

Roar!



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Roar! is the newsletter of the Red Lion Group, St. Mark's Hospital, City Road, London, EC1V 2PS

The Pouch Research of Dr Herbst

Rachel Nicholson recently spoke to Dr Herbst, Research Fellow at St Mark's, from a cramped phone box on Aldwych – not the best place to discuss microbiology and the latest pouch technology – and learned some interesting things about the noise of rush hour traffic and the kinds of research into pouch-related conditions going on behind the red brick walls of St Mark's.

Dr Herbst has been at St Mark's for eight months and has one more year to go. He will then return to his home, Vienna, to continue his previous job in general surgery.

Why would anyone want to specialise in colo-rectal surgery? It is not after all the most attractive part of the human form. Well, a budding surgeon needs to find a niche, or be "blown away". Also technology has not in the past played a great role in colo-rectal surgery. But now all sorts of new diagnostic tools are being used (like ultrasound), and new links are being discovered between colo-rectal problems, immunology and genetics. These complex relationships need exploring, and it is relatively uncharted territory – exciting stuff for any research fellow. Dr Herbst has seen that the deeper into a specialisation you get, the more you realise how little you know about it.

Some of Dr Herbst's research relates to the condition known as "pouchitis". You will probably have heard about this from your surgeon when you discussed the pros and cons of having pouch surgery, but for those of you who haven't heard, let me explain. Pouchitis is a non-infectious inflammation of the pouch lining with symptoms very like those of ulcerative colitis. If pouchitis does occur it is most likely to do so within

18 months of the pouch-forming operation. If you have had your pouch for more than 24 months with no signs of pouchitis you are probably in the clear.

One of Dr Herbst's projects aims to discover the effects of certain medicines on people with pouchitis. For example, is loperamide effective in reducing the troubling symptoms of pouchitis, such as the frequency of going to the loo, incontinence and soreness? Or does the inflammation of pouchitis override the usual benefits of the drug? Do the more frequent trips to the loo mean that you are passing a greater volume of stool per day, or are you just passing smaller amounts more often? Does the use of loperamide affect the volume of stool produced, or just the frequency?

A second project that Dr Herbst is working on investigates the exact nature and causes of pouchitis. Certain facts make this interesting. Firstly, pouchitis does not appear in patients who have been given pouches as a result of polypsis or constipation, but does appear in those who have had ulcerative colitis (UC).

This suggests that pouchitis is linked to UC. Genetic studies support this theory by showing a link between UC and other inflammatory conditions. Secondly, pouchitis does not occur if the pouch is not

functioning, for example if you have a covering ileostomy while the pouch heals.

So is pouchitis triggered when a particular type of faeces comes into contact with the pouch? This is unlikely because there is no difference between the faeces of a pouchitis sufferer and that of a healthy pouch owner. Dr Herbst is therefore studying the response of the pouch's mucosa to exposure to faeces to find out exactly which cell products are responsible for the inflammation, and why this inflammation only occurs in some patients with a history of UC.

Dr Herbst's third project (he's a busy man!) looks at aspects of immunogenetics in people who have had pouches for at least three or four years without problems, and in pouchitis patients. Apparently about 20% of UC sufferers may develop non-intestinal problems, while up to 20% of pouch owners with previous UC develop pouchitis.

Pouchitis has also been shown to be more common in patients who have had non-intestinal problems. Is there any genetic link between these statistics? Research of this type is only just beginning. If a genetic marker is discovered and confirmed on a wider scale it will be very useful in the counselling of prospective pouch patients. Those with an 'offending' gene can be advised that they are likely to develop pouchitis or other problems. This will arm the patient with additional information on which to base his or her decision whether or not to undergo pouch surgery. As many of you have written, "forewarned is forearmed".

I hope that you have found my telephone conversation with Dr Herbst interesting despite the traffic noise. If so, do let us know. Perhaps we can do similar features for future issues of *Roar!* ■

Rachel's Regional Reps

If you want to get in touch with a pouch owner in your area please contact one of the following regional reps.

Bedfordshire

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0525 220002

Berkshire

Liz Davies (Langley)
0753 586593

Cheshire

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Cumbria

Jon Caton (Kendal)
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Essex

Kate Batley (Colchester)
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Hampshire

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Hertfordshire

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0273 699286

Wales

Robert Challenger (Cwumbran)
0633 866820

Each regional rep in my book has a list of the names, addresses and (in some cases) telephone numbers and ages of Red Lion Group members in their area. If you have not already given me your phone number, please do pass it on to your regional rep.

The list also includes the names of members who have offered help and a sympathetic ear to any group member who needs one. Where possible I have indicated when a contact has experience of a particular area, for example pregnancy/child-birth and the pouch. We rely on you to let us know these details as we do not have access to hospital records.

You may have noticed that some of these reps have changed since the last issue of *Roar!*. This is partly due to pressures on people's time and also because I feel it is most useful if regional reps actually live in the country or region that they represent.

Can anyone help? Although the areas listed below contain Red Lion Group members, they do not yet have regional reps. Any volunteers?

Avon

Buckinghamshire

Cambridge

Cornwall

Derbyshire

Dorset

Gloucestershire

Leicestershire

London

Merseyside

Midlands

Shropshire

Somerset

Suffolk

Surrey

Tyne & Wear

Warwickshire

Wiltshire

Worcestershire

Yorkshire

Scotland

Northern

Ireland

Eire

Guernsey

Egypt

If you would like to get in touch with a Red Lion Group member but your area is unrepresented please contact me (my details are in the box at the top of this page).

Many thanks to all the regional reps who have offered their services (or been press-ganged by me). The amount of work involved de-

pends largely on how many Red Lion Group members there are in each region — this varies from one (not many group activities there) to over twenty.

There are well over 200 members in total, and the number is growing steadily as the word spreads (and the pouches multiply). Write to me if you are not already on our mailing list.

Some regional reps arrange small, informal meetings at their homes, others put those who contact them in touch with members who live nearby or who have had similar experiences with their pouch.

Apart from that there is not much to it. I send the reps copies of the Red Lion Group Steering Committee meetings, keep the mailing list up to date, and try to keep the reps informed of new members in their areas. **Please let me know if your contact details change.**

Kate's Correspondence

**Kate Batley
Spring Cottage
Spring Lane
Colchester
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CO3 4AN**



Floating titbits

Dear Roar!

Reading the latest *ia* journal number 144 and the formation of the Red Lion Group I was very impressed by your achievement in having convened this meeting of ileo-rectal pouch recipients. It was a noble idea to come together to exchange ideas and suggestions.

It is comforting to realise that isolation no longer exists when one is aware that there are other people with the same condition who through exchange are able to cope with their discomforts by the floating of various titbits which they share with each other. I hope success crowns your efforts.

Yours faithfully

EBM, Aylesbury

Thank you for your kind words.

Helped by metronidazole

Dear Roar!

I had my operation at the Norfolk and Norwich Hospital in July 1993. For the first six months I had so many problems; I was constantly on the loo day and night and everything I ate seemed to upset it. I went back into hospital in September to have it stretched but that didn't help. Then in February when I went to the clinic my consultant suggested I try metronidazole three times a day as well as the imodium and codeine phosphate that I was already taking. I am pleased to say since then it has been much better. I still have to go to the toilet several times a day and once or twice at night but I can eat most things, and can go out without having constantly

to look for a loo. I realise I cannot stay on this medicine indefinitely but hope it will not go back to the way it was.

Yours faithfully

PS, Norwich

I have never heard of metronidazole. Have any other readers?

Guinea pig

Dear Roar!

I feel alone with my pouch being the only person in my GP's surgery with one, but not only that it just is not working for me. Three years ago I had my total colectomy. Then six months later the pouch was made. But I was perhaps a bit of a guinea pig because the surgeon did the two operations in one without an underlying ileostomy. I often wonder if he had rested the pouch in the beginning if it would have worked better for me.

Twice now I have had the pouch and ileostomy reversed to try and rest everything but weeks later everything goes wrong again with pain and urgency, just like colitis again. I'm having to stay on antibiotics all the time which I don't like but I have no alternative.

Thank you for reading my letter but I need to know there are other people with 'bad' pouches out there.

Yours faithfully

PF, Clwyd

The 'all-in-one' operation is becoming more and more popular. I'm sorry to hear about your bad luck with it. Yes there are plenty of people with 'bad' pouches: you are not alone. Have any readers gone from having a bad pouch to having a good one?

Letters relating to medical questions should be sent to Dr Herbst at St Mark's Hospital (the address is underneath the banner on page one).

Fruit causes irritation

Dear Roar!

I had my ileo-anal pouch in December last year after which I seemed to go more than I used to.

Some fruits tend to make me very loose and I have to go more often. I also suffer from irritation a lot and have to take a paracetamol most evenings so that I can get some sleep. The only trouble with this is that I have driving lessons every Tuesday and Thursday so I do not want to take paracetamol as it makes me a bit hazy.

The funny thing is people keep on telling me I can eat what I want but I still find there is a lot I cannot have.

Yours faithfully

DG, Aldershot

Many people find there are foods, especially raw fruit, which do not agree with their pouch. If you suffer from irritation try dousing with tissue paper soaked in water and then patting dry very gently instead of rubbing. Some people keep irritation at bay by leaving at least three to four hours between visits to the lavatory. Good luck with your driving test. Please write in and let us know how you got on.

Coming up in the next issue of Roar!...

Christmas diet tips

Please share your favourite diet tips by sending them in to the Red Lion Group letters page so that the Season of Goodwill doesn't turn in to the Season of Sitting on the Loo.

The Good, The Bad and the Ugly

Apart from the obvious, five good things and five bad things about being a pouch owner.

Roar! is edited and typeset by Tim Rogers and printed by Dansac Limited. The views expressed neither reflect necessarily those of Dansac Limited nor St Mark's Hospital.

England's first pouch patient

Dear Roar!

I needed something like your group 22 years ago. I am 80 years old and here is my story:

1970 ulcerative colitis. Local hospital did not do much for me. Very ill.

1971 aged 57. Family doctor asked if I would travel to the Middlesex Hospital for treatment. Did a colectomy to try to heal the ulcers. In hospital five months.

1972 arrived back at the Middlesex. Still very ill. Operation for Koch pouch without the valve. In hospital three months. I was the first patient in England with a pouch. Not too good: leaked after three hours. Did not know what an ileostomy was. No stoma nurses.

1974 went back for the valve. My surgeon was very good. He phoned me to see how I was coping. After a while he left the Middlesex.

Then I started to go to ia meetings in Newcastle. It was quite a distance from my home. Of course there was nothing for me there in those days. I could not cope with the leaks which always happened when I was preparing a meal so now I use a bag. I can remove this to use the catheter four times a day. I have had one difficulty lately: I have gone very solid. Dare not eat vegetables or fruit as they block the catheter.

Otherwise I am pretty good except for a little arthritis and asthma. I live alone now and do my own shopping and housework. I miss my family doctor who died a while ago. The doctor I now have does not know much about a Koch pouch.

I have never spoken to anyone who knows about a Koch pouch and after 22 years I still don't know anyone who has received one.

I know the Koch pouch is redundant now but there must be a few people who have got one.

Yours faithfully

Mrs B, Congleton

If you have a Koch pouch, please write and we will put you in touch with Mrs Barrow who goes into the Red Lion Group Book of Records as England's first pouch patient.

Trumpet Voluntary

Dear Roar!

I am 41 years old and as a matter of interest I am just completing my finals for a BSc honours degree after attending full time university studying Biological Sciences.

I had an ileostomy in March 1990 and had my pouch constructed and in use by June 1991. I do have problems with my pouch with emptying and trapped gas and the noises this causes have been know to disrupt a lecture theatre!

Obviously I would be grateful for any advice on this as I am currently applying for jobs and should I be offered an interview the noises could be a difficult one to explain. (It's a good job I've got a sense of humour.)

Yours faithfully

RF, Peterborough

Quite a few pouch patients are disconcerted by their pouch trumpeting loudly on being emptied. Have any readers got a cure for trapped gas other than possessing a sense of humour?

Diet tips

Dear Roar!

Previous to my rejoin operation in April I had an ileostomy since March 1992 for ulcerative colitis. At present I tend to go to the loo about four or five times a day. I try to stick to three meals a day with plenty of fruit and veg. to keep everything reasonably solid.

I have found both digestion and frequency improved by making sure everything is thoroughly chewed and try to include as much raw and unprocessed food as possible. Nuts can be digested better if they are grated (I have mine with fresh fruit) and sweetcorn (on the cob) can be digested if the kernels are slit with a sharp knife first.

I am pleased that you have had the initiative to set up your group. It's very easy to get discouraged and feel isolated when there are problems and you think you are the only one who has them.

Yours faithfully

KJS, Clwyd

Thank you for those excellent tips.

Please support the Red Lion Group



All donations, however small, which would go towards our ever increasing administration costs will be gratefully received. If you have found this newsletter useful and wish to ensure that we have the funds to produce future issues, please send a donation to: **The Red Lion Group Treasurer, Mr. P B Johnson, 7 Chelston Approach, Ruislip Manor, Ruislip, Middlesex, HA4 9RY.**