



ROAR!

ISSUE 31 • LENT 2005

Roar! is the newsletter of the Red Lion Group
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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 Marion Silvey (phone number on inside back page).



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Notes from the Chair



What a dramatic end to 2004! Some of us had friends, relatives and colleagues in south-east Asia when the tsunami struck and then watched in silent awe as relief bodies, donors, charities and governments responded on an unprecedented scale. It certainly gave new meaning to the phrase 'charity-giving'. As the donations and rebuilding continue, let us pray for a speedy recovery.

Another, smaller appeal was run by the Charities Aid Foundation and *Daily Mail* shortly before Christmas. If you're a regular *Mail* reader, you probably know about the £500,000 donated to various charities. You may also have collected tokens and tried to raise £10,000 for your own favourite cause. Several of us sent in entries for the Red Lion Group, though none of us actually raised any money. Perhaps it's the thought that counts after all.

As for responses, forty-nine of you replied to the Expectations Survey we ran in the autumn *Roar!* [you can read Morag's report on page 13 of this issue]. That's almost 15 per cent of our total membership. As market research companies consider three per cent a fair response rate, ours was truly outstanding. Ok, so many of us had a personal interest in the theme of the research, but it's still encouraging when so many people make that extra effort to reply. Surveys like ours can often be used as key data sources (all are anonymous of course) for hospitals and medical research bodies.

Data: dontcha just love it? Well I do and if you do too, you're about to get your very own data check when you visit a new St Mark's Hospital website. For two years now, researchers have been creating an online database for pouchees. All you have to do is log on and reveal all about your operation, treatment and day-to-day life with a pouch. You never know, it might just turn out to be an irresistible read. You can hear all about it at this year's Red Lion Information Day and AGM at St Mark's on 30 April.

We've got some lively speakers for you too. The 'Independent' columnist and agony aunt Virginia Ironside will talk about her hilarious—occasionally distressing—moments as an ulcerative colitis sufferer and how she gets by without having had pouch surgery. While serious pouch-students can find out about all the latest research from our very own president, Professor John Nicholls.

What are you waiting for? The entry forms are inside this—your very own—Lent issue of *Roar!*. For now, have a healthy and happy 2005 and I hope to see you on 30 April.

Christopher Browne

Should human embryos be screened for genetic defects?

Stephanie Zinser investigates this morally thorny issue.

The issue of screening human embryos has dominated the media in recent months. Groups—both for and against—have represented their views, and the debate rages on.

Families who are genetically susceptible to Familial Adenomatous Polyposis (FAP) have dominated the current debate, for it is these people who have just been allowed by the HFEA (Human Fertilisation and Embryology Authority) to screen embryos in an effort to prevent the tragedy and misery that this dreadful condition brings.

Previously it was only untreatable illnesses like cystic fibrosis and Huntingdon's disease that were granted permission for embryonic screening. Then recently, the HFEA gave the go-ahead for the technique to be used so that embryos could be selected purely because they are a tissue match for a sick sibling.

And now families with FAP have been given permission. Why? In FAP, the faulty gene (found on chromosome no. 5) exerts a huge influence in causing active disease to develop—with it, there is an 80% chance of the aggressive cancer developing. Another disease with this high a level of risk is the genetic form of breast cancer, whose faulty genes BRCA1 and BRCA2 also give an 80% risk of cancer development in carriers. (This is still awaiting HFEA approval, however.) Although FAP generally occurs earlier than in the 'genetic' cases of breast cancer (FAP typically strikes during an affected person's 20's and 30's), treat-

ment of both involves gruelling, major surgery with no guarantee of eliminating the disease completely.

Pro-life groups such as Comment on Reproductive Ethics have been vocal in their disapproval of embryonic screening advances. Speaking to *The Times* recently, spokeswoman Josephine Quinteville says, "We are not thinking about curing the disease, but about eliminating the carrier."



It's an interesting point. With a huge family history of breast cancer, Jackie Hunter writes in a letter to the press that she also feels anger at the decision to allow embryo screening, because if this had happened 100 years ago, her entire family would now not exist. She points out that genes for disease aren't, perhaps, everything: "As well as our forefathers having cancer genes, they blessed us with entrepreneurial genes, artistic genes, literary genes, loving genes—indeed a veritable cornucopia of positive, wonderful genes." A persuasive argument.

History illustrates that many of our most famous names possessed a less-than-perfect complement of genes. Beethoven's mother, at the time she was pregnant with him, already had several children: three were deaf, two were blind, and one was mentally retarded. If she had had aborted the (also congenitally-deaf) Ludwig, the world would now be a musically poorer place. He's not the

only famous person to have been born less than perfect. Aristotle suffered from epilepsy, as did Vincent Van Gogh. The poet and philosopher Homer was blind from birth. Toulouse-Lautrec suffered an incurable congenital bone disease. Stephen Hawking has motor neurone disease. One may wonder whether their handicaps played a part in driving them to excel so magnificently in other areas.

Many of us (with FAP or without) might not be here if we had been genetically screened out by our parents for things that we suffer from today. How many of us would prefer to not have existed at all? We may not be famous, but I bet we're all happy to be here.

Life is all about risk. Whether we realise it or not, we spend most of our lives minimising risk. We choose a salad over chips to reduce our risk of obesity and coronary heart disease. We put our seat belts on to reduce the risk of death and injury in a car crash. We teach our children to read and

write to (ultimately) reduce their risk of poverty in later life. The more certain a risk is, the more likely we are to do something to minimise it.

And this is why the families with FAP have been sanctioned to screen genetically against the disease that they carry: there is a very high risk that any child carrying the FAP gene will develop the disease, and many of them wish to minimise that.

The Red Lion Group has a significant number of members with FAP, making the issue particularly relevant to us. So where do the answers lie? Is genetic screening the ultimate solution, or can it bring its own and complex issues? Ultimately, is it right or is it wrong? Socially desirable or undesirable?

Genetic screening and embryo selection is, to the many who carry the genes for debilitating and fatal diseases, a godsend. It offers an escape route, a hope for freedom from a curse that you and your children don't deserve. People that are affected say it's easy for those who morally object to screening to pontificate, but unless you have actually experienced the vulnerability and torture of watching your children suffer or die from something you unwittingly gave them, it is unfair and inappropriate to comment on the rights and wrongs of those who do suffer.

No doubt there must be some people out there who know what it feels like, and who still maintain a staunch position against screening and genetic selection of embryos. That is their right. They may argue that we're not eliminating a disease, *per se*, but a whole person—and that medicine would be better off focussing on curing the disease rather than eliminating the people that carry them. When put in such terms, it almost carries the same unpleasant whiff that was used to justify ethnic cleansing. And put in those terms, they score a point.

But, say you have decided in favour of embryo selection. Is this the end of all your troubles? Perhaps not. IVF has come a long way in terms of success rates, since its own conception 35 years ago, but it's not a procedure that is either pain-free or guaranteed. You don't always become pregnant during a course of IVF treatment—the average couple needs three rounds of IVF before producing a baby—and

it's expensive, around £3,000 per cycle. In the case of genetic screening for FAP, approximately half of a couple's embryos will be screened out, reducing the odds for success still further. There are risks associated with fertility drugs, such as ovarian hyperstimulation, and also the possibility of an increased risk of ovarian or breast cancer in later life. IVF pregnancies are more likely to result in premature births, with an additional increased risk of congenital abnormalities like heart defects or cerebral palsy.

However, even the increased risks associated with IVF are in reality very small—and most would say irrelevant—in relation to those that already face a family with a known and serious problem like FAP.

In the end, the debate does not rage because of science, or the lack of it. The debate rages because of the visceral and deeply-seated views of humanity and life that lie at the core. The real nub of the problem is that the arguments both for and against are extremely emotive.

The sheer pain of watching your child being diagnosed with a crippling illness is emotive. Holding your child's hand as they lie helplessly in Intensive Care, wrapped in a cold forest of tubes and drips is emotive. Helping them try to thread their lives together after major surgery is emotive. Watching them undergo surgery after surgery with no guarantee of a cure is emotive. Burying a beloved child who has suffered years of needless and undeserved pain is emotive. Indeed, it is torture.

But then, take a look at one of your children today, and imagine—for an instant—that they didn't exist because you had screened them out before they had a chance. You would never have seen the twinkle in their little eyes when they were excited, never have felt their warm, spontaneous cuddles, never felt their

soft breath on your cheek, nor heard the soft chime of their voice in your ear. This, too is emotive. Imagine that you'd never have seen them on their first day at school, nervous and out-of-place in their new, too-big school uniform. Pretend that you'd never have sat in the audience, wiping away a tear as you watched them mumble their lines in their first school play. Imagine that you'd never given the loving face that smiles at you as you kiss them goodnight the chance to exist, that you had decided they shouldn't live.

Isn't this also emotive?

The fact that the HFEA has offered people a choice is no crime and shouldn't even be up for debate. Nobody is forcing anyone to screen their embryos for defects, nor forcing them to terminate a life. People who wish to let nature take its course are still entitled to do just that, and those that wish to prevent a terrible disease in their future children are now also being given a chance. The decision to approve screening for FAP should be welcomed, and while all views are valid, it's time to accept that we all have a choice, and will all exercise it differently.



Colitis, Chemotherapy and Blood Counts

One week before Christmas two years ago, my life was saved by a surgeon for the second time. The first occasion was an emergency operation for ulcerative colitis ten years ago; the second was for breast cancer. I expect you are wondering what the latter has to do with pouch people. Read on and you'll find out.

My cancer was picked up by the regular three-yearly mammogram offered to all women over 50. A couple of weeks after diagnosis I was undergoing surgery, fortunately only a lumpectomy (aka wide local excision), not a full mastectomy. After my bowel operations, the surgery involved was a mere hiccup—I was only in hospital for just over 24 hours!

Waiting for the results of the laboratory tests afterwards was the most nerve-racking period. The pathology analysis revealed my axillary glands were clear, though I was hormone (oestrogen) receptor negative (ER-). This female sex hormone can cause the growth of breast tumours and the greater majority of women test positive. So most women post-operative are prescribed the drug tamoxifen or equivalent for five years or so, which greatly improves survival rates by reducing the levels of oestrogen.

However, my score was zero, so the drug would be of no benefit to me. Apart from recommending an essential course of radiotherapy, my surgeon suggested I see one of the hospital's oncologists to discuss chemotherapy. The very word frightened me, as fear of the unknown often does.

In this country, we are fortunate to have recourse to a prolific amount of illness-related literature and telephone helplines. Pouch people have *Roar!* and the Red Lion Group; breast cancer sufferers can seek support from Breast Cancer Care and Cancerbacup. I lost no time in contacting these two organisations, which sent informative booklets on chemotherapy. BCC also put me in touch with other women who had experienced chemo—and survived to tell the tale.

Adjuvant chemotherapy is a sys-

temic treatment—that is, it treats the whole body, unlike radiotherapy, which is precisely targeted. It kills any stray cells and reduces the chance of recurrence. As it affects all cells, various side-effects are unavoidable until the normal cells recover.

My regime was the standard for breast cancer: CMF (Cyclophosphamide, Methotrexate and 5-Flourouracil), twelve treatments in all, over six months. I could have opted for another shorter regime, AC, which would definitely have meant losing

poned until they recovered. White cells fight infection and I therefore had no immunity and was vulnerable to any stray bug.

When the count was abnormally low for the second month running, my oncologist decided to take action and put me on GCSFs (Granulocyte Colony Stimulating Factors). These work by encouraging your bone marrow to produce more white cells. The drawback is backache and limb pains as the bone marrow reacts. GCSFs are administered by a single-dose pre-filled syringe. After one short "lesson" with the district nurse, I could give myself the injections, thus saving a trip to the doctor's surgery every day.

When my husband and I decided to take a two-week holiday abroad in between treatments at this time, there were some minor obstacles. I acquired a letter from my oncologist stating that the syringes were for medical use—I didn't want Customs to think I was a drug addict! I also used a cool bag with special hospital-supplied icepacks to keep the contents cold while travelling. Our hotel room had a minibar where I was able to store the medicine.

If you've read this far, you are probably still asking yourself what this has got to do with bowel disease. My oncologist supplied the answer. It appears that my previous bowel problems had everything to do with my low white blood count and reactions to the chemo drugs.

If I hadn't been ER-negative, I wouldn't have needed chemotherapy. If I hadn't had bowel problems, it wouldn't have reacted on me the way it did. Ain't life strange?

Sandy Hyams



my hair. (As my regime was mild, it caused only negligible hair loss). I had read about all the possible side-effects and was prepared for the worst, most of which never happened.

My reactions to the cytotoxic drugs were not severe enough to disrupt my life, though each month brought another minor side effect. By the third month, though, my body said: that's enough, and stopped producing white blood cells. My blood count and neutrophils count dropped alarmingly and my treatment had to be post-

Going Nutty in Nepal

What is it about Nepal? It has the world's highest mountain, Mt Everest, and its capital is the lively, bustling city of Kathmandu, source of the first pagoda and the coveted pashmina shawl. Yet no one seems to know anything about this small Asian country. Apart from climbers and clothesaholics.

Whenever I say I spent my summer holidays there, the inevitable replies are: "Neepal, Neepal it's near Iceland isn't it and very, very cold I'm told. You must be delighted to be back," or "That's a North African city isn't it?" Or "I had a cousin who went there once, although I'm blown if I know where it is or what they went for," and so it goes on.

Nepal is in fact a kingdom that is two thirds the size of the UK. It has a population of 27 million and lies between northern India and Tibet in south-west China. Unlike its neo-Arctic image, this sublime country is a blend of the semi-tropical plains of the River Ganges and the harsh and rugged mountain ranges of the Himalayas.

Europeans and Anglophiles go there for two reasons. Trekking and curiosity. In the Sixties, the Lower Himalayas was the world's ultimate hippie trail, a place where the more adventurous could find enlightenment among these magisterial peaks and The Beatles could discover Transcendental Meditation in the Himalayan foothills.

Having got over an early TM phase, my cause was a far more prosaic one: a visit to my niece in Kathmandu. After a 16 hour flight, I wanted to do everything: white water rafting on the River Tamur, an elephant ride or two

in Chitwan National Park and a visit to the Taj Mahal, a mere one-and-a-half flying hours away in New Delhi. I settled for something local: a six day trek around Mount Annapurna, named after the Hindu goddess of fertility and the world's second highest peak.

Serious climbers and trekkies will tell you this is a soft option. It may have several longish walks and climbs, but there is no genuine hardship on this route—apart from the first day that is! Himalayan toughies spend an energy-sapping 20 days of mountain-scaling to the valley of Jomsom, capital of the Annapurna region, and then down again to the hot springs of Chame. Or they make the notorious ascent to Everest Base Camp.

I ignored Everest and followed a more gentle route to Michael Palin Camp instead. The ex-Monty Python star who had made the Nepal part of the TV film 'Himalaya' (did any of you see it?) a month before, went the same way as I

did refusing to budge each time the television cameras ranged over that rocky ledge of legend. One Irish group



who did were called the "Nepal Praying Trek". It might just prove handy if the weather turns treacherous, I mused.

After Kathmandu, I flew to Pokhara, a sort of elongated restaurant next to a three mile lake, and saw a tribute band play one of the finest versions of The Who's 'Tommy' I've ever heard. When a few of us bought them some beers in the interval, the singer Roger the musical Bodger suddenly went up-tempo and turned into Roger Daltry.

Unlike the band, I went solo, trekking with a guide, a charming, highly intelligent young Nepalese called Tek (without an 'r') whose frail English was more than discounted by his wicked sense of humour. More importantly, we got on very well. We needed to. In spite of Tek's obvious diplomatic flair, we were almost turned back at the first checkpoint. I'd left my Annapurna Conservation Area pass in Kathmandu and it took more than



two hours of negotiations and at least eight phone calls to confirm that I did in fact have one.

Things could only improve—and



they did after six hours of walking, clambering and climbing to Hille, a mountain village with little more than two beds and a bus-stop. The uncompaining Tek could have done with a bus, particularly as he had carried all my overnight gear. We spent that first night and every other one in tea-houses wooden mountainside shacks with basic food, running water (cold) and iron bedsteads. It was better than camping and set me off on a six-day noodle soup habit.

The weather was consistently dull apart from one sparkling morning which made me seize my digital cam-

era in a sort of gleeful frenzy and snap all four Annapurna peaks at once. It didn't take long for things to revert to decidedly dull, though. But then I was only there for the peace: a glorious and soundless aura of undulating valleys and majestic, snow-clad peaks. It's easy to imagine people finding nirvana here—or losing their marbles altogether.

The Nepalese are unfailingly friendly and hospitable and even let me play pool on their coveted table in Ghorepani, the town where most of the world's Ghurkas were raised. Just under 3,000

metres high and perched at a gravity-defying angle on a mountainside, the town was once the headquarters of the Nepal Maoists, a left-wing group that aims to overthrow the government. Their tactics are aggressive and range from "disappearance" to death. So far 10,000 people have died, though very few of them were

tourists. Each trekker must have 1,200 rupees (£9) protection money ready for an impromptu meeting. Maoists usually approach you in pairs and are disarmingly smartly-dressed and polite. Refusal however means a couple of months in a secret compound. You pay. I was never approached, though a few of the Antipodean, German, French, Israeli and British trekkies I met were.

On the last day, I had another blessed hour of sunshine. I gazed over a rocky river valley and thought that this could never happen in England. But then I didn't really want it to. Whenever I see that small patchwork of fields and villages around London from the plane, I feel fulfilled: a man content with his memories.

Christopher Browne



Land of the Big Wee

The World of Babies centre, sponsored by Procter & Gamble, which visited London in January 2005, aims to show life through an infant's eyes. The interactive experience includes a 'womb room' and a big loo.

We hope no-one's allowed to get too interactive on the toilet! The installation will be visiting other sites in the UK between now and March.

Dates and Locations

London (25-31 January)

London Zoo
Outer Circle
Regent's Park
London
NW1 4RY

Newcastle (8-12 February)

Life Science Centre
Times Square
Newcastle upon Tyne
NE1 4EP

Glasgow (19th-23rd February)

Braehead Shopping Centre
Kings Inch Road
Glasgow
G51 4BN

Birmingham (3-7 March)

Millennium Point
Digbeth
Birmingham



Manchester (15th-20th March)

Trafford centre
Barton Dock Road
Manchester
M17 8AA

Entry is free, but booking is essential. Contact 0800 106098 for more details.

Results of Expectations Survey

Actual results are shown after each potential option, with percentage figures in brackets following.

Q1 For what reason did you have a pouch? 1. Ulcerative colitis ... 43 (88%) 2. Familiar polyposis or similar 4 (8%) 3. Other 2 (4%)	Q5 How has your work experience matched up to your expectation? 1. About what I expected 24 (49%) 2. Better than expected 12 (24%) 3. Much better than expected 2 (4%) 4. Worse than expected 6 (12%) 5. Significantly worse than expected 5 (10%)	Q9 How has your social life experience matched up to your expectation? 1. About what I expected 20 (41%) 2. Better than expected 14 (29%) 3. Much better than expected 6 (12%) 4. Worse than expected 6 (12%) 5. Significantly worse than expected 3 (6%)
Q2 What did you imagine life would be like after your pouch operation? 1. As a healthy person's – with one or two visits to the loo a day 7 (14%) 2. Much better than when I was ill, though with the occasional problem 21 (43%) 3. Better than before, but with some spells of illness and discomfort 6 (12%) 4. I had no preconceptions 15 (31%)	Q6 How did you think the ileo-anal pouch would affect your relationships? 1. I didn't think it would have any effect 16 (33%) 2. It might cause occasional difficulties due to odd spells of illness 13 (27%) 3. It would mean making adjustments with my partner or any future partner 8 (16%) 4. I didn't think about it 12 (24%)	Q10 What expectations did you have of long journeys and overseas travel after your closure? 1. Straightforward and incident-free 5 (10%) 2. Slightly affected by loo visits or discomfort 29 (60%) 3. I would be less inclined to make a long journey or overseas trip 9 (19%) 4. I had no preconceptions 5 (10%)
Q3 How has your general experience matched up to your expectation? 1. About what I expected 10 (20%) 2. Better than expected 16 (33%) 3. Much better than expected 10 (20%) 4. Worse than expected 11 (22%) 5. Significantly worse than expected 2 (4%)	Q7 How has your relationship experience matched up to your expectation? 1. About what I expected 26 (53%) 2. Better than expected 9 (18%) 3. Much better than expected 6 (12%) 4. Worse than expected 4 (8%) 5. Significantly worse than expected 4 (8%)	Q11 How has your travel experience matched up to your expectation? 1. About what I expected 22 (45%) 2. Better than expected 12 (24%) 3. Much better than expected 7 (14%) 4. Worse than expected 5 (10%) 5. Significantly worse than expected 3 (6%)
Q4 How did you view your post-pouch prospects for work or full time parenting? 1. I would go back to full-time employment/parenting 24 (49%) 2. I would go back to work but at a slightly slower pace/coping with parenting in the same way 13 (27%) 3. I would work part-time/think twice about having children 3 (6%) 4. I didn't consider it .. 9 (18%)	Q8 What impact did you think a pouch would have on your social life? 1. None whatsoever . 12 (24%) 2. I expected the odd embarrassing moment or cancellation 25 (51%) 3. I would go out less 6 (12%) 4. I didn't consider it 6 (12%)	Q12 Did you intend to be open about your pouch with your friends and work colleagues? 1. Yes 32 (65%) 2. No, unless they specifically asked me about it 12 (24%) 3. No, as it might affect my career/social life life/relationships 2 (4%) 4. I hadn't thought about it 3 (6%)

Q13 And what's your experience of this?

1. About what I expected
35 (71%)
2. I've been more open than expected 6 (12%)
3. I've been less open than expected 5 (10%)
4. Other (please state) ... 3 (6%)

Q14 How has your temperament changed as a result of having the pouch?

1. Generally the same
..... 24 (49%)
2. Am happier now .. 11 (22%)
3. Am much happier now
..... 7 (14%)
4. Am less happy now
..... 5 (10%)
5. Am much less happy now
..... 2 (4%)

Q15 Overall, has the pouch lived up to—or even exceeded—your expectations?

1. Yes, it has improved my life
..... 23 (47%)
2. It's generally an improvement, although I've had one or two problems 20 (41%)
3. No, the pouch has reduced my quality of life 4 (8%)
4. The pouch has severely reduced my quality of life 2 (4%)

Q16 How do you view the future with your pouch?

1. I am very optimistic
..... 21 (43%)
2. I am content enough as it's been a reasonably good pouch, and I can cope with the odd blip 23 (47%)
3. Passable – though I can't do some of the activities I once took for granted 4 (8%)
4. I am considering reconstructive surgery or an ileostomy to make life more bearable 1 (2%)

Male replies 15 (31%)
 Female replies 34 (69%)
 Total replies 49
 Average age 50.5 years
 Average pouch age 8.5 years
 Surgery at St Marks 15 (31%)
 Surgery elsewhere 34 (69%)

Survey Analysis

Many thanks to the 49 people who completed the survey included with the last issue of the newsletter. Although this does not sound like a high number, it represents around 15% of our total membership, and so is in fact an excellent response rate.

What is really interesting, though, is that so many of the replies were positive or average, rather than negative. One of the dangers of requesting input from members of any support group is the risk that you may only hear from those who have had an extreme (for which read “bad”) experience, since they have most to say. That can end up giving an unbalanced picture overall. However, I'm pleased to say that this is not the case here.

As I said, we had 49 replies, 15 (31%) from men and 34 (69%) from women. My recollection of previous surveys is that a ratio of approximately 2 women to 1 man is the normal level of responses. I don't think this is representative of our database or of pouch surgery in general, but more reflects the fact that women are more likely to complete such surveys than men. So, lads, come on: we need you to talk to us more!

2:1 is funnily enough exactly the same split of figures for the location of your surgery. Although the Red Lion Group started life as a support group specifically for St Marks' patients, it has long since embraced many other hospitals. 69% of our respondents had their surgery done elsewhere, twice as many as had their surgery done at St Marks (either City Road or Northwick Park).

The average age of our respondents was 50.5 years old. The youngest was 26 and the oldest was 73, but most were in their 40s or 50s. And the average length of time the respondents had a pouch was 8.5 years. Which means our average age for the surgery was 42 years old. Most (88%) had a pouch because of ulcerative colitis, 8% because of familial polyposis of some kind, and 4% for other reasons.

Enough of the basic facts and figures. The rest of the survey was devoted to your original expectations, and how closely these were matched by your subsequent experiences. This makes the survey a fairly subjective exercise, and no less interesting in the

light it sheds, as a result.

There were a few mistakes I made in putting together the survey, for which I apologise. First of all, it assumed that you had enough time to have expectations in the first place. But of course if you had emergency surgery, that may not have been the case. “I only had a week or so, just before surgery, to think about what was going to happen” said one.

It also failed to take account of the fact (in discussing work/parenting) that some of you were already retired by the time you had your surgery. And, finally, in discussing relationships and social life, there was no option for you to have an expectation that these might be better, only that it would have no effect on them. For



those who were previously ill, the pouch could indeed have a major positive effect on many aspects of your social life.

As one respondent said: “I had closure 7 years ago, and therefore my memories of what I thought before closure are dim, as life has moved on. Also, for the question about the impact of the pouch on my social life, my automatic response was that it *improved* it, as I had been so ill, but there was no positive response under this question.”

Given these limitations in the survey, thank you all for answering as best you could.

Looking at the big picture, the good news is that the vast majority of people are either very optimistic (21) or content (23) with their pouch and

the future which awaits them – that equates to 90% of respondents. Only one respondent was considering reconstructive surgery because the pouch had been so unsuccessful, with another 4 stating that life with the pouch is bearable but has curtailed some of their activities.

This largely matches perceived level of satisfaction with the pouch: 23 reported that the pouch had exceeded expectations, with another 20 considering it a general improvement, albeit with occasional problems. If that's the case, medical staff ought to be very pleased with an 88% satisfaction rating. Only 2 reported that the pouch had severely reduced their quality of life; although that is 2 more than we would wish, it is a pleasingly low statistic overall.

We also asked about relative happiness, and 49% (24) of you felt that your temperament had not been changed by the pouch – not that this necessarily means you are happy: if you were a miserable git before surgery and remain a miserable git, you would still fall into this category! But, pleasingly, a full 36% of you are happier or much happier since your pouch surgery was done. As one respondent pointed out: "Without the surgery, I'd be dead so – yes – you could say I'm much happier now!" Fair point.

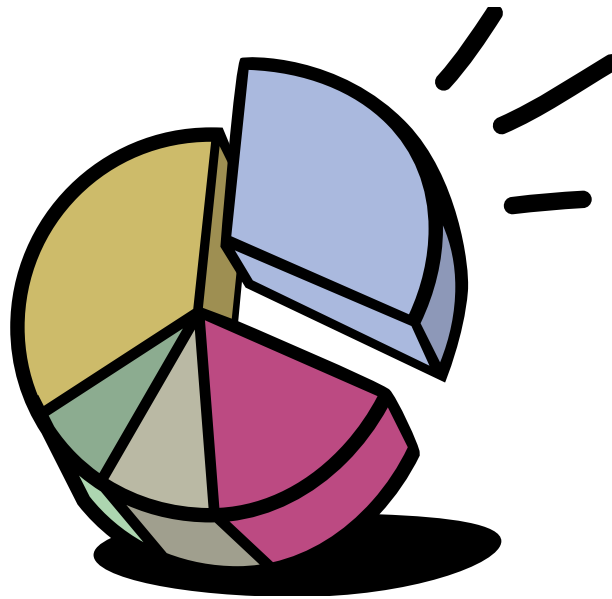
Of the 2 respondents who are much less happy now, one had generally expected life to become normal in most respects but in almost all areas found his experience to be significantly worse than this. No wonder he feels let down and much less happy now.

As for the other respondent, her expectation was that her quality of life would be at least comparable to when she had her ileostomy. Four years on from her surgery, she has not been able to work due to poor health, and is now considering going back to her ileostomy, which she wished she had stayed with in the first place. For her: "My whole life has dramatically altered. I was well with an ileostomy and had a life; now I have very little and life is very miserable and a real struggle." Again, her reasons for be-

ing much less happy are quite clear.

Rather than provide a detailed analysis of the percentages in the specific areas of work, relationships and social life, I refer you to the figures shown in the breakdown. In each area, the vast majority of people expected things to improve to some degree, and for most they either improved or at least stayed as before.

However, when collating the letters we invited as part of the survey, one theme came over again and again: *tiredness*. Even people who are happy with the pouch, because they prefer it to either an ileostomy or to being



dead, are simply exhausted all the time. Transcribing some of the letters for this newsletter has been an emotive experience, especially when I read about the lady who prepares her family's tea at breakfast time because she knows she will be exhausted by tea time.

Clearly, tiredness is often down to a lack of deep sleep during the night – any mother with a child under 2 knows all about that! The waking periods don't have to be long, but they prevent your body from reaching the level of deep sleep which is regenerative. Unlike the usual family cycle, where your toddlers start to sleep better as they get older (until it is almost impossible to remove them from their bed, during their teenage years, I'm told), and so your own sleep patterns re-settle, pouch owners needing to go to the toilet more than once a night are constantly being denied that deep sleep. There is a good

reason why sleep-deprivation is a form of torture adopted in many parts of the world and that is because it works.

I have asked Joanna Wagland, our pouch support nurse, to look into this issue in particular, to see if the causes of this tiredness (such as B12 deficiency etc) are treatable, or what the best ways to handle it are. By the time this newsletter is in print, Professor Winston's programme about tiredness will have been shown on the TV, and I hope it has some tips which may help some of you.

Perhaps the clue is in mental preparation. Those who are happiest with their situation are not necessarily those whose post surgical experience is closest to "normal", but those whose prior expectation has not been disappointed. If you had appreciated the possible negative impacts on your life after having the pouch, and then had these, you would probably feel less upset about this than if you had believed the pouch to be the "magic pill" which would solve all your ills.

This was summed up nicely by one female respondent who said:

"My general expectation was that things would be better than before. I didn't *expect* to be one of the fortunate ones, and was quite prepared for things to be considerably worse than they have been.

"... I did feel I was well prepared by the gastroenterologist, IBD nurse and stoma nurse where I was being treated, even though the surgery was carried out elsewhere. The variance in outcome from the surgery was properly explained (as was the surgery and immediate effects) and I was given the opportunity to talk to all manner of people and ask whatever I wished. I just knew by then that it had to be and I might as well get on with it!

"I am a very happy bunny – I am amazed by what can be done and what a difference it has made to me." This is a textbook case of how it should be done in an ideal situation: time to ponder the likely outcome, be informed about possible complications and to speak to other people about their experiences.

Letters

Dear Editor

Having the pouch has given me a lease of life I would never have had. I am quite convinced that without it I wouldn't be alive today. I had been suffering with ulcerative colitis since my early twenties, but took tablets to control it and carried on with my life.

After the birth of my son, the ulcerative colitis came back with a vengeance. I became very ill and couldn't leave the house or look after my baby, which was awful. Finally, after many stays in my local hospital and many different drugs which didn't help, I had the pouch operation done

pouch made out of my large bowel, I wouldn't be alive today. But, as it took my GPs 6 ½ years to send me to hospital, the illness was totally out of control. I was first ill in July 1985.

My consultant, Prof MRB Keighley, saved my life at the QE Hospital in Birmingham. But since the first operation in 1992 and then the pouch operation in 1993, I have had numerous operations.

The illness has left me with osteoarthritis in my left side and no feeling in my left leg. I fall over all the time with a balance problem. I'm told this is caused by all the drugs which I have been given since the start of my problems in 1985. They have affected the balance part of my brain.

Although I am a classed and registered Disabled, I still barely get enough money to live on (less than £4,000 a year), and cannot afford to pay for a subscription to the Red Lion Group.

My life, such as it is, isn't very good any more at all. I'm just waiting to die now—my illnesses are slowly killing me. In my case, it will be a relief to go. If I

had been sent to hospital in 1985, perhaps things would have been different for me.

John Drasar

Dear Editor

When you first have a pouch constructed, you have no idea how to use it. I had mine fitted in June 1998 and only now—6 ½ years and much mess, laundry and humiliation later—I have learned various things about mine:

1. Trying to use it like an ordinary bowel—e.g. straining to empty it—sends it into absolute chaos. At these times, it is extremely hard to control it and impossible to stay continent;
2. The longer I delay, by "holding on", when it has decided it is filling up, the more likely it is to play up by not emptying properly or by leaking;

3. Generally eating much less is both helpful to my pouch and also to my weight, as is sticking to low fibre and low fat foods;

4. One thing I wish I'd known sooner was where to get incontinence pads/aids for its dysfunctional times.

I didn't know about any of the above at the time, despite reading everything available. But then I suppose everyone's pouch is different, and you have to find out what works for you.

Female survey respondent

Dear Editor

I read in the latest issue of *Roar!* a letter from a gentleman in which he describes how exhausted he becomes.

I work full time in a nursery with the under two's, and most nights by ten o'clock my eyes are closing.

I saw my consultant recently for the first time since 2001. I brought up this point, and he said unfortunately this is a side effect of the pouch surgery. He has also ordered a blood test for my B12 levels, as he said this can deplete over time with a pouch, and lead to tiredness.

Female survey respondent

Dear Editor

Thanks for all your work on the magazines. It's a fine magazine—I read it from cover to cover as soon as it arrives. It is always interesting and often I can learn something new.

Male survey respondent

Dear Editor

I'd be interested in a survey about sex post pouch. Certainly, I feel my sex life was much better, even coping with a bag, than has been the case with the pouch. I do feel my libido has been seriously affected.

I did have a lot of problems in the first year, including a constant urging to go to the loo, which was an awful strain and hardly conducive to relaxation. The difficulty in conceiving that many have experienced suggests to me that some subtle change happens with sexual function post pouch surgery.

Thanks for all your good work.

Female survey respondent



in three stages.

It was done at a private hospital because, at the time, my husband had medical cover for the family with his job. The pouch worked very well right from the start, my only significant problem being obstruction from time to time, due to adhesions.

When I was well enough, we tried to have a second baby, but I was unable to conceive again, in spite of having some fertility treatment. Internal scar tissue has been mooted as a possible cause.

In spite of the few problems I have had, I haven't regretted having the pouch done. It has given me my life back, and I would anyone to go for it!

Judith H

Dear Editor

Without the pouch, a colonic J-

Dear Editor

I have suffered discomfort in my feet, and pain and weakness in my thighs since my colectomy. I have had a worsening of muscle and joint pain and have been unable to ride my cycle or climb a ladder. Although I do not have pain or bleeding from my gut, I still have 10+ bowel movements a day, despite Loperamide. I always have to get up during the night at least once.

It amazes me that I have put on 1 ½ stone (unwelcome!), but the consultant won't consider me dieting.

This all sounds very negative. However, I am very glad Mr Thompson persuaded me to have the pouch, as I found life with an ileostomy unbearable. I was suicidal, and I could never consider returning to one.

Mrs C A Tudor

Dear Editor

I have found the tiredness one of the hardest problems to cope with. I have now reached the menopause, so this has made my life and tiredness more difficult to cope with. Adding the 3 or 4 times a night trips to the loo to the 2 or 3 times a night hot flushes, and I feel I never get any significant sleep. Any tips from women of this "certain age" in *Roar!* would be very much appreciated.

I don't want to take HRT, and the consultant said my pouch inflammation should improve because of the hormone changes. I've yet to experience the advantages of that.

I read *Roar!* from cover to cover and look forward to the result of this survey.

My 10 year old nephew is now going through ulcerative colitis, and I hope it won't come to surgery, but it's very much on the cards. What will life be like for him at such a young age! Let's hope he can benefit from the cure in the Tale of Three Professors.

Female survey respondent

Dear Editor

I have found, since having surgery, my energy and stamina levels are much lower. Since my early forties, I've exercised by way of regular jogging (at one time it was running—now, I wish!). I managed a couple of full marathons and four half marathons over the years. No way could I do that now. In fact, I struggle to do a 2 mile jog.

I get tired very easily, and often indulge in daytime "cat naps". Having said that, I would probably be doing that anyway, and must be thankful for the quality of life I do have enjoy, compared to the suffering endured by many other poor souls.

Male survey respondent

Dear Editor

After being ill with problems after my pouch operation for about 5 years, it is just lovely to be able to say

I am well. How well is questionable. I can't work full-time, only very part-time, because I'm so tired.

That is my biggest problem. I can't put as much into life as I did before my

pouch operation, or as much as I'd like to. I don't mind going to the loo 7-12 times a day. I do mind having a sore bum.

If I could change one thing, it would be to have more energy to do the things I want to do. I prepare the family tea in the morning, in case I don't have enough energy at tea time, and 9 out of 10 times I don't.

I go to bed for half an hour to an hour five days a week. This helps. If I don't do that, I would have to go to bed at 7pm, which isn't fair on my family.

I've had a bag twice. Both times, I've found it to be a pain. It often fell off or leaked, filled up and showed under clothes, or was uncomfortable in bed. And always having to wear

large pants, to keep the bag in place, was horrid. Oh, happy times!

But thank God I'm still here. I wouldn't have been, that long ago, when medical operations would not have been able to save me. I am truly grateful.

Jackie Brooks

Dear Editor

I would like you to know I have had a post-pouch baby. A little girl born on 11 February 2004, after two years of trying!

I had an elective caesarean at Southmead Hospital Bristol, performed by a wonderful consultant, Mr Wrdele. He sorted out my right ovary, as it was completely caked up with adhesions from surgery. I had contact from one of your members, Ali, who was a great help as regards pregnancy and birth – so a big thank you to her.

Buddug Green

Ed's note: I remember talking to Buddug some years ago about her concerns about her ability to get pregnant etc, and put her in touch with Ali. I am so pleased to hear of the happy outcome!

Dear Editor

I had my pouch at the age of 25, after four years of colitis. I didn't hesitate to opt for surgery, or think about any complications regarding relationships, child bearing or socialising. It was only afterwards, when I thought about my future with a pouch.

Luckily, I have had a well-behaved pouch, only occasionally having had small problems of my pouch needing to be stretched. My surgeon, Mr Terry Irwin, is always easy to talk to, and to quickly put right any problems I seem to have, after just a phone call.

I am now a mother of a seven month old baby boy called Max. All during my pregnancy I was well, and my pouch gave me not one problem. Mr Irwin was present at the birth of Max, who was delivered by c-section. The obstetrician who delivered Max commented on how neat the pouch was, with very few adhesions or scar tissue. My pouch has served me well so far, and long may it continue.

Laura Greer



My Story...by Wendy Hind

I had my surgery back in February 1988 and consider myself to be a very lucky recipient of my pouch. I was very ill with ulcerative colitis for 7 years, and had a young family to cope with. I was a very regular visitor to hospital and recipient of blood transfusions before surgery.

When my daughters started school, I decided I needed to work, and found a job as a teaching assistant at a school. This was one year after surgery, and I felt great.

I loved being able to work, as I had thought that I wouldn't be physically able to hold a job down. But I did so for about 15 years.

Last year I decided it was time for a change. Our eldest daughter was travelling in New Zealand, and my youngest was in the second year at university.

I was pleased to get a job in a young offenders' prison. This has certainly been a change in direction and quite a challenge. I love it, and feel I have a lot to offer. The staff are brilliant.

My change in job means full-time hours and no school holidays, so I don't get the rest I used to get – working in the school, I had a week or more off after every 6 or 7 weeks. I really don't know if this has made me feel tired and exhausted, or if something else has contributed to it.

I put up with feeling out of breath, tired and lethargic for weeks and weeks. Recently, I gave in and went to my GP, who sent me for blood tests. These showed that I was well into my menopause (which I knew – I am 46),

and my Hb was low, so I am anaemic. There is also a query about diabetes, for which I am awaiting results. To cap it all, I have also been diagnosed with osteoporosis in my spine and hips. I take HRT now for the menopause and 4 x 60mg of codeine phosphate daily, plus 4 x 60mg of loperamide.



I feel a bit of a wreck at the moment. I went to visit my wonderful surgeon, Mr Knox – whom I can't praise enough. My pouch was troubling me, and I was up 10-15 times a night, emptying my pouch, going

back to bed, only to get up 15 minutes later with urgency to go again, only passing small amounts. Was it this making me so tired?

I visit the loo 7-10 times daily, which I can cope with, but the night times were getting to me. I have been advised to take a month off work and I will go in for an examination under anaesthetic and pouchoscopy, to see why I am experiencing this level of frequency. Mr Knox thinks it is mechanical and can be corrected. I hope he is right, and I have every faith in him.

As a consequence of having time off, I can write to you, as normally my days are so hectic with work and running a home. I consider myself very lucky. I would not be without my pouch, and the possibility of a permanent ileostomy does scare me – not for aesthetic reasons but because I was allergic to all the adhesives on the bags when I had one, so had leakage and discomfort during my months of "hell".

But I won't let myself go there. I am always positive and don't let things get me down. I only have to look back to when I had ulcerative colitis to realise how lucky I am. I do hope hearing my experience helps somebody somewhere.

Dan The Man

What do bodyguards do in those long, lingering hours between work assignments? They doodle, of course. Just ask 32-year-old Dan Staveley from Folkestone, Kent.

Dan knows a lot about doodling and if you've got a wedding, birthday or anniversary approaching, speak to him and he'll create a card for it, too. Several years ago, the 6ft 7in bodyguard could have designed a 'Get Well' card for himself.

For while he was guarding a famous politician, Dan collapsed with rectal bleeding and was later diagnosed with anaemia.

Last year, Dan's illness went a stage further. He developed polypoid. It means another long wait between assignments for the 16-stone



bodyguard—only this time instead of guarding a politician he will be going into London's Middlesex Hospital for colon surgery. His visit will be something of a unique one as he is one of only 22 patients in the UK to have a Whipple operation*.

Until then, Dan will be doodling for Britain, of course. "I drive my partner and my little boy to distraction, particularly when we are watching a film or some other form of entertainment on TV, and there I am drawing away, oblivious to everything else that's going on around me," says

Dan.

Not long ago he started going to drawing classes at a local craft club. "People are always surprised when I tell them I design cards, as they don't associate such a delicate hobby with a big man who used to work in a very tough trade. I find card-making very addictive, though. It doesn't need a lot of artistic talent, just a bit of imagination," he says modestly.

As a bodyguard, Dan covered key diplomatic and VIP events, protecting politicians and businessmen from hijacks and ransom attempts. "Sometimes I looked after singers and actors, but though many of my friends think the job was all glamour like the role played by Kevin Costner in the film 'The Bodyguard', I spent most of my time hanging around in ante-rooms," says Dan, who joined Red Lion last year.

However it was in some of those between-jobs moments, as he calls them, that Dan acquired the card-making habit, putting it to good effect recently when he sold some of them at two local car-boot sales and raised funds for Red Lion.

After his operation, Dan who has been studying IT at the University of Kent in Canterbury for 18 months aims to finish his degree and move into computers and website design—between doodling bouts of course.

* *Whipple operation.* Complex surgery in which the head of the pancreas, part of the bile duct, the gall-bladder and the duodenum are removed. The remaining parts are sutured back into the large colon.

Christopher Browne

Treasurer's Position Coming Vacant

We are *very sorry* to hear that John White will be stepping down as Treasurer after this year's annual general meeting, and would like to thank him for the sterling work he has done for us over the last few years. Every year he mentions retiring, and every year until now we have managed to persuade him that he doesn't want to really. However, he's now made a final decision, largely for health reasons.

On a personal level, I know he inherited enough disorganisation from my time as Treasurer to last anyone a lifetime. In addition, he has earned us lots of "free" money, by ensuring that as many people as possible signed the form enabling us to claim back the tax on their subscriptions over previous years. A previous life as a bank manager has certainly come in handy!

So, whoever takes over from him will have the advantage of acquiring a completely organised system and set of records.

The Treasurer's role includes:

1. Liaising with our Membership secretary, to ensure renewal sub-

scriptions are paid promptly (and encouraging people to pay by standing order);

2. Thanking donors for their gifts to the Red Lion Group;
3. Dealing with tax reclaims;
4. Producing basic financial accounts which agree to the source financial records;
5. Completing documentation for the Charity Commissioners;
6. Keeping the committee informed about the financial situation.

If you could do this job for us, please do get in touch as soon as possible.

Being Treasurer does not involve any travel beyond the very occasional face to face committee meetings (usually one a year at the time of the AGM).



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, Mr John White, 44 France Hill Drive, Camberley, Surrey GU15 3QE

**Red Lion
Group
Information
Day**

**Saturday
30 April 2005**

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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

Visit Our Website

www.redliongroup.org

Write for Roar!

Have you had any interesting or amusing experiences that you think other people with pouches might want to read about in the Red Lion Group's newsletter *Roar*!?

We are particularly looking for pouch-related articles, but we are happy to publish practically anything.

Perhaps you've taken up a new hobby since having your

pouch operation? Or are there any clever little tricks or diet tips you've picked up that you'd like to share?

We'd even be willing to publish an article about why having a pouch was a bad idea.

Even if you've never been published before please send us something.

You'll get the satisfaction of seeing your name in print and you

may give hundreds of fellow pouch people an insight into an aspect of their condition they hadn't noticed before. Most important of all you'll make the life of the newsletter editor a little bit easier.

If writing articles isn't your scene we are looking for other things too, including cartoons, crosswords and jokes.

With your contribution we can keep the newsletter bursting with life and make reading about pouch issues fun and stimulating.

