

ROAR!



WINTER 2023

#66



WORLD EXCLUSIVE!



Roar! speaks to
the son of the
world's first-ever
pouch patient

PLUS...

We need your vote!
Help Michelle win a
Smiley Film Award

Robots lead the world
Hi-tech surgeons
show their wares

See pages 4-5



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**

BRISTOL/AVON

David Mair
Bristol
0117 922 1906
07719 524 324

CLEVELAND & NORTH YORKSHIRE

Christine Jackson
Saltburn by the Sea
07815 322137
chrisjacks1960@btinternet.com

ESSEX

Peter Zammit
Benfleet
01702 551501

HERTFORDSHIRE

Susan Burrows
St Albans
01727 869709

LINCOLNSHIRE

Carol George
Holbeach
07720 867456
carolageorge2@gmail.com

NORFOLK

Sandy Hyams
King's Lynn
01485 542380
sandyhyams@btinternet.com

NORTHERN IRELAND

Sharon Hendron
Lisburn
02892 661559

WILTSHIRE AND SOMERSET

Bernadette Thorne
Farmborough
Bath
01761 472209

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The Red Lion Group is a charity run by volunteers with advice from St. Mark's Hospital (pouch department). The content of *Roar!* aims to help people with an internal ileo-anal pouch and anyone considering this type of surgery. It is not a substitute for professional medical advice or a medical examination. If in doubt consult a specialist. We do not promote or recommend any particular treatment or course of action.



RED LION

Pouch Support

All donations, however small, towards expanding the work of the group will be gratefully received. You can donate online via the donate button on the RLG home page **pouchsupport.org**

Please support the Red Lion Group

Registered Charity number 1068124



NOTES FROM THE EDITOR



My, oh my, oh my, oh my! This Winter 2023 edition of *Roar!* is full of scintillating, yes, I mean scintillating, news!

First of all we've got a remarkable scoop! Yes, we speak to the son of the world's first-ever patient with an ileo-anal pouch fitted by its inventor-surgeon Sir Alan Parks, no less – and what a story it is! You can read all about it on pages 4-5.

Then we can salivate once more over the recognition and achievements of the St Mark's Hospital pouch and stomacare nursing team. Their feats really set an example to all other gastroenterological (I can spell it after all!) departments at hospitals, units and clinics throughout the UK, Europe and the world (though some of them have also won an award or two as well!).

Ingenious

Wonderful stories they are indeed! But as we ponder these unique achievements, how much do we really know about the ingenious techniques and technology that help drive the hospital's daily output? It's a good question.

Did you know, for example, that there are some remarkable boffins and, dare I mention it, robots lurking behind the scenes of the fast-moving St Mark's machine.

Yes, in this *Roar!* we take you into

the complex, sometimes mysterious world of AI and robotic-assisted surgery – some of you may already have had a robotic-assisted op or perhaps you are about to.

To find out about the technical know-how and skills that are streamlining the surgical process, read the views of the experts on pages 5-6. Then if you're still yearning for more, turn to the first article in our robotic technology series on pages 4-5 of the Christmas 2019 *Roar!*.

"There are boffins and robots lurking behind the scenes"

A trophy-laden season

But RLG's end-of-year highlights don't finish here. On pages 6-7 our cheerful chairman

David Davies reflects on a trophy-laden season to remember and on page 12 membership secretary and website guru Gary Bronziet reveals some of the unique stats and figures about our very own global pouchcare sector.

And talking of trophies, RLG's communications officer Michelle Martin's latest film on fistulas and how to treat them has been nominated for the 2024 Smiley Charity Film Awards.

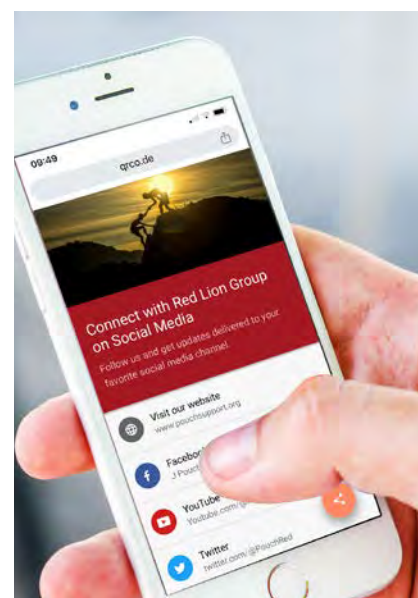
So please VOTE for her on page 7 and help her to achieve another accolade for the Red Lion Group!

Meanwhile enjoy your Winter *Roar!* and I wish you a very happy and healthy Christmas and New Year!

Christopher Browne

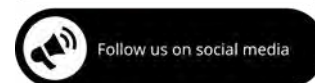
Editor

cbrowne@brownemedia.co.uk



IT'S GOOD TO TALK!

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





WORLD
EXCLUSIVE

The remarkable story of the world's first pouch patient

Roar! speaks to **Haresh Ruparelia**, son of the original ileo-anal pouchee

Remember the turbulent 1970s? Some of us do and RLG's new treasurer Haresh Ruparelia certainly does even though he was a mere toddler at the time. He also recalls the events of that decade for a completely different reason.

In 1972, Haresh, his parents and his

two young siblings were forced to leave their home, jobs and schools in the African republic of Uganda during the dictatorship of Idi Amin.

"After considering Fiji at one point, my father Pravinchandra (known as Pravin) moved the family to the UK. He managed to find work quite quickly and chose to settle in Ilford, East London," said Haresh.

Admitted to hospital

Then fate struck the family a second time when in 1974 Haresh's 35-year-old father was diagnosed with ulcerative colitis (UC). "His symptoms soon became chronic and physically he had gone from being a fit, strong and healthy young man to someone who was frail, very underweight, unable to work and seemingly staring death in the face," he said.

"As a child I was protected from the seriousness of it all, but knowing what I have since found out, it must have been a desperately difficult period for my parents," Haresh explained.

Pravin was first admitted to St Mark's Hospital, then based in London's City Road in 1974. However, as his symptoms worsened, he was re-admitted two years later in 1976. In

July of the same year, he had the first part of a radical new operation.

It was of course the first stage of an ileo-anal pouch – shaped out of the small intestine to replace the need for the large one – which had been created by the hospital's consultant surgeon Alan (later Sir Alan) Parks. The operation, which was also performed by Mr Parks, replaced the more conventional option of an ileostomy.

Pravin was the first of a group of five patients at St Mark's and the London (later Royal London) hospitals to have the revolutionary surgery. Just over a year later, Pravin had his final closure and became the proud owner of a pouch.

"This pioneering surgery gave my father and the family a new lease of life. Following surgery my father's physical condition recovered significantly and as a result he was able to start living a normal life again.

"He was able to return to working full time, earn a decent living for the family and fully enjoy social activities too. This in turn allowed the entire family to live normal lives for the many years that followed," said Haresh.

"My father's experience of the pouch



"A desperately difficult period for my parents"

Haresh Ruparelia



MAIN: Pravin and Kundanben Ruparelia and their young son in 1966
BELOW: Sir Alan Parks



“Pouch surgery was extremely successful for my father and for that the family will forever be indebted to the late Sir Alan Parks and his team”



“This pioneering surgery gave my father and the family a new lease of life”

was generally good. He had to use a catheter to empty the pouch and therefore needed to keep equipment with him wherever he went. He preferred to use disabled facilities wherever they were available and took care regarding the size and timings of meals when out and about,” added Haresh.

“I suppose that to him these were trivial inconveniences in light of the condition he had suffered prior to

surgery – and preferable to having an ileostomy.”

First pouch patient

After those first five pouch operations, Mr Parks and his senior registrar, John Nicholls (later Professor Nicholls and a patron of RLG), wrote an article titled ‘Proctocolectomy without ileostomy for ulcerative colitis’ for the British Medical Journal. In the report, Pravin is referred to as the first case to have a pouch fitted.

Commented Haresh: “A point made in the BMJ article about the importance of temperament was perhaps applicable in my father’s case. He was a very philosophical person and not shy. This perhaps allowed him to put himself forward as one of the early candidates for surgery and subsequently helped him to cope with having to use a catheter.

“The other significant factor that helped my father cope with his illness and the surgery was the presence and support of my mother. She coped with so much whilst Dad was ill and always remained by his side, providing practical and moral support through the darkest hours before the surgery in 1976 and thereafter when living

with the pouch, the ileostomy and the related issues that arose from time to time.”

Mainly incident-free

And Pravin’s life with a pouch was mainly incident-free for almost 40 years until 2014 when he developed pouchitis and due to complication with the pouch needed an ileostomy until he died in January 2022 aged 82.

“Overall, pouch surgery was extremely successful for my father and for that the family are grateful and will forever be indebted to the late Sir Alan Parks and his team, Professor John Nicholls and everyone involved for all the hard work in pioneering the surgery, providing treatment and support to patients pre- and post-surgery and for sharing the knowledge with the wider medical profession and patients.

“Dad could have gone to beautiful, sunny Fiji when he left Uganda... but he came to England, had the fortune of being referred to St Mark’s Hospital and the rest is history,” added Haresh.

■ **AND A VERY HAPPY FOOTNOTE:**
 RLG is delighted to welcome
 Haresh Ruparelia as our
 new treasurer



LETTER FROM THE CHAIR

Chairman David's Christmas message

The chair's full of good cheer with two remarkable achievements to greet the New Year

In global pandemic terms, the phrase “patient zero” refers to the first person who contracted the disease or condition and thus the source of all the mayhem beloved of TV and movie directors.

In a very different context – and a much more positive one altogether – we at the Red Lion Group have often wondered who “Pouch Patient Zero” might have been and how they came to be selected to be the very first recipient of a pouch and how they got on.

Global exclusive

Now, in a global exclusive in this issue of *Roar!* we can reveal Pouch Patient Zero was a gentleman called Pravinchandra Ruparelia (known as Pravin), who was admitted to St Mark's Hospital under the care of one Alan Parks in February 1976. The story of how Pravinchandra came to be operated on and his recovery is revealed in a fantastic article by his son Haresh Ruparelia in this edition of *Roar!* (pages 4-5).

Haresh still has copies of doctors' letters and – remarkably – the hospital notes penned by Sir Alan, which detail his father's admission to hospital in 1976, after suffering for over three years from debilitating ulcerative colitis. Haresh is not a pouchee himself, but stepped forward to volunteer for the

role of RLG Treasurer in memory of his much-loved father.

Pravin's pouch was formed in 1976 and his stoma closed in January 1977. His pouch was finally removed in 2014 after protracted issues with pouchitis. This first-ever pouch lasted for almost 40 years, which is amazing for what was an experimental technique at the time and is a testament to the skills

**“A testament to the
skills of the surgeons
and the bravery of
the patient”**

of the surgeons and the bravery of the patient.

An article describing the procedure and the first five pouch patients (with Pravin number 1) was published in the British Medical Journal in July 1978 and this paper confirms Sir Alan Parks, ably assisted by one Professor John Nicholls (patron of RLG), as the pioneers of this exciting and innovative procedure.

I am thrilled to finally know the story and we are delighted to bring it to you all here in this latest edition of *Roar!* Haresh has already started

contributing to the group and is indeed a most welcome addition to the team, especially with his very special connection to the origins of the pouch operation.

Recognition

Further spectacular news is the continuing professional recognition for our very own pouch nurse specialists at St Mark's Hospital. The team was strengthened five years ago by the arrival of Petya Marinova, closely followed by her identical twin sister, Rali, a couple of years later. The twins have thrived under the excellent guidance and mentoring of St Mark's nurse consultant Zarah Perry-Woodford and received national recognition with awards earlier this year (see the Summer *Roar!*, 2023).

However, the flow of silverware was not complete and in November this year Petya received the Healthcare Honours, New Talent Award for 2023 sponsored by the British Journal of Healthcare Management at an awards ceremony in the Houses of Parliament to showcase NHS leadership and management roles (see pages 8-9). Well done Petya! The pouch/stomacare team at St Mark's were also highly commended for the Improving Outcomes: Management Team Award.

Many of you will remember the great



job the team did during Covid to continue patient consultations over the internet via Zoom. So successful were these arrangements that the team has continued remote patient consultations over Zoom during the post-Covid period.

Fifteen-minute virtual consultations are very efficient and effective and mean that patients do not need to leave their homes and can better fit the consultation around their other commitments. Well done to Petya for this latest award and indeed to all the team for a fantastic year with much recognition of the superb work they have been doing to improve the lives and address the concerns of pouches and potential pouches.

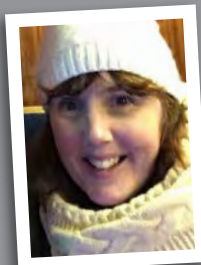
Zarah, Petya and Rali attend the RLG Committee meetings and we are very grateful for their support and for letting the Trustees know exactly what is happening at the clinical forefront of pouchcare – ensuring our activities and energies are channelled in the best way and in the best interests of the pouch community.

All that remains is for me and the rest of the Trustees to wish you all a super Christmas and a happy and healthy New Year.

David Davies
RLG Chairman

Vote now!

Your vote for the Red Lion Group's latest special pouch film could make all the difference to its success!



RLG communications officer Michelle Martin's latest film about the treatment of fistulas has been nominated for the prestigious Smiley Film Awards. And we need your vote to help the film reach the final.

All you have to do is go to:

smileycharityfilmawards.com/films/patient-information-film-fistula-by-mr-toby-hammond

and VOTE or visit our website **pouchsupport.org**

and click on the "VOTE FOR US" link.

The film features Michelle's pouch surgeon Toby Hammond and focuses on fistulas, how they are formed, their different symptoms and how to treat them.

Michelle's first film – about the mechanics of the pouch operation – went global and received almost 20,000 views when it was nominated for the 2019 Smiley Film Awards.

"Not only did it help people access vital and accurate information but it also raised the awareness of pouch surgery among patients, families and medical professionals," said Michelle.

"So please help us once again to spread the word and raise awareness about a condition not often spoken about.

"Every vote counts and it's easy to see the film on pouchsupport.org/resources to see our amazing and important work and then give us your vote.

Voting is completely free and takes moments!



The Smiley Film Awards are the world's largest campaign for cause-based films and are a platform for people driving positive change.



Consultant
colorectal surgeon
Toby Hammond



St Mark's nurses celebrate a Christmas bonanza

The awards and nominations keep on coming for our outstanding nursing team

Anyone heard the rumour about members of the St Mark's Hospital pouch and stomacare team running for parliament?

Well, they came pretty close in November this year when they were invited to the Houses of Parliament and presented with yet more awards and nominations for their diligence,

skill and expertise.

And if St Mark's Hospital's nurse consultant, Zarah Perry-Woodford, was elected my MP, I would be the first to vote for her – as I would for Petya Marinova, lead nurse for pouch and stomacare at St Mark's.

Both were named by the judges of the Healthcare Honours awards sponsored by the British Journal of

Healthcare Management, Petya as the winner of the New Talent award and both Zarah and Petya as nominees for the Improving Outcomes: Management Team award.

Zarah told *Roar!* magazine: "The New Talent award shortlisted individuals with up to five years' experience in a leadership or managerial position who had shown remarkable potential as a



THE HONOURS LIST

LEFT: The winners enclosure: St Mark's nurse consultant, Zarah Perry-Woodford (l); pouch nurse practitioner, Rali Marinova; lead nurse, pouch and stomacare, Petya Marinova and pouch nurse practitioner, Athira Kunnumpurathu

BELOW: Winning smile: Petya Marinova, St Mark's lead nurse, pouch and stomacare

RIGHT: Dynamic duo: St Mark's nurse consultant Zarah Perry-Woodford (l) and lead nurse, pouch and stomacare, Petya Marinova



Care in the comfort of the patient's home

leader and made outstanding contributions to their organisation, either with their own projects or in support of colleagues and/or more senior leaders.

"The award nominee could be in a clinical or non-clinical leadership role, which provided some stiff competition, but Petya claimed the prize for us all. We are so proud of her."

Digital service

And there's more. The St Mark's pouch and stomacare team were also nominated for Best Use of Workplace Technology in the Nursing Times Workforce Awards 2023 also in November this year. "The nomination was for patient care in the comfort of

the patient's home and our digital service which includes nurses working from home and giving video, telephone and email advice to home-based patients and so sparing them the need to attend hospital clinics," Petya told *Roar!*.

Such deserved recognition follows the team's prize-winning efforts earlier this year when Zarah was voted Nurse of the Year in the 2023 British Journal of Nursing (BJN) awards and, in 2022, nominated as Nurse Manager of the Year by the Nursing Times, while the St Mark's pouch and stomacare team won a silver – or runners-up – medal in the 2023 BJN Stoma Care Nurse of the Year category.

Jason Bacon, CEO of the St Mark's Hospital Foundation which funds and supports projects at St Mark's, said:



"We at the Foundation and the St Mark's Academic Institute are very proud of our hospital's dedicated team of surgeons, doctors and nursing staff and, as these awards attest, the pouch and stomacare specialist team who continue to provide exemplary care for patients both locally and nationwide.

"The St Mark's nursing team's unstinting work and concern for their patients and families sets both a powerful precedent and example of the care sector at its best to gastroenterology departments, hospitals and clinics throughout the UK and overseas."



TECHNOLOGY REPORT

In this, the second of our two-part series on robot technology, we reveal the skill and ingenuity of the St Mark's Hospital surgeons (You can read the first report on pages 4-5 of the 2019 Christmas issue of *Roar!*)

Why St Mark's is a world leader in robotics

Do you dream of owning your own robot to do the housework, shopping, car-cleaning, gardening, painting and decorating and even driving you to work? Don't we all!

It just sounds so cool, but lifestyle and easy living aside, today's robots are simplifying and streamlining a growing network of manufacturing, packaging, assembling, product delivery, agriculture and shipping industries.

The first robots were static machines that were used in factories to help assemble parts and products and to perform tasks normally carried out by humans. They still are, but many of them have been superseded by a concept called a humanoid robot.

These are shaped like humans, hence the name. The first ones were relatively clumsy and awkward, however as their designs evolved so did their versatility and the growing number of tasks they could perform.

Then came the cobot – a robot designed to work with humans – helping to eliminate tasks considered too dangerous or strenuous for humans and enabling their human co-workers to achieve more than they could before.

So when and how did robots start to be used as surgical aids in hospitals you might ask (See the Christmas 2019 issue of *Roar!*)? The answer is a

surprising one. It was an Italian surgeon who before he was qualified was known to faint at the sight of blood who is credited as the pioneer behind robotic-assisted surgery.

After conquering his fear the surgeon, Signor Pier Giulianotti, started to experiment with a device called a da Vinci – a multi-armed robot. Such was Giulianotti's skill with the new machine that his fellow surgeons were often left in awe, one of them remarking: "He has single-handedly started the area of general surgery in robotics".

Giulianotti was based in Florida in the USA in the early-1990s and such was his expertise that he became the first surgeon to perform more than a dozen robotic procedures.

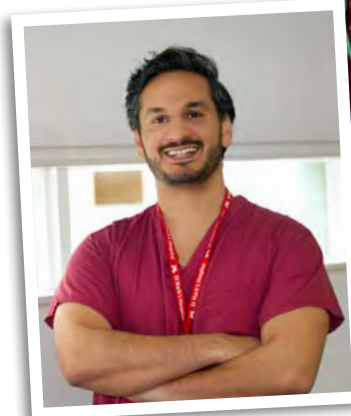
Though it must be said that in the interests of historical fact a more

primitive device called a PUMA 200 had been used in California a few years before to perform a brain biopsy.

St Mark's is the only specialist robotic colorectal hospital in the world

Guided by a surgeon

So what exactly does a surgical robot do? The answer is: Whatever its surgeon/operator tells it to do. What is amazing is that, unlike many other modern robots, surgical ones don't have minds of their own and are guided by a surgical supervisor – ie a surgeon – hence the name robotic-assisted surgery.



LEFT:
Kapil
Sahnani

The surgical robot has two or more arms which rotate over the patient on the operating table (see photo above) while the surgeon sits in front of a viewing screen or console where he or she has a three-dimensional view of the patient's abdomen via a camera.

What then is the difference between open surgery and robot-assisted operations?

The answer is size and scale. When a patient has traditional surgery, he or she is literally opened up ready for the surgeon and his or her team to carry out their skilful surgery.

The key difference is that robotic-assisted surgery is performed using minimally invasive techniques. A series of tiny incisions (usually 1cm to 2cm) are made over the patient's abdomen to allow the robot's arms to insert very small tools – guided by the surgeon – into the patient's body.

Another technique some of you will have heard of is laparoscopic surgery. The advantages of laparoscopic and robotic-assisted surgery, which can only be used for certain types of operation, is the patient has less scarring, spends a shorter time in hospital, recovers from their surgery more quickly, experiences less pain or



MAIN: A robotic-assisted operation
ABOVE: A surgeon's console

Robotic-assisted surgery is performed using minimally invasive techniques

trauma and has fewer chances of infection. It also helps reduce a surgeon's fatigue or the possibility of hand tremors in longer ops.

Kapil Sahnan, consultant colorectal surgeon and joint lead in robotic surgery at St Mark's, said:

"Patients at St Mark's are often complex and there are some who will need their operations completed through an open rather than a minimally invasive approach."

As Kapil pointed out: "Robotic surgery is not offered by all hospital units or all surgeons because it requires a special sort of training."

"In general the robot can be particularly advantageous in operations which involve operating in difficult-to-reach places such as the pelvis or for operations where part of the bowel is being joined inside the abdomen."

First surgical robot

St Mark's bought its first surgical robot, a Da Vinci Xi – made by the California-based Intuitive Surgical Systems – in March 2018.

A month later, consultant colorectal surgeon Danilo Miskovic, leader of the hospital's robotic programme, performed the hospital's first robotic colorectal operation on a patient with rectal cancer.

The following year a team of four surgeons carried out a 12-hour pelvic

exenteration – an op to remove multiple organs in the pelvis – on a young father with cancer caused by complications with ulcerative colitis.

That same year a team headed by Professor Omar Faiz, St Mark's clinical director and a consultant colorectal surgeon, and Mr Miskovic performed the hospital's first-ever robotic-assisted ileo-anal pouch surgery on a St Mark's patient.

Since then the hospital's surgeons have carried out robotic-assisted surgery on a variety of conditions ranging from advanced cancer, hernias, abdominal wall reconstruction, pelvic floor problems and IBD.

"Our robotic surgeons at St Mark's are now very close to helping 700

patients through major colorectal surgery via our robotic platform.

We were already the only hospital in the world to specialise entirely in intestinal and colorectal medicine and are now the only specialist robotic colorectal hospital in the world," said Kapil.

And the future? "I think we can look forward to a really exciting future. The advances in my opinion will include more sophisticated robotic systems with greater dexterity, precision and versatility and smaller and more compact robotic platforms will become the norm. For example, Intuitive has developed a single port robot where all the robot arms can be inserted from a single, small incision on the patient's abdomen," he added.

Jason Bacon, CEO of the St Mark's Hospital Foundation which funded the capital costs of the Da Vinci Xi robot, said:

"The London North West University Healthcare NHS Trust [parent body of St Mark's] is now looking to purchase two additional surgical robots as there is demand from surgeons across all disciplines for the wider use of robotic surgery."

A new report titled St Mark's Hospital's Surgical Robotics Research Programme (see above) will be published by the hospital in January 2024.





MEMBERSHIP REPORT



RLG keeps on winning the numbers game

Our growing membership and website figures make this a season to be merry, says membership secretary and IT guru **Gary Bronziet**

Another busy year in the life of your membership secretary! Our membership continues to grow steadily. We had 72 new members of the Red Lion Group in 2023, and the Facebook Group now stands at 1,435 subscribers.

I have continued making improvements to the website. One of its finest new features is the re-introduction of the FAQs (Frequently Asked Questions) page. It was evident that many of the questions that popped up on our Facebook group were addressed by previously published articles on the website and I was frequently referring to them.

It seemed logical therefore to bring back the FAQs page. You can see a section of the page in the picture below. There is a handy search bar at the top for locating the pertinent question. Click on the plus sign (+) on any of the questions, and it expands to show the answer. You can see the FAQs page at pouchsupport.org/faqs/

Visits to our website

Earlier this year we hit the milestone of 100k visits to our website (since the inception of the new site in 2018). The number of visits is increasing year on year, with the number for 2023 over 44k, with still a few weeks to go. I hope this is testament to the quality of information we are providing to the J-pouch community.

Although we are primarily a UK-based support group, our website gets

visits from all over the world, with the top 10 countries for 2023 shown in the right-hand picture. Earlier this year I shared the complete list of countries visited, and there were some quite surprising names on the list. See <https://pouchsupport.org/red-lion-group-website-hits-100k-views/> for more details and statistics.

The picture below shows the growth in visits month-by-month since 2018: Website visits since new website inception in 2018 – as of 4 December 2023.

We continued our series of live webcasts on Zoom from leading practitioners in the field of pouch surgery and pouch management. All of the recordings are available on our YouTube channel. You can find handy links to the recordings at pouchsupport.org/events/

We look forward to being able to present another exciting programme of events in 2024.

Countries	Views
United Kingdom	28,832
United States	7,429
Australia	1,107
Canada	1,091
Ireland	564
India	387
Germany	363
New Zealand	265
Greece	263
Netherlands	246

I'd like to sign-off by wishing you a joyful festive season and a happy and healthy New Year!

Gary Bronziet
Membership Secretary and IT
membership@pouchsupport.org



ABOVE: Website visits since inception of the new site in 2018 – as of 4 December 2023

STAR LETTER

What's the answer?

I have repeated bouts of chronic pouchitis and continue to successfully manage it with Metronidazole suppositories.

I recently saw a new consultant at my local hospital who suggested I try a biological antibody treatment called Adalimumab (who dreams up these drug names?), a medication one self-injects weekly. It is supposed to suppress the unwarranted immune response to conditions like ulcerative colitis to which pouchitis is related and thus reduce the associated inflammation of the bowel.

It sounded like a miracle cure! However, when I read through the

pages and pages of possible side-effects, I changed my mind. It seems that using the drug can weaken one's overall immune system and make one more susceptible to infection.

After having had two really bad episodes of Covid this year, I didn't fancy compromising my apparently weak immune system any further!

I wonder if any other Red Lion Group members have considered using Adalimumab?

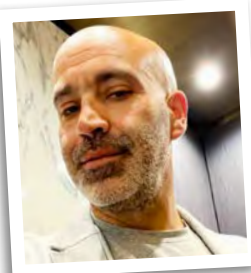
John Weight



LEFT: John Weight looking and feeling on top of the world in Zermatt, the famous Swiss ski resort

The Editor writes:

If any of you have tried Adalimumab please let me know at info@pouchsupport.org or send me a Reader's Letter at the same address



Bums and bowels can be funny too, says Ben Bernabel

The Red Lion Group member finds an original way to celebrate his pouchee-versary

How do we usually celebrate anniversaries? With a big party for friends, family and colleagues or more intimately perhaps with a tête-à-tête with a loved one in a favourite restaurant.

Not Ben Bernabel. The RLG member and City banker marked the five-year anniversary of his unique Pouch Treatment Plan (see page 10 of the Summer 2023 *Roar!*) with a talk in Vilnius, capital of Lithuania.

The title of Ben's talk which he gave at the annual conference of the European Society of Coloproctology (ESC) in September this year was 'What do the public expect from surgeons?'

"I shared the story of my disease, surgical history and pouch regime,

and I was completely honoured and humbled to be delivering a talk to the incredible community of talented bowel surgeons who dedicate their lives to putting us right," Ben told *Roar!* afterwards.

"I gave my views on what patients want from surgeons which is very personal and dependent on each individual patient - some want all the details; others want none! I'm one of those who wish to know everything.

"I was touched to be able to answer a few questions at the end from this wonderful community, who really were genuinely interested in hearing from me," he said.

Among the audience was St Mark's Hospital's lead consultant colorectal surgeon Janindra Warusavitarne, who was also Ben's surgeon. Said Janindra:

"The concept of shared decision-making is vital to ensure that in these challenging times we as clinicians hear what patients have to say and how the services we provide can ensure that their quality of life is also improved, particularly in the context of chronic diseases.

"Ben explained his experiences through his own journey and provided some great insight on how clinicians can look at the patient's perspective," added Janindra, who is a patron of RLG and chair of the ESC's education committee.

And finally Ben couldn't resist a light-hearted quip about the visit. "Early in my speech I told a joke that not one person laughed at! Note to self: Bowel surgeons don't laugh at bum jokes!"



MARATHON MAN

Our man in Havana

RLG's energetic liaison officer **David Skinner** has just completed his third marathon in three weeks in the Cuban capital of Havana, the city where Graham Greene's novel is based



David
Skinner at
the finish

"I live to fight another day," sighed David Skinner. The first challenge was getting out of bed at 4.15am to eat a banana and energy bar ready for my second marathon in three weeks (the first was in Frankfurt*).

Knowing that there were only five toilets at the start for over a thousand runners (10km and half marathon runners were catered for) I gave my porridge pot I'd brought especially from Blighty a miss.

We lined up for a 6am start in the dark. Other marathoners thought it was 6.30am, which it was, before they changed it without telling anyone. Mind you that will come as no surprise when I tell you not one marshal knew how many water stations there were or where they were. They didn't even know how many toilets were on the course! Answer: There weren't any!

As the morning light came so did the sun. With daylight it became apparent I was last in the starting pack, well someone has to be.

I caught up with a couple of friendly Danes, Renne ('allo, 'allo) and Hele. Renne has run 1,140 marathons but he and his

girlfriend were run-walking this one so I tagged along with them until halfway when I needed a loo break. I heard some Americans speaking at the halfway stage and said in as surprised a voice that I could muster, have you finished the marathon already, to which they said they'd only done the half.

The second half was far more enjoyable as by now I was a long way off the two tail-end Danes and was only just inside the cut-off time.

I realised this when I looked round and saw an ambulance trailing me along with an organiser's car. But what really made this a great second half was that I also acquired my own police outrider who would drive ahead and stop all the traffic for me. This went on right to the end. It was bloody marvellous!

You'd have a major crossroads come to a complete standstill with cars backed up for about 50 yards either side, with the occupants expecting to see an amazing Kenyan runner sprint through, only to get me going at about 5 mph, sometimes slower, I loved it.

Behind Renne, Hele and me, the ambulance and organiser's car still

trailed us and when we'd turn round we'd see more cars stacked up crawling along with us as we walked in the middle of the road.

Spectators were virtually non-existent and around mile 20 when you start to lose the plot in a marathon, I would shout at them VIVA MARABANA which was the name of the race. When that achieved no reaction I changed to VIVA INGLATERRA, followed by in no particular order, VIVA BOBBY CHARLTON, VIVA BOBBY MOORE, VIVA WINSTON CHURCHILL.

Sadly, the end came all too quickly as I really was losing the plot and enjoying myself telling anyone prepared to listen that "no hablo espanol.. INGLEESE.. INGLEESE". My non-existent Spanish got worse as the race went on and my accent and arm-waving totally exaggerated.

All good things have to come to an end, and after 6 hours 59 minutes and 28 seconds mine did.

■ **FOOTNOTE: David plans to run his 10th Frankfurt marathon in 2024 and so achieve a UK record!**

This article first appeared on Facebook



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Contact us



CHAIR
David Davies
Tel: 07764 682332
dbd60@hotmail.com



SECRETARY
Sinead Mannion
Tel: 07507 879684
sineadpmannion@gmail.com



TREASURER
Haresh Ruparelia
haresh.ruparelia@btopenworld.com



**MEMBERSHIP SECRETARY/
IT CO-ORDINATOR**
Gary Bronziet
Membership@pouchsupport.org



ROAR! EDITOR
Christopher Browne
Tel: 07939 110842
cbrowne@brownemedia.co.uk



ROAR! DESIGNER
Michele Hall
Tel: 07976 964067
michelehalldesign@gmail.com



LIAISON OFFICER
David Skinner
Tel: 01708 455194
davidjohnskinner@hotmail.com



COMMUNICATIONS
Michelle Martin
michelle.martin1510@hotmail.com



HOSPITAL LIAISON
St Mark's Pouchcare Team
Tel: 020 8453 2099
lnwh-tr.internalpouchcare@nhs.net



Theresa Parr
theresa.parr@talktalk.net



PRESIDENT
Professor Sue Clark



PATRONS
Professor John Nicholls



Janindra Warusavitarne

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