



**Welcome** to the first news letter of the CLLSA. I hope to get a copy out to you every month or so, with the latest news and exploits of your organisation.

There is a huge amount of news and information, both from the support and clinical fields. Coming events include the November meeting of the UK CLL forum, the medics association that deals with research and treatment of CLL. A few years ago, CLL was a deeply unsexy disease from a medical point of view. The majority opinion was that the condition was not interesting, and rather unimportant. Many leading doctors have been fighting that view for some years, and now the UK CLL Forum has a growing membership and a programme designed to bring registrars and developing doctors up to speed. Their aim- the aim of us all- is that eventually CLL will be a chronic condition to be managed.

Jane Barnard

*You have received this newsletter because you have shown an interest in the activities of the CLLSA*

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### Local Meetings

It can be awfully lonely out there- it's a rare disease, no matter what your friendly neighbourhood consultant tells you, and you may never have met another patient or carer? The CLL trustees have organised 2 local meetings so far, and a couple of patients have decided to organise local meeting for their area.

Jaqui Williams-Durkin organised the Cambridge meeting, at Wolfson Hall, Girton College, Cambridge. Local members were invited by e-mail and by post, within a 50 mile radius of Cambridge. About 30 people attended, and enjoyed the meeting with presentations by Jaqui and Howard Pearce, the Chairman of the CLLSA. Buffet lunch was laid on.



Howard organised the Ampsfield meeting, near Romsey. Members within a 50 mile radius were contacted, and about 30 people attended, for Howard's talk, socialising and a buffet lunch. The meetings ran from about 12.30 until 4 o'clock.

Jaqui and Howard got very positive feedback from the meetings.

Patients are arranging meetings in Birmingham, Northants. News, as we get it, on the web site and to members likely to be able to get to the meetings.

## Chronic Lymphocytic Leukaemia

*-What have I got?*

CLL is a disease of a part of your immune system, the B cells. Your healthy B cells are the key to your immune system 'remembering' past infections and throwing them off. In many patients, the disease never develops to a life-threatening condition, but we all have to have regular check ups with our haematology departments. In the standard text books CLL is described as a 'having a peak incidence between 60 and 80 years of age'.

It doesn't matter whether you are a 'typical' CLL patient- male, white and elderly, or young, female with no co-morbidities; CLL is a disease that can affect everyone, and this is a community to support you.

*-What can I do?*

CLL is only a part of your make up- hopefully a small part.

Your best bet is to keep yourself as healthy as you can. Depending on your age and general condition, you can try to keep yourself fit and healthy. If you can't do the gym, can you walk? If not every day, some days? Have healthy eating days. Have treats and enjoy yourself. Ask your local health board if they have management sessions for chronic diseases.



**Hand to Mouth-**

While I'm one of the world's great organisers, one of the reasons that this Newsletter is late is that I had a visit from a neighbour. He told me as he left that he hadn't been well. What a pity he could not have asked me for the information he needed by telephone. I've had the bug, now the family is getting it as well.

None of us want to live in a bubble, and there are literally thousands of posts on the net describing one way or another that you can avoid disease (without becoming a hermit). Viruses, bacteria and other infectious particles arrive by many different routes. Let's get back to basics. Primary and Junior schools where pupils are taught to wash their hands after visiting the loo have far fewer days off due to sickness.

The first thing you teach microbiologists is not touch your face in the laboratory. Check yourself- how often have you touched your lips, hair, ear while you were reading this? Quite a few times. Everyone does this, unless they train themselves not to.

That is why it is really important that your hands are clean. When you are at home, you can wash your hands after touching dirty surfaces. In my home, despite what we know, this includes the dog, the banister, the sofa, the kitchen cloth.... The list is endless. Actually, probably the cleanest objects in my home are the loo and sinks- those get disinfected most often.

Don't panic and don't fret...before you prepare food, or eat it, wash your hands. Even a sweet. Always wash your hands after dirty jobs- the garden (if you still garden), the pets, the bathroom. Soap and water is very effective at cleaning hands if you do it properly. Out of the house, you might want to take a waterless hand wash with you- try Superdrug or Boots, sold as 'antibacterial hand gel', it is alcohol based.

Another vital tip, from Professor Hamblin- if someone sneezes, close your eyes. The virus infect through the mucous membranes.

## It's Not Easy being Green (and neutropenic)

At the last trustees meeting some wag told me that I could be in charge of the carbon footprint for the Association...

Some of us have fully functioning immune systems, some less so. That's why I greeted the latest 'green' pronouncement from my friend, Masie, with a little dismay. She has decided that one of the ways to lower the carbon footprint worldwide is to eat more shellfish. And use the shells in paths and roadways. Carbon in the shells permanently removed from the system, Ideal if you can do it- all those yummy omega oils and protein. But neutropenic people (not enough good white cells) can't eat shellfish; they are a high-risk food. Sighing, I picked up the newspaper. Eureka. Common wildlife species are suffering because of over neat gardens- we are all urged to have a wild spot, even if it is a metre square. Long grass, nettles, brambles and even thistles provide good habitat. Gazing out over my rampant garden, I realised that I was being green after all.



### *Meetings- continued*

Why were the meetings held in Cambridge and Romsey?

Looking at the membership list, there are concentrations of members in some areas. It is probably related to the number of people living in those areas, but it meant that it made sense to trial local meetings in the areas where there was a trustee and a relatively large number of members. Don't feel left out, we hope to be able to cover most of the country.

### **On the Net.**

If you have access to the World Wide Web, you have a virtual ocean of information out there. Just like the real ocean, its only too easy to drown. Lots of the information is outdated, or just plain wrong. Even the stuff that is trustworthy can be so complicated it makes your head ache...where can you start?

In the UK, of course, [www.cllsupport.org.uk](http://www.cllsupport.org.uk)

Help, support and chat at; [www.leukaemicare.org.uk](http://www.leukaemicare.org.uk)

In the states, for the absolute best translations of the real science, [www.clltopics.org](http://www.clltopics.org)

Have a good whinge and feedback on all sorts of cll-life related problems at [www.cllforum.com](http://www.cllforum.com) (not always pc here, go on, guess my avatar, small prize to the winner)

And last but not least, the daily ACOR list, with the UK's very own Professor Terry Hamblin, start to access that through <http://ccl.acor.org/help.htm>

Sanity warning; I'd say that it was health warning, but this is more honest. Only read what you want to. A lot of us have a break from the lists and sites for a while if we feel overwhelmed. You don't have to know the latest science, or any science, to receive good treatment from your healthcare providers. Some of the social sites are strictly controlled, and others can be outspoken.

## Report from the UK CLL Forum

Wednesday 23<sup>rd</sup> May 2007- Annual Education Day.

Howard Pearce gave a presentation on the work of the CLLSA.

<http://www.clisupport.org.uk/UK%20CLL%20Forum%20presentation%20May%2007.pdf>

All the medics attending this conference have a serious interest in CLL. Among the CLLSA members at this meeting, 2 of us tried to take notes at break-neck speed.

We will put summaries of the CLL Forum UK meetings on the CLLSA website.

Dr C. Fegan, a CLL specialist from the Chronic Lymphocytic Leukaemia research Group of the University Hospital of Wales, is a member of the committee of the UK CLL Forum. He gave a talk on the 'Overview of immunodeficiency and auto-immunity in CLL.'

Dr Fegan concluded that CLL is a deeply politically incorrect disease

It is Ageist- it most usually develops in the 60-80 age group.

Racist- your ethnic background determines your chance of developing CLL. If you are Japanese, there is next to no chance of developing CLL. If you are of a white northern European background, your chances are much higher (though still very low).

Sexist- CLL cases are two thirds male.

Shows Favouritism - CLL encourages the development of it's own clones.

And CLL is ungrateful as well, because in some cases it harms it's own host.

Dr Fegan's talk was followed by several others which were more specialised.

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## In Our Thoughts

Donations have been received in memory of Jan Tabero and of Sheila Doris Good.

Thank you to all those who have given donations to CLLSA.

## Bouquets and Good wishes

To those of you who are really poorly, whether due to treatment or not. Jaqui Williams Durkin is not well at present, please include her in your kind thoughts, and any others that you know of.

## Officer Changes

The CLLSA Officers are as follows;

Chair- Jane Barnard

Past Chair- Howard Pearce

Secretary- Garry Bisshopp

Treasurer- Chonette Taylor

Membership Secretary- Garry Bisshopp

Eddie McIntyre and Jaqui Williams Durkin remain as trustees.

## Disclaimer

The content of this newsletter is for information only. It is not intended to be a substitute for professional medical care and we would always advise you to check with your doctor if you have any concerns about your condition or treatment. We make every effort to ensure that the content of the newsletter is accurate and up to date, but we accept no liability in relation to typographical errors or third-party information. Although we attempt to link only to appropriate organisations, we cannot accept responsibility for the content of any external website.



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