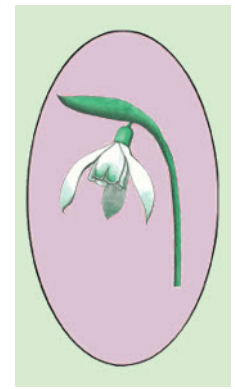


# Galanthus

Newsletter of the CLL Support Association



OCTOBER 2006

## PATIENT MEETING NOVEMBER 2006

Just to let you know that we are having a Patient Meeting on Wednesday 8th November at the Institute of Cancer Research, Fulham Road, London (next door to The Royal Marsden Hospital).

We have a meeting room booked for 2 pm and there is a talk by Dr Ruwani Gunaratne. Dr Gunaratne is leading the study into Familial CLL working with Professor Danny Catovsky. Many of our members have already signed up to be part of this research project which is the biggest study of its kind in the world.

The plan is to assemble in the ICR cafe on the 6th floor from 1pm for tea/coffee and a sandwich. As well as the talk from Dr Gunaratne

I am hoping to have another speaker from the Royal Marsden/ Institute of Cancer Research as well as an opportunity to discuss what the association is planning. Of course this also gives the opportunity to meet other members of the association and perhaps get answers to some questions or share experiences.

There will be a small charge of £10 per head to cover the cost of attendance and refreshments. The meeting is open to members of the association and friends and family. However numbers are limited and will be allocated on a first come basis. If you would like to attend then please write to me at the CLLSA address at the foot of the page. Cheque to be made payable to 'CLL Support Association'.

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**All articles contained in this newsletter have been written by Dr Howard Pearce**

### New Trials articles on the CLLSA website

We have a very important new article on the UK CLL Trials scene. This article has been written exclusively for the CLL Support Association by Dr Peter Hillmen, Consultant Haematologist at Leeds Teaching Hospitals, NHS Trust. Peter is Chairman of the CLL Trials Group of the National Cancer Research Institute. This is a complete and up-to-date view of the CLL trials scene and contains information that is very difficult to find elsewhere. We are very grateful that Peter has taken the time to write this article for the association which I am sure will be very useful to anyone approaching or considering treatment.

If you would like a copy then please complete the return slip below and we will send you one.

# WAS IT A NICE MEETING?

Jane Barnard and I attended the National Institute of Clinical Excellence (NICE) Appraisal Committee meeting in London on Tuesday 19<sup>th</sup> September 2006. The purpose of the meeting was to review the clinical and cost-effectiveness of Fludarabine either on its own or in combination with Cyclophosphamide in the initial treatment of CLL. The end result would be to approve, or not, the use of Fludarabine on the NHS as an alternative to Chlorambucil.

As a small and relatively new charity, to gain recognition from NICE was a bit of a coup and I am delighted that our views are being heard and considered.

We attended as 'Patient Experts' nominated by the CLL Support Association. In addition there were two Clinical Experts. Professor Terry Hamblin who was nominated by the Leukaemia Research Fund, and Dr Andrew Pettitt who was nominated by the British Committee for Standards in Haematology.

Prior to the meeting Jane and I had submitted our written views on the use of Fludarabine to treat CLL. These detailed submissions are available elsewhere on the website. Similarly, Prof Hamblin and Dr Pettitt had submitted their own assessments on the merits of the drug.

The meeting was chaired very ably by Professor David Barnett from the University of Leicester. Jane and I had each received prior to the meeting a very detailed 300+ page document which included:-

- the manufacturers submission on the drug
- details of trials involving Fludarabine
- the clinical and patient expert submissions
- The NICE technical committee economic and technical appraisal

We had been asked to keep the contents of this document and the proceedings of the meeting confidential so we are limited in terms of what we can say about the meeting.

There were about 35 people at the meeting which included the NICE technical team, economists, various other medical experts, a representative of the pharmaceutical manufacturers association (but not Schering the manufacturer of Fludarabine) and also lay members.

A member of the technical committee gave a presentation on the NICE appraisal of the manufacturer's technical submission. Many aspects of the technical and economic case for Fludarabine over Chlorambucil were discussed.

Dr Pettitt and Prof Hamblin were asked individually to confirm their views on Fludarabine. Dr Pettitt, representing the UK's haematologists argued strongly for Fludarabine in combination with cyclophosphamide to be available on the NHS and to stop the existing 'Postcode Lottery'.

Jane and I confirmed to the meeting that we both supported the approval of Fludarabine but expressed our concern that it is a powerful drug and should only be used appropriately and with due regard to the result of prognostic tests.

After about 2 hours the patient and clinical experts were then asked to withdraw as arranged whilst the remainder of the committee considered their findings. We understand that we will be advised of their decision in about 2 weeks which could be either a 'Yes' or 'No' with or without qualification.

We left the meeting feeling more impressed with the quality of the NICE review panel and their thoroughness, than we had expected. We also both felt that the committee had gone to great lengths to ensure that our opinions as patients, and those of the experienced clinicians, had been listened to and considered.

In summary then, yes it was a nice experience! We will keep you posted on the final outcome.

# FAMILIAL RESEARCH STUDY

All CLL patients are invited to join this study which involves providing a small blood sample and a mouthwash (for DNA analysis) and to complete a Family History Questionnaire and a Consent form. If you wish to participate in this study, and I would encourage all members to do so, then please send your name and mailing address to Dr Gunaratne directly at

Dr Ruwani S. Gunaratne  
Study Coordinator  
Section of Cancer Genetics  
The Institute of Cancer Research  
Cotswold Road  
Sutton, Surrey.  
SM2 5NG

You will be sent a welcome pack including Freepost envelopes for replies together with sample collection systems. Patients can then take the sample collection kit to their next outpatient's clinic or make an appointment with their GP, who can take the samples for them.

I have participated in this survey, which is the biggest of its type in the world, and it really is very simple. If you have any questions then you can contact Dr Gunaratne directly on 020 8722 4431.

If patients have other family members that are also affected with CLL or other B-cell disorder, the research team may seek permission to contact these family members so that they can also be invited to join the study. However this would require your prior written consent before they contact other family members.

So that's it and it's your chance to participate in world class UK based research that really could improve the understanding of why people get CLL. What could be more useful than that?

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## Bristol Cancer Help Centre launches new Self-Help Starter Pack

The Bristol Cancer Help Centre has recently launched a new Self-Help Starter Pack for those who have had a cancer diagnosis. The pack contains a new DVD entitled 'The Bristol Approach to Living with Cancer' to give a better understanding of the work of Bristol Cancer Help Centre, the various therapies and courses offered and an introduction to the Bristol Approach. The DVD also features personal stories from people who have been to Bristol Cancer Help Centre, giving a first hand account of the Bristol Approach. For those without a DVD player there is a VHS version.

The pack also contains a new audio CD – an Introduction to Self-Help Techniques: Relaxation, Meditation and Imagery. The pack costs £12.50 plus £2.50 p&p and includes a £12.50 money off voucher for Can Help Now products.

You can order by calling 0117 980 9522 or writing to:-

Bristol Cancer Help Centre  
Grove House  
Cornwallis Grove  
Bristol BS8 4PG

My wife and I both attended Bristol in 2003 following our joint diagnosis and treatment for breast cancer and CLL respectively. I can honestly say that it was a life changing experience and one that I would recommend to anyone living with cancer. If you have any questions on whether Bristol is right for you then please do write to me and I will try to help. I have to say that I was very sceptical when I went there but I was won over completely by their approach.

# NEW ARTICLES AVAILABLE

We have a number of new articles that you may be interested as follows:-

***'Making sense of Prognostic Factors in CLL'*** by Dr Andrew Pettitt, Reader and Consultant Haematologist at Royal Liverpool Hospital (Exclusively written for CLLSA)

***'The role of Complementary Therapies within orthodox medicine'*** by Suzie Ruggles who is Complementary Team Leader in the Haematology and Bone Marrow Transplant Unit at St George's Hospital in London. (Exclusively written for CLLSA)

***' CLL Trials in the U.K'*** by Dr Peter Hillmen, Consultant Haematologist at Leeds Teaching Hospitals, NHS Trust. (Exclusively written for CLLSA)

***'Useful Patient Advice'*** Advice for those living with CLL

***'CLL Consultant Haematologists in the UK'*** Our unique list of Consultants in the UK who specialize in CLL

***'Travel Insurance'*** Advice on where to obtain competitive quotes for travel insurance.

***'Understanding Your Blood Results'*** A table of advice and typical values to help you better understand those all important numbers.

***'The Diagnosis and Management of Chronic Lymphocytic Leukaemia'*** A 2004 article published by the British Committee for Standards in Haematology. A little out of date but still the main reference work used by UK haematologists. Currently being updated.

Further articles under development are as follows:-

- Diagnosis of CLL
- Treatment of CLL
- Quality Of Life
- Familial CLL
- CLL FAQ (a fact sheet booklet on all aspects of CLL)
- Patient Records (a booklet for patients to keep blood results etc)

I will let you know when these are published.

Lastly our membership is continuing to grow but we do need your help in spreading the word and placing our mini leaflet in hospitals etc to attract new members. Just let me know if you can help and I will get some leaflets to you.

I do hope that you found our very first Newsletter useful.

**Best Regards and Good Health to everyone.**

# CLLSA RESEARCH PROJECT

CLLSA is pleased to announce that it has agreed to support a new research project being developed by Chaya Venkat at CLLTopics. The research, which will be carried out in the UK by Professor Terry Hamblin, is aimed at improving the effectiveness of the pneumonia and influenza vaccination in CLL patients.

Pneumonia is by far the biggest single cause of hospitalisation and death in CLL patients. This research looks at a novel way of possibly improving the effectiveness of vaccinations in CLL patients by applying a novel new cream (Imiquimod) to the skin prior to vaccination

One of the objectives of the CLL Support Association is to promote scientific research into the treatment and care of CLL patients. The trustees have considered this research proposal carefully and are pleased to confirm their support for this project which could make a real difference to the

lives of CLL patients. CLLSA have therefore agreed to assist with the project and have pledged an initial \$1000 dollars to the research costs. Depending on the final budget for the research programme, and our success in raising additional funds for this project, then this contribution may be increased further.

If you would like to make a donation to our research fund then please send your donation to CLLSA made payable to CLL Support Association and mark your donation 'Research'.

As a registered charity, if you are a taxpayer, all donations to CLLSA qualify for full tax relief and in addition by completing a 'Gift Aid' form CLLSA is able to reclaim from the Inland Revenue 28p tax from each £1 donated. We can supply the necessary Gift Aid form which is very easy to complete.

I am so very sorry to announce the death of Mike Bush who was a member of the association. Mike joined the association in March 2006 and some of our members will have met Mike and his wife Sarah earlier this year talking about the fact that they were about to go kite surfing in Cyprus. They had a great holiday but sadly after treatment Mike died on 27th August. Sarah says he died peacefully and with some style. They have raised over £2000 for the Leukaemia Research Fund in the 'Mike Bush Forget Me Not Fund' and of course would appreciate any more donations in Mike's memory. I am sure you join me in sending our thoughts and prayers to Sarah and family.

**Our 24 hour membership telephone numbers are:**

0207 644 3052

0800 977 4396



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[www.clisupport.org.uk](http://www.clisupport.org.uk)

**All articles contained in this newsletter have been written by Dr Howard Pearce**

## **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.