# ROAR!

ISSUE 55 • SUMMER 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 liaison@redliongroup.org.

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Bernadette Thorne
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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: New Zealand Flower, by Susan Burrows

# Notes from the editor

Hey fellow Red Lions! We've joined the 21st century with a brand-new WordPress website www.pouchsupport.org.

So log on until your fingers hurt and your sugar levels cannot take any more as you find out the subtle tricks, secret links and online surprises of our glamorous new site.

You'll also love our new logo of a sleek red griffon poised ready to soar, glide and swoop down on us with its latest batches of news, up-to-the-minute bulletins and headlines from the world of the Parks and Nicholls Pouch.

Then, when you can take no more, turn to *Roar!* and delve into another realm of invention and research into such topics as new ways to combat pouchitis, how today's pouchee can handle family planning and pregnancy and the pioneering work being forged in biologics, robots and keyhole surgery.

Then, on a slightly lighter but equally important note, you can read about our intrepid membership secretary Susan Burrows and her adventures in New Zealand and Singapore and how she met her first-ever travelling pouchee thousands of miles Down Under among the ancient islands, volcanoes and peaks of the Antipodes.

And talking of pouches and pouchees, you can find out about the Ruby anniversary of the ileoanal pouch in an article by its co-founder, Professor John Nicholls, who led a Ruby anniversary masterclass at St Mark's Hospital on 29 June this year and – finally and fascinatingly – why the pouch's founder, Sir Alan Parks, said "sorry" to one of his youngest and earliest patients.

In this issue, we've 10 pages on the 12 May Information Day which had its highest-ever attendance of just over 80 pouchees, relatives and professionals. Among the many optimistic words that were spoken were such topics as rising Red Lion Group membership, new ways for Red Lion to fundraise and why pouches and pouch care need to be everyday talking-points in GPs' surgeries.

But hold on a minute, all this celebrating is becoming a habit. Next year marks the 25th anniversary of the Red Lion Group. Yes we're really that old! And speaking of summer fireworks and poolside hi-jinks, the committee has already started planning for the event – and of course we'll keep you informed with our ideas for 2019.

Meanwhile have a very happy, and an even longer, hot and sultry summer! And don't forget to log on to www.pouchsupport.org today, tomorrow and the next day and then tell us what you think of it.

CHRISTOPHER BROWNE

## Letter to the Editor

A letter sent to Susan Burrows after Roar's article on barrier creams in the Summer 2017 issue and two Letters to the Editor about a product called Comfeel published in the December 2017 edition:

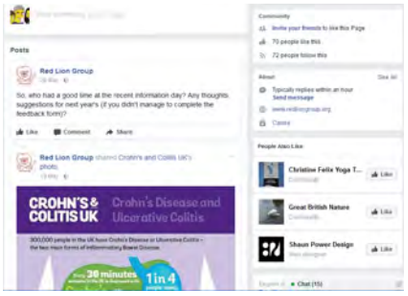
*Dear Susan*

Seeing the letters in Roar! magazine about Comfeel barrier cream, I asked Coloplast for a sample to try. They told me they had no samples of Comfeel but could send some of its replacement, Brava Barrier Cream, as Comfeel is being withdrawn. So I'll give Brava a go!

With regards

David Lister

**Ed: David, please report back on how you get on with the new barrier cream.**




## Find us on Facebook

www.facebook.com/theredliongroup/

## Visit our website

pouchsupport.org

Browse nearly every copy of *Roar!* that has ever been published (including issue 1 from 1994) at 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/

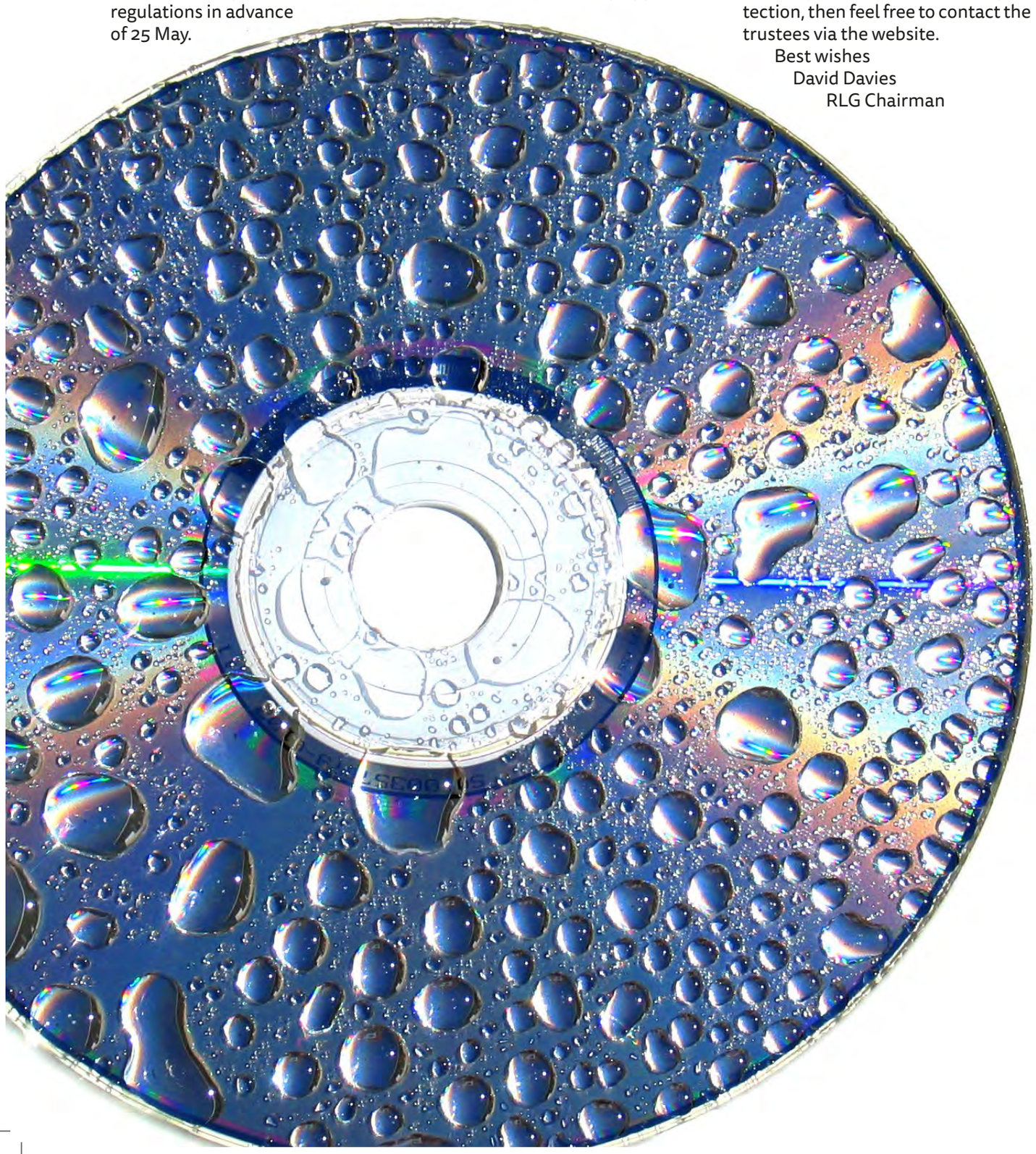
# GDPR and the Red Lion Group

You may already be familiar with the initials "GDPR" from the bombardment of emails and letters up to and, it seems, after 25 May. This was the deadline for organisations holding personal data to comply with new General Data Protection Regulations. RLG holds the data you submitted on your original application form for membership and therefore your committee acted responsibly and in a timely manner to ensure we complied with the new regulations in advance of 25 May.

The specific requirements of the new regulations are vague, but the intentions are clear. The Red Lion Group has an obligation to hold your data in confidence, not to release it to third parties without your permission, to delete the data should you request it and to tell you what we will do with the data if you cease to be a member. We have therefore introduced a data protection statement which is included on the footer of the membership application form. There are only two trustees who have access to the data and this is on a need to know basis. The only third party who sees any of your personal data is the mailing company we use to send out *Roar!* and such companies have a professional commitment to confidentiality.

We hope you are comfortable with these steps and that we maintain our absolute commitment to protect your personal data. If you have any concerns about data protection, then feel free to contact the trustees via the website.

Best wishes
David Davies
RLG Chairman



# Do you wear your pouch with pride?

If you do and your pouch has been relatively trouble-free, the leader of a St Mark's Hospital study would very much like to hear from you

Have any of you heard of the word 'pouchography'? No, nor had I until Guy Worley, St Mark's Hospital's research fellow (pictured above), told me about it.

Guy is leading a project into how MRI (magnetic resonance imaging) scanning can aid research into pouch conditions – a practice known as pouchography. So far the study, which started a year ago, has successfully tested 12 pouch owners and is actively seeking four more.

To qualify for the pouchography study you need to have relatively good pouch function (and there are plenty of people with those). You then have two MRI scans, the first at St Mark's and the second in London's Harley Street. Your travel expenses for the two visits will be funded by up to £30–a-trip by the NHS.

"The aim of the study is to refine the [MRI] technique and to establish normal measurements in participants with 'normal' pouches before it is used to investigate patients with pouch problems," Guy told *Roar!*.

The preliminary results of the 12 tests so far will be presented at the annual conferences of the European Society of Gastrointestinal and Abdominal Radiology (EDGAR) and the Association of Coloproctology of Great Britain and Norther Ireland (ACPGBI).

"We are reliant on the goodwill of healthy participants for this research and are very grateful to those who have taken part so far," added Guy. If you would like to take part, please contact Guy at guy.worley@nhs.net for more information. If you wish, you can also email Lisa Allison lisa.allison1@nhs.net or Sam Evans samantha.evans12@nhs.net at the St Mark's Hospital pouch care department for more details.

# Why E-mix is a recipe for success

As anyone who has had ulcerative colitis and similar intestinal conditions knows, you lose a lot of fluids and become thirsty because the sodium (salt) in your body is flushed out and you become dehydrated.

The answer is to turn to St Mark's Hospital's unique electrolyte mixture known as E-mix. This is an oral rehydration solution that contains glucose, sodium bicarbonate and sodium chloride.

The great merit of E-mix is that its high sodium content is readily absorbed from the intestine and allows greater fluid absorption to occur. The glucose also boosts the absorption of both salt and water and so helps to keep you hydrated.

Put simply, it means that instead of drinking low sodium drinks such as water or soft drinks when you are thirsty, you should take oral hydration solutions like E-mix.

**How do I use E-mix?**

You need to make a fresh jug of the solution every day and include the following ingredients:

- **20g (or six level 5ml spoonfuls) of glucose**
- **2.5g (or one heaped 2.5ml spoonful) of sodium bicarbonate**
- **3.5g (or one level 5ml spoonful) of sodium chloride or salt**

Then dissolve the mixture in 1 litre of cold tap water which you then drink throughout the day. The mixture provides 90 mmol/l of sodium which is your recommended daily concentration.

However, all fluids should be avoided for 30 minutes before and after eating, as eating stimulates gastric fluid production and therefore increases fluid losses.

**What are the side effects?**

Because of the sodium bicarbonate content, you may find the solution tastes bitter. This can be minimised by storing the mixture in the fridge and/or by adding a small quantity of fruit juice or squash (lemon or lime squash masks the taste most effectively). Or else you could sip it with a straw. If this continues to be a problem, the sodium bicarbonate can be replaced by the same quantity of sodium citrate, which can be prescribed by your GP.

**How do I store the E-mix?**

E-mix can be stored at room temperature or in the fridge, and must be discarded after 24 hours after mixing – if you have not drunk it all.

**Additional information**

If you need further information or have any questions, please contact St Mark's Hospital's Medicines Information department on 020 8869 2762 (Monday to Friday, 9am–5pm). If you have any questions about the medicines you have been prescribed, call the same number. Or email www.nwlh-tr.medinfo@nhs.net.

**How can I get a further supply?**

You can buy the powders from any pharmacy and some supermarkets. They are cheaper to buy than to get through a prescription if you happen to pay prescription charges. If you need to get E-mix prescribed, you can ask your GP to supply you with original packs (boxes) of the three powders (glucose, sodium bicarbonate and sodium chloride). You will then be able to use these to measure out and make up the E-mix as in the section *How do I use E-mix* above.

# INFORMATION DAY 2018
## *A day of records, results and revelations*


*St Mark's Hospital Clinical Nurse Specialist Sam Evans and Red Lion Group chair David Davies*

Information Day was a day of records, with more than 80 attendees from all over the UK and Europe, a rise in membership of the group, and the 40th – or Ruby – anniversary of the founding of the ileoanal pouch.

May 12 2018 may not have been the sunniest Saturday we have ever enjoyed – it's a historical fact that the sun tends to shine on Information Day – but the extra numbers and some stimulating talks more than made up for the patches of grey and the sparse sunshine.

In the next 10 pages we give a full account of the AGM speeches and the infectious enthusiasm that resounded through St Mark's Hospital's Himsworth Hall

# Chairman's report

# We're Living the Dream

"We're living the dream." That was the uplifting theme of the annual report of chairman David Davies (pictured above)at Information Day. And his optimism was reflected in the many achievements of the group over the past 12 months including the day itself which marked the Ruby Anniversary of the pouch – the first pouch operation was performed 40 years ago.

In his introduction David gave a very warm welcome to Red Lion member Paul Mulot, who was Red Lion treasurer and a very active member of the committee for several years, and joined the audience in St Mark's Hospital's Himsworth Hall after recovering from a long spell of illness. Welcome home Paul!

David then gave a *résumé* of the group's activities and achievements over the past 12 months starting with Information Day.

"It is the pinnacle of our activities and during the year we have also had two editions of *Roar!* magazine and a series of teleconferences and face-to-face committee meetings," he said.

Another 2018 highlight was the website. David said the committee had hired a design company to update the site and make it "a more modern and interactive forum". He said the committee were also spreading the message via Facebook – facebook.com/theredliongroup – adding a Twitter account and had achieved some good results with MailChimp. "We are using social media to improve our communications with our members," he said.

They say records are meant to be broken and we certainly achieved that on Information Day. A record 82 pouch owners, families and professionals came to this year's event –compared with 55 last year and the 60 or so total of the previous highest attendance. The rise in numbers and the enthusiasm of the higher turnout was infectious and could be felt throughout both the talks, the lunch interval and the members' workshops later in the day.

**Reaching out**

Red Lion Group membership has also risen from 306 members to 320 this year. "We had a goal to increase the number of members and the general awareness of the Red Lion Group. The increase was very nice to see but I'm sure we are just scratching the surface...and the increase in attendance at Information Day is another indication that we are reaching out more to the pouch care community," said David.

The committee also widened its network of hospital contacts during the year, sending out information and leaflets to 27 UK hospitals involved in pouch operations "that do not have the same infrastructure and support groups that we have at St Mark's and in Oxford with its Kangaroo Club support group". The mail-out not only helped to increase membership but also attracted very favourable feedback, he said.

In the past 12 months the committee has forged links with the Association of Coloproctology of Great Britain and Ireland (ACPGBI), the St Mark's Foundation, the Inside Out Support Group at St Mark's and the Kingston Trust CIO, which provides assistance to ileostomists and pouch owners aged 16 or more who have been facing temporary or long term financial hardship.

"It is good for us to reach out and attract more cross-sections of people to become involved in post-operative activities and the challenges pouch patients face and to network with the different groups involved in pouch care and support," said David.

Looking ahead, he said the group's aim for the second half of 2018 and beyond was to do more of the same and to extol the value of events like Information Day which give people "a unique opportunity to discuss and share their personal experiences".

**Pros and Cons**

Interestingly during David's report seven members of the audience said they planned to have pouch operations and had come to listen to the experts and to talk to pouch owners about the pros and cons of having a pouch.

David was in no doubt. "Day in and day out pouch owners, their relatives and friends are living the dream," quipped our ever-optimistic chairman.

# Treasurer's report

## ...and moving on to money matters

In his treasurer's report, acting treasurer Peter White (pictured above) said the group "delivers quite a lot for small amounts of money".

The biggest source of income, he said, was subscriptions while the main items of expenditure were *Roar!* and Information Day "and this year the largest expense will be the website."

He said he would be claiming back two years of gift aid this year adding that former treasurer Paul Mulot's initiative to recoup money from HM Revenue and Customs for the previous five years of gift aid had added around £500 to group funds.

Peter said Red Lion Group's bank balance was stable and "the bank reserves will cover more than two years' expenditure." Income for 2017 was £3,395 compared to £3,378 in 2016 and expenditure £2,340 (£1,910 in 2016). The bank balance was a healthy £6,082 compared with £5,028 in 2017.

Meanwhile, answering a question from the audience about fundraising, David Davies said: "If people want to raise money for Red Lion Group, you can see the sort of impact even small donations will make to our finances. The more money we get in, the more we will be able to deliver to our members in terms of benefits. At the moment it is fairly low key, but there are great opportunities out there not only for this group, which is fairly well-informed, but there are a lot of people at satellite centres throughout the UK where there isn't the infrastructure for support. We really want to reach out to them to raise money and ensure they have the benefit of the support the Red Lion Group provides."

David said the committee is setting up a MyDonate site for fundraising which is far cheaper than most of the other UK-based fundraising websites.

# Do you have a head for figures?

Acting treasurer Peter White appealed for someone to volunteer to do the treasurer's job. "I am the acting treasurer and willing to do the job for now, but I don't know if I can carry on doing so," he said.

The committee is a friendly bunch and your key job as treasurer is to keep an eye on the accounts and make sure we balance the books. We also have four teleconferences and a face-to-face meeting each year.

With a job spec like that how can anyone refuse?! The man to contact is Peter himself on 07787 706919 or p_terwhite@yahoo.co.uk.

But hang on a minute! How about this for an idea? There's another vacancy on the committee.

Andrew Millis who managed to do a little work for the Red Lion Group between marathons (in fact he has been a key committee member variously holding down the posts of chairman and vice chairman, teleconference meeting organiser and mail-out specialist) is standing down from the committee as he and his family are moving to the South Coast.

So why not do a double and apply for the treasurer's and the vice-chair's posts as a dual package. It will give you the kudos of being a vice-chair and playing the key role of group treasurer at the same time.

Interested? If you are, please contact Peter using the contact details above.

## Ruby Jubilee celebrations

# The Pouch Revolution

PROFESSOR JOHN NICHOLLS (pictured left with David Davies), co-pioneer of the ileo-anal pouch, gave his Information Day audience an absorbing account of the device's first 40 years and how it has transformed surgery for uc and FAP sufferers

One of the highlights of the May Information Day was a personal reflection by Professor John Nicholls on the creation of the first pouch which he helped pioneer when he was senior registrar to Sir Alan Parks at St Mark's Hospital. The two surgeons then wrote a paper on the pouch in the British Medical Journal.

The paper which was published in 1978 went viral – to use modern-day parlance. It was greeted with international acclaim and marked a revolutionary breakthrough in the treatment of ulcerative colitis (uc) and Familial adenomatous polyposis (FAP). Although several eminent surgeons had previously experimented with different methods of proctocolectomy they all needed a stoma to work properly. The pouch didn't.

Prof Nicholls said uc was a relatively recent condition and the mortality rate among sufferers in the early 1900s was very high. Patients often died before they reached the operating table and the surgical risk factor meant surgeons were often reluctant to operate on patients for fear of upsetting their next of kin.

"However, the most important date in terms of mortality is really 1948 when colectomy was courageously formed on very, very sick coletic patients and it transformed a very high mortality rate to something where the mortality fell below 5%," said Prof Nicholls.

The next pivotal date was 1978 when Prof Nicholls joined St Mark's and collaborated with Sir Alan Parks on the formation of the pouch. It meant that for the first-time operations could be performed without the need for an ileostomy – or stoma bag – that the patient wore on the outside of their abdomen. The Parks Pouch then became the standard operation for uc and FAP sufferers worldwide.

The two surgeons worked together performing pouch operations and improving the pouch until Sir Alan's death at only 62 in 1992. Prof Nicholls continued the pioneering work with the pouch. He later became St Mark's clinical director and in 2010 founded the Pouch Registry, a database of around 50% of all pouch operations in the UK and several other countries.

When he retired in 2006 he is said to have carried out more pouch operations than any other international surgeon.

Among the key changes in pouch care in the past 40 years, said Prof Nicholls, were the J-Pouch which is now the pouch of choice and the idea of having pouch support nurses and pouch support groups which Prof Nicholls said were "brilliant ideas" and, more recently, the introduction of keyhole surgery and the evolution of biological drugs for treating uc and Crohn's disease.

# The day Sir Alan said 'sorry'

Another pouchee who has vivid memories of pouch founder Sir Alan Parks is Red Lion member Stephen Want (pictured above). Stephen was one of the first uc sufferers to be fitted with a Parks Pouch at the Royal London Hospital – he was the 16th to be precise – in 1980 just two years after the first one was formed in 1978 (you can read Stephen's story in *Roar!* issue 47, page 9).

After his admission Stephen, a 22-year-old trainee teacher at the time, was moved to a side-room at the hospital. "Some days later Sir Alan who was my surgeon came to see me, entering my room at the head of quite a long crocodile of doctors, nurses and students. He spoke to me in a very calm and caring way whilst examining my abdomen and then performed a digital examination.

"The thing that stayed with me most clearly from that time is the fact that Sir Alan apologised for the digital examination saying: 'I am sorry to be so unpleasant'. Nobody before that time or in all the years since has ever done that – although I have been told that Sir Alan had hands like a bunch of bananas," he told an Information Day audience.

"After examining me, he sat in a chair by my bed and asked members of the crocodile various questions while scratching the inside of his ear using his glasses. Finally, Sir Alan decided I would be added to the operating list for the Wednesday of that week and he and the crocodile left my room."

"The thing that stayed with me most clearly from that time is the fact that Sir Alan apologised for the digital examination"

But like all good TV hospital dramas, Stephen's story has a romantic twist. When he went back into hospital for the final stage of his pouch operation, he made frequent visits to the ward's loos. "During the night I used to sit at the nurses' desk with the night staff because the desk was much closer to the lavatories than my bed which was at the far end of the ward.

"There were lots of lovely young student nurses on the ward so sitting at the desk through the night meant that there were opportunities to chat to them.

In fact, when I was discharged from the ward, quite a few of the nurses gave me their telephone numbers, although I had to ask for the telephone number of one very sweet nurse whose name was Mary," recalls Stephen.

When he returned home, Stephen asked Mary out on a date and they started going out together. They later got married and now have two children.

"St Mark's Hospital provided me with a pouch along with the most valuable resource I could wish for – a wife," quipped Stephen to loud applause.

# The remarkable evolution of the pouch

In his talk "Modern Developments in Pouch Surgery", St Mark's lead IBD surgeon JANINDRA WARUSAVITARNE highlighted the key changes in pouch surgery in the past 35 years

One of the most important changes in ileoanal pouch surgery in the past three decades has been improvements in the way the pouch functions, Janindra Warusavitarne told an Information Day audience of more than 80 pouchees, their relatives and pouch professionals.

"Moving from the 1980s to now there have been a number of [different] pouches created and as our experience has got better so has the pouch function, and I think a lot of that has come from trying to understand the problems, where things have gone wrong and the ways we can make things better for patients," said Janindra.

However there had also been a "slightly disturbing" trend linked to inadequate experience, said Janindra. "If we look at the UK, or at least England, there are about 300 pouches performed annually and a lot of those are being done in centres where the experience is very limited. This has been our big push – and especially with the Association of Coloproctology in particular – to centralise certain centres so that the expertise remains not within one centre like St Mark's but in a number of centres around the country which I would say have experience," he explained.

"We know very clearly that once a surgeon's experience goes to over 40 cases – and I don't mean 40 cases in a year because given the number of pouches that are done every year it is almost impossible to get a caseload of 40 in a year – we know that their experience gets better," said Janindra.

He said that the more pouches a surgeon performed the more skilful he became. He said he had the benefit of a very good support team because "when things are not working well for patients" they mostly speak to the pouch support nurses who come and tell me things are not quite working the right way. "It means we can as a group think about how we can do things differently for patients," he said.

"It is really important for us as surgeons to listen to you guys as well as whoever else you communicate with. There has been a culture change in surgery as well which is probably one of the big developments ..... where we look at things a lot more holistically than things have been in the past," said Janindra.

**Keyhole surgery**

One of the biggest recent advances in pouch surgery has been the introduction of laparoscopy or keyhole surgery, said Janindra. "What it means is you do surgery with less cuts and there is an obvious cosmetic advantage to it and certainly a better recovery in terms of less pain and shorter hospital stays."

Another benefit was adhesions. "The number one cause of re-admissions for people with pouch surgery is bowel obstructions which are mainly related to adhesions and these are your body's way of forming a healing process after surgery..... sometimes you have an over-active response and sometimes you have an under-active response. If everything gets stuck together sometimes things don't pass through and you naturally develop kinks within the bowel. If that happens the bowel gets blocked and typically the tummy gets bloated and you have pain and vomiting and so on."

The St Mark's surgeon said that figures show that keyhole surgery "significantly reduces the number of adhesions that actually happen, and this has a much better outcome in terms of reducing the admissions related to adhesions."

Janindra said one of the main advantages of laparoscopy was "the ability to see a lot better" in the pelvis "which is traditionally a very difficult area to see." He added: "We think this might be related to sexual dysfunction as well as we can see the nerves in a magnified state and in a much better way than before."

Pregnancy and family planning have always been major talking points for pouchees. Traditionally the ability for women to become pregnant after pouch surgery is "significantly reduced" due to adhesions created by surgery in the pelvis which causes the fallopian tubes to get stuck and to prevent the eggs from entering the tube.

*Janindra Warusavitarne*

However, on an optimistic note, because of its low adhesion count, laparoscopic surgery meant "we don't normally need to talk to people about waiting till their families are complete before having pouch surgery – we can carry on with all of the stages of the operation" and couples could choose to have children whenever they wish to do so and regardless of the surgery, said Janindra.

**Coping with sepsis**

More than 50% of pouch failure is down to complications from sepsis. This causes leakages in the pouch's join – a point raised by Professor Nicholls in his earlier talk. A major innovation of the past two to three years, said Janindra, was a special device called a Trans Anal TME – or TATME – which is placed through the anus. Using a stapler, "we have been able to align the pouch and the rectum in a much better way," he said, and patients were left with just a small scar as a result.

"We have been able to significantly cut down the amount of leaks we have had at St Mark's and this has been replicated worldwide – with a group of four or five of us who have very large experience in this type of procedure," he said.

Choosing a pouch was a quality of life decision, said the St Mark's surgeon. "As I always say to patients, [pouch surgery] is a quality of life operation because there is a choice between having a permanent ileostomy or a pouch, and people choose a pouch because they want a different type of quality of life and it is our duty to make sure that we provide this to the best of our abilities.

"While we can argue about the shape of pouches, I think these days most people tend to choose a J-pouch and a J-pouch works very well, but the way we do it and how we try to produce better outcomes is certainly changing and I think laparoscopy and now the Trans Anal approach have made pouch surgery very much different and with it I hope much better outcomes.

"I think it is a very safe procedure but it has to be done in centres with big volumes and I always say to people there is nothing wrong with asking your surgeon how many of these do you do and what is your experience, and there is nothing wrong with saying I would rather go to a centre with high volumes because at the end of the day this is going to be your quality of life; not your surgeon's ego," added Janindra.

# Taking the ouch out of the pouch

Opting for an ileoanal pouch has many benefits but you also need to understand a few snags to help improve your quality of life, says St Mark's clinical nurse specialist LISA ALLISON

After a long spell of ulcerative colitis or FAP why do most of us choose to have a pouch instead of an ileostomy? The answer? Because we wish to have a better quality of life – as several speakers pointed out on Information Day.

Although we will never return to the "normal" way of life we all once took for granted, those of us with good, well-managed pouches can come pretty close. Some pouchees have even run marathons, others have turned into energetic mountaineers and many of us lead extremely full lives.

But sometimes there can be unavoidable snags and this is where the NHS's teams of pouch support nurses come in.

In her very informative and carefully-researched talk, St Mark's clinical nurse specialist Lisa Allison highlighted the after-effects and post-operative conditions pouchees sometimes have to face.

"Expectations are huge when having a pouch and I think it's really key when people are considering having a pouch to know what your function could be like and how it is going to fit into your life," Lisa told her Information Day audience. "There's no such thing as 'normal' with a pouch as it varies hugely from person to person," she said.

As a rule, pouchees will need to empty their pouch of a porridge-like consistency four to six times in 24 hours – with one, if not more, of those visits at night. Pouchees should be able to hold on for at least an hour "once everything has settled down" and with no faecal leakage or seepage during the day – and any they do have will usually be at night, said Lisa.

In the weeks after ileostomy closure, it is "very normal" for people to have perianal soreness "or what some patients refer to as 'butt burn'", nocturnal seepage, increased

*Lisa Allison*

frequency – i.e. the pouch won't settle into a pattern straightaway which can involve going backwards and forwards to the toilet with ineffective emptying – "and also feeling pretty exhausted with the whole process," said Lisa.

So when should a new pouchee seek the advice of a pouch support nurse? When a patient suffers from symptoms "which have been going on for a few days, are not getting any better and actually gradually getting worse" said Lisa. These were: pouch frequency, urgency, bleeding, abdominal pain, fever and night sweats, lethargy, bloating, ineffective emptying, nausea, vomiting, incontinence, leakage and fistulae symptoms such as sepsis and vaginal and perianal discharge.

She said there were two main types of complication with pouches: flammatory and non-inflammatory. Inflammatory included pouchitis, cuffitis (in the retained rectum), pre-pouch ileitis (inflammation above the pouch), Crohn's disease and fistulae (openings that shouldn't be there).

Among the non-inflammatory complications, she said, were pelvic sepsis from a leak at the join where the pouch has been stapled together and irritable pouch syndrome – someone who has irritable bowel syndrome before having ulcerative colitis may end up with an irritable pouch which can be very difficult to manage and creates ineffective emptying of the pouch.

The key Investigations pouchees can expect to have when they attend clinic range from the consultant examining your abdomen with a finger during a visit to clinic to flexible pouchoscopies and also annual blood tests which Lisa said were an essential part of pouch care.

One of the commonest conditions is pouchitis, with approximately 20-50% of pouchees experiencing it at some time or another, she said. The causes were unknown, but it is thought to be triggered by changes in the pouch's intra-luminal bacteria.

The two main types of pouchitis are simple or acute pouchitis, which tends to happen once a year and can be treated with antibiotics, and complex or chronic pouchitis with pouchees tending to have more than three episodes a year. The most common treatment for acute pouchitis was a 14-day course of Ciproflaxicin. However, there are other antibiotics used to treat the condition.

Other pouch problems were cuffitis – where the cuff or rectal tissue becomes inflamed – which has some of the same symptoms as pouchitis and a persistent feeling people describe as an ache or a golf ball up their bottoms. Others include symptoms of ineffective emptying and strictures which are most commonly found at the pouch anal anastomosis.

Among the techniques used to help pouch performance, said Lisa, were the Hegar dilator – a long thin metal tube otherwise known as the St Mark's dilator – which helps those with narrowing problems, defaecating pouchograms and Medina catheters – plastic tubes for functioning problems which can "work wonders in improving patients' quality of life" – biofeedback which consists of retraining the brain and the pouch when visiting the toilet, and two products known as Renew inserts and the Qufora – the equivalent of a mini irrigation pump – used to help pouchees' emptying problems.

Lisa advised anyone planning to have a pouch to prepare thoroughly, talk to others who have had the operation and to know exactly what the process involves. "People undergoing pouch surgery really need to be fully informed before they sign on the dotted line. That is one of the reasons for the Red Lion Group being very much here in this current climate which is to talk to people and see what their experiences are all about – i.e. those people with good pouches and those with less good pouches – to get a balanced view of what having a pouch is all about.

"Pouches can have complications, but as both surgeons have alluded [in their Information Day talks], they can commonly be fixed. It is not all doom and gloom with a pouch and I know many, many people out there who are having a brilliant life with a pouch," said Lisa.

And on a final campaigning note, Lisa said St Mark's Hospital's pouch care professionals were heading an initiative to educate and pass on their specialist knowledge of pouches to all the UK's GPs and medical centres and to give exclusive national support to pouchees and those considering pouch surgery.

# What could possibly go wrong with your pouch?

Not too much that today's skilful treatment techniques can't sort out. DR JONATHAN SEGAL (pictured above), St Mark's gastroenterology research fellow, looks at the latest findings

How do we treat chronic pouchitis? That is the $10,000 question that has baffled and bemused doctors, surgeons, healthcare experts and pouchees for many years.

The latest research shows that we are getting closer to finding a way to beat this painful and, for some, unyielding condition. A St Mark's Hospital research fellow who knows more than most is Dr Jonathan Segal, who has made pouchitis the theme of his doctoral thesis.

He told attendees at the Red Lion Group Information Day on 12 May that "reassuringly most patients – ie 85% to 90% – react to a single course of antibiotics and that's the end of it. But there are this 10 to 15% of patients who grumble along with a condition called chronic pouchitis and that can mean that patients have frequency, urgency and pain and it can be quite a nasty condition," said Dr Segal.

Dr Segal said he and his group of researchers at St Mark's researched 2,954 articles on chronic pouchitis and chose 22 seminal papers that focused on the treatment of the condition. "Our knowledge on how to treat this before this piece of work was quite limited and so I though this piece of work needed to be done," he said. The group found that of those who suffered from chronic pouchitis about 60% eventually got back to health or back into remission.

One of Dr Segal's concerns was antibiotics. "When I first started [at St Mark's] I encountered many patients with pouchitis on long-term antibiotics," he said. "it's been in the news a lot about super-bugs and antibiotic resistance, and all these things I am sure you have read about, and this worried me as a physician.

"It was like am I just giving my patients antibiotics and what is going to happen to them? Are there going to be complications?" he said. "We don't really know the safety and long-term effectiveness of giving patients antibiotics. We tend to just give them and hope at the time that these are making them better. But we really don't know. And we wanted to assess the long-term outcomes of what happens to these patients," he said.

The group followed up all patients who had been on antibiotics for chronic pouchitis for more than a year. "We looked at their notes retrospectively and followed them up for as long as we could," he said.

They found that 21% of patients on long-term antibiotics went into remission, while pouch failure – people who needed surgical intervention – linked to chronic pouchitis occurred in 18% of patients after 8.5 years, while 28% of patients suffered side-effects – the antibiotic Ciprofloxacin is associated with Achilles tendon problems and Metranizadole with nerve problems – after using antibiotics long-term; while 78% of patients experienced resistance to antibiotics, he said.

Dr Segal and his group concluded that "although antibiotics for chronic pouchitis may be needed we have to carefully think about the

complications, the side-effects and only really use them when need be. I also think it means we need to constantly search for new therapies for patients with chronic pouchitis," he said.

For anyone wishing to find out more, Dr Segal referred to a research paper he recently published with several other specialists called *Long-term follow-up of the use of maintenance antibiotic therapy for chronic antibiotic-dependent pouchitis.*

**Inflammation**

Another condition some pouchees experience is known as pre-pouch ileitis. This is inflammation of the ileum (the final section of the small bowel).

It only occurs in 6% of pouchees and Dr Segal said the condition was very similar to pouchitis and tends to be a persistent problem. Although in the past, people sometimes mistakenly confused ileitis with Crohn's disease, he said.

Dr Segal and his group followed up 31 patients with the condition and, of those, 25% had surgery to fix the problem.

He said more research was needed "into finding out how to treat this and treat this better." Pouchees and pouch professionals who wish to find out more can read a new paper by Dr Segal and others titled *Incidence and long-term implications of pre-pouch ileitis: an observational study.*

Biofeedback has recently become an important going-to-the-toilet technique for pouchees with functional problems.

"Incontinence and evacuatory disorders associated with the ileoanal pouch can be particularly problematic and difficult to treat using conventional therapies," said Dr Segal adding that St Mark's uses a team of specialist nurses to help patients practise biofeedback.

Dr Segal and co carried out a study of 26 patients who had used biofeedback. Of those, nine pouchees reported much improvement, 11 some improvement and six no improvement, he said. Their findings also showed that biofeedback reduced pain, bloating, straining and laxative use in those with evacuatory disorders.

> "I've been studying at St Mark's for three years and I've fallen in love with the pouch."
> *Dr Jonathan Segal, gastroenterology research fellow*

He said they found that biofeedback "significantly improved patients' quality of life" partly because it gave them an opportunity to discuss their problems and also to be listened to.

Recently a growing number of specialists have studied how biological therapies can treat pouch-related problems. Dr Segal recently carried out studies to assess the effectiveness of the biological drug Infliximab or IFX.

After contacting gastrointestinal centres in the UK, New Zealand and Australia, he recruited 34 patients with pouches who had used biologics. He found that nearly three-quarters of them had managed to avoid a stoma.

As part of his research, Dr Segal also assessed how a device called a Renew Anal insert (see Lisa Allison's talk on pages 13-14) helped patients who had incontinence immediately after pouch surgery. Describing the device as a "success" story, Dr Segal said nocturnal incontinence tended to occur in a quarter of patients after surgery. It was often under-reported as patients were embarrassed to tell their physician they had it and tended to hide it, he said.

In a trial Dr Segal conducted, he said 50% of patients found the Renew – an inert silicone plug which is used once and then discarded – useful and led to a significant reduction in night seepage. As a result, patients were able to sleep much better and found they had more energy, he concluded.


# Happiness is the key to a healthy pregnancy

Scare stories about pouches and pregnancy are a thing of the past – particularly for women who have had keyhole pouch surgery, reports St Mark's clinical nurse specialist SAM EVANS (pictured above).

Good general health and happiness are two of the key factors that help patients with uc conceive and have successful pregnancies. It is also vital to try to keep an open mind about the effects medications and treatments may have on fertility, said Same Evans in her Information Day talk "Fertility, fecundity and sex with an ileoanal pouch".

Although she and her fellow pouch nurses are often asked about pouches and pregnancy, people's natural reserve often prevented them talking freely about sex or fertility before they were due to have a pouch operation, she said.

As Sam pointed out, pouch nurses could help patients by ensuring there was effective communication between them and by "giving out information about potential risks and benefits while on medical treatments while pregnant, and having an open mind about medications that you might not be able to take when you are pregnant."

Among the risk factors pregnant or potentially pregnant patients faced were age – with the biggest decrease in fertility stating when a woman is in her mid-30s – being overweight or underweight which could affect ovulation; environmental factors such as exposure to certain pesticides and solvents; smoking; sexually transmitted infections (STIs); alcohol and, finally, stress which could "affect your relationship with your partner and cause a loss of sex drive – and in severe cases stress may also affect ovulation and sperm production," she said.

In the past, statistics have shown that a woman's chances of becoming pregnant are reduced by around 50% when they have open surgery, she said. However, laparoscopy or keyhole surgery had markedly improved the chances of someone becoming pregnant.

A good time for couples to conceive when a woman has an open operation is between the three stages of the operation, said Sam. "C-section is sometimes favoured as there is less stress on the sphincter, pelvic floor muscles and nerves – and if you are going to have a pouch in the future you usually want to save those muscles and the sphincter, so it is always worth having a good chat with your consultant," she said.

Sam also advised those who wish to have a family during or after pouch surgery to agree a birth plan with their colorectal surgeon who "sometimes like to be present during the birth just in case something might happen," added Sam. She also said that like normal pregnancies, IVF treatment and assisted pregnancy worked with a lot of patients.

**So how does pouch surgery affect your sex life?**

In a survey of pouch patients, 25% of men and women said it improved their sex lives, 16% said they found it mildly restricting and 3% severely restricting, said Sam. Post-surgery, the main snags for women were low self-esteem, urinary incontinence and a feeling of loss of attraction due to illness and multiple surgeries while the main drawbacks for men were erection difficulties and fear of incontinence.

Sam closed her talk with the heartening story of a 22-year-old Muslim woman who was so ill that she was unable to ask questions or listen to advice about conception and pregnancy.

However, she bravely went ahead with a three-stage pouch operation and later gave birth to a boy and a girl – both by caesarean section.

# Photos from the St Mark's Academic Institute's Pouch Masterclass 40th Anniversary event on 29 June 2018


*Christopher Browne represents the Red Lion Group*


*Our patron, Professor John Nicholls, visits the Red Lion Group stand*

*Membership secretary Susan Burrows and Professor John Nicholls*

# Yes, even Michelin star chefs have pouches!

The celebrated restaurateur TOMMY BANKS (pictured above), who won TV's *The Great British Menu* twice says having a pouch helped develop his remarkable culinary skills

The UK's youngest Michelin-star chef, Tommy Banks, perfected many of his celebrated cooking skills during a 12-month spell of ulcerative colitis when he was 18.

After having his colon removed, Tommy had a colostomy bag which he says now is "the least cool thing you can have as an 18-year-old. I had gone from being a bit of a lad, into my sport, going out drinking, having a good time, chasing girls, to being bedridden, undesirable, thin and with a colostomy bag."

However, Tommy later opted to have a pouch operation and after 12 months was able to go back to work in his parents' pub, The Black Swan – which many of you may have heard mentioned in recent TV programmes and daily newspapers – in Oldstead on the edge of the North Yorkshire Moors.

And to add even more glitter to Tommy's extraordinary story, he was the sous chef when the pub – now restaurant – won a Michelin star, adopting and continuing to maintain the award when he took over as head chef at the age of 24.

But our story doesn't end there. In 2016 and 2017 Tommy competed with some of the UK's most celebrated chefs to win the TV show *The Great British Menu* – not once but twice. Then, not long after winning his second award, Tommy's restaurant was voted the best restaurant in the world, let alone the UK and the rest of Europe, by TripAdvisor.

Tommy recently created a dish called "Deer, Beer and Woodland Gear" – a venison tartare where the meat is lightly smoked and flavoured with a special dry-tasting real ale from his local town of Ampleforth.

You could say the dish is a tribute to Tommy's misspent youth when he used to visit the local woods with a pal, smoke and drink beer and then, when they had nothing else to amuse them, enjoy watching the wild deer rampaging among the trees.

His aim now is to win more of those coveted Michelin stars. I don't think any of us would bet against him doing so!

*Aerial view of New Zealand's Queenstown*

# Susan Burrows and her tour of surprises

When RLG's membership secretary went on a five-week trip to the other side of the world she made a few unexpected discoveries of her own

Jaw-dropping scenery, extraordinary architecture and intriguing local rituals. These were some of the sights and experiences that greeted Susan Burrows when she toured Singapore and New Zealand recently. But then something occurred that took Susan completely by surprise. She met a fellow tour party member with a pouch – and, even more unexpectedly, another who had ulcerative colitis.

It could happen to any of us I suppose - during a short family trip to the Pembroke coast perhaps or a day spent admiring the beauty of Bath - but not on an elaborately planned tour of two of the world's most exotic destinations.

"There were to be many surprises on this tour, the first one was the many changes in Singapore. It was over 20 years since I last visited and one of my first long flights with a pouch. There has been a huge amount of land reclamation and now there are fantastic buildings and gardens where there was only water when I last visited," says Susan.

"Museums, concert halls, theatres, the fantastic Marina Bay Hotel with what looked like a ship across the top of its three towers and the horticultural wonders of the Gardens by the Bay and the vertiginous trees in the Supertree Grove.

"From Singapore we flew to Christchurch in the South Island of New Zealand and here we met up with our fellow travellers. There were 18 of us and we were to spend the next three-and-a-half weeks together travelling around New Zealand," she adds.

And it was here that she had her first surprise. "One of my fellow travellers also had a pouch, and so I was not the only person on the bus with a pouch. As you probably know it is quite unusual in daily life to meet another pouch patient and my fellow traveller Tony Branwhite had never met anyone else with a pouch while I had only met people because of my association with the Red Lion Group," she says now.

"There were many conversations about our experiences as pouch patients and how well we feel compared to pre-surgery and Tony has written a short account of his illness and how he is now (see the item below this article). There was also another traveller on the bus who had ulcerative colitis. He had had most of his bowel removed and only had a short bowel," recalls Susan.

For two weeks Susan and her fellow tour party travelled around South Island, starting in Christchurch, the island's largest city "which still showed a great deal of damage wrought by the earthquake in 2011," says Susan. "A total of 185 people were killed and several thousand were injured and there is still a great deal of work to do in rebuilding the city."

They continued the tour by train from Christchurch across the Canterbury Plains and through the island's Southern Alps. Then down the west coast to see a series of glaciers in Franz Joseph Glacier. They then visited the town of Queenstown in Otago, a popular place for tourists, in South Island. "We saw (but none of us took part in) the bungee jumping. We sailed on the lake, visited

*The world's most stylish toilets in New Zealand's Kawakawa*

Arrowtown, took a jet boat ride on the Dart River and rode the gondola to get a wonderful aerial view of the area," she says.

Susan and her party's next stop was Dunedin, South Island's second largest city. Here they watched royal albatrosses, seabirds with wingspans of 3 metres plus, flying around and "putting on a great show for us". They sailed on Milford Sound, Doubtful Sound, saw Mount Cook and the final stop on their South Island tour was Kaikoura on the east coast, the site of another earthquake in 2016.

They took the coastal road from Kaikoura to Picton which fortuitously had just reopened after the 2016 earthquake and enjoyed spectacular views of the Pacific Ocean.

From Picton they took the ferry to Wellington, the New Zealand capital on North Island. "We then went on to visit the city of Napier with its beautiful art deco buildings which were completely rebuilt after an earthquake in 1931."

Their next stop was Rotorua with its geysers, bubbling mud pools and distinctive sulphur smell. "It was here that we had a traditional Maori welcome, entertainment and meal," says Susan.

Their penultimate stop was the Bay of Islands on North Island's east coast where they boarded a small aeroplane and flew to Cape Reinga at the very far north of the island – "a special spiritual place for the Maori people," says Susan.

The tour ended in Auckland, a bustling city with a large harbour. "It was an excellent tour. We had seen dolphins, whales, penguins, royal albatrosses, brown fur seals and many examples of the famous New Zealand bird, the kiwi.

"There were so many highlights that it is difficult for me to single out any but in the South Island I would have to say Doubtful Sound for its peace, tranquillity and wonderful waterfalls. In the North Island, Cape Reinga, again for its peacefulness and for the different colours of the sea which reflects the expanse where the Tasman Sea meets the Pacific Ocean. It is a beautiful country with many different landscapes and friendly residents who are very proud of their country," says Susan.

After New Zealand she flew to Melbourne to stay with some family friends. "It was a great end to five weeks of travel with my pouch. I have to say that my pouch behaved well. The bus made regular stops at generally excellent loos and here I must mention the toilets in the North Island of Kawakawa.

"The toilets were designed and built by the Austrian-born Friedensreich Hundertwasser, an internationally renowned architect and ecologist. The Kawakawa toilet block with its ceramic columns, garden roof and carvings has put the Northlands-based town of Kawakawa on the international tourist route!" says Susan.

"As usual I carried with me a letter from my consultant detailing my surgery and the travel certificate which I obtained from the IA (Ileostomy Association) for those with ileoanal pouches. It is in 12 different languages and must be signed by your GP or consultant," adds Susan.

*A maori ritual on Susan Burrows's antipodean tour*

*A royal albatross*

## ...and here is the story of Susan's fellow traveller and pouchee, Anthony Branwhite

After a long spell of illness, Anthony Branwhite was referred to a consultant, Mr James Tweedie, in 1989 and told he had a large number of polyps on his colon – or FAP (familial adenomatous polyposis) – and would need a complete colectomy.

The operation went ahead at Paddocks private hospital in Princes Risborough, Buckinghamshire. Here Anthony stayed for 15 days. "The first 13 days were nil-by-mouth. Then food and drink were gradually introduced in very small quantities and I returned home to recover.

"Recovery was slow at first but, to my everlasting amazement, after about two weeks my recovery rate became quite substantial. After a month I started eating normally and after about two months I began to do some gentle swimming. Four months later I started playing rugby again with Mr Tweedie's permission.

Eighteen months later some more polyps were detected near the join in Anthony's large bowel. Then in 1991 Mr Tweedie performed another operation, this time at The Chiltern Hospital, Great Missenden, Bucks, to remove the polyps.

"This was successful, and I underwent another period of recovery which went slightly quicker than my initial period of recovery in 1989," he says.

Since then, Anthony has had regular three-year check-ups in endoscopy departments and has been largely polyp-free. "I now lead a normal life in all regards with the small exception of regular visits to the toilet (including at night) and a few dietary restrictions such as 'no peas'," he says.

Anthony is the proud father of a 33-year-old daughter and a 31-year-old son.

"They have had check-ups which turned out to be clear and are now of an age that requires no further check-ups," he says.

"I must stress that I am in no way medically qualified but, with the benefit of my own personal experience of pouch surgery, it would seem that the effects of this can be managed afterwards in a very successful way," adds Anthony.

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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

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

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(July 2018)

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