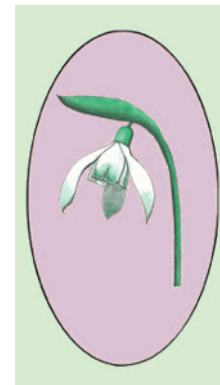


# Galanthus

Newsletter of the CLL Support Association

November 2011



## Farewell to our Chairman

Jane Barnard has stepped down from her role as chair of the CLLSA and as a trustee, we wish her an enjoyable retirement and a well deserved break.

We are grateful for her work in assisting us to build a strong and viable charity, helping everyone who, before the start of the CLLSA, had little means of finding information and support.

Jane had the post of Chairman of the CLLSA for about 4 years. During that time she went through treatment but continued with her voluntary role.

Her microbiologist background was an invaluable asset in translating very complicated medical papers into layman's language as well as representing the CLLSA in the NICE appraisals of new treatments.

Thank you, Jane, for all the hard work you have done over the years and we wish you good health and an enjoyable retirement.

CLLSA Trustees

### Middlesex Meeting GSK House

Our meeting at GSK house last September was well attended. Our thanks go to GSK for hosting the event and especially to Philippa Manning who helped us with the organisation at the GSK.

The meeting was run in a different format from our usual meetings. Three of our members held question and answer sessions to help share their varied experiences.

Nick York talked about being newly diagnosed and his experiences with Watch and Wait. A useful insight into the role of a carer was provided by Margaret Bisshopp and Garry Bisshopp imparted his knowledge surrounding the immune complications of CLL.

A separate session was also held by Chonette Taylor for all of those who wished to discuss Stem Cell Transplants. Two interesting accounts of the journey faced by CLLers who have Stem Cell Transplants were shared with the group.

We received very positive feedback about the format of this meeting and would like to thank the members who suggested this change to the usual meetings. It has been a very useful exercise for the CLLSA and we would appreciate any further feedback members have.

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# T-CLL by Prof. Terry Hamblin

There are a lot of people who have been told that they have T-CLL. Many years ago this was a proper diagnosis. Indeed, it was taught that there were two types of CLL: B-CLL and T-CLL. This is no longer the case. What used to be called B-CLL is now just CLL (or CLL/SLL) and what was T-CLL is a number of different conditions.

T-PLL is the condition most commonly mixed up with CLL. It comprises about 2% of mature lymphoid leukaemias. It occurs in the same age group and the cells in the peripheral blood film look similar though on average the cells are slightly larger than those of CLL, the cytoplasm tends to be bluer. Although in most cases a nucleolus is visible, in 25% of cases it is not. The characteristic feature is of surface blebs in the cytoplasm. Occasionally the nucleus is very irregular.

The immunophenotype shows positivity for CD2, CD3, CD5 and CD7. B-cell markers are negative. Most cases are CD4+, CD8-; but in 15% it is the other way round and in 25% they are doubly positive. TCL1 over-expression can be demonstrated by immunohistochemistry and the TCR genes are clonally rearranged. The commonest chromosomal abnormality is inversion 14 (q11;q32) which is seen in 80% of cases and in 10% there is a reciprocal translocation t(14;14)(q11;q32). These all involve the TCA@ and TCL1A and TCL1B loci. Often the karyotype is complex with abnormalities of chromosome 8, deletions at 12p13 and 11q23 and sometimes p53 abnormalities.

T-PLL is more aggressive than CLL. It presents with an enlarged liver and spleen as well as widespread lymph node enlargement. The skin is involved in 20% of cases. Anaemia and thrombocytopenia are usual and the white count usually exceeds 100. Serum immunoglobulins and HTLV1 serology are normal.

The median survival is less than a year, although more chronic cases have been reported (I saw one patient who responded well to chlorambucil for more than two years). The best responses have been seen with Campath. A trial of PARP1 inhibitors has started. Stem cell transplant should be explored in patients who are young enough and who have a donor.

The other condition most commonly confused with CLL is large granular lymphocytic leukaemia (LGL leukaemia). This is a heterogeneous disorder characterized by a persistent increase in large granular lymphocytes (usually between 2 and 20) without an obvious cause. LGL leukaemia comprises 2-3% of mature lymphoid leukaemias. Most cases are CD3+, CD8+ and show a clonal rearrangement of the TCR alpha beta genes, but occasional cases express CD4 rather than CD8 and gamma delta genes rather than alpha beta. Loss of CD5 and CD7 is rather common. Expression of CD57 and CD16 is usual. However, not all cases are derived from T-cells - some seem to be derived from NK cells and some have evidence of a mixed origin.

NK cells have CD56, CD57 and CD16 on their surface and NK-associated MHC class 1 receptors CD94/NKG2 and KIR families. Expression of a single isoform of KIR receptor is accepted as evidence of NK monoclonality. It is sometimes difficult to distinguish between T and NK LGL leukemias.

There are no characteristic chromosomal abnormalities. Non-malignant conditions may mimic LGL leukaemia. Felty's syndrome (rheumatoid arthritis with splenomegaly and neutropenia) may be a separate disease or part of the clinical picture. LGLs are increased post splenectomy, post stem cell allograft and in autoimmune diseases.

Clinically, LGL leukemias are almost always indolent. Neutropenia and moderate splenomegaly may be seen and most cases do not require treatment. Treatments that have been tried with some success include splenectomy, ciclosporin A, cyclophosphamide, steroids, low dose methotrexate and pentostatin.

Sezary syndrome is sometimes mistaken for CLL. Although the circulating tumour cells are characteristic with 'cerebreform' nuclei, the nucleus may be contracted and quite small, so that it escapes detection. Sezary syndrome is a disseminated form of mycosis fungoides and therefore has its origin in the skin. One finds generalized erythroderma (red skin), enlarged lymph nodes and the characteristic cells in the blood.

Sezary syndrome accounts for only 5% of skin T-cell lymphomas, and since skin lymphomas are usually the

# T-CLL by Prof. Terry Hamblin cont.....

province of dermatologists, they represent the only skin tumours that haematologists are likely to see.

The immunophenotype is CD2, CD3, CD5 and TCR beta positive. Most cases are CD4+ and expression of CD8 is very rare. They express the cutaneous lymphocyte antigen (CLA) and the skin-homing receptor CCR4.

The clinical features apart from those mentioned are itching, hair loss, thickening of skin on the palms and soles, nail atrophy, and problems with the eyelids. It is an aggressive disease with only 5-10% surviving for 5 years. Treatment is experimental but may include fludarabine, pentostatin, steroids and immune therapies.

**From "Mutations of mortality" © 2010**

## In brief...

### CLL FATIGUE

CLL fatigue is not like the feeling of being tired.

It is caused by the good B-cells recognizing the malignant B-cell as antigens and raising the immune system's alarms, signaling a release of cytokines IL-6 and IL-10.

These put the body in a state of 'feeling sick', the kind of feeling you get when you are coming down with the flu or a cold.

However, some CLL patients remain in this state and continually produce high levels of the 'alarm cytokines'.

### THE NOCEBO EFFECT

Every day, many of us take clinically proven drugs that fail to work as planned or that trigger unexplained side-effects.

The reasons for this can be chemically complex, but new research suggests that there may also be a far simpler explanation: we think that they are having a bad effect.

It is called the nocebo effect, and it's the dark side of the well-known placebo effect, when a patient's health improves because he or she believes that a treatment is going to make them better. The nocebo effect can worsen symptoms, exacerbate side-effects and can render drugs less effective. In other words, expectation of sickness begets sickness.

There are a lot of pessimistic patients: one report suggests that more than a quarter of us may experience the nocebo effect when we take a drug. Researchers from the Cardarelli Hospital, Naples, say in the *Journal of Investigational Allergology and Clinical Immunology*: "Our data, collected in a large population, confirm that the nocebo effect occurs very frequently in clinical practice."

# Shingles and the CLL Patient

*This is not meant to be a comprehensive article; if you have any reason to think that you may have shingles, contact your doctor. If you want more information on symptoms, and an excellent guide to treatment that you can take to your GP, then go to <http://www.shinglessupport.org/>*

All CLL patients have a damaged immune system. With shingles, this means that you can get shingles more often, it can spread through your body faster, and you could be in pain for some time.

The first symptoms of shingles is very sensitive tingling or burning skin on one side of your body or your face. This can happen before you get a rash. There can even be a burning pain as the first symptom.

If you believe that you may have shingles, contact your doctor immediately.

If you are going through a service such as NHS direct, <http://www.nhsdirect.nhs.uk/> repeat to every person that you talk to that you have Chronic Lymphocytic Leukaemia and you have a damaged immune system.

The sooner you get treatment, the less the shingles will spread. You may be able to avoid

post herpetic neuralgia, a condition that can follow shingles. Post herpetic neuralgia is unremittingly painful, sometimes for months.

Most adults have the shingles virus living dormant inside them. If you ever had chicken pox, then you have the shingles virus. The virus, herpes varicella-zoster, is transmitted through contact with the contents of the blisters that form in chicken pox or shingles, and in the crusts from the scabs. No-one knows what triggers shingles attacks.

You should be aware that during the infectious blistering stage of shingles you could transmit the virus to someone who has not had chicken pox. You can infect other people.

Three types of people are vulnerable to infection:

- Immune suppressed people like yourself
- Pregnant women
- Children who have not had a vaccination against chicken pox, and have not had the disease.

**Please note that the shingles vaccine contains live virus and should NOT be used for CLL patients or for anyone who is immune suppressed.**

## Flu - it is that time of year again

This is the time to get in touch with your GP's surgery and book your influenza vaccination. If you ever think that you have flu symptoms, then you can go to:

<https://www.nhsdirect.nhs.uk/CheckSymptoms/SATs/coldandflu.aspx>

But the message remains the same - you are immune suppressed because of CLL. Report to your GP as soon as you feel ill with any symptoms at all - tell every health care professional that you speak to that you have CLL and are immune suppressed.

Being immune suppressed means that your body doesn't fight infections as well as other people your age. Talk to your GP and Hospital Consultant about your needs as an immune suppressed person.

Take care of yourself.  
J. H. Barnard.

# A jewel of a resource **Dr Melanie Oates, Biobank Manager**

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**Dr Bob Harris, Biobank Assistant Director**  
**Garry Bisshopp, CLLSA**

Patients entering the ADMIRE, ARCTIC and some other recent clinical trials of Chronic Lymphocytic Leukaemia (CLL) have been asked to give blood samples to the UK CLL Trials Biobank.

## **What is this Biobank?**

Advances in current treatments generally arise from one of two research areas. One is the clinical trial and the other is the laboratory based scientific study. These scientific studies need a steady supply of samples of CLL and it was agreed amongst clinicians and researchers that a dedicated Biobank for CLL samples was needed. After much work the “UK CLL Trials Biobank” was set up by Professor Pettitt who is also the Director of the UK CLL Forum . This Biobank, supported equally by Leukaemia Lymphoma Research and Cancer Research UK, is independent of clinical trials organisations. It is based within the University of Liverpool and meets all current ethical, quality and safety standards for the long term storage of blood samples and the support of future research.

## **How does it work?**

The samples collected from you for the Biobank are blood, saliva and in some cases bone marrow. These samples are in addition to the samples required by the trials that you are taking part in. This additional amount of blood being taken should not have any adverse effect on you.

The samples are then sent to the Biobank where they are collected, processed and stored by trained and dedicated staff under strict controls. Bar-coded labels and databases are used to keep detailed records of the sample’s whole history from the point of donation to its storage in freezers. These details allow scientific researchers to know the exact condition of each of the samples that they use. The samples are identified by unique references which do not identify the donor. Patient details are retained by your hospital and confidentiality is thereby maintained.

Once samples are stored within the Biobank they are available for use for scientific research. Researchers will submit a formal request for samples to the National Cancer Research Institute (NCRI) CLL trials subgroup. This subgroup then considers the request on its merits before authorising the Biobank to release samples, or not, for testing. Currently samples are being used for discovery and validation of disease biomarkers which will identify those patients who will respond well to particular treatments and those who will not.

To ensure that samples contained within the Biobank are utilised effectively, and to the maximum, a Governance Committee, with an independent chair, and broad stakeholder representation, including the NCRI CLL subgroup, The UK CLL Forum, the CLL Support Association, Cancer Research UK, Leukaemia and Lymphoma Research and Cancer Research Technology, bi-annually review the Biobank, its operation and its use.

## **Why should we support the Biobank?**

The value of the Biobank and the samples it contains cannot be under-estimated.

Advances in the knowledge and treatment of CLL can only come about by studying all aspects of the disease. The collection and storage of samples from all NCRI clinical trials provides the UK and research staff with a resource the envy of many other countries.

If you as patients wish to see advances in the management and treatment of CLL, initiatives such as the Biobank must be supported and patients should be prepared to donate samples for research. The existence of the Biobank, and your contribution to it, allows us to be at the forefront of such research for CLL.

# Walnuts are the healthiest nuts

Scientists from Pennsylvania told the American Chemical Society that walnuts contain the highest level of antioxidants compared to other nuts and eating raw walnuts gives the full benefit of these antioxidants, which are known to help protect the body against disease.

The scientists said that all nuts have good nutritional qualities but walnuts are healthier than peanuts, almonds, pecans and pistachios.

Dr Joe Vinson, from the University of Scranton, analysed the antioxidant levels of nine different types of nuts and discovered that a handful of walnuts contained twice as many antioxidants as a handful of any other commonly eaten nut.

He found that these antioxidants were higher in quality and potency than in any other nut.

Antioxidants are good because they stop the chain reactions that damage cells in the body when oxidation occurs. The antioxidants found in walnuts were also two to 15 times as powerful as vitamin E, which is known to protect the body against damaging natural chemicals involved in causing disease, the study says.

Nuts are known to be healthy and nutritious, containing high-quality protein, lots of vitamins and minerals as well as dietary fibre. They are also dairy and gluten-free.

Previous research has shown that regular consumption of small amounts of nuts can reduce the risk of heart disease, some types of cancer, type two diabetes and other health problems.

Dr Vinson said there was another advantage in choosing walnuts as a health source: "The heat from roasting nuts generally reduces the quality of the antioxidants.

"People usually eat walnuts raw or unroasted, and get the full effectiveness of those antioxidants.



## EYES AND CLL

It is probably wise for CLL patients to visit to an ophthalmologist every two years, perhaps annually in some cases. CLL can infiltrate the eye...although fairly rare.

"Ocular involvement in leukaemia can precede the diagnosis of leukaemia, can occur during the course of the disease, or be a sequel to therapy with steroids, chemotherapy, bone marrow transplantation or total body irradiation. From an aetiopathogenetic standpoint, ocular involvement can be direct as a result of leukaemic infiltration or indirect due to effects of anaemia, thrombocytopenia, hyperviscosity, immunosuppression or infections."

(from [www.nature.com](http://www.nature.com))

# Macmillan Learning Zone

We can all benefit from reaching out. Supporting each other through volunteering, self help and support groups can bring great rewards. Learning about CLL was perhaps my first step in self help. It was not long before I ventured on-line and found a few communities. Their familiarity of living with CLL perhaps was the greatest influence in helping me come to terms with the disease and allowing me to live again. Just having the support of other people in the same boat made the difference.

This of course led me here to the CLLSA, where as well as gaining information I was able to meet with others in a supportive environment. Much of this time spent with others involves a lot of sharing and listening to others experiences. Not the most natural environment for me. Discovering Macmillan's on-line learning Zone very quickly made a difference.

It was the; **Members of the public supporting others**, section at:

<http://learnzone.macmillan.org.uk/course/view.php?id=264>

This helped change things for me. A learning place that helps us develop skills, confidence and knowledge. Important when meeting and supporting others. This is now part of my self development and underpins my work here and online.

There are many **FREE** certificated courses available to members of the public supporting others. The course calendar and map have been updated to allow a much easier way to search for what courses are available in your region.

The site provides access to **FREE** certificated E-learning courses and the workshops and courses listed below:

Buddying and Befriending	Putting Life Back into Your Group
Cancer and Its Treatments	Running Effective Meetings
Cancer and Relationships	Supporting Others Through Loss
Cancer Support Course	Talking to Children about Cancer
Developing Your Group	Telephone Skills
Good Practice in Starting a Group	Using Macmillan's L&D Toolkits with Your Group
Listening and Responding	

Many courses and workshops are completed in one day or there are more substantial E-learning courses that can be completed in your own time tackling modules in any order. There are also courses that involve a few days in class plus course work and learning over several months. For example the Cancer Support Course is equivalent to an NVQ2 and accredited by the Open College Network. This gives you a recognised qualification that aims to build your skills and confidence so that you become the best supporter you can be.

Nick York

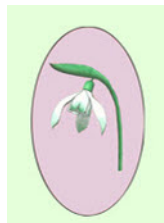


*Our thanks to Roche for funding*

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