

ROAR!

ISSUE 43 • EASTER 2011

Newsletter of the Red Lion Group
St. Mark's Hospital • Watford Road • Harrow • HA1 3UJ

Regional Reps

HERE IS our current list of regional reps with home telephone numbers — please feel free to contact your local rep and get acquainted.

If you would like to be a regional rep, please contact Mike Dean on 01702 552500 or liaison@redlion-group.org.



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Please support the Red Lion Group

Registered Charity number 1068124



All donations, however small, towards expanding the work of the group will be gratefully received.

If you would like to send a donation please make your cheque payable to The Red Lion Group and send it to: **The Red Lion Group Treasurer, Mrs Marjorie Watts, 11 Meadow Way, Upminster, Essex, RM14 3AA**



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Thank you to the following contributors to the stock.xchng website for uploading such great images.

Page 2 – Self Portrait in Mirror by Nick Winchester from Reading, UK

Page 3 – Journey Home by James Maskrey from West Midlands, UK

Page 5 – Workers by Carlos Chavez from Mexico

Page 6 – Cat Face by 'ilker' from Turkey

Page 7 – Sunday's Crossword 'jaylopez' from Philippines

LETTERS

Dear Christopher

I found the summer issue 42 *Roar!* very interesting, thank you. Your comments on dermatitis prompt me to relate my own experience.

I am 78 and my pouch is 26 years old. I experienced dermatitis periodically from my mid-twenties. My father and a cousin also had it.

In late 2005, I developed myasthenia gravis (a neuro-muscular disease that causes fluctuating muscle weakness and fatigue) which involves the immune system. In early 2006 I was prescribed the steroid prednisolone and the immunosuppressant azathioprin. Within a few weeks my dermatitis had disappeared.

Eventually the steroids were gradually reduced and in June 2010 I stopped taking them altogether. However I am still taking a reduced dose of azathioprin and there is no sign of dermatitis. How fortunate I am!

Since I started taking the two medications at the same time, it is not clear which had the good effects on the dermatitis. As ever medications – specially two such as these – must only be taken under medical supervision, but it might prove interesting to some researcher somewhere.

Very best wishes
Bob Gordon

Dear Sir

Sarah Bowes' letter about eczema and ulcerative colitis got me thinking. My brother and I both have ulcerative colitis and we both suffer from childhood eczema – along with a host of other allergies such as hay fever, allergic conjunctivitis and, in my brother's case, asthma. In fact everyone in our immediate family has some sort of autoimmune disease or allergy, so clearly

there's something genetic going on.

The link between allergy and inflammatory bowel disease was investigated in a scientific study published in 2006. Researchers talked to 200 uc patients and 300 people with Crohn's disease. They were all asked if they'd ever suffered from asthma, hay fever, allergic rhinitis or eczema. Turns out that these allergic conditions are twice as likely to appear in the medical history of uc patients than you'd expect in the general population. People with Crohn's are more likely to suffer from eczema than most people, but they're no more likely to have any other allergy than the next guy.



Why? This is where it gets complicated. An American study two years ago (published in *Clinical and Molecular Biology*, if you're interested) looked at babies' poos to examine a suspected link between microbes in the guts and the likelihood of infant eczema. Here's their finding: 'Reduced microbial diversity is associated with the development of eczema in early life.' So gut bugs and eczema are certainly linked, at least in infancy.

Rates of eczema, asthma and autoimmune disease are rising around the developed world, and many scientists now blame our clean-living ways. Some say the solution is for parents to protect the next generation by making sure young children are exposed to as many bugs and parasites as possible. If that sound too yucky, just get a dog – several studies have linked pet-owning with a healthy immune system.

Susan Walls
Alwoodley
Leeds

Read Susan's tale of the unexpected and why children, animals and the immune system all have something in common on page 6.

Dear Chris

I have just received the latest *Roar!* issue and have read that the next Information Day is 16 April 2011 and is once again at St Mark's Hospital.

Why can't it be at a different place at another hospital for people like myself who don't live in London.

In this area we have a large hospital and one which is classed a super-hospital. I am sure there are other pouchees like myself who would come if it was nearer to where we lived.

I look forward to hearing from you in the near future.

Yours sincerely
Mrs J Teasdale
Gosport
Hants

Red Lion chairman Morag Gaherty replies:

Dear Mrs Teasdale

Thank you for your letter about the location of Information Day. This is a subject the committee have discussed one more than one occasion – for exactly the reason you mention.

The Red Lion Group is strongly linked with St Mark's Hospital in Harrow, which is a specialist hospital for ileo-anal pouch surgery. Not only do we have a long link with the administration, which makes planning of the AGM much easier, but also it is a location with good transport links, for both patients and speakers. Overall,



we feel that we would lose more potential attendees than we would gain by changing the location. Quite apart from the difficulty of attracting good speakers who often combine coming to the event with their work at the hospital. Taking an hour or two out of a busy work schedule is much easier than travelling to a quite different location for only a short walk.

Obviously, we would be delighted to hear from other RLG members



about their views on this subject. Please do appreciate, however, that we have very limited funds in the RLG and moving the venue would almost certainly end up in an increase in the membership fee – which has been held at the same level for many years – for everyone in order to fund it.

Sophie Robinson from London SE23, a new member of the Red Lion Group, wrote and told us of her experiences with Primary Sclerosing Cholangitis (PSC), a liver condition linked to uc. She says:

I have PSC and was told that I had a higher chance of suffering from pouchitis after my pouch operation. Just a few months later I had a lot of problems and they were diagnosed as pouchitis.

I have been on rotating antibiotics for just over a year now to treat it and will be for the foreseeable future. I would be keen to hear of other people's experiences with pouchitis and if any of you has PSC.

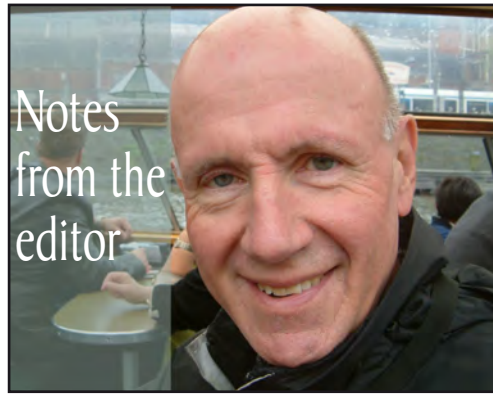
Claire Rayner

Claire Rayner was the patron saint of problem-solving. Nothing, however extreme or embarrassing, could defeat her as she listened and then spoke with breathless enthusiasm about health, female and male problems and social dilemmas such as what to do with an overbearing partner.

However for the past few years Claire was unable to help her admiring radio and TV audiences as she too was suffering from several serious conditions, sadly passing away at the end of 2010.

For 10 years Claire was patron of the Red Lion Group (as well as a saintly president of the Patients' Association), something she agreed to do after several visits to St Mark's Hospital from her home a few miles away in Harrow.

After working as a nurse at a north London hospital, Claire decided to train as a doctor. When she met her husband Des, she changed her mind and stayed in nursing, later becoming a paediatric sister. Soon after the Rayners' first daughter was born, Claire wrote a novel and started writing for



Lively letters - don't you just love 'em. Well even if you don't I do! And you'll find plenty of them in this issue.

Letters are talking-points that stir feelings and create feedback and, apart from debating, public speaking and lecturing are one of the most natural ways we communicate.

Someone who could talk and write with equal dexterity was our former patron Claire Rayner (see the obituary on this page). Claire was outspoken, empathetic and no-nonsense with each of the readers, listeners and viewers who wrote to her for advice. She answered every letter that arrived in her various postbags personally. In one week she sent 18,000 replies.

Her correspondents may not have always liked what she wrote, but they knew her advice was honest, carefully thought-out and, above all, knowledgeable.

Claire's son Jay Rayner, the journalist and restaurant critic, once described her as an "agent provocateur who liked to infuriate". Yes, like all good journalists, she had an ear for sensation, but she was also a quite brilliant writer with abundant humanity and warmth. Three of the key qualities of the communicator.

Claire was passionate and crusading, someone who was quite prepared

to tackle such taboo subjects as bottoms, ileostomies and premature ejaculation. And happy to take on such causes as bereavement and depression which she suffered from for most of her life.

When she appeared in an advertisement for sanitary towels in 1991, the public response was both dismissive and admiring, and certainly changed attitudes to the idea of displaying sanitary products on television. Claire was also one of the pioneers of safe sex advertising during the first campaigns for HIV and Aids. She referred to it as "waving condoms over the cornflakes on breakfast television".

Information Day

We've also got a spirited group of communicators at Information Day on Saturday, 16 April. In a lively question-and-answer session, St Mark's pharmacist Yee Kee Cheung will give us his inside view of drugs, when to take them, which ones tend to work best and how to avoid some of the side-effects.

You can look forward to an incisive look at the whys and hows of pouches and pouch surgery by St Mark's consultant colorectal surgeon Sue Clark who is also our president, while Dr John Landy, a St Mark's research fellow, will talk about the symptoms, treatment and possible causes of pouchitis. There are also workshops on pregnancy and fertility for pouch-holders, how to maintain a healthy diet and the benefits of Medina catheters.

You can find out more about Information Day and the Red Lion AGM on the website www.redliongroup.org.

I look forward to seeing you there and a very happy Easter to all of you.

Christopher Browne

women's magazines, becoming one of the UK's first agony aunts.

At one stage, she was working simultaneously for TV-am, Sky TV, the Sunday Mirror and Woman's Own, employing six secretaries, a research assistant and a post clerk and answering more than 1,000 letters-a-week.

Later in her career, Claire was an inspired campaigner, a founder member of the Forum on Children

and Violence, a member of the Royal Commission on Long-term Care of the Elderly and president of Gingerbread, the National Association of Bereavement Counsellors, the British Humanist Association and, of course the Patients' Association. She also found time to write more than 90 novels and non-fiction books.

Claire, who was 79, left a husband, three children and four grandchildren.

'Gutless' kayaker raises £14,500 for St Mark's

A man calling himself the "gutless kayaker" has just paddled 240 miles from Manchester to Harrow and raised almost £14,500 towards St Mark's Hospital research.

Fifty-year-old Justin Hansen who lost most of his bowel through complications from Crohn's disease did not eat a single meal during his 20-day voyage surviving on an intravenous feed pumped through a tube from a backpack.

"I was surprised how I managed because I have not been able to do any real exercise for seven years. It was just a voyage of discovery for me in terms of what I could do if I had the medical support. I've found I can do lots of stuff," said the St Mark's patient who ended his aquatic adventure on 1 October.

"I want to raise awareness of bowel disease but also to show it's not the end of the world. Three to four years ago I couldn't have even imagined doing something like this, but now I wanted to show there are still things you can do despite all the restrictions," he told local reporters.



Justin who travelled with a fellow kayaker via canals, waterways and 166

locks says he owes everything to two St Mark's specialists, consultant gastroenterologist Dr Simon Gabe and clinical director of radiology Dr Michele Marshall who both cycled part of the way with him.

Dr Gabe said: "This is something that is truly inconceivable for a patient at the beginning of the road when they are in a hospital bed coming to St Mark's with bags on their abdomen, in pain, losing weight and having repeated infections.

"It is people like Justin who can show other patients that life ...and dreams are still possible despite intestinal failure. Justin is an inspiration to us all and is the very reason I do the job that I do," he told the *Harrow Times*.

Justin's next goal is to raise £20,000 towards intestinal failure research at St Mark's. He has so far reached around £17,500. To donate to his appeal, visit www.gutlesskayaking.com.

Changes to the Disability Act

Andrew Millis reports on changes to definitions under the Disability Act, which may be of interest to those with a pouch.

The Disability Act now makes it easier for a person to show that they are disabled and protected from disability discrimination.

Under the Act, a person is disabled if they have a physical or mental impairment which has a substantial and long term adverse effect on their ability to carry out normal day-to-day activities. This includes things like using a telephone, reading a book or using public transport.

As before, the Act puts a duty on employers to make reasonable adjustments for their staff to help them overcome any disadvantage resulting from an impairment (e.g. by providing assistive technologies to help visually impaired staff use computers effectively).

The Act includes a new protection from 'discrimination arising from disability'.

This states that it is discrimination

to treat a disabled person unfavourably because of something connected with their disability (e.g. a tendency to make spelling mistakes arising from dyslexia).

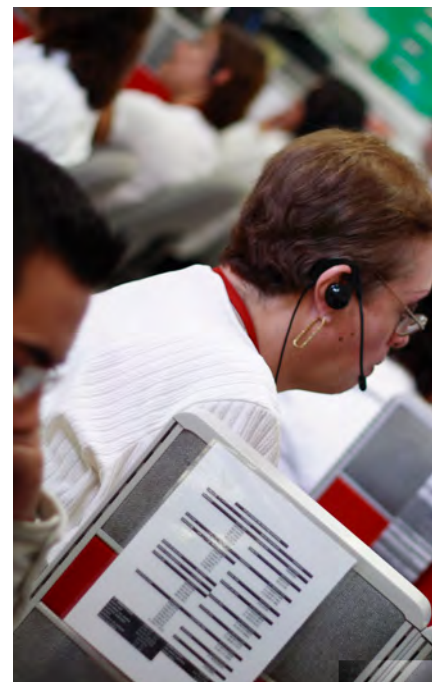
This type of discrimination is unlawful where the employer or other person acting for the employer knows, or could reasonably be expected to know, that the person has a disability. This type of discrimination is only justifiable if an employer can show that it is a proportionate means of achieving a legitimate aim.

Additionally, indirect discrimination now covers disabled people. This means that a job applicant or employee could claim that a particular rule or requirement disadvantages people with the same disability.

Unless this can be justified, it would be unlawful.

The Act also includes a new provision which makes it unlawful, except in certain circumstances, for employers to

ask about a candidate's health before offering them work.



Purrfect companions

Red Lion Group member Susan Walls, a writer on child development, says evidence shows that children brought up with pets tend to have robust immune systems

What's your view on family pets? Everybody's got an opinion. They range from the hardline "Smelly, flea-bitten things that make children go blind" to the soppy "Children and pets have such magical relationships".

Make way then for a new take on the subject: the family pet as a pragmatic parenting choice. Because having a pet can seriously improve your child's health. New studies show that pet-owning children have better immune systems. They're less likely to suffer from eczema or allergies in childhood, or to develop serious autoimmune diseases such as ulcerative colitis later in life. (An autoimmune disease is when your immune system attacks your body's own tissues).

But for this animal magic to work, you have to get a proper pet and "one you can play with", says health psychologist June McNicholas. "Preferably a dog or a cat or at least a 'small furry' like a guinea pig – goldfish don't count," she says.

McNicholas has spent more than a decade investigating the subject of pets and childhood health. She believes there's a window of opportunity when children will benefit most from having a pet to cuddle. "From birth to seven years old – that's when the immune system is developing," she says. "And a developing immune system needs something to react to. If children grow up in a squeaky-clean environment, they're much less likely to develop a properly-balanced immune system." Children need to get dirt under their fingernails and pet hair on their clothes if they're going to grow up strong and healthy, says the health psychologist.

The notion that our modern, clean-living ways could be harmful to health has been around for a while. Scientists coined the term 'hygiene hypothesis' to sum up the idea that cleanliness might be at least partly responsible for the allergy epidemic sweeping the western world. More than 300 million people now have asthma and in some parts of the UK the number of child sufferers has quadrupled in the last 30 years. In America, almost half of all children have allergic rhinitis, which includes hay fever and allergies to dust and cat

couple of years intestinal whipworm has been shown to help adult sufferers of ulcerative colitis. The beauty of pig whipworm is that it won't survive long in the human digestive tract – you need to 're-infect' yourself by drinking a solution containing thousands of eggs around twice a month.

New research also suggests that children who grow up on farms have a much smaller chance of developing allergies and auto-immune disease than those who live in the city.

Graham Rook, professor of immunology at London's Royal Free and University College Medical School, believes there are many harmless – or relatively harmless – organisms out there that could have a positive effect on children's burgeoning immune systems. He calls these organisms 'old friends', a catch-all term for the bugs, microbes and parasites that were present in everyday life throughout our evolutionary development. But 'old friends' don't work by boosting chil-



dren's immune systems – quite the opposite. Old friends teach the immune system to regulate itself by holding it back and making it less aggressive.

Now science is piecing together a richer and more sophisticated version of the hygiene hypothesis based on the idea that young children need to have contact with certain microbes to develop a healthy immune system. The question is, which microbes? Parasitic worms can certainly play a part in helping the immune system flourish. South American children with worms have hardly any allergies, but as soon as they're treated for worm infestation they become sensitive to house mites. But it's not just children who benefit from a dose of worms. In the past

dren's immune systems – quite the opposite. Old friends teach the immune system to regulate itself by holding it back and making it less aggressive.

"The problem in rich countries is that the immune system is too strong, so it attacks things it shouldn't attack," says Prof Rook – things like allergens in the air (hay fever and asthma), and even your own body tissues (ulcerative colitis, MS and rheumatoid arthritis).

Allergies and autoimmune diseases can develop when the body's regulatory systems fail. "Regulatory T cells are the police force of the immune system," says Rook. 'Old friends' then train the police force to work

effectively. Happily you don't have to live on a farm to infect your child with worms, to get the benefit of these immune-improving bugs and beasts.

Family pets work wonders too, apparently. "Contact with 'old friends' is greatly diminished in rich countries. But it's increased on farms, in cowsheds and through contact with pets," says Rook.

Pets alone are not the whole story, says Rook. For full health benefits, children should live the pet-owning lifestyle, romping in mud, splashing in puddles, throwing dirty sticks and being generally carefree and mucky.

Contact with animals does help

the immune system develop, apparently, but getting down and dirty has a big effect too. Rook and his team treated mice with respiratory allergies by giving them dead *Mycobacterium vaccae* – a harmless bacterium found in mud. He's since developed a 'mud-bag' vaccine for treating children with eczema and asthma. It's currently being tested in clinical trials and showing promising results.

But prevention is always better than a cure or a vaccine. So for now Prof Rook has this advice: "Mud, muddy water, dogs and cats and farm animals – all these things probably help to protect children against allergies

and auto-immune disease."

So it's official. It really is good for children to enjoy all the things they naturally want to do, such as splashing about in puddles, digging around in the dirt and playing with animals. As June McNicholas points out, families who love animals are more likely to be the sort of people who don't mind a bit of mud and a few puddles.

"Parents who own pets tend to be less hung-up on having a scrubbed and spotless house And scrubbed and spotless children," she says. "They're healthy families in every way. Not just physiologically, but psychologically too."

Crossword *by Sarah Bowes*

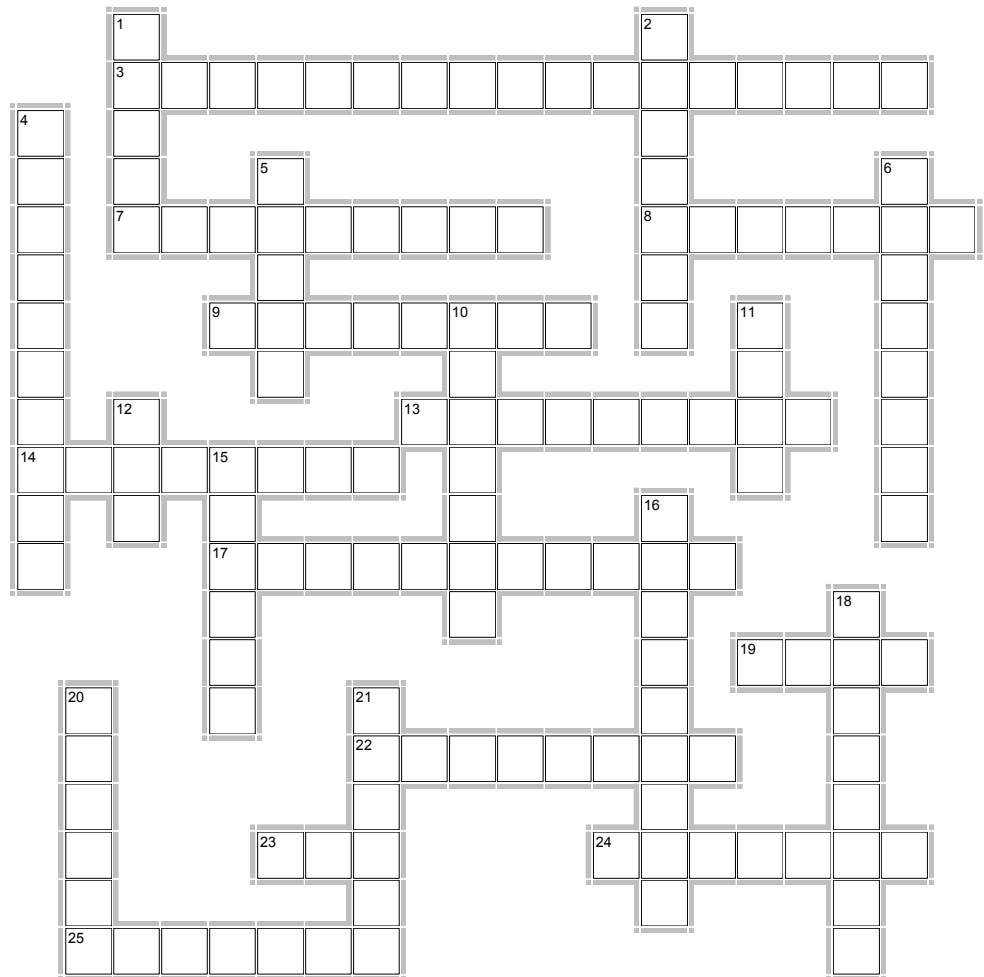
Answers will appear in the next issue

Across

3. Form of IBD
7. Instrument used for internal examination
8. Antidiarrheal
9. Establishment providing healthcare
13. Food adviser
14. Pain relief
17. Sleep inducing
19. Fluids
22. Investigate the answer to this clue?
23. Genetic mutation in APC gene (init.)
24. Physician
25. World-leading hospital

Down

1. Even Blackadder had one of these!
2. Alternative antidiarrheal
4. Treatment for Crohn's, administered via infusion
5. A break in a sentence, taken away
6. President!
10. Frequently visited!
11. I can see right through you!
12. Medical imaging technology (init.)
15. A new bill!
16. Antimicrobial cleanser
18. Much needed company
20. Form of IBD also affecting small bowel
21. Well-meaning gift but not to be taken to excess!



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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

Write for Roar!

Ideas, Ideas, Ideas and More Ideas

Yes Tim Rogers and I thrive on them for it's ideas that make *Roar!* the readable package we like it to be.

Whether it's something that happened to you on the way to work, an interesting holiday or personal experience, an insight into your life with a pouch or a lively letter, please don't hesitate to send it in.

But then if writing articles isn't exactly your favourite pastime, we are always looking for cartoons, jokes, crosswords and competition ideas too.

That way we can keep your news-

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

Please send your articles, letters and ideas to:

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Visit Our Website

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