

# ROAR!

**ISSUE 28 • SPRING 2004**

*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 Red Lion Group rep, please contact Morag Gaherty (phone number on back page).



<b>AVON</b>		
David Mair	Bristol	0117 922 1906
<b>BEDFORDSHIRE</b>		
Wendy Gunn	Luton	01582 423714
<b>BERKSHIRE</b>		
Liz Davies	Langley	01753 586593
<b>CAMBRIDGESHIRE</b>		
Joyce Shotton	Peterborough	01733 706071
<b>CLEVELAND &amp; NORTH YORKSHIRE</b>		
Christine Jackson	Saltburn	01947 840836 chrisjacks@supanet.com
<b>CUMBRIA</b>		
Jonathan Caton	Kendal	01539 731985
<b>DERBYSHIRE</b>		
John Roberts	Derby	01332 361234
<b>DEVON</b>		
Gill Tomlin	Kingsbridge	01548 810028
<b>DORSET</b>		
Clive Brown	Bridgeport	01308 458666
<b>DYFED</b>		
Briony Jones	Haverfordwest	01437 765359
Bruce Dibben	Haverfordwest	01437 731436
<b>ESSEX</b>		
Peter Zammit	Benfleet	01702 551501
Clare Shanahan	Ilford	01708 444359
<b>HAMPSHIRE</b>		
Phil Smith	Portsmouth	023 9236 5851
Les Willoughby	Winchester	01962 620012
<b>HERTFORDSHIRE</b>		
Carol George	Stevenage	01438 365707
Susan Burrows	St. Albans	01727 869709
<b>KENT</b>		
Phil Elliment	Barnehurst	01322 558467
<b>KENT (WEST)</b>		
Rosalyn Hiscock	Pembury	01892 823171
<b>LANCASHIRE</b>		
Joan Whiteley	Clitheroe	01200 422093

### MERSEYSIDE

Blanche Farley Liverpool 0151 924 4282

### NORFOLK

Sandy Hyams King's Lynn 01485 542380

### NORTHAMPTONSHIRE

Cynthia Gunthorpe Kettering 01536 482529

David Smith Northampton 01604 450305

### NORTHERN IRELAND

Sharon Hendron Lisburn 02892 661559

### SOUTH LONDON

Andy Jones SE6 020 8690 1360

Jonathan English SW12 020 8673 3092

### SUFFOLK

Anna Morling Leiston 01728 830574

### WEST LONDON

Dee O'Dell-Athill W10 020 8960 6726

colin@odell-athill.demon.co.uk

### WEST MIDLANDS

Linda Bowman Birmingham  
0121 766 6611 ext 4332 or pager 0027

### WILTSHIRE & DORSET

Bernadette Monks Salisbury 01722 327388

### YORKSHIRE

Neil Anderton Leeds 0113 258 2740

Sue Appleyard Huddersfield 01484 641227



## The Worm That Churned

Did you know that worms hatch from eggs? If you've ever tried keeping a wormery, to help with your kitchen waste, you'll know this. But the chances are, most people had never asked themselves that important question. You'll not have noticed them in the garden, because they are only about 1mm across, but keen gardeners will spot them in the soil now that I've mentioned them – little balls of a slightly yellow/green tinge. That's worm eggs for you.

So, you'll be asking, why is it important?

Well, it turns out that there's a woman in Iowa, in the USA, who drinks a regular solution containing worm eggs as part of ground-breaking research into ulcerative colitis.

She takes a glass once every three weeks, and says her terrible cramps and sudden, intense attacks of diarrhoea have stopped. Since taking the brew, she has been in remission.

Not surprisingly, she says it helps to think of the concoction as medication rather than as something alive!

The worms grow inside her gut and then pass out through her faeces after a few weeks. Just in time for the next intake.

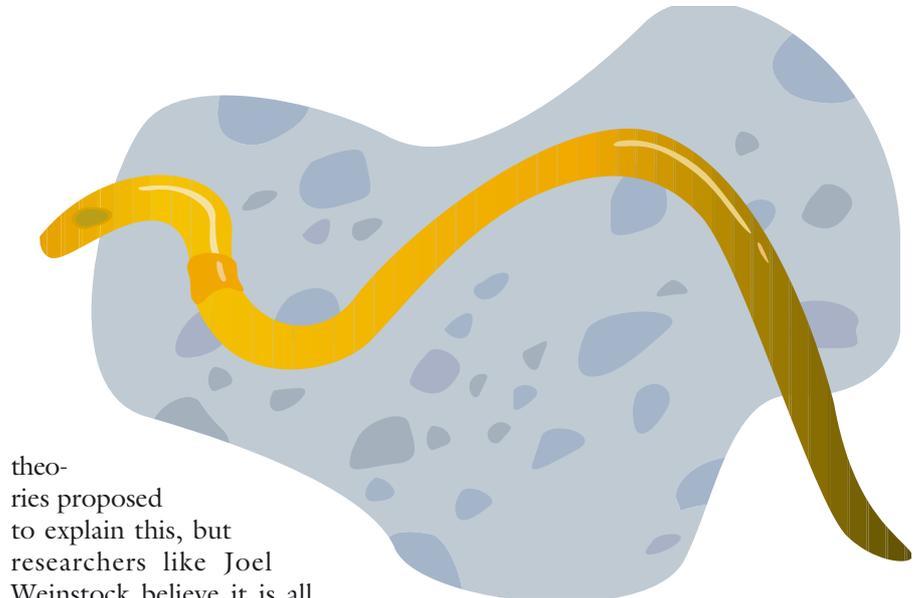
Before you all rush out with a spade and start looking for worm eggs, I'd advise you to read on.

These are not ordinary worms we're talking about, but gut worms. They were eradicated in the West about half a century ago, probably as a result of better sanitation. Nobody thought there could be a plus side to having them, so no-one realised the implications of eradicating them. Come to think of it, no doubt no-one thought about them at all.

Dr Joel Weinstock, specialist in bowel disorders – and the man who gives out the gut worm drinks – has a theory that the gut worm is a parasite which has evolved with us, and which is actually needed by our bodies. He says "Worms require humans to survive. In essence, the worms are part of us and it's possible that we've become interdependent, and removing worms has resulted in an imbalance to our immune systems."

There are many unknowns about ulcerative colitis, but one thing that is known is that it is a disease of the intestine caused by the immune system over-reacting: the white blood cells mistaking the gut for a foreign invader and attacking it.

As well as ulcerative colitis, allergies also barely existed fifty years ago but are endemic now. There are many



theories proposed to explain this, but researchers like Joel Weinstock believe it is all part and parcel of the same change in our body environment. Allergies are also generally recognised as being the result of an over-reaction of the immune system.

Mind you, it's not just gut worms claimed to be beneficial.

One UK academic researcher accidentally picked up hookworms while on a foreign field-trip. The hookworm is found in damp earth or water droplets, and when it makes contact with skin it burrows through the skin and then locates the gut, where it attaches itself to the gut wall and drinks blood to live.

Alan Brown (host to the hookworm family) is not unhappy about his hookworm infestation, as he says it has virtually eliminated his hayfever. In fact, he's working on developing an asthma drug from the knowledge he has gleaned.

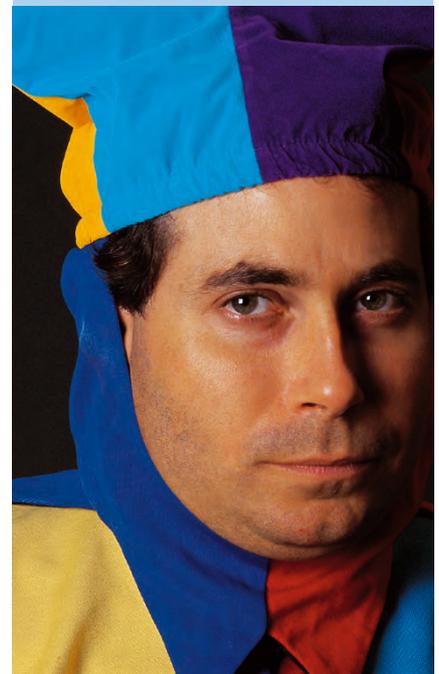
However, not all are so thrilled. "My wife's horrified", he said "– she's totally convinced that one day I'm going to infect the whole family".

Mind you, it's probably not that which horrifies her, so much as the fact that he checks his own faeces under the microscope to see how big his inner family is. He reckons it's about 300-strong at the moment.

Give me the egg drink any day!

*Morag Gaherty*

In need of a click?



Visit our website

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

## Editorial

Welcome to the current issue of *Roar!*, and I hope the lead story won't put you off your tea. Although it's a bit of a squirmy subject, I rather like the potential low-tech and drug-free approach to solving both allergies and UC which it implies.

Although how you sell the idea to a public which continually tries to ring fence itself from any of the grittier aspects of life by using anti bacterial sprays, and disposable nappies so you do as little thinking about wee and poo as possible (you knew I'd get a mention in one day, didn't you!), I have no idea.

There you go, Mrs Jones – a few worms in the intestines should do the trick .... Oh no, it will have to be marketed more attractively than that!

I'm very much a mother who agrees with the Hygiene Hypothesis (that keeping our children from dirt does no favours for their immune system) – the fact that it supports my non-housework stance is merely a side benefit, I assure you! – so I wonder how much of my children's robust health is due to them having

helped themselves to a few helpful parasites in early years. Who knows? I can't say I'll be rushing to send Alan Brown a poo sample, so he can confirm or deny it! But it certainly confirms my view that over-sanitisation does none of us any favours in the long run.

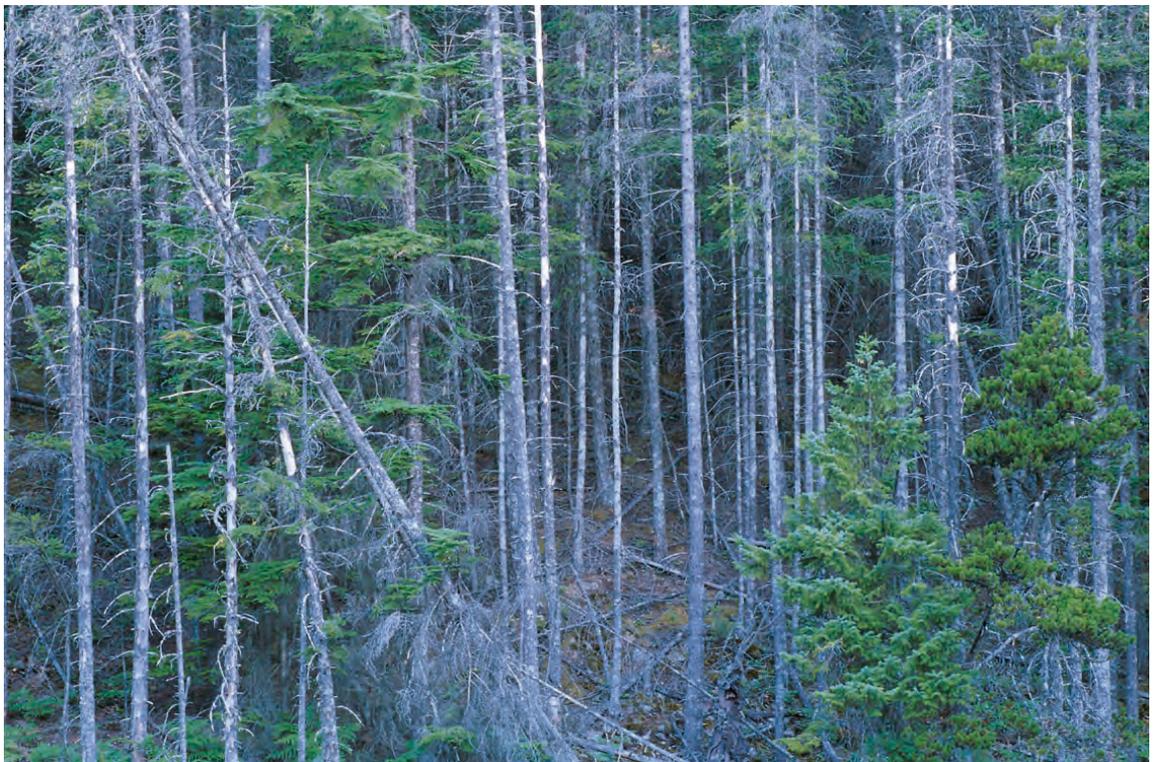
Anyway, let's get off worms for a bit. On a lighter note, Chris Browne has provided us with another quick quiz for the newsletter, and also an article about running a marathon. If you're interested in that sort of thing, why not get involved in the 2005 London Marathon, and run it to benefit your favourite charity. Someone like...oh, I don't know...let's pick a

name at random here...what about The Red Lion Group, for instance? We promise we would organise a Red Lion Group T shirt with a really big friendly lion, for the world's cameras to see. Go on, talk to Chris about it.

And big friendly Red Lions are mentioned elsewhere in the newsletter as well – along with the unspoken word “ouch”. It wouldn't be my choice to have a tattoo, but if you're going to do it, why not have our

involves, and let Chris Browne have all the data he will need to compile his database of contacts.

Thank you to everyone who has contributed to this issue of the newsletter, which I hope will be both an entertaining and informative read. I would like to remind you, though, that we are always after articles and letters. To this end, JLT Risk Solutions Limited, employers of our Chairman Mike Dean, have kindly provided



lovely lion?? We promise not to sue, Kendra, although I think we really must insist on a photograph for a future issue! Given the location of the lion, you'll have to get someone else to take the picture, but if you're as proud of it as you say you are, that should pose no major difficulty.

And talking of spreading the word, Stephanie Zinser, who did so much to increase intestinal knowledge with her book *The Good Gut Guide* ([www.goodgutguide.com](http://www.goodgutguide.com) and available from all good booksellers), has asked Red Lion Group members to consider putting themselves forward as being available to speak on matters related to their illness. Again, see the article for more details about what it

3 pairs of open-ended UCI tickets for the contributor of the best letter to the letters page. These tickets will be distributed with effect from the next issue, giving you all a chance to write in. There are still remaining prizes to be allocated for articles submitted, as detailed in the last newsletter. For this issue, Kate Wright has won the £20 Boots voucher available for her story.

Finally, don't forget the AGM on **Saturday 24 April!** We've included the booking forms with this issue, as well as nomination forms for various posts, and a breakdown of the expected timetable. We so hope you will be able to come, and I look forward to seeing you then.

*Morag Gaberty*

## A Chairman's Farewell From Mike Dean

This year sees the end of my tenure as chairman and I must say I have very much enjoyed the role. It has been extremely difficult for me to imagine, let alone understand, what it is like to be a pouch holder (my wife is the pouchee) but from the experience I have drawn from her and talking to other pouchees, I am now beginning to appreciate what the ups and downs of your life can be like.

It is through groups like ours that pouch holders can find help and sometimes solace either by reading *Roar!* or making contact with other members.

I firmly believe that the RLG has a very important role to play in the welfare of all pouch holders and as a vehicle that can be shared by all. Over the last year we have made contact with many Stomacare Units throughout the country from which we have had a positive response.

Our aim has been to promote the RLG as a help group for any pouch holder, not just for St Mark's patients.

The Information Day programme I believe covers many of the issues raised during the last year. Of course, there will always be subjects we have missed but this is where you the member comes in.

If you think that one of the issues we have not covered is worthy of a seminar or workshop, or indeed if you would like to be included in future Information Days, please write to me with any suggestions. The RLG is there for you so please make use of it.

Enclosed with this edition of *Roar!* is the Information Day registration form, which **needs to be returned to us by the 31 March**.

There is, as last year, a registration fee of £2.50, which covers our expenses as well as tea, coffee and soft drinks.

Nomination forms for all posts are included within this package. All present committee members are willing to stand, however, all posts are open for nomination.

We are always looking for members to participate in the running of the Group as this can bring in new ideas and a different perspective. All nominations should be submitted prior to the AGM.

**I would like to take the opportunity to thank all the committee members for their tireless work, without which the RLG would not be possible.**



## Letters

*Dear Editor*

I am wondering if anyone can give me some help or information? I had the pouch operation over ten years ago. I had many problems so I had to revert back to an ileostomy, I have a loop one. The problem is I still have the pouch it was never removed. I am having a lot of pain in my tummy over the last few weeks so I am wondering if it could be the pouch maybe I need it removing or would that not make no difference? I don't want to volunteer surgery so I have just left well alone.

*Anonymous*

[Ed's note: Unfortunately, this e-mail was sent anonymously to the website with no return e-mail address, so we have no idea if the writer is a member of the Red Lion Group and will see this letter and any replies printed in *Roar!*. However, we have printed it in the hope that this is the case. If the response is not seen by the writer, it may be that it helps another Red Lion Group member who might have a similar situation].

*Dear Website Editor*

About six years ago I decided I wanted a tattoo of a lion on my lower back. So I started searching the net for the perfect lion to fit my personality. That's how I stumbled on your old page and fell in love with your lion. Everything else I'd found was tribal which is not me, so when I saw him I thought he was great.

Then I looked at your web page and realized what you were about. That's what sealed the decision. I have Crohn's Disease. It just felt right.

At this point I have a four inch version of your lion (with pink and blue mane) tattooed on my tailbone. Please don't sue! After I had it done I lost your url and couldn't seem to find you again, until today.

I guess I just wanted to say thank you for having such a cute mascot, he has served me well and I love him so. I had to tell you that he's actually tattooed on someone!

Thanks for your time,  
*Kendra*



## Are You a Marathon Man or Woman?

When I was chatting to my pal Dave the other day, I mentioned the word "marathon". He paused for all of five seconds and said: "Yes, I remember the binges, pub crawls and all-night clubs we used to go to - you were much more fun then."

"Undoubtedly," I replied, "but what I really want to talk about is those arduous slogs over dirt-tracks, highways and cobbled streets that are great to watch and gruelling to take part in." "Yeah, yeah, I know, but you're not thinking of doing one yourself are you, yawn, yawn," he said.

Most of us are a bit like Dave. We may admire, respect and even envy anyone who runs a marathon, but we are unlikely to actually join in and do one too. A few press-ups perhaps, a monthly visit to the gym or a game or two of tennis and badminton, and that's usually our lot. Even though we may be rather taken with that new get-fit-quick regime in the newspaper or know someone who's on the Atkins diet, we usually prefer the more gentle approach to exercise.

The Greeks didn't, though. The first unofficial marathon was run by a soldier named Pheidippides in 460BC. His route from the little town of Marathon was both scenic and tortuous as he clambered over crags, hobbled down valleys and padded across plains until he reached Athens and told the Greek king about an invasion by the Persians. The Greeks then adopted it as a 26-mile race and included it in the modern Olympic Games in 1896.

When the Olympics was held in London in 1908, the organisers made the marathon a royal event, adding 385 yards so that it finished in front of King Edward VII's box at White City Stadium.

The distance has remained 26.2 miles ever since as it acquires near-cult status and new races open up in such countries as China, Dubai, Morocco,

Bermuda and Egypt.

And no doubt you've done a longish ramble or two yourself recently to recover from all that festive jollification - I'll certainly never forget the day my aunt sent out a search party when six nephews and nieces disappeared for eight hours after going for a Boxing Day stroll. They'd met up with a few locals and gone to the pub - with inevitable consequences!

But back to that m-word again. If you know anyone who likes to keep fit, whether doing marathons, 10-kilometre walks or a spell or two of fell-walking, ask if they'd be interested in joining a Red Lion team in the 2005 Flora London Marathon. For Mike Dean and I are trying to secure several golden bond charity places - slots put aside each year for the likes of Shelter, Children with Leukaemia and the National Asthma Campaign among others.

Entry forms will be issued on 1 August and close on 24 October, so you've ample time to attract potential fund-raisers before then. Last year, 33,000 London Marathon runners raised just over £1.3m for charity. This year, a slightly larger number hope to collect £1.5m.

Though I'll be wearing the Macmillan Cancer Relief vest on Sunday, 18 April - six days before the AGM and Information Day - I'd love to put on a Red Lion one in 2005.

So even if you don't don track-suit and trainers yourself, please have a word with a few likely-looking marathon men or women. Then contact me on 0208-894 1598 or [cbrowne@brownemedia.co.uk](mailto:cbrowne@brownemedia.co.uk).

*Chris Browne*



## Jottings from the Treasurer

Not much to say at the moment. A big thank you to all those people who have signed standing orders and especially the gift aid forms. I was able to claim back £397-60 for the year ended 5th April 2003 which was very useful.

Hopefully the next claim in April this year will yield a lot more than that.

I would also like to thank all the members who have so far renewed and for the generous additional donations. The post has been thudding on my mat and as it mostly came with the Christmas cards, I guess that the postman must have thought I was very popular.

Last time I wrote I said I thought I should hand over my pen (or mouse) but I have now decided (unless someone wants to take it on) that I will continue in my position as it gives me something to do for a very worthwhile cause. To be honest I would miss it!!

Look forward to seeing a lot of you at the AGM in April.

*John White*



**RED LION GROUP  
ANNUAL GENERAL MEETING AND INFORMATION DAY  
SATURDAY, 24<sup>th</sup> APRIL 2004  
St Mark's Hospital  
Northwick Park, Watford Road,  
Harrow, Middx  
PROGRAMME**

9.45 – 10.25	Registration and coffee		
10.30 – 10.35	Welcome/nomination forms		Michael Dean/Chris Browne
10.35 – 11.05	<u>Seminar One</u> – Pouch Function		Prof Christine Norton Nurse Consultant – Contenance, St Mark's Hospital
11.10 – 11.35	<u>Seminar Two</u> – Research on Quality of Life for Pouch Owners		Paris Takkis, Senior Registrar, St Mark's Hospital
11.40 – 12.15	<u>Seminar Three</u> – Pouchitis & Probiotics		Matt Johnson
12.20 – 13.00	Red Lion Group Annual General Meeting		
13.00 – 13.55	Break for lunch and exhibition of RLG merchandise/ Christine Lawton		
14.00 – 14.40	<u>Seminar Four</u> – Dietary Needs		Janeane Dart – Chief Dietician, Gastroenterology, John Radcliffe Hospital
14.45 – 15.25	<b>Workshop 1</b> Inflammatory Bowel Disease - Lisa Young, Clinical Nurse Specialist, St Mark's Hospital	<b>Workshop 2</b> Pregnancy & Fertility – Joanna Wagland, Clinical Nurse Specialist, Pouch Care	<b>Workshop 3</b> Manifestations of FAP- Kaye Neale, Polyposis Registrar
15.30 – 16.10	<u>Seminar Five</u> – Have pouch will travel		Chris Browne
16.15 – 16.30	Closing remarks		Chris Browne

**Toilets**

Please note that we have paid for the services of a cleaner for the day to deal with any issues arising with any of the toilets in the immediate vicinity of the main meeting locations. If you become aware of any problems please speak to any member of the committee *as soon as possible*.

Toilets are situated in 3 main locations:

- two toilets in the Medwar Centre (turn left as you enter), which is situated opposite the Himsworth Hall;
- the main block is located in the basement at the foot of the stairs leading to the Himsworth Hall; and
- alternate floors have Ladies and Gents toilets, at the first staircase that you meet if you take the corridor to the left as you leave the Himsworth Hall

**Car Parking**

Please remember that if you have a car park notice it needs to be displayed on your dashboard.

## Let's Make the Red Lion Group Media Friendly

No charity can survive without cash, and one of the better ways of getting it is by regularly featuring in the press. This can happen in many forms - it can be a spokesman for the charity commenting on a topical 'hot' issue, it can be because a member is featured as a 'case history' that illustrates a news story, or it can also be because someone has a tale to tell that is newsworthy in its own right as a health-related feature.

I'm a journalist who's been asked on many occasions to find someone who will agree to be interviewed, at often impossibly short notice.

A few charities I know have databases of members who are willing to be interviewed, photographed and so on, and these are invaluable sources of help (the IBS Network, for example, have a great list with potted summaries of their media volunteers' backgrounds and contact numbers, and it's an immensely helpful resource). Red Lion could really benefit from such a list, as it would then be very media-friendly.

So here's the crunch question: Are you willing and able to help? If you are, we need to know the following...

Your Name

Your Age

The medical condition that led to your pouch, and current medical position (in brief), e.g. "UC, healthy, occasional pouchitis."

Your address and phone details, including mobile and email address

Whether you have experience with media, and any papers or magazines you have appeared in before (e.g. "Some radio work, + Marie Claire 2001")

Which media you are comfortable with: Print, radio, television

Whether you would be happy to do live interviews or only pre-recorded ones

Whether you would be willing to have a picture taken (most print media usually insist on a photograph)

Any other information that might help (e.g. "Work, but can be contacted in evenings only" or "always abroad in January")

Any other interesting information about you and your pouch - e.g. "youngest pouch patient" or anything that might be of interest to the media, e.g. "Jonny Wilkinson's brother" !!

An email address will help whoever collates the database make sure

that details are kept up to date, as there's nothing more frustrating for a journalist working to a tight deadline than finding that all the details they've been given are out of date.

If you can help, please email Chris

Browne (details on page 11) with your details, and these will then be collated.

Thanks in advance for your help - it really is valuable.

*Stephanie Zinser*



### Let's Get Quizzical!

1. Name the world's largest lake
2. Which bird is the largest member of the crow family?
3. What was the duration of Big Ben's longest known stoppage - 11 minutes, 13 days or 50 seconds ?
4. Who designed the first ileo-anal pouch?
5. Who is the only British woman to have won Wimbledon since the mid-1970s?
6. Which city is the 2008 European Culture Capital?
7. Who wrote the play The Crucible - Christopher Marlowe, Arthur Miller or Edgar Allan Poe?
8. Liza Minnelli is the daughter of which female Hollywood star?
9. Name the poet laureate who recently wrote an anti-Iraq war poem?
10. Is a charabanc a plane, boat or a large bus?
11. Name the founder of penicillin.
12. How many species of fish are there in the River Amazon - 6,000, 48 or 700?
13. In what year did Diana, Princess of Wales, die in a Paris car crash?
14. In which year was the fax machine patented - 1843, 1935 or 1958?
15. Name the queen of the fairies in 'A Midsummer Night's Dream'.
16. In which city would you find the Book of Kells?
17. Which British architect designed St Paul's Cathedral?
18. Does France or the UK own the Channel Islands?
19. When was 'The Spectator' magazine founded - 1796, 1828 or 1948?
20. Who composed the famous Trumpet Voluntary?

*Answers on page 10*

## My Story ... by Kate Wright

I've put my story down on paper in the hope that it might help somebody in some way, or at least that people will enjoy reading it. I'm keen to share what is proving to be a very positive experience of being a pouchie! However, I know that not everybody is as lucky as me and I don't take any of it for granted for one minute. My other motive for writing this is to get a bit of coverage for a minority group! By this I mean people who have pouches because of genetic cancer conditions such as FAP and MYH. I'm happy to be contacted through the Red Lion Group, by anyone who wants to talk about any aspect of what's happened to me.

In March 2002, at the age of 26, I read an article in one of the Sunday papers about a woman in her twenties who had been diagnosed with bowel cancer. She described her symptoms as diarrhoea and blood in her stools. Alarm bells started ringing for me immediately. I'd had these symptoms for the past five years and they'd been getting progressively worse. Up until now I'd put it down to various things including diet and stress but now I was starting to worry that it might be something more sinister. I immediately made an appointment to see my GP. Because of my age, general good health and lack of any family history of bowel problems, he was fairly convinced that it was nothing serious. But as he couldn't find any obvious explanation for my symptoms he referred me to my local hospital, the John Radcliffe in Oxford, just as a precaution. Ten months later and after some administrative problems with the hospital I was finally given an appointment.

The surgeon who examined me told me that he was surprised at what he found – six large polyps in my rectum. He explained that a polyp is a small tumour or growth and that there are lots of different types of polyp. Some are harmless, but others, called adenomas, are likely to develop into cancer if left untreated. A colonoscopy was arranged so that my colon could be examined and biopsies could be taken. As I was coming round afterwards, the consultant told me they'd found many more polyps in my colon and that I might need an operation to remove my entire large bowel. This all sounded very far-fetched to me. After all I felt fit and well apart from the symptoms I've told you about, but they didn't seem to be any worse than those of someone suffering from IBS or piles.

I went home in shock and after spending a lot of time doing Internet research, found out about a genetic

condition called Familial Adenomatous Polyposis (FAP). People with the affected gene develop hundreds or thousands of colorectal adenomas. As I had been told that I had less than 100 I assumed that I might have the lesser or *attenuated* variant (AFAP). This was of little consolation as treatment for the condition is the same. Because of the high number of polyps – each carrying its own risk of cancer - the only way to be safe is to remove the entire colon and rectum.

The next time I saw the consultant he confirmed that FAP was a strong possibility. Biopsies taken during the colonoscopy had shown that the type of polyps I had were indeed adenomas (thankfully none of those polyps biopsied were cancerous yet). My worst fears were realized when he told me that I needed an operation to remove my entire colon and rectum. He talked about the possibility of using part of my small intestine to make a "pouch" to take on the role of a rectum, and the need for a temporary ileostomy while it healed. I went home with a pile of leaflets to read, an ileostomy bag to look at and a very bad headache.

Being the mistrusting type I wasn't happy to take one person's word for it. The consultant offered to refer me to St Mark's for a second opinion. So, another hospital, another colonoscopy. The colonoscopy at St Mark's confirmed everything that the John Radcliffe had already said. I decided to continue my treatment at St Mark's as I'd begun to learn of its excellent reputation.

My consultant was Professor Robin Phillips and he patiently explained on several occasions why the pouch surgery was absolutely necessary. The surgery would be done in two stages: the first to remove my colon and rectum, construct the pouch and create a temporary ileostomy (necessary to give the pouch a chance to

heal before being put to work); the second to reverse the ileostomy. Right up until three days before the scheduled date I was emailing, phoning and turning up at clinic wanting to know if there were any drugs I could try, or a less drastic operation, or maybe we could just keep our fingers crossed and hope for the best! He eventually convinced me of the need to go ahead with surgery and we did on April 17<sup>th</sup> 2003.

I was terrified. The night before surgery I stood in front of the mirror, staring at what looked like a perfectly healthy body, knowing that in just a few hours it would have drips and tubes coming out of it, wounds and metal staples and hardest of all to come to terms with for me, an ileostomy – the exact site had already been marked on my stomach in black ink by the stoma nurse. I was still waiting for somebody to tell me that all this had been a huge joke, and hand me a tube of cream for the piles that were undoubtedly causing all my symptoms. It wasn't really until I was woken up for a wash on the morning of surgery that the reality hit me and then I sobbed until the anaesthetist put me under two hours later.

Recovering from that first operation was harder than I'd anticipated. I was hit with a bad dose of pneumonia in hospital, and on top of that I seemed to react to every form of pain relief I was given with nausea, asthma or both. But the main thing is I did get better and two weeks later I was home. Very weak and very tired, but home nonetheless. And what perfect timing! I had the whole summer – the best one we've had for a long time - to sit in my garden and convalesce.

After my colon was removed and examined 140 polyps were found, ranging in size from 1mm to 5cm. Several of them had reached the advanced stages of dysplasia, meaning that they were well on the way to becoming cancerous, but thank good-

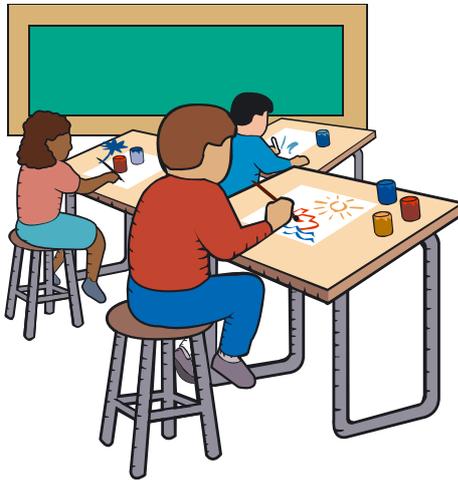
ness none of them had undergone that critical change. At least this information removed all doubt about whether I'd done the right thing.

It still hasn't been confirmed whether or not I have a form of FAP. I'm sure I have read somewhere that up to 20-30% of people diagnosed with FAP are "new mutations", meaning that there is no family history. If you do carry the gene though, any children that you have will have a 50:50 chance of inheriting it. I've been tested for this and another recently discovered condition called MYH (no idea what it stands for!). But it could also be any number of as yet unidentified genes that caused these polyps to grow. Hopefully I'll get a positive result back from the genetics lab in the not too distant future.

Four months after the first operation I had the ileostomy reversed, a minor procedure by comparison. I was prepared for the worst as I had read about people going to the toilet 70 times a day with their new pouches and I was dreading that wretched butt burn! I was lucky though. After 10 days in hospital with a slightly obstructed bowel, everything suddenly started working, and my pouch appeared to be doing a splendid job. Two weeks after surgery I was going to the toilet an average of 5 times a day and it's been the same since I came home three weeks ago. Apparently it's likely to get even better with time so I've got a happy future with my pouch to look forward to. Yes, I do get a sore bottom from time to time but this seems a relatively small problem compared to the alternative, which is of course almost certainly bowel cancer at a young age.

The next hurdle to overcome is seeing my family undergo tests to ascertain whether they have the same condition. One sister's clear so far, but my mum, brother and youngest sister are waiting for colonoscopies. I know that in the future there will be

difficult decisions to make about starting a family myself, and possible problems conceiving if I do decide to have children. I also know that 1 in every 10 people with FAP suffer from aggressive tumours called desmoids. But all I can do is hope that the worst is over for me and keep thinking positively. Just a few weeks after the re-



versal surgery I'm already eating more or less what I want, taking trips to see friends all over the country, and have started salsa dancing lessons...just because I flippin' well can!

Reading my story back, it sounds like I've been

through this all on my own, but this is not the case. My best friend Sean, and my wonderful mum have been there every single step of the way. I've also had the support of lots of caring family and friends, and the school

community where I was lucky enough to be working as a teacher when all this began. The only reason I've come out the other end smiling is because these people made me feel loved and cared for even at the worst of times. If any of you are reading this – thank you.

*Quiz answers from page 8*

20. Jeremiah Clarke
19. 1828
18. UK
17. Sir Christopher Wren
16. Dublin
15. Titania
14. Irish mechanic
14. 1843 by Alexander Bain, a Scot-
13. 1997
12. 6,000
11. Sir Alexander Fleming
10. Large bus
9. Andrew Motion
8. Judy Garland
7. Arthur Miller
6. Liverpool
5. Virginia Wade
4. Sir Alan Parks
3. 13 days (from noon on 4 April until noon on 17 April 1977)
2. The Raven
1. The Caspian Sea

## 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**

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### PATRON

Claire Rayner

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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

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## 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,

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## Visit Our Website

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



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.



