

ROAR!

ISSUE 38 • SUMMER 2008

Roar! is the 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 Inez Malek on 020 7581 4107 or liaison@redliongroup.org.



AVON

David Mair Bristol 0117 922 1906

BEDFORDSHIRE

Carol George Sandy 01767 263092

CLEVELAND & NORTH YORKSHIRE

Christine Jackson Saltburn by the Sea
01947 840836
chrisjacks@supanet.com

CUMBRIA

Jonathan Caton Kendal 01539 731985

DERBYSHIRE

John Roberts Derby 01332 361234

DORSET

Clive Brown Bridport 01308 422281

ESSEX

Peter Zammit Benfleet 01702 551501

HAMPSHIRE

Les Willoughby Winchester 01962 620012

HERTFORDSHIRE

Susan Burrows St. Albans 01727 869709

KENT (WEST)

Rosalyn Hiscock Pembury 01892 823171

LANCASHIRE

Joan Whiteley Clitheroe 01200 422093

MERSEYSIDE

Blanche Farley Liverpool 0151 924 4282

Anna Morling Newton-le-Willows
01925 229648

NORFOLK

Sandy Hyams King's Lynn 01485 542380

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NORTHAMPTONSHIRE

Cynthia Gunthorpe Kettering 01536 482529
David Smith Northampton 07768 400406
mansfieldsmith@hotmail.com

NORTHERN IRELAND

Sharon Hendron Lisburn 02892 661559

SOUTH LONDON

Jonathan English SW12 020 8673 3092

SOUTH WEST LONDON

Dec Odell-Athill W10
colin@odell-athill.demon.co.uk

SUFFOLK

Anna Morling Leiston 01728 830574

WILTSHIRE & DORSET

Bernadette Monks Salisbury 01722 327388

YORKSHIRE

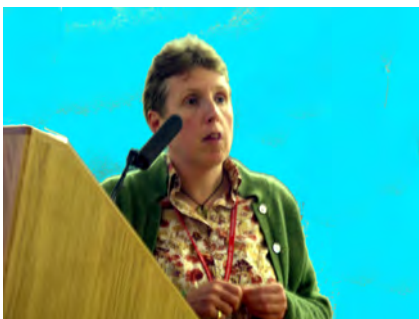
Sue Appleyard Huddersfield 01484 641227



ALTHOUGH NO ONE actually started chanting “bring on the bag” during journalist Virginia Ironside’s spirited talk at this year’s Information Day, some of us came agonisingly close.

For so persuasive was *The Independent* newspaper’s agony aunt that she almost managed to convince us that wearing a stoma was an infinitely better idea than having an internal pouch.

But her oratory was based on a misunderstanding. For when I phoned and asked if she would like to give us a talk on “How I learned to love my pouch”, Virginia thought pouch meant stoma-bag, not the ileo affair we Red Lions wear, the truth only dawning on her as she drove up to St Mark’s on



Information Day itself on 26 April. But instead of pulling out of her talk and refusing to speak to a bunch of converts she bravely went ahead.

“I’ve got a bag. It’s neat, discreet and easy-to-change so why should I consider having a pouch,” she said in so many words. The journalist, author and agony aunt who once wrote a book called “Problems, problems, behind the scenes on the problem page” said that to her an ileo-pouch was like an internal worry-bag – an extension of all the anxieties and fears she had suffered with uc. Why should she prolong the agony when she could have an ileostomy – a practical accessory over which

she had almost complete control.

Virginia’s talk had the same wit and pithy humour as the one she gave three Information Days ago. In her “Confessions of a UC-sufferer” she told us why she always preferred to wear the trousers – and who wouldn’t after her experiences at various European airports, formal dinner parties and friends’ houses with white carpets. Since then life in stomadom had been relatively straightforward and, so far, acci-

dent-free, she said, teasingly asking her audience to sell her the benefits of the pouch.

We tried. Oh, how we tried. But after several lively exchanges Virginia was resolute. It was a bag or nothing. After all she could swim as often as she liked in a one-piece and lead almost as normal a life as everyone else – pouchee or otherwise. Although she did find stomas somewhat dull and unimaginative-looking. Why not bring out a range of stomas in trendy shapes and colours, she asked. They could become fashion statements and young people would be able to compare trophy-stomas. Or how about a rainbow-coloured stoma? Just how cool would that be.

Thanks Virginia for being so brave, funny and honest. Your talk made us re-consider our own options and realise that pouches are not the only solution to intestinal conditions.

Good News Roar!

Tim and I are calling this the Good News Roar! You’ll find every article, letter and contribution ends on an upbeat note. Instead of the confessionals that we tend to print – and there’s nothing wrong with those – all the items in this issue have a cheerful and optimistic theme. We just thought you’d like to sample the feelgood factor this time.

Our first piece of good news was Information Day. Once again the day began and ended in sparkling sunshine with a very high turnout of 90 plus Red Lions, their partners, relatives, friends and pouch professionals. Prof Nicholls set the tone with a guided tour of the pouch and facts and figures about its longevity, performance, success rates

and future. Perhaps we should call his annual talk “Taking the Ouch out of the Pouch”. Let’s hope this one wasn’t his last, for after 10 year of inspiring helmsmanship, the Prof is reluctantly standing down as Red Lion president. We’ll all miss his wisdom, kindness and hands-on approach to members and patients and as a tribute we presented him with a set of hand-blown wine glasses (see picture of prof and vice-chairman below).

The new Red Lion president is Sue Clark (see picture in left hand column),



St Mark’s consultant colorectal surgeon, who needs little introduction to most of us. On the day, both she and Dr Simon MacLaughlin, research fellow at St Mark’s, gave us an animated question-and-answer session – or Brains Trust as we call it – and we’ll be carrying a full report of this in the next edition. Among the other highlights were Miss Clark’s “Surgical Overview of the Pouch”, and two lively workshops by Dr McLaughlin and St Mark’s general surgery registrar Julie Cornish on “Pouchitis Diagnosis and Management” and “Fertility and Pouches” respectively. You can read Julie Cornish’s report on page 14.

Apart from a resoundingly popular raffle which raised £105 and had at least a dozen prizes, many of which were kindly donated by our liaison officer Inez Malek, the day’s success can probably be attributed to four factors – the unstinting organisation of Mike and Margaret Dean assisted by Sarah Varma from the St Mark’s stomacare department and members of the committee, a very high turnout, the radiant April sunshine and some forthright and original speakers.

Have a great summer!

Christopher Browne

A Surgical View of Ileo-Anal Pouches

HERE IS the Information Day talk by Sue Clark, St Mark's Hospital's consultant colorectal surgeon.

Questions

is a pouch an option for this patient?

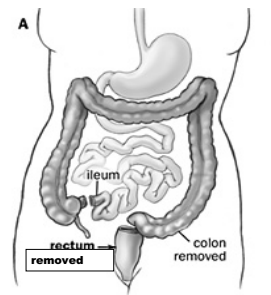
when should it be done?

what surgical technique?

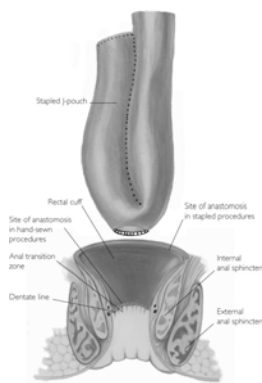
what follow-up is needed?

how should we deal with problems?

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Patient group

disease requires removal of rectum and all or most of colon

healthy small bowel

healthy anal canal

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Patient group

ulcerative colitis

FAP

others

- Lynch syndrome
- Crohn's disease
- other rare situations

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Confirm diagnosis

UC

- histology review
- further biopsies and imaging if unclear

FAP

- genetic testing
- colonoscopy and biopsies

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Is proctocolectomy necessary?

UC

- dysplasia / cancer
- severe acute episode with failed medical management
- failed medical therapy / steroid dependence

advances in drug therapy

other surgical options

- IRA

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Is proctocolectomy necessary?

FAP

- severe polyp burden
 - > 1000 colonic polyps
 - > 20 rectal polyps
- 1309 mutation
- age over 25

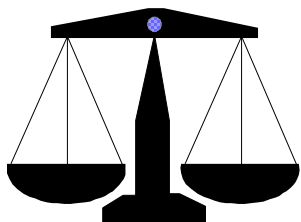
other surgical options

- IRA

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It is the proctocolectomy that is necessary,
not the pouch!

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Pros of pouch

avoids permanent ileostomy in 85%

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Cons - of proctectomy

may influence timing of RPC

- pelvic nerve damage
- effect on female fertility
- major surgery

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Cons - of pouch

- temporary ileostomy
- variable function
- seepage
- pouchitis
- some need catheterisation
- anal / vaginal fistulas
- pouch failure
 - sepsis
 - pouchitis
 - fistulas
 - mechanical problems

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Higher risk groups

- Crohn's disease
- Indeterminate colitis
- UC with primary sclerosing cholangitis
- FAP with desmoids / desmoid predisposition

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Questions

- is a pouch an option for this patient?
- when should it be done?
- what surgical technique?
- what follow-up is needed?
- how should we deal with problems?

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Timing

urgent if cancer / dysplasia

soon if medically unwell

- may be better with 3 stage

after subtotal colectomy

- wait at least 3 months
- may want to wait longer
 - fertility
 - male sexual function

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Questions

is a pouch an option for this patient?

when should it be done?

what surgical technique?

what follow-up is needed?

how should we deal with problems?

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Surgical technique

laparoscopic vs open

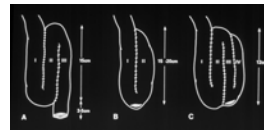
defunctioning ileostomy

pouch configuration

anastomosis

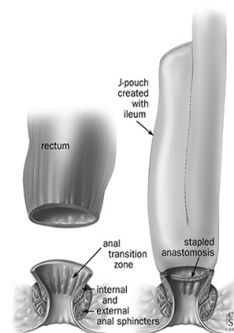
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Pouch configuration



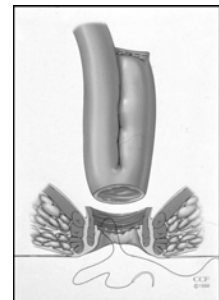
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Anastomosis



This picture shows an ileal pouch anal anastomosis (mucosal lining left intact).

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Questions

is a pouch an option for this patient?

when should it be done?

what surgical technique?

what follow-up is needed?

how should we deal with problems?

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Follow-up

purpose

- research
- to identify complications
 - vit B12 / iron deficiency
 - vit D / calcium deficiency / osteoporosis
 - pouchitis
 - anastomotic stricture
 - fistula
 - cuff cancer

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Current protocol

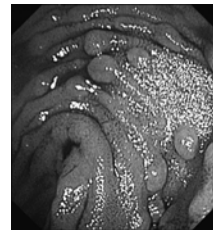
back to GP for annual FBC / B12 / ferritin / folate

- pouch nurse advice
- re-referral for any problems

except

- FAP
- cancer / dysplasia
- PSC
- chronic pouchitis

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Questions

is a pouch an option for this patient?

when should it be done?

what surgical technique?

what follow-up is needed?

how should we deal with problems?

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Problem pouch - key is accurate diagnosis

inflammation

- cuffitis
- pouchitis
- Crohn's disease
- pelvic sepsis

perianal fistulation

mechanical problems

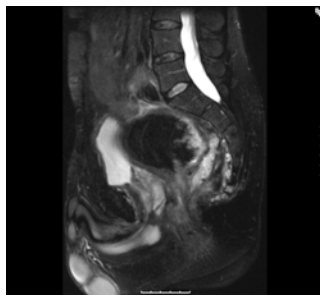
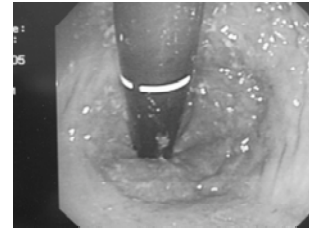
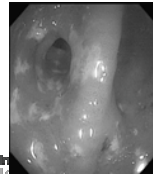
- anastomotic stricturing
- small pouch
- big pouch
- outlet problems
- twists - u-bends

no cause identified

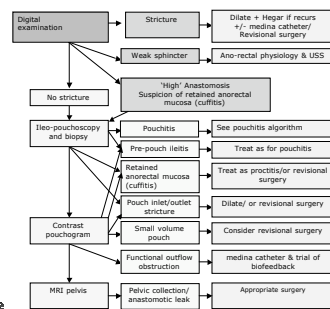
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Investigations

- inside the pouch
 - pouchoscopy and biopsy
 - pouchogram
 - EUA
- outside the pouch
 - MRI
 - CT
- defaecation and continence
 - anal physiology
 - anal ultrasound
 - defaecating pouchogram
- the rest of the bowel
 - small bowel follow-through
 - capsule endoscopy



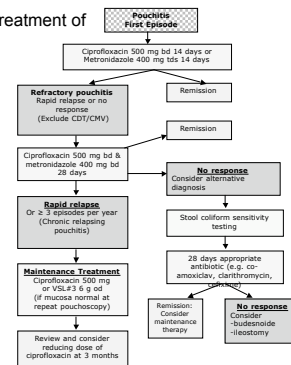
Algorithm for the investigation of pouch dysfunction



Problem pouch

- treat pouchitis / Crohn's
 - drain sepsis
 - control fistulas - seton
 - biofeedback / catheterisation
 - redo pouch surgery
- know when to stop!

Algorithm for the treatment of pouchitis



Red Lion Officers Ahoy!

YOU WOULDN'T normally associate Roar with recruitment ads. However this time we've decided to break with tradition. And you won't be surprised to hear it's for three roles on our committee. Read on and find out more...

After two successful spells as chairman of the group, Mike Dean has decided to retire at the end of the current financial year (spring 2009). Margaret who has been a more than able and hard-working group secretary for the last three years is also giving up her post early in 2009. We'll really miss the Deans and their unrelenting stewardship. Apart from their regular committee duties, this dynamic duo have prepared and organised six Information Days, sent out the annual membership reminders and packed and posted at least 15 Roars during their time on the committee. And they're good mates too!

That's the bad news. The good news is that Mike and Margaret have both agreed to stay on the committee which means they will still be offering us their wise counsel and advice at meetings and will be able to help guide their successors into their new posts. But to continue with my earlier theme for a few moments. I too have reluctantly decided to give up co-editing Roar after the next issue in 2008. The reason is pressure of work – although I've got to say a lot of my work is not half as enjoyable as helping to edit Roar. I'll find it very hard to leave such a cheerful, and sometimes pleasingly forthright, group of readers.

And now for the advertising bit. The committee is looking for three new recruits to help run the group – a chair, a secretary and a co-editor. Taking on one of these roles could be a neat little time-filler for someone who has just retired or has some spare-time on their hands. We're a small charity with just over 300 members, so the workload is not exactly onerous and would appeal to anyone who likes helping with projects and seeing them through.

So what exactly does this trio do? The chair organises and runs four committee meetings a year (one face-to-face; the others via tele-conference), acts as the committee's front-man/woman with the charity commission-

ers, St Mark's Hospital and all external contacts, liaises with our sponsors Dansac and Ostomart and helps run the annual Information Day and AGM. The secretary meanwhile drafts the agenda for committee meetings and the

Lawton who is our roving photographer and often acts as an impeccable note-taker, Tim of course and several others – Morag Gaherty, who used to edit Roar and was our liaison officer for several years, John White, our previous



AGM, takes the minutes of committee meetings and handles the group's correspondence. Finally the Roar co-editor (content) commissions articles, letters and contributions to Roar (some are also sent in voluntarily) and helps to edit and write the magazine. Then the half-finished product is sent to Tim Rogers who designs and lays out the pages and chooses the covers of Roar. He also adds a touch of finesse to some of the editing.

As for the committee, we're a happy bunch of coves. We've a highly energetic treasurer and liaison officer in Marjorie Watts and Inez Malek respectively, a vice-chair (myself), Christine

treasurer, Stephanie Zinser who wrote "The Good Gut Guide" and handles the press side and Lorraine Howell who has been an active committee member for two years. Our patron is the journalist, author and broadcaster Claire Rayner and our new president is St Mark's Hospital's consultant colorectal surgeon Sue Clark.

We'd very much like to hear from you or a friend or relative perhaps who is looking for a part-time hobby or occupation.

If you'd like to join us, phone me (Christopher Browne) on 020-8894 1598 or Mike Dean on 01702 552500

Christopher Browne

Letters

Dear Editor

After suffering with ulcerative colitis, losing my colon, having pouch surgery and a hysterectomy..... I took up line dancing! This literally helped me to get 'back on my feet'! I found the music really lifted my mood and I gradually got my fitness back. Three years later I started my own line dance class, and now have two classes running a week.

Each year we, at Brookmount Dance Ranch, try to support a local charity, or one which is very often overlooked. The Royal Victoria Hospital's Colo-Rectal Fund in Belfast, Northern Ireland is unfortunately one such charity.

We not only wanted to raise money for this charity but also raise awareness. We did this by getting sponsored for doing a local fun run (ending with a wee

line dance of course!); running a raffle with prizes generously donated by local businesses; line dance demonstrations and a few social nights.

We were thrilled to present RVH Colo-Rectal Fund representative Mr Roy Maxwell, (also my surgeon and life saver!) with a cheque for £2,500 (see picture below), and would like to say a huge thank you to everyone who supported our fund-raising efforts this year.

Our line dance classes for beginners and intermediates are held every Monday night in Lowquarters Orange Hall, Ballinderry Road, Magheragall, Lisburn.

So if you want a fun way to keep fit and an opportunity to do your bit for local charities, then give me a call on 02892 661559.

Sharon Hendron



Sally Thelen asked the Brains Trust at last year's Information Day: 'Is it advisable for people with pouches to have a hysterectomy?' The reply was: "A gynaecologist should perform the operation with a pouch surgeon in attendance as it can be complicated and the pouch may be at risk. St Mark's Hospital does not have a specialist gynaecologist service so you should go to a hospital that has one."

As Sally commented in the January 2008 Roar!: "The answer was not encouraging so it would seem wise for me not to pursue that route. I wonder if any other readers have fibroid problems and whether they have come across any procedures other than embolisation or hysterectomy?"

Sally's letter drew this reply from Jane Humphries:

I am a pouch owner of 18 years and in late 2003 it was discovered I had an ovarian cyst. An ultra-sound was closely followed by an MRI and CAT scan to try and distinguish between the pouch and the cyst and then decide on the appropriate course of action. If we waited six months to access the growth rate it could in fact make matters worse so it was decided that a hysterectomy would be required sooner rather than later.

My gynaecologist scheduled surgery for 15 March 2004 with a bowel surgeon in attendance who was familiar with pouch surgery should he be required. I was told there could be complications due to adhesions but was never led to believe that the procedure could be life-threatening. I was allowed home six days later and haven't looked back since.

I hope this gives encouragement.
Jane Humphries

Travel Insurance for Pouch Owners

IF YOU have been looking around for travel insurance you may have found it difficult to find quality cover at a reasonable price once you have declared a medical condition.

That's why we have worked with Leisure & Lifestyle Insurance Services Limited to offer a travel insurance policy specifically for the Red Lion Group.

Both single trip and annual policies are available. Cover includes:

- Emergency Medical Expenses up to £5 million

- Cancellation cover up to £5,000
 - Personal Liability cover £2 million
- Leisure & Lifestyle understand that not everyone has a perfect medical record and that this shouldn't preclude you from enjoying a holiday as much as everyone else.

You will be asked a few simple pre-screening questions to help you get the cover you need with a minimum of fuss (although in some instances a more detailed medical screening may be required).

For a free quotation, phone 08445 763029 and quote reference RL1, or visit the Leisure & Lifestyle website for more information.

Red Lion Group accept no liability in respect of the sale of this or any other travel insurance product nor do they have a financial interest in the sale of such products.

Leisure & Lifestyle Insurance Services Limited is authorised and regulated by the Financial Services Authority reference number 477114.

Why I'm No Longer Stuck Up...

ADHESIONS – IT sounds like a box of plumbing aids in a DIY store. If only they were as useful. They are in fact strands of fibrous tissue that form after colon operations. Red Lion committee member Christine Lawton suffered from them for years. But five hospital spells and a J-pouch later she's as happy and carefree as she's ever been. Here's her story:

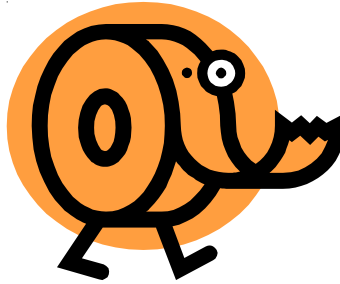
How many of you have suffered adhesions? It is a more common medical problem than many of us realise and I thought I would tell you about my experiences.

In the late 1970s after a long spell of ulcerative colitis, I had a total colectomy with my rectum joined directly onto my small intestine. I remained in this state until 2001 when a pre-cancerous change in my cells and tissues known as dysplasia meant I had to have my rectum removed and a J-pouch formed.

However 12 years after my colectomy, I suffered from my first intestinal obstruction due to a series of adhesions. Fortunately the discomfort did not last long and after a two-day rest in hospital and a spell of drip feeding, the intestine became unblocked and everything went back to normal.

These blockages occurred five times over the next three or four years until, after the fifth, Mr Peter McDonald, my surgeon at St Mark's Hospital, offered to operate and release the adhesions as they were causing me repeated prob-

lems. After the operation I was in hospital for 10 days and I am pleased to say it all went very well.



Since then I have not had any more obstructions even though I still believe my inside is pretty glued up. It doesn't cause me any discomfort, and when I had my J-pouch fitted seven years ago, I was told that it took the surgeons some time to cut through all the adhesions before they could get to the parts that mattered. I can imagine their frustration!

However since my J-pouch operation, I have been perfectly well and have had no more obstructions. In fact my pouch has behaved impeccably. I am

also extremely happy to say that I have been able to eat absolutely anything, including crunchy, raw things, fruit, all kinds of vegetables and even nuts. Naturally I don't go overboard when I'm eating something which I know is quite hard and not too digestible because obviously one must be sensible about this but I have been able to lead a very normal life.

I love art, photography and natural history and enjoy visiting museums, galleries and art exhibitions. Now I'm retired, I will hopefully have more time to enjoy these.

I am lucky that I have had such superb care from, in my case, St Mark's. I know that if there are any problems, they will sort them out. But most of the time I don't think about them. I just get on with my life and count myself very lucky indeed that the surgery for my adhesions and pouch has been such a wonderful success. The J-pouch has certainly given me back my life. May I extend my good wishes to anyone who is about to undergo surgery. I hope you will find it as successful as I have.

New Red Lion Group Website

AFTER FIVE years the Red Lion Group website was beginning to look a little stale. The site has now been relaunched using new content management software and can be found at www.redliongroup.org.

The Red Lion Group website has recently been revamped. The new site contains an archive of recent editions of *Roar!* which can be downloaded in PDF format. We have also published some interesting articles from early editions of *Roar!* which are still of interest today, starting with a number of old 'My Story' articles and some diet tips from the early days of the Red Lion Group. The new site is managed using software called 'Joomla!' which has given it a fresher, more polished look than the old website. If you haven't looked at the website for a while, please go and take a look and let us know what you think.

The web address is www.redliongroup.org.

Tim Rogers

RED LION GROUP
Registered Charity number 1088124 in the United Kingdom

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MAIN MENU

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ROAR! ARCHIVE

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- 036: 2007 Summer
- 035: 2006 Christmas
- 034: 2006 Summer
- 033: 2006 New Year
- More

Welcome to the new Red Lion Group website

The Red Lion Group is a UK charity for people who have, or are considering having, an ileo-anal pouch.

The charity was founded in 1994 by a group of patients and staff at St Mark's Hospital in London. Members receive a newsletter two or three times a year containing useful advice and support. Every year in late April we hold an Information Day consisting of seminars and workshops covering a range of topics of interest to pouch owners and those considering having the operation.

Travel Insurance for Pouch Owners

Thursday, 08 May 2008 22:31

If you have been looking around for travel insurance it is likely that you will have encountered the following problem: finding quality cover at a reasonable price once you have declared that you have a medical condition.

That's why we have worked with Leisure & Lifestyle Insurance Services

New Committee

Sunday, 04 May 2008 17:18

The new committee was elected at the Red Lion Group information day on 26 April.

It is largely unchanged from last year, with Mike Dean remaining chair and Christopher Browne vice-chair.

[READ MORE...](#)

LOGIN FORM

Username

Password

Remember Me ☐

- [Forgot your password?](#)
- [Forgot your username?](#)
- [Create an account](#)

WHO'S ONLINE

We have 1 guest online

Why I Chose My One-Hit Wonder

RED LION member Marica Pilkington from Hampshire is one of life's optimists. After an intense spell of ulcerative colitis she opted to have a one-stage pouch operation and says she has never looked back

I have had my pouch for 12 years and we are definitely very good friends. It took a while to get used to it and to learn how to care for it but it rarely causes me problems. I am careful about what I eat most of the time, however if there's something I really fancy like mushrooms, nuts, oranges and stewed plaice that I know my pouch will react to, I occasionally take a risk and eat it.

Sometimes I'll be lucky and get away with it, but usually it reacts and gives me a restless night. But then my view is if I enjoy the experience a little bit of suffering is a small price to pay. After all the problem never lasts for too long anyway.

I have also travelled extensively since having a pouch. Shortly after the operation my husband Robbie and I spent a summer holiday in the Greek island of Hydra. We stayed in a rented house at the top of a steep hill with donkeys to carry our luggage. We spent much of our time climbing (pouch notwithstanding) up and down from the village to our island idyll although I will say our progress was more like two tired donkeys than a pair of mountain goats. Another of our holiday favourites is north-west Cyprus where we rent a hillside villa with spectacular views in a village called Latchi near Pathos. But we'll never forget the fortnight we spent sun-bathing and generally chilling out in the sunshine state of Florida. We stayed near Orlando and saw Kennedy space centre and the Disney resorts in between bouts of serious relaxation.

I do find my pouch reacts to long air journeys and gets bloated due to high cabin pressure, although it doesn't take long to settle down after we've landed. When I go overseas I make sure I take precautions such as not drinking the local water or having iced drinks and always using bottled water for making tea.

When I am at home in Hampshire I often stay with friends for a day-and-night during the week or a weekend and although I recently retired I keep active with daily activities like cooking, barbecues and entertaining, although I'm not particularly fond of walking. I find

rather than allowing them to rule their lives. If you do suffer problems, seek help from a support group like Red Lion (which some of you have undoubtedly done or you wouldn't be reading this!). Also don't hesitate to speak to the stoma or pouch nurse and



climbing over stiles or over soft muddy patches just a bit too tricky in high heels. I really enjoy my life, particularly when I compare it with the pre-pouch days of pain and suffering. In fact one of the reasons I wrote this article is to highlight my good experiences with an ileo-anal pouch and to try to give those who have had recent operations some genuine hope. You may find, for instance, that it takes a little while for your pouch to settle down and allow you to lead a normal life. However if you remain upbeat and optimistic you will find life far better than it was before you had the surgery.

I really urge all pouchees to make sure they are in charge of their pouches

surgeon at your local hospital. But don't delay as the sooner you seek help, the sooner things can be put right.

Almost two years ago I celebrated my 60th birthday in great style at a local hotel and had the opportunity to thank Robbie and our three grown-up children Alex, Adam and Verity and my various relatives and friends for all the help and support they gave me when I was so ill with ulcerative colitis.

My message is that I intend to go on celebrating life and living it to the full for many years to come. And I hope this article will help you to do the same.

What a splendid article. We're awarding a prize for the next upbeat article you send in (Ed).

Fertility and inflammatory bowel disease

INFORMATION DAY talk given by Ms Julie Cornish, general surgery registrar of St Mark's Hospital.



IBD

- onset in peak reproductive years
- more women choosing to have families later
- increasing age assoc with ↓ fertility



infertility

“one year of unprotected intercourse that does not result in pregnancy”

How is fertility affected by inflammatory bowel disease?

Crohn's disease and female fertility

- older studies: 30-42% infertility in Crohn's disease
- more recent studies suggest similar infertility rates (5-14%) to normal population
- ? surgery for CD decreases fertility more than medical treatment

Crohn's disease and male fertility

- ? ↓ in number of children born to men with CD
- infertility due to reversible semen abnormalities in 60% men taking Sulphasalazine

ulcerative colitis and fertility

- 'normal' female fertility in UC
- 'normal' fertility in men with UC

what is the effect of IBD on pregnancy outcomes?

Cornish JA et al, Gut 2007 Jun;56(6):830-7

- inflammatory bowel disease
 - ↑ risk of premature birth
 - ↑ risk of low birth weight
 - higher rate of caesarean section

medication for IBD and pregnancy outcomes

review of current literature

- 19 studies
 - 5 ASA, corticosteroids, azathioprine & anti TNF α
- 1,626 women

- no increase in
 - stillbirths
 - ectopic pregnancies
 - miscarriage
 - low birth weight infants
- higher incidence of terminations (anti-TNF α)

what is the effect of disease activity on pregnancy outcomes?

- if conceive with active disease
 - ↑ premature birth
 - ↑ low birth weight
 - stillbirths & miscarriage

key points

- during pregnancy it is important to control disease
- if required can give IBD medications during pregnancy (except methotrexate)

restorative proctocolectomy and female reproductive health

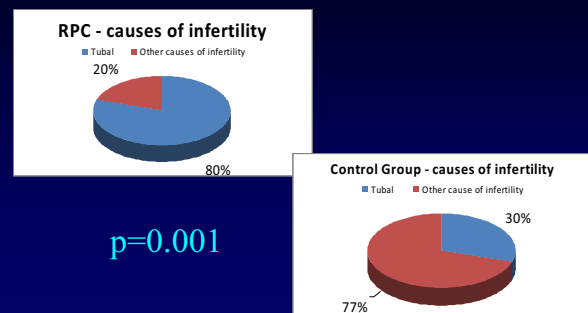
female fertility following RPC

- 2-3 fold increase in female infertility following RPC
- ↑ infertility RPC > IRA

why?

- ? adhesions
- ? due to IBD and pouch
- ? ovarian reserve

cause of infertility post RPC



what is the effect of RPC on pregnancy outcome?

Cornish JA et al, DCR 2007 Aug;50(8):1128-38

- similar rates to normal population
 - stillbirths
 - miscarriage
 - premature birth
 - low birth weight

method of delivery: caesarean section

- incidence general population UK =28%
- incidence following RPC = 47%

delivery method



method of delivery and long term bowel function

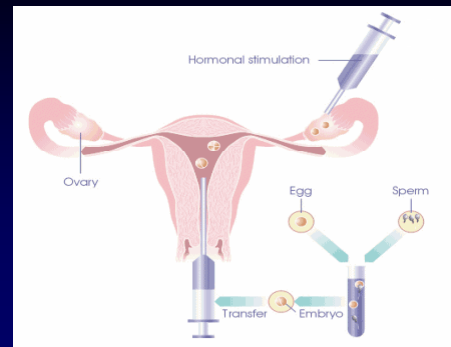
- some concerns about long term effect of vaginal delivery on continence
- evidence that continence worsens over time (20 years) for RPC

method of delivery

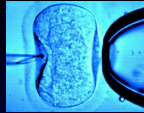
- definitive indication for C-section post pouch
 - scarred or rigid perineum
 - obstetric concerns
- first pregnancy - consider C-section

fertility treatment following RPC

IVF

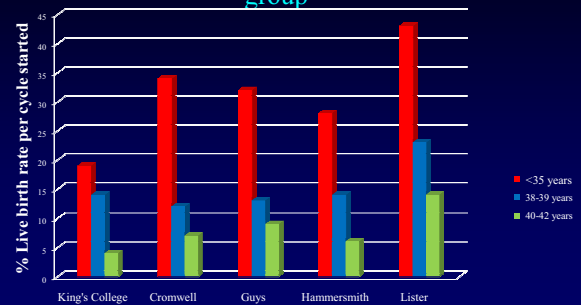


background IVF

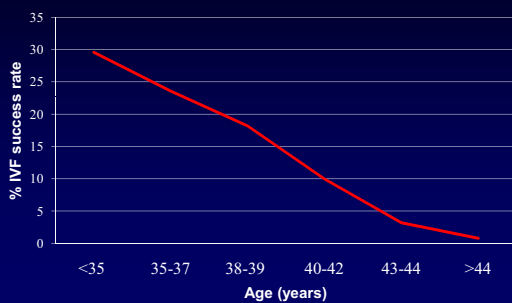


- factors that affect IVF success
 - age
 - obesity
 - smoking
 - centre of treatment

% live births per number of IVF cycles started – variety between centres and patient age group



changes in % success of IVF cycles with increasing female age



What is the cause of infertility
problems?

summary

- normal fertility IBD
- reduced female fertility post RPC
- debate over delivery method
- consider IVF early - as age important
- more research needed

How losing weight made me a winner

RED LION member Bharat Sharma was told that he was too heavy to have a pouch operation. So he decided to prove everyone wrong

When I was diagnosed with ulcerative colitis about 10 years ago, I was told that although there is no known cure for it, the condition could be controlled by medication. For the first four years I was on different medications and my uc was fairly under control.

In 2002, I developed an ulcer on my ankle which got progressively worse. I had to have a minor operation and I was in hospital for about 10 days. As I was on steroids at the time, the wound on my ankle took a long time to heal. For some unknown reason my uc also declined and the only way to maintain control was to take more steroids. Whenever I tried to come off them, the uc got worse and I was in pain all the time and had to run to the toilet 10 to 15 times a day.

In 2005, St Mark's Hospital decided to operate and I was told it would be done in three stages – removing the colon, making a pouch and finally closing the stoma. Before my operation I weighed around 87 kilos. The first part of the procedure went OK. The following day the surgeon informed me that it had been a very complicated operation because of my weight and long-term dependency on steroids.

A year later, I asked the doctors when I could have the next stage of the operation. I was told that because of my weight this was impossible. I was also told that unless I lost 25kgs (25% of my body weight), there would be no fur-

ther operation and I would have to live with my stoma for the rest of my life. I was very depressed and did not know how to start losing weight – as a food and drink lover it was not something I



had considered before.

I spoke to Zarah Perry-Woodford, St Mark's pouch nurse specialist, about my problem and her first suggestion was that I should do more walking. When I tried I found it did not lose weight quickly enough. She then suggested I join a gym to do some other kind of exercises. She also spoke to Mike Dean, then vice-chair of the Red Lion Group, about my problem. Mr Dean was very supportive and kindly arranged some financial help from the group which enabled me to join a gym.

Zarah managed to use her influence to get me a discount at her own local gym.

I went to the gym three to four times a week and also became very conscious of my diet. I went for long walks on the days I did not go to the gym and the weight started to come down slowly but steadily. I was very determined to reach my goal and checked my weight every week. There were some weeks when it did not come down and I felt pretty down. But Zarah was always there to encourage me when I was feeling low and gave me very good advice to help me get my weight down to 65kgs.

I had my second operation in September last year. It went well and the next day the surgeon came to see me and said I had been my own best friend during the months I had been losing weight. He said he had no problems during the operation as there was no fatty tissue on my body.

I now feel energetic and healthy and my weight is a steady 65kg. It has also encouraged me to continue with my exercises at the gym and stop my weight rising again. I have also been able to travel to India to see my family which was wonderful as the last time I was able to travel was in 1992.

This operation has been a great liberation for me and given me a new lease of life – thanks to St Mark's and all those who encouraged and pushed me to achieve my goal.

Cartoons



Max was astonished to find himself in the middle of a Pouch and Judy show



Chairman's Report

PRESENTED TO the Annual General Meeting of the Red Lion Group on 26 April 2008.

I hope you have had a chance to read last year's AGM Minutes which are included in your welcome pack. If agreeable can we take them as read and are there any matters arising from the minutes.

I would like to say a warm welcome to everyone and looking around it is good to see some familiar faces again this year. I believe that these information days are extremely beneficial as it is a chance to catch up with old friends and at the same time be able to talk to health professionals in an open environment let alone the exchanging of experiences on how each of you cope. Whilst on the subject of coping I would welcome, as would Chris Browne, if you could write to us and share these experiences which we can put into the *Roar!* magazine as you are aware not everyone is able to get to these information days.

Insurance

We have received a number of enquiries about travel and the problems that are experienced for people with bowel problems in obtaining travel insurance only to be told they will not be covered or it will be excessively expensive. I am pleased to announce that we have teamed up with Leisure and Lifestyle Insurance Services who will be able to offer members of our Group travel insurance cover at an affordable rate. We are fortunate to have Grahame Hamilton the Managing Director with us today who will be available during the lunch break to answer any questions you may have.

There will also be some promotional flyers available for you to take away. I would stress that the Red Lion Group have no liability or financial interest in Lifestyle and Leisure Insurance Services or in any of the insurance products; this is purely a facility we have managed to obtain for members

or any other person who has a bowel disability.

Laptop

After much badgering from Zarah for a constructive aid to the department we were able to donate a laptop which will be used as a teaching aid for other nursing staff to learn about pouches and improve pouch nursing skills. It will also be used to give presentations to new pouch patients on diet, pouch care etc.



Staffing

It is, therefore, rather unfortunate that two key members of the Stomacare Dept. went on maternity leave at the same time and with additional loss of other members of staff. The Red Lion Group were unhappy at the lack of cover and wrote to both Professor Robin Phillips and the Chief Executive of the Health Trust pointing out we consider it to be inappropriate that there was no pouch cover for the period of their maternity leave. We were assured that this would be rectified and there would be adequate cover provided. Unfortunately due to budgetary constraints this did not happen, however, it must be said that both Sarah and Becky have, under difficult circumstances managed to keep things ticking over in that department and indeed have stepped into the breach to help us with this Information Day.

Website

The website is gradually being updated and I am extremely conscious that it is looking rather stale but we are hoping to have it rectified in the near future.

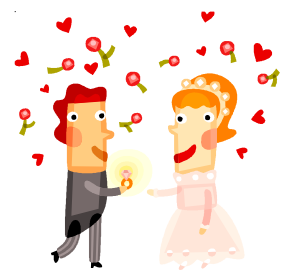
Blue Badge

I would also like to add that one of our members Bill Shepherd has been very active in talking to his local MP and the various Ministers of Transport regarding the controversial Blue Badge Scheme which, as you are aware, is

open to misuse. Bill has been campaigning for people who have pouches to be able to be given the blue badge or another type of badge for short stays to enable emergency use of toilets. As we all know being caught out at the wrong time is a perennial problem especially when driving with nowhere to park, which is not only distressing but expensive when fined for having to park on yellow lines.

Bill please stand up. This everyone is Bill Shepherd and I am sure he has lots of information to impart so if you wish to discuss any issues of the blue badge I am sure he will be able to assist you during the lunch break.

As you all will no doubt appreciate there is one absentee today and that is Zarah Perry-Woodford our Pouch Support Nurse. She is in a better place, 40,000 feet above the Atlantic, where she is flying off to be married early next



week. I am sure you will join with me in wishing her and her fiancé all the best for the future.

I would ask that you support the raffle as this is a good source of income for us and also helps to go towards the cost of the information day.

Finally, I would like to thank all of our committee members who have put in a great deal of work in the background and to Chris Browne and Tim Rogers for their editorship of the *Roar!* magazine. My thanks also go to both Dansac and Ostomart for their continued help in both their support and promotion of the Group.

Treasurer's Report

PRESENTED TO the Annual General Meeting of the Red Lion Group
on 26 April 2008.

Hello and good to be with you to present the Treasurer's Report.

I would like to thank Brian Withers for auditing the accounts again this year, it is very much appreciated.

I also thank John White, the previous Treasurer, for his help. Sorry you are not too well at present and unable to be here with us this year. I hope you will be feeling better soon.

Now I hope you have a copy of the accounts for the year ended 31 December 2007, so you can join me in looking through them.

Income

Subscription income is £75 less this year, due to a reduction in membership which was 291 compared with 302 at the end of 2006. Thank you to the 163 members who pay by standing order, this is very helpful.

Donations have increased this year due to the generosity of members and two companies all wishing to support the work of the Red Lion Group.

Sale of merchandise was similar to that of the previous year. Please everyone remember to visit the table today to browse and donate!

Income from interest has improved due to the larger balance in 2007. The gift aid amount has grown for two reasons. Firstly more tax paying members have completed gift aid forms; secondly, due to the gift aid on the sponsorship of Zarah and Sarah Half Marathon run in 2006. Many thanks to you all, as you can see £955 is a considerable amount.

AGM registration and raffle income was higher due to the increased attendance at the 2007 AGM

Expenditure

The cost of AGM and Meetings is very similar to 2006.

The reduced figure for the printing and postage of Roar reflects the cost of the one magazine produced in 2007, due to ill health of the Editorial Team, compared with three magazines in 2006.

Postage and stationery shows an increase due to renewal invitations being sent independently and not included with the magazine.

The website hosts failed to charge the Red Lion Group and have kindly waived the fee for 2007.

One Hardship Payment was made in 2007.

The Excess of Income over Expenditure has enabled the Committee on your behalf, to donate £3,000 this year.

£2,589.44 donated to St Mark's Foundation for use in pouch research and £410.56 for a laptop computer to

be used by the Pouch and Stoma Care Dept at St Mark's Hospital.

The year's surplus after donation payments of £998.35, together with the balance brought forward at the start of 2007, results in a final year end balance, of £9,138.97 for the Red Lion Group.

Thank you for your attention and if you have any questions for me or other committee members we will try to answer them.

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 Red Lion Group Treasurer, Mrs Marjorie Watts, 11 Meadow Way, Upminster, Essex, RM14 3AA**

Contact the Red Lion Group

CHAIR

Michael Dean
9 Mornington Crescent
Hadleigh
Benfleet
Essex SS7 2HW
Tel: 01702 552500
chair@redliongroup.org

VICE-CHAIR AND NEWSLETTER EDITOR (CONTENT)

Christopher Browne
89 Fulwell Park Avenue
Twickenham TW2 5HG
Tel: 020 8894 1598
vice-chair@redliongroup.org

SECRETARY

Margaret Dean
Address, and home telephone
number as for Chair.
secretary@redliongroup.org

NOTES SECRETARY

Christine Lawton
19 Nathans Road
North Wembley
Middlesex
HA0 3RY
Tel: 020 8904 7851
notessecretary@redliongroup.org

TREASURER

Marjorie Watts
11 Meadow Way
Upminster
Essex
RM14 3AA
Tel: 01708 445199
treasurer@redliongroup.org

LIAISON OFFICER

Inez Malek
33 Trevor Square
London
SW7 1DY
Tel (home): 020 7581 4107
liaison@redliongroup.org

CLINICAL NURSE SPECIALIST

Zarah Perry-Woodford
St Mark's Hospital
Northwick Park
Watford Road
Harrow HA1 3UJ
Tel (work): 020 8235 4126
pouch@redliongroup.org

NEWSLETTER EDITOR (LAYOUT)

Tim Rogers
30 Amberley Gardens
Epsom KT19 0NH
Tel: 020 8393 6968
newsletter@redliongroup.org

PRESS OFFICER

Stephanie Zinser
Tel: 01932 867474
Fax: 01932 867444
pr@redliongroup.org

EX-OFFICIO

John White
44 France Hill Drive
Camberley GU15 3QE
Tel: 01276 24886
john@redliongroup.com

Morag Gaherty
16 Hill Brow
Bearsted
Maidstone
Kent ME14 4AW
Tel: 01622 739034
Fax: 020 7691 9527
morag@redliongroup.org

Lorraine Howell
125b Welldon Crescent
Harrow HA1 1QJ
Tel: 020 8723 4801
lorraine@redliongroup.org

PRESIDENT

Sue Clarke

PATRON

Claire Rayner

Join the Red Lion Group

- Newsletter three times yearly with all the latest news, views and events
- Membership is £10 (£5 for hardship cases, and free for under 16s) per annum
- Write to Liaison Officer at the address above for a membership form

Write for Roar!

Ideas, Ideas, Ideas and More Ideas

Yes Tim Rogers and I thrive on them for it's ideas that make Roar! the readable package we 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 news-

letter bursting with life and information and make reading about pouch issues fun and stimulating.

Please send your articles, letters and ideas to:

Christopher Browne
Roar! Content Editor
89 Fulwell Park Avenue
Twickenham
Middlesex
TW2 5HG

or
cbrowne@brownemedia.co.uk

Visit Our Website

www.redliongroup.org

