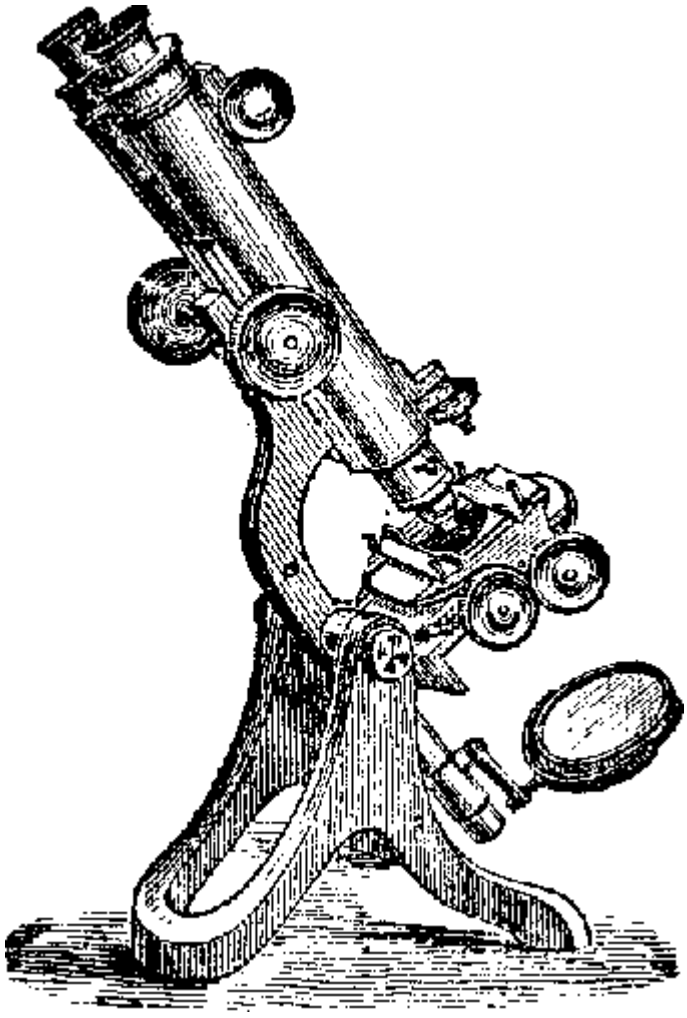
Roar!

Issue number 20 • Easter 2001

Roar! is the newsletter of the Red Lion Group • St. Mark's Hospital • Watford Road • Harrow • Middlesex • HA1 3UJ

Measles, Mumps and Bowels

There has been much in the press in recent years over the possible link between the MMR vaccination and both bowel disease and autism.



As a result many parents have opted out of the triple MMR vaccine for their children. However, the controversy that has blown up in some ways obscures the real point of the research done by the Royal Free School of Medicine's inflammatory bowel disease study group.

The research, based on 7,000 children born in the same week in 1970 was not, in fact, looking at the impact of multiple vaccination, although the questions that the findings raise do have a direct relevance to safety of the MMR vaccine.

The study was all about the link between measles, mumps and bowel disease, where the measles and mumps were caught "in the wild" (rather than through vaccination). The study found that four per cent

In This Issue...

Information Day Reminder

If you haven't booked your rail tickets or serviced the car, now is the time to do it: the Red Lion Group Information Day and Annual General Meeting 2001 takes place at Northwick Park Hospital on 7 April.

Invitations have been sent out and a reply is required by 30 March at the latest if you plan to attend.

We have a full day planned with talks and workshops. The boring part of the day, the Annual General Meeting, should only take ¾ hour just before lunch (to give you time to work up an appetite), and the rest is all fun, fun, fun. Well, I lie, the rest is all pouch, pouch, pouch, but it amounts to the same thing.

For those who are unable to attend, there should be an Nataional Association of Pouch Groups conference later in the year which you may be able to get to. Also, there will be a write up of the day in a later edition of the newsletter, and handouts from the workshops may well be available: watch this space.

of the children in the study caught mumps and measles *in the same year* of their life. This group was seven times more likely to develop ulcerative colitis and four times more likely to develop Crohn's disease by the time they were 26 years old.

Other childhood diseases were examined as well, but only the measles/mumps combination showed a strong link to inflammatory bowel diseases. Dr Andrew Wakefield, part of the team involved, made the point that this research was *not* about vaccination, but that it contained an inference about the MMR vaccination which should be investigated further. The British Government has declined to do so.

Before the issue of this report, which was published in the respected American journal *Gastroenterology* in 1999, Dr Wakefield's team published a small study which suggested a link between MMR vaccine, inflammatory bowel disease and autism. But because the study was very small Dr Wakefield concluded that extensive further study into the subject was needed to see whether the results shown would be replicated on a larger-scale.

In response, the Department of Health has relied on a Finnish study of 1.8 million children (3 million jabs) which found no link between the MMR vaccine, bowel disease and autism rather than undertaking a specific trial. This sounds impressive, until the following points are taken into account:

- The study is based on "passive surveillance" - i.e. it relies on people telling the research team of their adverse reactions. In the UK, we have a yellow card system for GPs, but how many of us actually report events which should go on those cards, and when we do report them, how many people have ever seen a GP complete the form? Even the research arm of the Department of Health, the Public Health Laboratory Service is on record as saying that passive surveillance is a highly unreliable method.
- The timescale of reported side effects was very short, not long enough to pick up even convulsions which tend to occur 7-10 days later, let alone the long term development of autism or bowel disease.

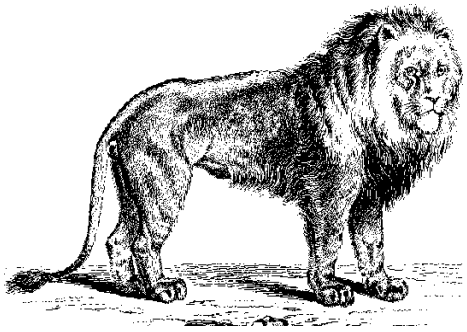
Even the senior medical officer in the DoH, Dr Peter Fletcher, agrees that the MMR vaccine never had adequate safety testing.

All that the current furore proves is that the British Government is not seriously interested in finding out whether there is any link between the MMR vaccine and autism or bowel disease. As a consequence, we may never know whether the Royal Free research suggesting a measles/mumps connection to inflammatory bowel disease is accurate.

Donna Swift is desperate to speak to other pouch owners who may be going through the same problems as she is experiencing.

If you have a "dysfunctional pouch" or have problems emptying your pouch, please phone her on 02392 712641. An answer to her problems would be great, but even just the chance to talk with someone who understands would be a huge relief.

Editorial



One disadvantage of running late with one issue of the newsletter is that you run straight into deadlines for the next one almost before you've packed your pen and paper away. Well, that's not quite true - there are no pens and paper involved in the production of this newsletter! But it does seem like only yesterday that the proof for issue 19 went to the printers.

This issue should come out just before our Information Day on 7 April, which will be held once more at Northwick Park Hospital in Harrow. There will be talks on emptying the pouch properly, how to deal with a leaking pouch, and hints and tips on diet and cooking. This year, rather than have the AGM at the beginning of the day, we are slotting it in just before lunch. Hopefully you'll hear everything clearly over the rumble of your tummies/pouches, but we promise to whizz through business as fast as possible. I doubt we'll be able to match the 15 minute sprint of last year, but we'll do our best.

The 6 afternoon workshops will cover the following topics: ulcerative colitis, familial adenomatous polyposis, family planning, travel and exercise, sharing pouch problems and living with a pouch. Obviously, you won't be able to attend all six, but there should be handouts available for those workshops which you cannot get to.

As in previous years, our range of merchandise will be on sale and there will also be a tombola. Inez has got us some lovely pampering prizes - that's what happens when you're a regular at all the best places! Profits from both activities go to the Red Lion Group, so please do bring some money and get ready to spend it. If you have any items suitable for the tombola, please do bring them along and give them to Inez when you register. We promise not to have any tins of baked beans this year (but cannot guarantee a spaghetti hoop-free zone)…

This year is the first year that the Red Lion Group has funded the Information Day completely, and once again we are making it free of charge (there is a refundable deposit of £15 per person attending, as

we did for last year). However, for future years we will probably have to ask an entrance fee, largely to cover the cost of lunch, so as to avoid an increase in the annual subscription. This will also bring us into line with the financing of the NAPG annual conference.

Elsewhere in this issue is yet another appeal for new committee members - don't just flick past this page! As those strange financial services ads say (but it's the truth in our case): This is Important. In the long term, it's as simple as this: no new committee members, no Red Lion Group. If this is not what you want, you know what to do - get involved. It isn't hard, it doesn't necessarily involve travel, and it won't tie up your weekends. What more do you want?

I'm not asking for a lot of letters saying what a wonderful job the committee is doing - though we are very appreciative of those. That does not solve our problem. What we need is practical involvement.

There will be nomination forms available at the lecture theatre, for you to nominate yourself - we just need your completed form before the AGM begins at 12.05pm. You can offer yourself as a co-opted member ready to take on specific tasks rather than a full committee member if preferred.

Even if you can't join the committee, why not take the time to write an article for the newsletter? This issue, so much of the newsletter came from me that I gave up mentioning the author's name at the start of the articles - I'm sure people must get sick of seeing my name all over the place.

Let me just say a big thank you to Michael Dawson, Christine Jackson and those who sent in letters. At least I'm not (yet) reduced to making those up.

I am pleased to say that Christine Lawton has accepted the task of contacting potential advertisers for *Roar!*.

As this has only just happened, and her surgery due for the end of January has been switched to the latter part of March, there is no advertising supplement contained with this newsletter. We hope it will resume with the Summer edition.

I do hope that you enjoy reading this quarter's newsletter and I look forward to meeting some of you on 7 April.

Here's Looking at You, Kid

Ever wondered what all those "oscopies" are that you get threatened with? Here's a run down of the ones you're most likely to meet:

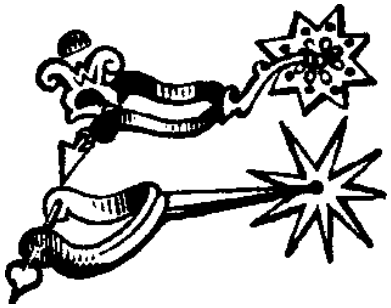
The visual examination of an internal part of a patient's body. Early forms of endoscope, such as the ophthalmoscope and laryngoscope (for examining the eyes and vocal cords, respectively), were developed during the 19th century. Since the 1960s, the use of optical-fibre systems, which permit the 'bending' of light rays, has revolutionized endoscope design, resulting in smaller instruments which can be introduced through bodily orifices or, more recently, through tiny incisions. The latter technique is used, for example, to examine joints (arthroscopy), the abdominal cavity (laparoscopy), or the foetus in the womb (foetoscopy). Most endoscopy is for diagnostic purposes (such as to reveal peptic ulcers or stomach cancer), but modern endoscopes can also take a biopsy (tissue sample). Therapeutic procedures, such as cutting away an enlarged prostate gland, can also be performed through an endoscope. (#)

Colonoscopy

A procedure for examining the interior of the entire colon and rectum using a flexible illuminated fibreoptic or video-camera instrument (**colonoscope**) introduced through the anus and guided up the colon by a combination of visual and X-ray control. It is possible to obtain specimens for microscopic examination using flexible forceps passed through the colonoscope and to remove polyps using a diathermy snare. (*)

Sigmoidoscopy

Examination of the rectum and sigmoid colon with a sigmoidoscope. It is used to investigate diarrhoea or rectal bleeding, particularly to detect colitis or cancer of the rectum. (*)



Gastroscope

An illuminated optical instrument used to inspect the interior of the stomach. For many years these were rigid or semirigid instruments affording only limited views, but modern fully flexible instruments, which transmit the image through a fibreoptic bundle or by a tiny video camera, allow all areas of the stomach to be seen and photographed and specimens taken for microscopic examination. Therapeutic procedures (e.g. to arrest haemorrhage, remove a polyp, or produce a gastrostomy) may be performed. As the same instruments can usually be introduced into the duodenum they are also known as **gastroduodenoscopes** or **oesophagogastroduodenoscopes**. —**gastroscopy** *n.* (*)

Proctoscope

An illuminated instrument through which the lower part of the rectum and the anus may be inspected and minor procedures (such as injection therapy for haemorrhoids) carried out. —**proctoscopy** *n* (*)

Laparoscopy (Peritoneoscopy)

Examination of the abdominal structures (which are contained within the peritoneum) by means of an illuminated tubular instrument (laparoscope). This is passed through a small incision in the wall of the abdomen after injecting carbon dioxide into the abdominal cavity (pneumoperitoneum). In addition to being a diagnostic aid, it is used when taking a biopsy, aspirating cysts, and dividing adhesions. Surgery, including cholecystectomy, fundoplication, colectomy, hemicolectomy, and the occlusion of Fallopian tubes for sterilization, can also be performed through a laparoscope, using either a laser or diathermy to control bleeding (see also minimally invasive surgery). The laparoscope is also used for collecting ova for in vitro fertilization and in performing certain gynaecological operations using a laser (**laser laparoscopy**). —**laparoscopic** *adj.* (*)

Red Lion Group Web site

One of our members recently contacted the group to query whether our web site www.red-lion-group.mcmail.com had some kind of technical problem, or whether he was having access problems, because every time he went to our site, it showed the message "last updated April 1998".

The answer is neither: the simple fact is that this was the last time the site *was* updated.

We have had no-one with the skills or the time to take on updating the web site.

This doesn't mean the site has been forgotten - on the contrary, we have plans to update it and link back issues of the newsletter to it, so that new members can simply download these from the internet. It's just that rare commodity time (and a bit of skill!) that is needed.

In the meantime, we have acquired the domain name www.redliongroup.org for our new site when it is built.

As soon as any progress is made on the Red Lion Group web site, we will let you know…

Ulcerative Colitis and Crohn's Disease

Most members of the Red Lion Group have had (or are considering having) a pouch formed because of ulcerative colitis. In some cases, that diagnosis is later changed to Crohn's disease, for which an ileo-anal pouch is not considered to be an appropriate option.

It can be confusing for patients to have one diagnosis, for which a pouch is suitable, only to discover further down the line that their illness is in fact another one, for which that particular surgery should not have been offered.

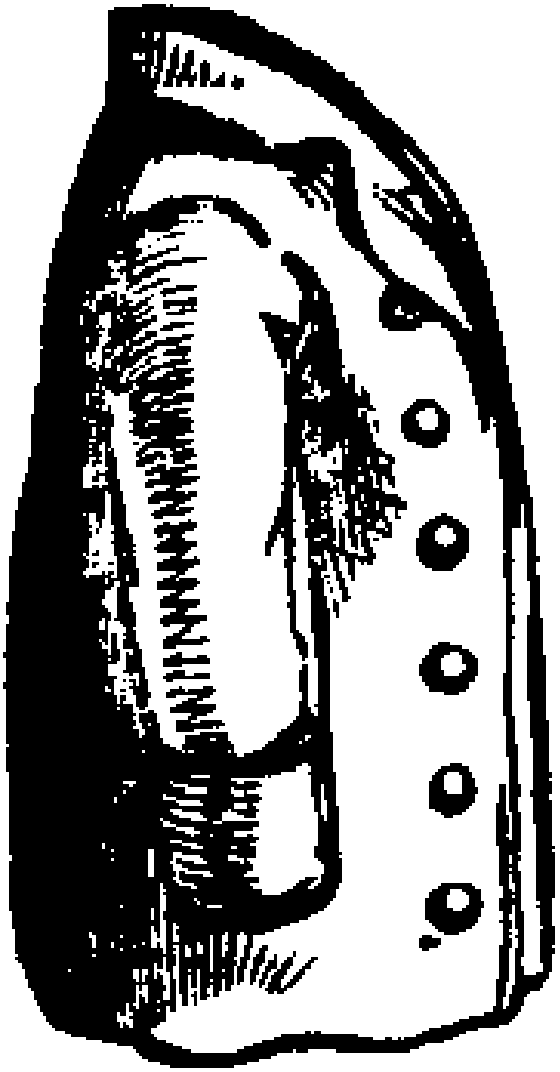
Sometimes, the pouch is reversed to a permanent ileostomy, although we do have some members with both Crohn's and an ileo-anal pouch. In these cases, disease monitoring is probably higher than for other pouch owners, to ensure that creation of a permanent ileostomy takes place if and when symptoms require it.

Both Crohn's and UC fall within the general category of inflammatory bowel disease (IBD). IBD is largely thought to be autoimmune in nature: for some reason, the immune system attacks and inflames the body's own tissues.

UC and Crohn's are considered to be separate diseases, and there are distinctive characteristics of each. Crohn's involves all parts of the bowel, but can affect any part of the gastro-intestinal tract from mouth to anus. UC on the other hand affects only the colon and rectum areas.

This is why an initial diagnosis of UC can turn into a later diagnosis of Crohn's: at the time of the initial diagnosis, it may simply have been the case that the disease was not found outside the areas which UC reaches, whereas later it was.

Medically speaking, the two are thought of as separate, but there is an argument that they are simply two examples of the same process which affect different areas and to a different degree. It is worth pointing out that "in 10-15% of patients it is almost impossible to differentiate between the two diseases" (Postgrad Med J, 1995; 112: 46-8; and 54: 57-8). There is no single test for either Crohn's or UC. Endoscopic, radiological and histological assessments, laboratory testing and bowel studies may all be required before a definitive diagnosis is obtained.



The situation is complicated by the fact that IBD mimics many other disease processes, and the following should all be ruled out before the diagnosis is confirmed:

Intestinal tuberculosis, which has a bacterial cause. The symptoms are almost indistinguishable from IBD, but the treatment is very different (see Debbie Chaplin's letter in this issue). Corticosteroids, often used in managing Crohn's, may make intestinal tuberculosis worse (J Gastroenterol Hepatol, 1996; 11: 532-4)

Endometriosis of the bowel, caused by pieces of the womb lining attaching to the intestine. The result is many similar symptoms to Crohn's.

Diverticulitis, an inflammation of one or more of the diverticula (pouches) in the wall of the large intestine.

Lymphoma (cancer in the lymph nodes), causing liver enlargement, sometimes resulting in gastro-intestinal and bone problems.

Complications from other drugs. NSAIDs cause ileal and colonic inflammation, sulphasalazine can cause symptoms which mimic Crohn's. Gold salts used to treat rheumatoid arthritis have also been associated with Crohn-like symptoms.

Bowel inflammation caused by a food allergy - dairy, yeast and wheat are all common culprits.

Whether emotional and psychological factors are considered a symptom or a cause of IBD, it is known that how the patient adapts to the illness can exacerbate or help ease the symptoms of the disease. In addition, anxiety and depression are common in patients with abdominal symptoms (Can J Psychi, 1993; 38:475-9).

Donating to a Charity (like ours!)

Morag Gaherty has a few words to say about doing a good deed…www.allaboutgiving.org

The Charities Aid Foundation have recently launched a fabulous web site for those who like to do their giving on-line. Since its launch in November 2000, online giving has jumped by 50%, because this site makes it so easy.

Www.allaboutgiving.org enables you to make online donations using your CharityCard to the charity of your choice, and tthe Red Lion Group should recently have been added to its list.

If you do not already have a CharityCard, you can apply for one online as well, and the site gives information on how to make both regular and one-off payments to it. It also advises on how to increase your donations to the Charity Card scheme by 10% at no cost to yourself by signing up to the Give As You Earn Scheme through your employment.

There are a number of ways to find a charity to donate to on this site. You can either enter the charity name, registered charity number, first letter of the name or search for a keyword (each charity has a simple mission statement, so a search on "pouch" should bring up the Red Lion Group). Also, a novel idea is the Discover a Charity section which shows random charities from their list for you to find out more about - this would appeal to the fruit machine enthusiasts among us! It also means the Red Lion Group could receive donations from people who were previously unaware of our existence and who have no connection to pouch surgery at all.

Finally, for those who are interested in receiving latest news and tax information about charitable giving, you can sign up to receive the e-newsletter. Fundraising ideas can also be found at this site.

www.care4free.net

This internet service provider (ISP) gives 75% of its profits direct to the charity you choose to nominate when you sign up to its subscription free service. Care4free has all of the information services offered by other ISPs and supports both modem and high speed ISDN connections. Calls are charged at local rates, through whatever phone company you use.

The Red Lion Group will shortly be added to its list of charities, for you to select as your choice if you wish. When we do so, which may have already happened by the time this goes to press, you will also be able to make online donations. These won't attract the tax advantages the donations through a CharityCard (see above) or Gift Aid (see below) do, but this method is ideal for those of you who are not taxpayers or do not have a CharityCard account. There are no charges for this service, so 100% of your donation goes to the charity of your choice.

Not only that, its sister site www.CaringShop.co.uk (which you can access via the care4free homepage) contains thousands of gift and card ideas. Whenever you shop there, you simply choose the charity you want to benefit, and they get a 10% commission. Take a look around - it's not just Christmas cards and gifts, but all sorts of lovely items. It is hosted by Webb Ivory, a respected name in charity shopping.

Gift Aid Donations

Apart from all this, however, let me give another plug for the Red Lion Group Gift Aid donation form - another copy of which is enclosed with this newsletter.

If you are a taxpayer, you really should complete one of these. It costs you nothing extra, but the Red Lion Group can recover (currently) £2.80 on top of your annual £10 subscription and 28p extra for every pound you give in donations. *Make sure the form is with the Treasurer by 5 April 2001 so that all your payments in the tax year 200/2001 get this generous tax top up.*

PLEASE PLEASE PLEASE do this little thing - all it costs is the price of a stamp, but the Red Lion Group has so much to gain from it.

Articles from Back Issues

For the benefit of newer members, this section mentions the most important articles for pouch owners that have appeared in previous issues.

Earlier issues can be obtained on request from the Liaison Officer (address on back page).

Please enclose a large stamped addressed envelope with a 31p stamp for 1 issue, 60p for 2 or more.

Prescription exemptions (and update) - issues 4 and 10
Family planning - issue 5
Keys for disabled toilets - issue 13
Regaining bowel control after bowel surgery - issue 14
Joint pain - issue 15
Getting help with paying for your water bill - issue 18

Resolution to be Voted on at the AGM

To make a donation of £160 to the Marksman Appeal, being the money raised by Katrina Marshall's parachute jump in aid of bowel research.

Letters

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Dear Newsletter Editor

I have just read Susan Walls' article "Gutsy to Gutless" and would like to congratulate her on her honesty. It is now nine years since my colectomy, and I have tried very hard to go down the jolly, grateful road, aren't I lucky sort of thing. In truth, I am still haunted by the trauma of the ordeal. Mutilation is a word I've thought of so often, but never dared say. The surreal pre-op moment when I was approached by an attractive young lady waving a felt tip at my abdomen, asking "Where would you like your stoma?" **Like** your stoma? Are you mad? And Susan's description of her first confrontation with her ileostomy and her first effort to change the bag was exactly the same as my experience - word for word.

I feel a huge weight has been lifted from me, simply by reading Susan's article - so thank you Susan. You're right, things do improve, but I still live in terror of a time when I may lose the pouch and have "the loathsome thing" back permanently.

Sandra E Allen

Dear Newsletter Editor

My closure was carried out in the Autumn of 2000. As my output is the consistency of "sausagemeat", I am syringing with water to enable me to pass a thinner stool. I am also taking a laxative twice a day to thin output. Two weeks ago, my surgeon found I had a stricture in the join from my pouch to my anus. For just a day it was corrected, but seems to have closed again, and I will be seeing my consultant about it shortly.

The combination of thick stools and stricture gives me discomfort and constant pressure. I wonder if there are any other members who have experienced these things and - if so - the outcome. My consultant and stoma nurse have told me they have never had a patient experiencing this. Usually most patients 3 or 4 months post operatively would be taking Imodium to thicken output, not laxatives to loosen it.

In desperation, I rang Julia Williams at St Mark's and she gave me lots of advice on syringing, laxatives and dilating. I was unaware of dilating prior to speaking to Julia, but she told me that I was not alone, and that quite a few patients have a thick output and need to dilate themselves 3 times a day to keep the stricture open.

I would be interested to talk to any other member who has had similar experiences to me.

Anne Lane
Tel: 0117 960 6442

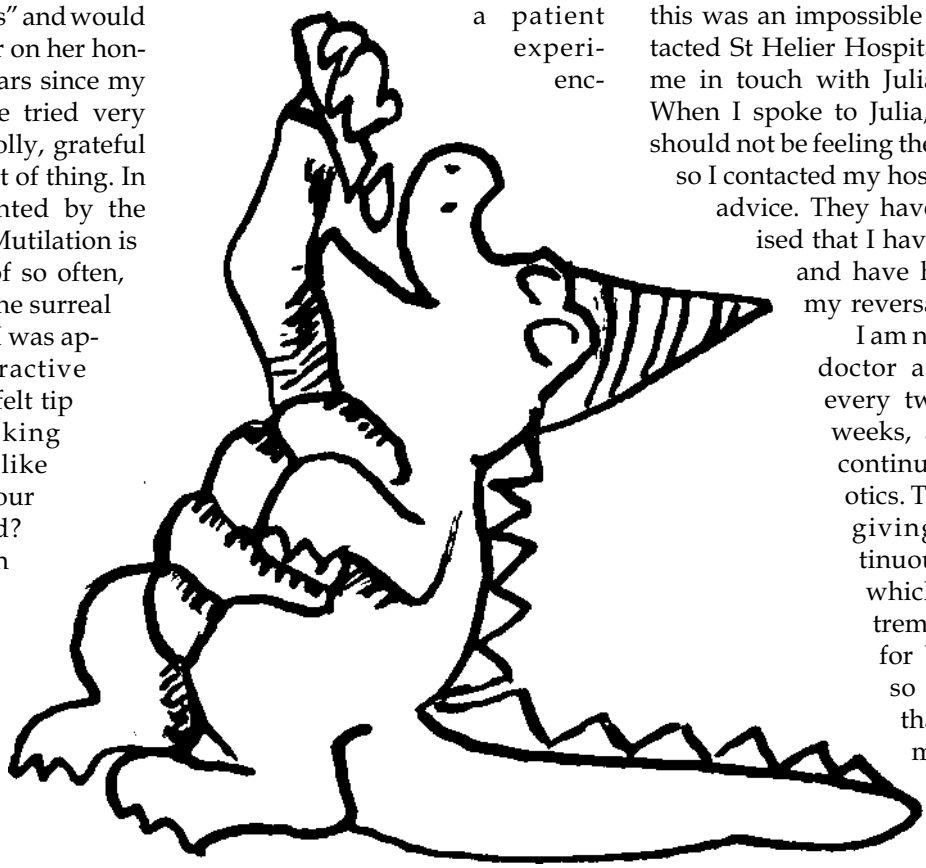
Dear Newsletter Editor

I had my first operation in June 1999. I didn't cope very well with having a bag, so I ended up losing 2 stone in weight. My reversal was in August of the same year. Unfortunately at the time the stoma care nurse had just retired, so there was no-one to talk to.

Up until October 2000, I tried to cope as best I could, but I felt that this was an impossible task. I contacted St Helier Hospital, who put me in touch with Julia Williams. When I spoke to Julia, she said I should not be feeling the way I was, so I contacted my hospital on her advice. They have now realised that I have pouchitis, and have had it since my reversal.

I am now seeing a doctor at St Helier every two or three weeks, and am on continuous antibiotics. They are also giving me continuous support, which I am extremely grateful for because for so long I felt that I was on my own.

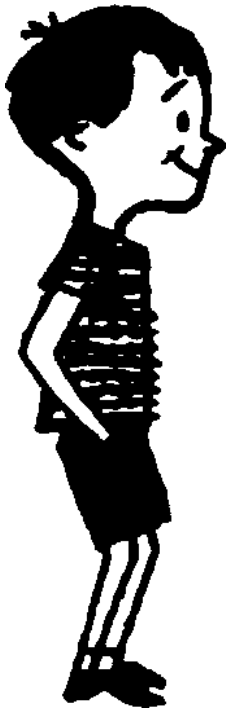
Julie Clayton



Dear Newsletter Editor

I had my pouch formed in 1989. Although I was originally diagnosed with UC, I became ill again two years after the pouch was formed and subsequently Crohn's was diagnosed. More recently, I have been suffering from severe anaemia, despite intravenous iron, and the pouch has been playing up a bit. I am currently undergoing tests at St Marks because Prof Kamm thinks that many "pouchies" who have later been diagnosed with Crohn's may not have it at all! A bacterial problem may be the cause instead.

My son was born in 1997, eight years after my pouch op. Mr Northover advised my local hospital that I should have a caesarian, which was fine by me as I did not want to risk damage to the pouch or anal muscles. However, despite having a completely trouble-free pregnancy, I went into premature labour at 30 weeks and had an emergency caesarian. Toby weighed 3lbs 3oz and had to stay in the neonatal unit for six weeks (he's now a noisy boisterous normal 3 year old!).



Nobody could tell me why he was premature, but they could not discount the Crohn's or my previous surgery as the cause. I also had a very early miscarriage in 1999. Again, we don't know if my medical history and anaemia may have played a part. My husband and I are still hoping to have another child.

I am currently undergoing training at St Marks biofeedback department on how to empty the pouch better. Prof Kamm believes this may be a cause of some of my problems.

Debbie Chaplin

Corrections and Apologies

Perhaps this could become like the Guardian corrections section, which is a hoot to read, and a reason in itself to buy that newspaper. For those of you who have not yet discovered this little gem, I recommend its dry wit, which I am unlikely to be able to match.

Anyway, here are the things I got wrong with issue 19:

Many apologies to cartoonist Stuart Hiern-Cooke for inadvertently not crediting the cartoon "Invasion of the steroid heads" to him.

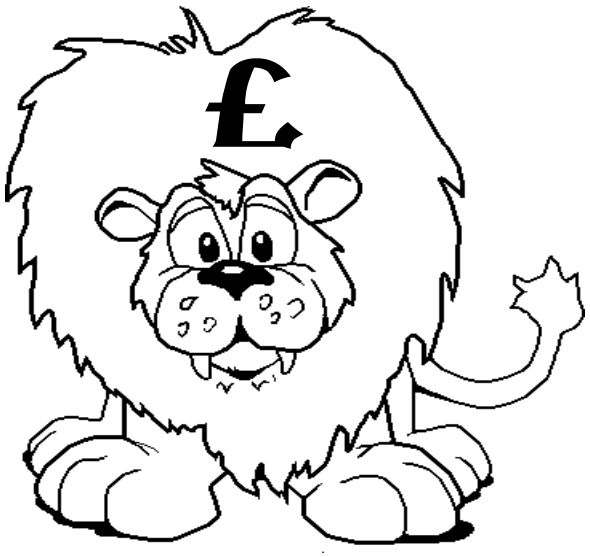
My editorial did mention that the article about art as therapy was written by Christine Lawton, although the article itself was left anonymous. If you were tempted by the offer to "contact me" for help or advice on how to get started with art, but confused as to where to write, I can only apologise.

When sorting out subscription renewals, I completely forgot to take account of the fact that some of you have standing orders set up - these people should have received a note that their subscription would renew automatically unless they advised otherwise, rather than the subscription reminder that actually went out. As a consequence, a few cheques have had to be returned. Luckily not too many. The silly thing is, we have the technology to ensure that this sort of silly mistake does not happen - the trouble is, it is operated by someone who is all too human! I blame the medical condition known as post-pregnancy whoosh brain.

On the plus side, for once I did remember to tell you how to buy your Alexandra Rose Day raffle tickets, and many thanks to those of you who so far have done so. A few more tickets will be available for sale at our Information Day on 7 April. Please do come and buy them - the prizes are really worth having, and the cause is a good one.

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**

My Story...by Michael Dawson

As it is just over twenty five years since my first operation, I thought I would write my story.

After suffering with the classic symptoms of ulcerative colitis for about three weeks, I was admitted to the isolation ward of Seacroft Hospital Leeds in 1975, aged twenty three. The initial diagnosis was Shigella dysentery and then UC. The standard treatment at the time had little or no effect on my condition and I was transferred to Leeds General Infirmary with a view to surgery.

My condition continued to deteriorate and the houseman came to tell me that my colon had perforated, and that they would be operating that night. It was planned that I would have a panproctocolectomy, but due to my poor state of health the operation was cut short, so I had a sub total colectomy with ileostomy. The operation was performed by Prof Goligher. I was very ill before my operation but even more so post operatively.

I made good progress after surgery and gradually all the tubes and drains were removed, except the ileostomy bag which was firmly adhered to the right side of my abdomen. The next event to happen was that I contracted salmonella, and I was transferred back to the isolation ward of the first hospital. The source of infection was never traced.

Everything went well for a couple of weeks and I was discharged. All these dramatic events happened in a period of about eight weeks.

On subsequent visits to outpatients, I always had a proctoscopy. I was told that my rectum was still very inflamed and to think about having it removed, to eliminate the chance of a tumour developing later. I never agreed to this because I hoped eventually the inflammation would spontaneously heal up and I would be able to have an ileo rectal anastomosis.

In 1977 I met a new surgeon in clinic, Prof Johnston, who had developed a procedure to restore bowel continuity, a variation on today's ileo anal pouch operation. He offered this to me as an alternative to an ileostomy, and I jumped at the chance to have a continent bowel. I was told it would be done in two stages: at the first stage I would have a mucosal proctectomy with ileo anal anastomosis and a covering ileostomy.

This operation had to be postponed for a few months while some abscesses healed up. I had the first stage operation and an hernia repaired at the same time without problems, and the second stage (ie closure of ileostomy) went ahead three months later.

I was about the tenth person in this country to have this particular procedure. All went well for about twelve days until I started on a full diet, when I developed bad diarrhoea, and at its worst I was averaging about twenty bowel movements in twenty four hours.

The diagnosis was stenosis just above the anastomosis due to an abscess which had healed up. I went back to theatre to have the stricture dilated, but unfortunately on dilatation my bowel perforated so I had no choice but to have a conventional ileostomy re-established.

Later I read about another technique to restore bowel continence called a Kock pouch, which had been developed in Sweden. I asked Prof Johnston if he would consider this for me and he eventually agreed to do it. Again, this was a two stage procedure.

In 1982, I had a Kock pouch constructed with a covering ileostomy to allow the pouch to heal up. Three months later at the second stage I had my ileostomy closed and connected to the pouch. Bad news again - the pouch was incontinent because the nipple valve had unintussuscepted. After the first

stage operation I had had problems with infection and sepsis inside the pouch.

I now had the worst case scenario ie I had to wear a bag and intubate the pouch four times a day. I asked my surgeon if he would consider implanting an Erlanger magnetic cap, but he wasn't keen and said they were prone to infection and rejection.

The next operation I had was an incisional hernia repair, which went relatively trouble free.

I was still keen to have a continent bowel, so I wrote to Mr Ian Todd at St Marks hospital, explaining my predicament. He wrote back to tell me that a device for incontinent Kock pouches had been developed at the Mayo Clinic USA, but was rather cumbersome and probably not suitable. I wrote another letter to St Marks and was given an appointment at Mr Hawley's outpatients clinic, where he asked me to try a Coloplast colostomy plug before considering surgery.

The plug did not work, so he constructed a new Kock pouch for me in 1988. This operation was extremely successful and I had no problems at all, even though he told me afterwards that it was a difficult procedure.

The legacy for me after all this surgery is adhesions. I have lost count of the number of times I have been admitted to my local hospital with small bowel adhesions and obstruction. In 1989 I had surgery for division of adhesions which gave me only temporary respite, knowing it is a vicious circle and that surgery can cause more to grow back again, which proved to be the case.

The last surgery I underwent was a laparotomy and excision of a fistula which was connected to the pouch.

To this day I am still plagued by my adhesions, so I asked about laparoscopic surgery, as it is less invasive, but was given a big no no, as the chances of perforating the bowel would be extremely high. If I ever have any more abdominal surgery, I think I would be a good candidate to have Seprafilm squirted in at operation.

Get Involved with the Dream Team!

As ever, we need to put out a plea for more volunteers to join the Red Lion Group national committee. The more committee members we have, the less reliant we are on specific individuals, and therefore the greater the likelihood of the Red Lion Group remaining strong and active.

Now that most of our committee meetings are held by telephone conference, it really does not take up much time: an hour's conference in the comfort of your own home once a quarter, plus whatever tasks you agree to do. There is one face to face conference per annum at St Marks, and travel expenses are paid for this. If it were impossible to get there, you could still be an active committee member by joining in the telephone conferences alone, so it really does not matter if you are in Cornwall or Shetland.

Many of you have written to me to say what a great job the Red Lion Group is doing. We do appreciate those comments, but you must appreciate that it is not the Red Lion Group doing it, it is *people* - individual members - who do the work. The fewer the people involved, the more work they have to do. Not only does this increase the risk of those few committee members deciding enough is enough, but each committee member can only hold an individual post for so long, according to the terms of the constitution, however much work they are willing to do.

Put it this way, one day there may not be a Gaherty to do the newsletter or maintain the member database…

We have received very few nominations for the posts falling vacant at this year's AGM, and those which have come in are largely for people who are already playing their part. If the Red Lion Group is to thrive, this is not enough.

Why not nominate yourself for something? We promise to take into account your skills and the time you have available, and not to overload you with stuff. It is in our interest to keep you happy.

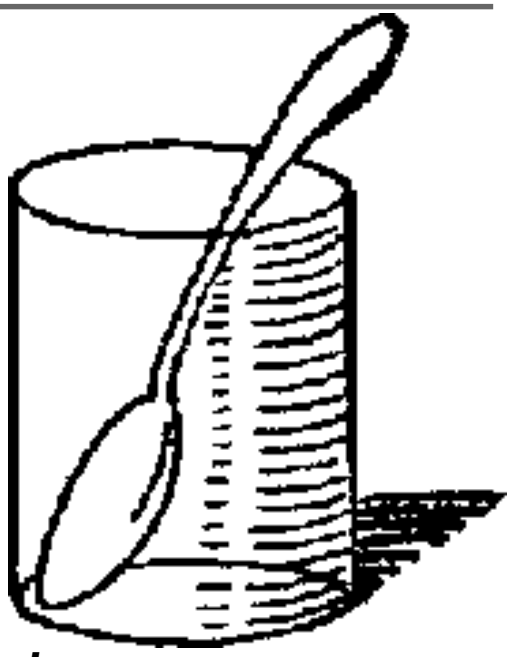
Nominations can be made in writing or verbally at any point prior to the start of the AGM. Please make the effort to get involved.

Statistics on Steroids

The development of osteoporosis is clearly linked to steroid use in many cases. This is particularly true in patients with either Crohn's or UC, because the inflammatory bowel disease often results in a secondary malabsorption of calcium and vitamin D, thus exacerbating the problem.

In one study, among patients with UC, hip density was 43% diminished by steroid use, and spine density was 48% diminished. The figures are even higher for Crohn's sufferers. Even more importantly, steroid use was the only significant predicting factor for reduced bone density (J Bone Miner Res, 1995; 10:250-6).

Electrolyte Mix - St Marks Formula



If you have been prescribed Electrolyte Mix, you will need to make up the solution fresh each day. The ingredients are:

Glucose powder
6 level 5ml spoonfuls

Sodium chloride powder (table salt)
1 level 5ml spoonful

Sodium bicarbonate powder (also known as bicarbonate of soda)
1 heaped 2.5ml spoonful

Mix all of the above in one litre of tap water.

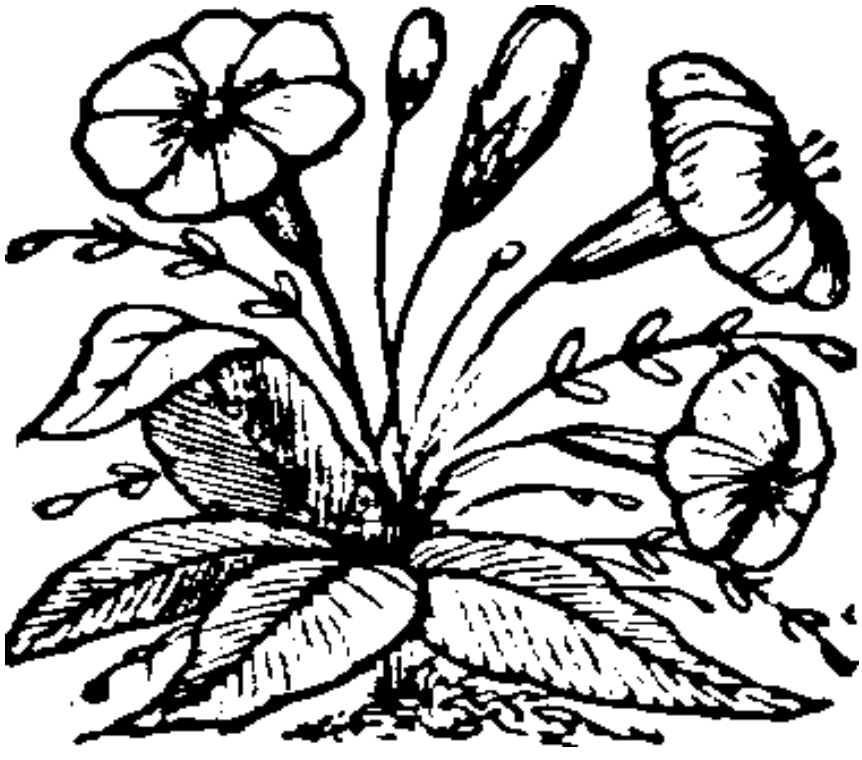
All of these ingredients are available in pharmacies or supermarkets, and are cheaper to buy than to obtain under prescription, if you pay prescription charges. If you have any queries, telephone the St Marks Pharmacy on 020 8235 4100.

Anal Fissure self help page on the web

While surfing the web one evening, I came across a self help web site for people who suffer from anal fissures, a problem I know that some pouch owners have. I can't recall exactly what I was looking for, but it certainly wasn't this! Anyway, having found it, I thought you would like to know about it.

The web site is written by a man named Jack, who was disappointed by the lack of information when he tried to search for this topic on the internet. So he went off and created this self help site. There are case histories here and suggestions of things to try.

There is also an anonymous survey being run in conjunction with a Kansas-based professor which you can take part in. You can have your case history added as well - which might be useful, as there are no pouch patients on there to my knowledge.



Jack has summarised all the case histories and provided links to each one. Some are what he calls "must reads". The case history for Patient 8 is particularly useful as it contains a good discussion of the risks of becoming incontinent as a result of surgery, and a section about the possible causes of anal fissures.

There is also a link to Patient 8's suggestions of Do's and Don'ts regarding anal fissure care. This is presented in tabular form and can be found at the following address:

http://www.boardsailor.com/jack/af/patient_8_regimen/regimen2.html.

There are also case histories from people who have managed anal fissures without resorting to surgery, with separate subsections for pregnant women and children, whose needs may be different.

The anal fissure self help site can be found at:

http://www.boardsailor.com/jack/af/index.html

And your specialist subject is...

In recent years, the role of specialist nurse practitioners has been created, for those nurses who deal with specific patient groups. Julia Williams, the Red Lion Group's clinical nurse specialist, is one of these.

Before the creation of this role, nurses were unable to carry out endoscopies: these had to be performed by a qualified doctor. Now, after suitable training in both the mechanical skills and the diagnostic skills required, plus involvement in a high number of procedures under supervision, a colorectal nurse specialist is able to perform flexible sigmoidoscopies for her patients without a doctor's involvement.

A colorectal nurse specialist can also prescribe drug treatments and be responsible for screening arrangements, which effectively means that they can run their own clinics on a more independent basis.

Apart from being a fundamental recognition that nurses have a high degree of medical expertise in their own right, this also has advantages for patients, who can be seen by someone with whom they have had regular dealings. An endoscopy is not a pleasant procedure at the best of times, but in the hands of someone you know and feel comfortable with, you are likely to feel less discomfort. From the appointment point of view as well, more of the necessary procedures can take place under one roof, thus reducing the need to attend different clinics.

No doubt, there will be further developments in the responsibilities of specialist nurse practitioners, as they continue to show the medical hierarchy exactly what they are capable of!

Smile, you're on candid camera

As many Red Lion Group members know, having an ileostomy, either permanent or preparatory to having the reversal operation, is a huge step. Whether we adjust well to it, or whether we simply get by, in the first instance we have to know exactly what is going to happen.

I well remember the day we were (wrongly) told that Brian would have to have a permanent ileostomy. I was in such a daze at the news that - even if the registrar explained it well (which I doubt), I had no idea what an ileostomy looked like: I was convinced that Brian was going to have his bottom sewn up all along the buttocks!

This is where having a book or a video to take away and absorb at leisure really comes into its own. There is a video called *What You Really Need to Know about Colostomies, Ileostomies and Urostomies* (catchy title, eh?!) which is worth a look.

It stars John Cleese as the patient. I have not seen the video myself, but it is apparently very informative about the details of this surgery and the usual questions people need answers to. Quite apart from the information content, three ostomists talk about life with their stoma, including work, play, travel and sex.

Of course, the three participants are those who handle their stoma well and make it seem really easy - but on the other hand, confidence from someone who manages well is likely to rub off on the watcher and may make them less apprehensive about their own impending surgery.

The video is available for £17.50 for £17.50 (including p&p) from Videos for Patients Ltd, PO Box 22547, London, W8 7GW. Tel: 020 7727 2690.

Making your bowels less irritable

The following are a number of possible approaches to managing your ulcerative colitis/ Irritable Bowel Disease (IBD) before considering drugs or surgery.

Dietary Changes

As many Red Lion Group members know, certain foods make them better and certain foods make them worse. Unfortunately, which foods in particular seem to be very individualised, and what works for one pouch owner may be a disaster for another. However, what is clear from the research (J R Col Physicians London, 1986; 20:45-8; Postgrad Med, 1983; 50:690-7) is that Crohn's and UC patients often have a wide range of nutritional imbalances.

One approach which works well for many sufferers is to change to a diet which is high in fibre and low in sugar (Gastroenterol, 1987; 92: 1483; J Gastroenterol, 1981; 19: 1-12; Br Med J, 1979; 2: 764-6). In particular, polyunsaturated fatty acids and food with the amino acids glutamine and argenine should be avoided.

Nutritional Supplements

Patients with UC can be helped by taking increased supplements of fish oil (J Clin Gastroenterol, 1990; 12: 157-61). A small placebo-controlled, double blind study showed that fish oil capsules also reduced the rate of relapse in Crohn's patients (N Eng J Med, 1996; 334: 1557-60).

Studies have shown that extra folic acid, which may be deficient because of inadequate diet or malabsorption (which is often a feature of IBD), can help, as can supplementation with vitamin E.

Healthy gut mucosa depends on the presence of several nutritional elements. UC sufferers should ensure that they get enough of vitamins A, B, C and D. Those with chronic gastro-intestinal disorders may also be deficient in vitamin K (Am J Clin Nutr, 1985; 41: 639-43). Zinc, iron and calcium levels may also require boosting.

Taking Probiotics

Issue 17 contained an article all about the advantages of probiotics and their newer relation prebiotics. The idea is that the gut's friendly bacteria are reinstated in order to boost immune system function. You should note, however, that a temporary allergic response (known as the Herxheimer reaction) may result, because of the death of large amounts of pathological organisms. This may cause some discomfort, but is a sign that your body is beginning to recover.

Yakult, available from the supermarket, is an example of a live probiotic. Freeze dried capsules of probiotics are also available, and have the advantage that they can be stored until required, unlike Yakult and similar products, which have to be taken while fresh.

Herbal Preparations

Several herbs have been shown to help soothe gastro-intestinal tract disorders, including goldenseal, licorice root and papaya leaf - these latter two have specific anti-ulceration properties.

However, do please bear in mind the cautionary tale of homeopathic practitioner Julia Peters, as reported in issue 19: herbs are still drugs, however natural, and they are very powerful. Taken inappropriately they can do serious damage to a body already weak from IBD.

Rule out Food Sensitivities

Dairy and yeast products are the most common allergens, possibly because they are high in histamine. Patients with Crohn's were found to be 50% deficient in diamine oxidase in their guts, which is required to metabolise histamine. It is not possible to increase this element by supplementation, so diet control may be the only way to manage this kind of intolerance. The situation is likely to be similar for UC sufferers.

Rather than elimination, desensitisation methods may be the best way to manage food sensitivities. Minute doses of what you are allergic to can be given in order to desensitise. In effect, this is a form of vaccination, and is known as enzyme potentiated desensitisation.

Lifestyle Changes

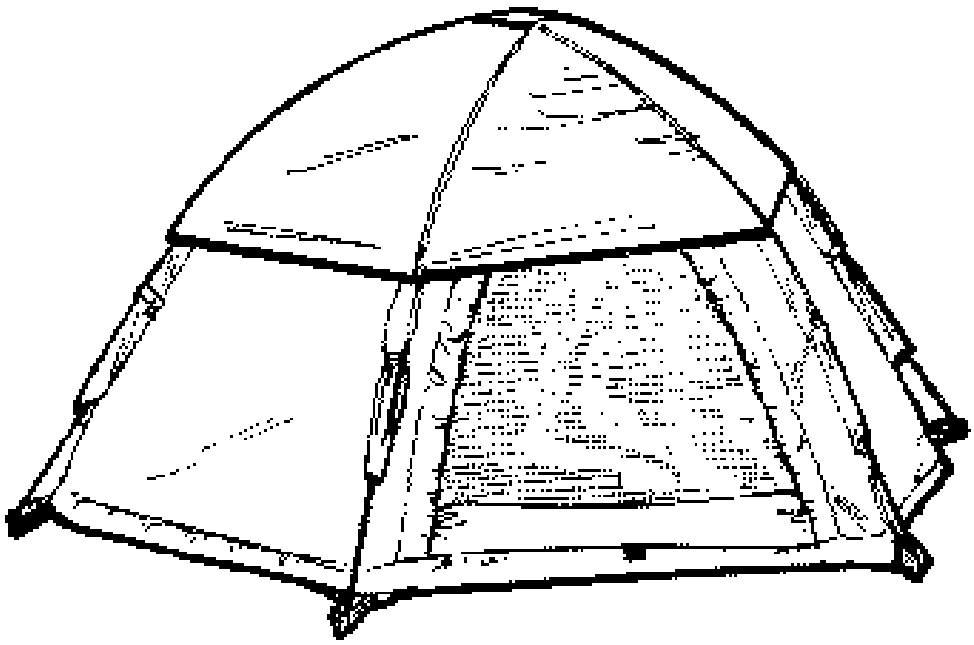
Both smoking and the contraceptive pill aggravate the tendency of the blood vessels to block, so stopping both may also be helpful.

Introducing our Regional Reps...Christine Jackson

My name is Christine Jackson. I was diagnosed with UC in October 1995 after 10 years of symptoms that were ignored by my GP in Middlesbrough. Apparently it was a tummy bug and I was just sent home and told to starve for 24 hours each time. I lost so much weight. Wish I could lose some now.

After being told what I already knew (I am a qualified nurse), I then had a year of steroids that didn't help the symptoms: they only made me fat. I struggled to bring up my two daughters by myself, then aged 6 and 7. I had no family locally or close friend that could help. When I was too poorly, I was being cared for by my eldest daughter Leanne who learned to do things that she shouldn't have to do. This is a fact that I will never forget and what no 7 year old should have to cope with, but I had no choice.

I then got a council house 3½ miles from my parents, 9½ miles outside of Whitby. This enabled them to look after the girls for me when I was very ill or when surgery called. I was referred to a surgeon – Mr Corbett - and subsequently had my first operation: a panproctocolectomy and formation of internal parks pouch on 23 October 1996.



I was told at the time that I could have the reversal operation within 3 months, but as I felt so well when I woke up after the first operation (even with drips and drains from everywhere, and a pink thing we named 'Horace' on my side), I decided to try and give the kids their childhood back. I wanted to be a proper active, happy and normal mum (very hard, as I have never been normal!), to have fun with them and enjoy their childhood with them. Take it from me, we give it a good try and succeeded.

Horace never was too much of a problem. It leaked for a while when I first 'brought it home' but we went camping together. The kids would stand guard at the toilet block when I was changing the bag, and it didn't stop me swimming in the sea at all. It made funny noises in the night in the tent which we would have hysterics at. At home the kids took over the job of getting all the bits together to

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).

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David Mair	Bristol	0117 922 1906
BEDFORDSHIRE		
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BERKSHIRE		
Liz Davies	Langley	01753 586593
CAMBRIDGESHIRE		
Joyce Shotton	Peterborough	01733 706071
CLEVELAND & NORTH YORKSHIRE		
Christine Jackson	Saltburn	01947 840836
		chrisjacks@supanet.com
CUMBRIA		
Jonathan Caton	Kendal	01539 731985
DERBYSHIRE		
John Roberts	Derby	01332 361234
DEVON		
Gill Tomlin	Kingsbridge	01548 810028
DYFED		
Briony Jones	Haverfordwest	01437 765359
Bruce Dibben	Haverfordwest	01437 731436
EAST SUSSEX		
Lisa Critchley	Brighton	01273 699286
ESSEX		
Peter Zammit	Benfleet	01268 752808
Clare Shanahan	Ilford	01708 444359
GWENT		
Robert Challenger	Cwmbran	01633 866820
HAMPSHIRE		
Phil Smith	Portsmouth	01705 426541
Les Willoughby	Winchester	01962 620012
HERTFORDSHIRE		
Carol George	Stevenage	01438 365707
KENT		
David Irving-James	Folkestone	01303 894614
Phil Elliment	Barnehurst	01322 558467
KENT (WEST)		
Rosalyn Hiscock	Pembury	01892 823171
LANCASHIRE		
Joan Whiteley	Clitheroe	01200 422093
MERSEYSIDE		
Blanche Farley	Liverpool	0151 286 2020
NORFOLK		
Sandy Hyams	King's Lynn	01485 542380
Sylvia Mist	Norwich	01692 580095
NORTH LONDON		
Susan Burrows	N14	020 8882 5318
NORTHAMPTONSHIRE		
Cynthia Gunthorpe	Kettering	01536 482529
David Smith	Northampton	01604 450305
SOMERSET		
Clive Brown	Chard	01460 234439
SOUTH LONDON		
Andy Jones	SE6	020 8690 1360
Jonathan English	SW12	020 8673 3092
SUFFOLK		
Anna Morling	Leiston	01728 830574
WEST LONDON		
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		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

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change the bag and actually took it in turns to do it for me. I never once felt that I hated it. It was part of me and it saved my life. I should have called it my partner, but it was less trouble than that.

After a phone call from the hospital a year and a half later out of the blue I finally felt physically and psychologically ready to have the second surgery. I was in and out in a flash and can honestly say that then and now I feel brilliant.

Yes, I can say that food does upset my pouch but it is worth the pain to enjoy the food at the time. I can (and do) eat anything, drink Guinness and live a normal life. I just get on with it and never think about it. Actually I don't have time. I am into computers and have done a number of college courses, as I don't think I will be able to get back to nursing even when the kids are older. By the time my youngest is say 16 I will be 47.

The girls are now 10 and 12 and the eldest has just been diagnosed with UC this last summer.

Being a Red Lion Rep fulfils the need in me to care for people as I can't be a nurse again just yet. I would especially welcome e-mails from anyone with questions and queries, as phone calls can be a little awkward and inconvenient with 2 kids to sort out and the fact that I am in bed usually at 2100hrs. My e-mail address is chrisjacks@supanet.com.

Contact the Red Lion Group

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FUNDRAISING OFFICER
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* contributions to the newsletter should be sent to Morag Gaherty

PRESIDENT
Professor John Nicholls

PATRON
Claire Rayner

Join the Red Lion Group

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

Don't forget to look at the Red Lion Group website on the internet:

WWW.RED-LION-GROUP.MCMAIL.COM/

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.