

Galanthus



Newsletter of the CLL Support Association

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June 2008

Welcome to the newsletter. So much has happened in the CLL arena in the UK in the last few months it has been difficult to keep up. Two major figures have retired, we have had another highly successful regional meeting, there is a NICE Scoping workshop for Rituximab planned for June 2nd, the world of research moves on.

Two requests; I have included a flyer for the DIPEX study on 'living with CLL'. Please consider taking part. We all have a story to tell, and all ages and stages including watch and wait are needed. The study will be a resource for patients and doctors; any patient will be directed to the site and can dip in to find out the implications of their condition, physically and mentally.

Secondly; I've included a poster for you to use, print out and distribute. Please. There are still many patients who have not heard of the CLLSA, and your putting a poster in the surgery and the hospital might mean that people who need to get in touch. If you want any trifold leaflets, get in touch and we will send you some.

Jane Barnard, Chairperson, CLLSA.

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Howard Pearce Retires



Howard and a group of Internet buddies founded the CLLSA; Howard was appalled by the idea that patients with the numerically most common form of adult leukaemia had no voice or dedicated support organisation, so developed the concept of the CLLSA. Howard was the first Chairman of the CLLSA, founded vital links with the UK CLL Forum, and other organisations. Howard's charisma is well known. Respected as a scientist and businessman, Howard liaised with many groups to the advantage of the CLLSA. Howard has decided to spend more time travelling, and has now retired as a trustee. Howard, we cannot thank you enough, and wish you a long, happy retirement.

Change in Trustees

Eddie McIntyre has retired due to pressure of work, and we welcome Andrea Cockburn, our first carer trustee.

Professor Terry Hamblin Retires

Professor Hamblin is one of the foremost proponents of the CLL patients' voice. He spent a lifetime treating CLL patients, and observed his work carefully throughout that time; he has tracked great changes in treatment and understanding of CLL. He retired this March from seeing patients and from his priceless contributions to the ACOR CLL list. Thankfully,

the ACOR archives have full records for us to search on <http://cll.acor.org/help.htm>. There is also Professor Hamblin's blog at <http://mutated-unmutated.blogspot.com/> from which you will notice that Professor Hamblin is a lay preacher and is writing a novel, in addition to the many posts on CLL. This blog also has searchable archives, another huge resource. Professor Hamblin has written many contributions to our leaflets, and will continue to help the CLLSA in this way. Again, a long and happy retirement to Professor Hamblin.



Midlands Meeting

A very successful Midlands Regional Meeting was held on the 3rd April. There were 30 attendees, and for many people it was the first time that they had met another CLL patient- at least to socialise. The meeting started earlier than scheduled, as many of us had arrived by 12 noon, and we enjoyed a buffet lunch. Members had travelled from as far away as Kent and Norfolk. A great deal of information was exchanged- it seemed as if the majority of us suffer from immune system problems as well as CLL- joint pain, arthritis and psoriasis were some duplicated conditions. Members noted that the cramps associated with CLL went away after treatment, to re-appear as the CLL did. Interesting- as were the number of people who started their comments with 'My consultant doesn't believe me but.....'.only to find one or more of the rest of us having noticed the same problem seemingly associated with CLL .

It was a very informative day, folks, and I know that a lot of you enjoyed it as much as I did.

Many thanks to Tricia and Robert Gardom for organising the event (and it was a great deal to organise), and to you all for coming along.

Now Wash Your Hands- **keeping safe and well.**

One of the hazards of CLL is that we can suffer from incompetent immune systems- whether we need treatment or not. One of the implications is that any vaccination that we have may not work as well as in our non- immune compromised peers, and another is the risk of infection.



We all know that we should wash our hands after going to the loo. Unfortunately, after that we then often have to touch the taps that we turned on with dirty hands, the door handle out of the loo; many surfaces that in a public place other people will have touched- often with dirty hands.

If you have visited a hospital in the last few years you will have been asked to disinfect your hands with the alcohol containing gel in dispensers in the wards. The same product for hand cleansing is available very readily from shops and the Internet. If you frequent 'Pound Shops' then you can often pick up a 100 ml bottle suitable to carry around for less than £1. Soap and water are the best way to get dirt off your hands. After you have left the loo, use the alcohol gel to disinfect any pathogens off your hands. You might think of other times you would want to disinfect your hands- before eating, for example. Anyone who is concerned about their personal hygiene can do this. It will decrease your chances of getting an infection.



If Chronic Lymphocytic Leukaemia is the most common adult leukaemia, why don't I know anyone else with CLL?

We do. We are the Chronic Lymphocytic Leukaemia Support Association- CLLSA. We have hundreds of members. To get in touch and stay in touch- our website is www.cllopspot.org.uk

Or write to- CLL Support Association, c/o 3940 Eagle Street, London, WC1E 4TH

Our 24 hour membership telephone numbers are: 0207 644 3852 and 0800 977 4396-

Lines are monitored regularly by us.

Membership is free. Newsletters, Regional Meetings, leaflets, publications, website up to date information and human contact.

We are sending this poster with the May edition of Galan- thus.

Please print and take to your GP and Haematology Department for display

Breaking News

Wirral Regional Meeting 15th September 2008- Professor Andrew Pettit is speaking-good rail and road communications- more soon.

News from Ron Goldsmith on the ACOR list- he has told us about some incredibly useful free booklets from Leukemia and Lymphoma Society (United States- hence the spelling). If you want copies and don't have computer access, drop us a line or use the free phone number. The titles are;

Understanding Drug Therapy and Managing Side Effects

http://www.leukemia-lymphoma.org/attachments/National/br_1171992654.pdf

Blood Transfusions

http://www.leukemia-lymphoma.org/attachments/National/br_1144786293.pdf

Insure-rants

I have has a couple of complaints about the CLLSA website insurance page, so . I have made some changes intended to make it more realistic.

I think that we all forget that insurance companies do not take risks. If I'm offered insurance for a 4 day trip to Europe for £12, with *ten million* pounds cover, for relocation and medical emergencies, I can be quite confident that the insurance company believe they are never going to pay out on that. Or at least, not to the tune of ten million pounds. They have share holders, owners, employees, are in business to make money; my premium

goes to pay them and any pay out that might be necessary. The agent works out if I can be offered the insurance by the equivalent of ticking boxes in from of him. If all the answers agree with what the company believes is a good risk, I get the insurance. [this is like the bookie accepting your bet on a 100-1 outsider]

Once I declare that I have cancer, the odds change. The company might not want my business at all, and decline to sell to me. They might *exclude* anything that involves CLL. They might ask more questions, and if I can satisfy the answers, offer me cover at a much higher premium. Both of the above happened when I made enquiries. Cancer puts up the cost of travel insurance because I am now more likely to require treatment abroad. [this is the like bookies giving virtually no odds if you bet on the favorite - they don't really want your business]

If you have existing travel insurance before diagnosis, check that you are still covered. Read the small print. You have to inform your insurer of your change in status.

The CLLSA have no links to any insurance companies. We do not get any income from putting the names of companies who *may* be able to insure you on the web site. We only know that in the past these companies have offered insurance to CLL patients, and offer them as a place to start.

The latest and best advice that we have (April 2008) is that arranging travel insurance through a broker is the best way. The broker will have resources for searching for travel insurance that are probably superior than your own web search; for instance, the broker is aware when insurance is being offered by a third party on behalf of an insurance company.

I hope that you all have success getting the necessary travel insurance, and enjoy your trips.

The phone line

To those of you who have used the phone line and been surprised when we take a day or so to get back to you, can I explain that the line is monitored by one of the trustees. She monitors the line every couple of days, and often wants to consider her reply, or do some research. We don't employ anyone, and there aren't enough of us to run a 24 hour service. My apologies to those who were expecting an instant reply, we are a small organisation; even with 450+ members we are tiny compared with the bigger leukaemia and cancer charities.

What is a NICE scoping meeting?

Most of us have a vague idea that NICE controls what drugs are available on the NHS in the UK. When a drug is released for use in a certain area, which is the result of an appraisal. Before that, someone asks NICE for a scoping meeting to see if there is a demand for the drug. I understand that someone is usually the Department of Health, or an interested minister. The meeting on Monday June 10th is to determine if it is in the public interest to have a Rituximab appraisal (a monoclonal antibody with a history of use in other countries for CLL) for first line and relapsed CLL. I believe strongly that this drug should be available to our medics for this purpose. We are one of several organisations who will be attending the workshop.

Regional Meetings.

Norwich- now well underway, being organised by two members, Trisha and John Roberts; the speaker will be Dr Kris Bowles, the date is the **24th October**. The venue is the Norfolk and Norwich University Teaching Hospital.

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

Fund Raisers

Latest news from our fund raisers-David Critchley wrote; ' I completed the Edinburgh Marathon on Sunday in 4 hours 15 minutes, a creditable time considering the strong head wind. At least it was dry ...' the sky diving fundraisers have had their jump dates moved because of the bad weather.....they weren't so lucky. You can contribute to any of our fund raisers at

<http://www.justgiving.com/process/ParticipantSearch/default.asp? FundraiserId=183147>

Thank you to all the fund raisers; we really appreciate what you have done for us.

UK CLL Forum News

The UK CLL Forum Clinical Science Day was held on the 29th April. As usual, the meeting was rather technical, but of great interest to patients and researchers alike. The update of the UK Treatment Guidelines has been promised for the near future.

Kings College Hospital- 1,000 transplants and beyond.

To celebrate 1,000 bone marrow transplants, the King's college Hospital, Dulwich, London, is staging a celebration day on the 30th June. The CLLSA trustees will be there, sharing a stand with the Lymphoma Society; we hope to use the occasion to spread the word of our association and what we do.



Postal Address

CLL Support Association
c/o 39/40 Eagle Street,
London, WC1R 4TH.

Our 24 hour membership telephone numbers are:

0207 644 3052

0800 977 4396

www.clisupport.org.uk