it has set, and a glue-like layer protects the skin from water (and infection). It can sting a bit, but it's well worth it, as you can wash hands and have a shower without the inconvenience or discomfort associated with plasters or no covering. It's my favourite plaster! I have even started using it for prevention on my feet, instead of taping them with micropore tape.

So, if you have a pouch, and have other tips for dry and cracking skin, why not send them to the Letters to the Editor page ([cbrowne@browne-media.co.uk](mailto:cbrowne@browne-media.co.uk)) or share them on the website [pouchsupport.org](http://pouchsupport.org).





SAVE THE DATE

THE RED LION GROUP

**25<sup>th</sup> Anniversary**

**Internal Pouch Information Day**

SATURDAY 27<sup>TH</sup> APRIL 2019  
10 AM REGISTRATION  
AT  
ST.MARK'S HOSPITAL, HARROW HA1 3UJ

Keep an eye on our website for further details

[www.pouchsupport.org](http://www.pouchsupport.org)



## Roar!'s twenty-fifth anniversary special

Two founder-members of the Red Lion Group reflect on those heady moments after the launch of the Red Lion Group on 10 April 1994

### The thoughts of Chairman Peters

The Red Lion Group's first chairman, Dr Martin Peters, recalls the excitement and some of the key players of the group's early days

I remember well my time in St Mark's Hospital in City Road. I was very ill with a severe case of ulcerative colitis that had not responded to medication. I was admitted to the very old and rather shabby St Mark's in London's City Road in a very weak state to be treated with intravenous steroids and methotrexate. After some weeks I was advised to have surgery and offered a pouch operation by my surgeon Mr Peter Hawley.

I was warned of all the possible complications but I was so ill that I didn't take any time to decide on surgery as soon as possible. All went well and, by day two, I was feeling so much better but very weak. Over the next two years I was readmitted to St Mark's on numerous occasions because of obstructions due to adhesions requiring a number of major surgeries to combat the problem. This all happened over 30 years ago and now seems just like a bad dream.

Twenty-five years ago I was contacted by the St Mark's stoma nurse specialist Celia Myers to see if I was interested in discussing ways in which we could help pouch patients and those considering pouch surgery. The group met in the then new St Mark's Hospital in Watford Road, Harrow [the original launch of the group was in London's Syon Park – see next page].

Celia's name should go down in history as she was the inspira-

tion that caused the group to come into existence. Tim Rogers, *Roar!*'s editor at that time, was there too. The names of the other founder-members are recorded elsewhere.

We were told that we needed a chairman to run the meetings and perform certain tasks and duties. No one seemed keen to take on this job so I volunteered.



Martin Peters with his wife Amanda and Spanish granddaughter Camille

I was chairman of a number of charity groups and medical conference organisers so I thought that one more job could be fitted in somehow. We decided to call the new charity The Red Lion Group and chose the cute little lion as our logo as we felt that it was non-threatening to new members.

After about two years the group had an established membership, a newsletter run by the same team as it is now, and we were a registered charity. At this point I felt that it was time for me to pass on the chair to new blood.

I have always maintained an interest in the group and receive *Roar!* regularly. I believe the group does a wonderful job because I have always maintained that no matter how experienced a pouch nurse or consultant may be only someone with a pouch can really understand what it feels like to have a pouch with all its peculiarities of sound and motion!

I know that when I was faced with the choice I would have loved to have someone to talk to who had been there, done it and got the T-shirt.

I am very lucky to have a pouch which behaves itself almost all the time. I have lived in Spain permanently for 20 years now and can eat anything and what's more do. I have been admitted to hospital once here for an obstruction and was delighted to find that

the surgeon in charge had been trained at St Mark's by Peter Hawley and knew all about pouches.

I am looking forward with great anticipation to the April 2019 Information Day and the 25th anniversary of The Red Lion Group. I hope to see lots of you there and swap pouch stories.



# ...and here are the highlights of the first meeting recorded by the then editor of Roar! Tim Rogers in his first-ever issue!



During the discussion that followed it became clear that the day had been a great success. People found it a relief to be able to talk to fellow pouch patients and swap hints and tips.

Up until today most of us had had to learn how to live with our pouch without the benefit of talking to someone else who had already been through it.

It was soon apparent that some of us had been through quite different experiences.

One of those present said he only goes twice a day. This made

those with 'bad pouches' rather peeved. However, there was plenty of common ground and everyone came away having learnt something.

As the afternoon drew to a close we split into regional groups and took down each other's names and addresses. The day had been more successful than I could have possibly imagined. The group seemed genuinely excited about building up a support network of people with pouches.

As I drove home I could not help thinking that this was the beginning of something big.

## UK charity helps pouchees in need

The Kingston Trust was set up to help pouchees and ileostomists aged 16 or more who face financial hardship

If you have a pouch and are facing financial hardship, there is a charity that may be able to help you.

It is called The Kingston Trust (KT) and was founded in 1962 by a former general secretary of the IA (Ileostomy Association) Leslie Kingston.

An ileostomist himself, Mr Kingston noticed a gap in the support network for those with ileostomies and ileoanal pouches – particularly older individuals – who needed financial help.

The Trust then raised the funds to set up four residential and recuperative holiday homes where older people could be helped and cared for. However, the limited number of homes meant many of their permanent residents had to relocate away from their families, friends and local communities. So Mr Kingston sold the homes and used the money to help fund today's Trust and its current grant schemes. KT is also funded by donations and legacies.

Seeing a need to help young people in financial difficulties, KT now supports with individual grants any UK resident aged 16 or over who has

an ileostomy or ileoanal pouch and faces financial hardship. It also funds research projects including studies run by the IA through its partnership with the Bowel Disease Research Foundation (BDRF).

Applicants can apply for grants for any purpose apart from previously purchased items (which, in exceptional circumstances, can be at the Trust's discretion). Although grants for those with outstanding debts are not considered.

For those who don't require a grant but know of a pouchee or ileostomist who does can pass on KT's contact details to them.

Grant application forms can be downloaded from the Trust's website [www.kingstontrust.org.uk](http://www.kingstontrust.org.uk) or requested from the KT secretary at [secretary@kingstontrust.org.uk](mailto:secretary@kingstontrust.org.uk). The charity's postal address is: The Kingston Trust, PO Box 6457, Basingstoke, RG24 8LG or you can phone 01256 352320.



Leslie Kingston



## 2018 Christmas Quiz

1. Which English king won the Battle of Agincourt in 1415?
2. What is a palindrome?
3. Which actor has won the most Hollywood Oscars (four)?
4. There are five teams in the English football league whose names start and end with the same letter. Which are they?
5. Which four English counties border Wales?
6. Name the longest-serving British prime minister
7. Which is the southernmost US state?
8. Which Christmas song was composed by James Pierpoint in 1857?
9. In which year was the Conservative backbenchers' 1922 committee formed?
10. What is the title of Charles Dickens's final novel?
11. Name the day and month of the 2018 winter solstice
12. Which actor played Liberace in the 2013 film *Behind the Candelabra*?
13. 'Schnee' means 'snow' in which European language?
14. How many novels did Emily Bronte write?
15. In which town were the first Winter Olympics held?
16. In which country was St Nicholas born?
17. How tall is Mount Everest – 30,100ft, 29,002ft or 28,998ft?
18. How many times does the sun rise and set in the Arctic?
19. Name the largest country in Europe, excluding Russia
20. In which year did the UK join the European Union?

## Do YOU think YOU can help?

**Y**es YOU. Are you in your 20s or 30s and want to improve your CV? Are you in your 40s and 50s and have life experiences you could share? Are you in your 60s or 70s and have a little spare time?

On or before 31 March 2019 our acting treasurer will be standing down for family reasons.

So far, we have not found anyone willing to take on the role. We are therefore asking every member of the Red Lion Group plus family members, friends and any others you may know to see if they can help.

In the past, the role has been taken on by one person, but it doesn't need to be.



Could YOU (or someone you know) help with any of these:

Making payments by online banking or cheque and keeping records of what you've done (Typically less than 20 payments are made throughout the year, so this is not an onerous task).

Putting together the end-of-year accounts in a spreadsheet, showing what was received and what has been paid out of our bank accounts. (Our accounts are very simple, we have no staff and no assets and run on very small sums of around £5,000 per year. Our financial year ends in December – and 95% of credits [membership fees] take place in January. The person doing this will need to finish the accounts and send

them to our independent verifier so the accounts can be confirmed).

Claiming Gift Aid on donations made (and keeping up-to-date gift aid declarations).

If YOU (or someone you know) can help with any or all of these it would help the Red Lion Group to continue to meet its responsibilities to manage its finances legally and effectively, and enable us to continue all the good things we do for our members.

No previous experience is required, and we can provide training and support.

If you think you might be able to help we would love to hear from you. Please contact us at [info@pouch-support.org](mailto:info@pouch-support.org).

## News In Brief

### *Professor Phillips ‘transformed’ modern colorectal surgery*



Professor Robin Phillips

**P**rofessor Robin Phillips, who was Clinical Director of St Mark's Hospital for 14 years, recently retired from the role. His successor is Professor Omar Faiz, a St Mark's consultant colorectal surgeon.

Prof Phillips joined St Mark's as a consultant surgeon in 1987. He later became director of the St Mark's Polyposis Registry and in 1999 was appointed civilian consultant in colorectal surgery to the Royal Navy.

In a tribute to Prof Phillips's "illustrious career", Janindra Warusativarne, a St Mark's consultant colorectal surgeon who was trained by him, said Prof Phillips was a "true giant in the profession" who helped

to transform modern colorectal surgery. "His many innovations made him a renowned expert and he was sought for his opinions from practitioners from all over the world," he said.

"He remains an amazing teacher and has been influential in paving the way for a whole lot of future leaders around the world – his legacy lives within all of us who were blessed enough to be trained by him," added Mr Warusativarne.

Prof Phillips was a pioneer in FAP (familial adenomatous polyposis) and anal fistula research, including the revelation that fistulas are not driven by infections.

## *Hidden depths*

**G**utted is the title of a one-woman show written by Liz Richardson, an actor from the Peak District, and theatre director Tara Robinson. It is based on Liz's experiences living with ulcerative colitis.

Describing the show as "a tale of love, laughter and loos", its programme notes call it "an engaging investigation into how we think about illness, femininity in the face of taboo, the boundaries of shame and the nature of hidden disabilities".

*Gutted* is based on Liz's relationships with doctors and nurses during her numerous stays at the West Cumberland Hospital in Whitehaven, Cumbria.

Supported by the Wellcome Trust, the show has toured hospitals, theatres and medical conferences throughout the UK.

As one Twitter pundit put it: "Who knew a one-woman show about broken digestive systems could be so funny."



Liz Richardson



Dr Misha Kabir, dysplasia survey coordinator

## *A St Mark's team wants to hear from you*

**A** team of research doctors at St Mark's Hospital want to speak to people who have had an ileoanal pouch due to inflammatory bowel disease. In particular, they want to speak to those who chose to have the surgery after discovering changes in their colon lining (a condition known as dysplasia).

The team wants to learn how to communicate and support patients better while they are deciding whether or not to have a pouch for the condition. It can only do this if it

hears directly from those who have experienced this and can tell them their personal experiences and what worked or didn't work when speaking to their doctors.

If you are interested in taking part in the survey then please read the information via [goo.gl/forms/Gnvrga854ltkCGCq1](https://goo.gl/forms/Gnvrga854ltkCGCq1). Or else contact Dr Misha Kabir, a Clinical Research Fellow in IBD at St Mark's and one of the coordinators of the survey. You can email her at [misha.kabir1@nhs.net](mailto:misha.kabir1@nhs.net) for more information.



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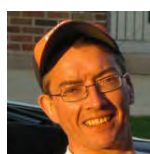
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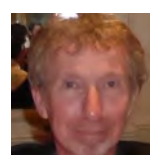


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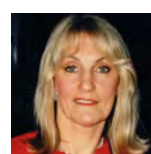
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Lynn Faulds Wood

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



(December 2018)

To: The Treasurer

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

**Please send this form to Peter White, 34 Everton Road, Potton, Sandy, SG19 2PA, 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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**Signature** ..... **Date** .....

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