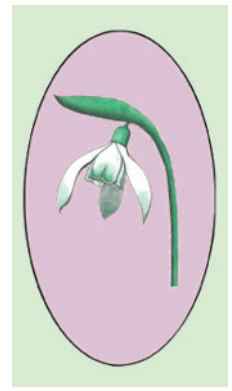


Galanthus

Newsletter of the CLL Support Association



November 2010

THE NIGHTS GET LONGER

In Britain, 31st October was the celebration of All Hallow's eve. Every society has a date or festival when we remember the dead, and this is the date that was originally set by the church in England.

I got into the habit of burning a candle for lost members from the ACOR list when I was first diagnosed. As you can imagine, there is often a candle burning at my home.

If you are reading this, then the odds are that you have attended many funerals in your life - most of our members are over 60. Sadly, however young you are, you will probably have been to the funeral of a contemporary, or even someone younger than you. Funerals are a way to record a closure to a life, and I believe to celebrate it.

Among the raw grief and anger that accompanies a death, there are many positives. What my friend enjoyed, what he built or maintained.

Most of our members, CLL-ers or not, live active lives, as far as we can. We act for our community, the local and wider community, for our families, places of worship, clubs and friends.

From looking after ourselves and our carers to picking up after the grand kids, we are an active lot. Yes, there are bad days, and our energy levels vary. But from what I know of you, you use your time well. I know that many of us seldom feel well, and this wears us down. The good days, we do stuff. Don't be hard on yourself if you are not active 24/7.

I salute you, and those that we lost this year. They made a positive difference, and so will we. To paraphrase what an engineer member told me this year, plan for the worst, and enjoy the rest.

Jane Barnard

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AN UPDATE FROM ONE OF OUR MEMBERS

By Daniela Soaves

Patients and Careers Meetings

If you have never been to a members' regional meeting there's a good chance you might worry whether it's a good idea. You might belong to the Groucho Marx school of thought, preferring to keep your distance. What if you are faced with a bunch of miserable sick people? Or you are bombarded with too much science? What if it scares the living daylight out of you? There's such a thing as too much information ...

These are all valid concerns, especially if you are newly diagnosed, but please banish any misgivings and come along the next time that CLLSA shows up in your neighbourhood. I promise you will be enlightened and empowered. You might even make new friends!

CLL is often dubbed the forgotten cancer, because in most cases it's a slow-progressing disease that doesn't require instant treatment. Once you've got your head around watch and wait, it's wonderful to be able to get on with life. That's the theory, at least. But more often than not it isn't what happens. The fact that there's little hospital support for us in the way that there is for patients with other acute cancers means we can feel as if we are on our own. There is something surreal about life going on more or less the same as it was before diagnosis, yet knowing in the back of your head that it's not the same. It's not CLL that's fallen through the cracks. It's *us*.

That's why these regional meetings are invaluable. You have time to share experiences, pick up information and tips, as well as hear from experts in the field – all the more important if your particular hospital doesn't have a CLL specialist. We're all of us different and the path of our CLL is individual to each one of us, and it is enormously reassuring to look around these regional meetings and see healthy, happy people – young and not so young – who are getting on with their lives and who are amazingly well-informed and articulate.

In Oxford last April, Consultant Haematologist Dr Anna Schuh talked to us about Living With B-Cell CLL. She discussed the improving treatment of CLL, the value of prognostic markers and the importance of

keeping up our immunization against infections. It was perfectly pitched – the right level of information and a real sense that we could do much to contribute to our ongoing health.

And in September in London, Professor Daniel Catovsky focused on three key questions – who to treat; when to treat, and how. He gave practical advice on how to keep healthy and discussed the improved survival rates in CLL, looking at the how treatment has changed over the last four decades and what has been learned from German research and how that will impact on future treatment.

At the end of their keynote speeches, both of these eminent doctors opened up the floor to take questions, not about people's specific case histories, but to share their knowledge and enlighten us on general questions we haven't been able to ask our own consultants. Their enthusiasm is infectious, as is their optimism. Along with better therapies in the here and now, there is hope for the future.

As the London meeting drew to a close, I felt the same burst of positivity that I'd experienced at my first CLLSA meeting in Oxford. It's amazing that this modest charity, run entirely by volunteers, can call upon eminent physicians who happily give their time to talk to us. And it was fantastic to hear from another member the other day, whose experience at the London meeting so closely echoed mine at Oxford. "I too was worried about a cancer club," she emailed me, "and was quite overwhelmed by the friendly welcome combined with such high quality medical info. I left feeling very motivated."



Chonette Taylor and Sue Waldie - London Meeting

On 10th November I went to Manchester, to help ask for Bendamustine to be added to our drug cupboard by the NICE (National Institute for Health and Clinical Excellence) drug appraisal system. Bendamustine has shown itself to be a useful drug for those CLL people who have what the docs call 'co-morbidities'; the other problems that we get in later life. We got the Rituximab, fludarabine and cyclophosphamide combination (FCR) for our fitter people, now we need some good drugs for the others.

As usual there has been a lot of hysterical tabloid activity in the last few weeks about NICE's demise. So have a look at what NICE do.

They have serious professional people to look at the claims of drug companies for their drugs. There has to be hard evidence, real statistical evidence from trials for a drug to be considered. Levels of evidence are interesting things; NICE is concerned with trials in people, not in vitro (test tubes) or animals. They must be safe (for a certain level of safe - cancer drugs are never 'safe' in the same way that an over the counter painkiller is safe).

Statistical evidence from phase III trials tells doctors and NICE how likely the drug is to be effective, how good a treatment it is from the results, and eventually how good a remission we may get, and if it increases our life span. NICE are critical - if two academic papers give different results, they want to know the reason why.

This is a lot harder evidence than 'it worked for me'. Why do we need this level of evidence?

When the drug is tested in animals, every animal that it is tested on is nearly an identical twin of all the others. That is what the animal stocks are selected for. People are so different. That last 1% of our genes that separate us from each other not only makes us tall, short, dark, light or even ginger, but our biochemical insides are equally different.

You probably know that many Chinese people are violently ill if they eat any dairy product. That is just one of thousands of differences that can be between me, and you.

Not every doctor has the time to check on all the combinations of drugs that might suit people with diseases in his speciality, especially with a condition that can be so different for different people like CLL. If you think it is easy, look on Terry Hamblin's blog - the comments that doctors make especially. They are grateful for someone to get beyond the adverts that the drug companies put out. (<http://mutated-unmuated.blogspot.com/>; just as it is spelt)

So the NICE appraisal - the process that I went to will go. But we the UK public, the end user, needs the expertise to answer the questions - is this likely to work, how much will it help, how much will it cost?

The size of the money pot is going down people; it is up to all of us to make better use of it.

I am pretty sure that some people will not understand what I mean, and think that I am saying that we should not have new, expensive drugs. What I am trying to say is that it is no good taking the money for expensive drugs if they are not likely to work.

We need the expert medics (UK CLL Forum) and the phase III drug trials to tell us that the drugs work. We then need someone to work out the costs - drugs, nurses, pharmacy time, day hospital, costs of probable side effects. At the moment, this is NICE.

NICE isn't perfect, there are people who feel that the government experts could do with some real world experience, but it is fairer than either a static situation with no new drugs or a free for all, with ineffective drug use draining our limited resources. There is no point in having an expensive treatment that is not likely to work - the whole point is that there are good treatments out there.

The NICE appraisals are confidential, so I cannot report on them. There are things that I want to change, and I don't think it is a secret.

Much of the work of NICE depends on Quality of Life' data and this is a very blunt instrument. It is easy to 'prove' that a CLL patient has a huge increase in quality of life on first treatment. Job done.

Continued on next page.....

NICE Continued.....

It is not easy to prove that a patient in his/her 4th treatment, getting near the end of life, has an improvement in quality of life. Lymph glands get smaller, but don't go away - 'nil points' by the present rules. WBC (white blood cell count) goes down, but not like the first treatment, fatigue gets less, but not a whole lot less....The criteria that are worked on are very strict. The allowed cost per 'quality of life year gained' for a new drug is presently about £25000, and will go down. I don't believe that the 'Quality of Life criteria' used now are always appropriate *for the small numbers of patients who come under the multiple treatments umbrella.*

This is the area that I want to concentrate on with NICE - the next generation. The appraisals will go away but there will be something else. With your help CLLSA will still be there fighting for what we need, when we need it. First reports of the 'Cancer drugs fund' would indicate that it is cumbersome and at least as unfair as any former system.

Solstice Edition

As it happens, this will be the solstice edition - we are not planning another Galanthus this year. So to all of you, a warm happy and peaceful solstice and years end. I wish you as much health as possible. For solstice substitute festival of choice - Christmas, Chanukah, hogmanay, even Hog's Watch.

I will be happily home alone, giving the chickens their Christmas treat and not eating any of them. The only home produce on Christmas day will be some Jerusalem artichokes. Most of my family will be off looking after other bits of the family, so the telephone will be in constant use.

Season's Greetings.

Jane B

UK CLL FORUM

Three Trustees together with three other CLLSA volunteers attended the UK-CLL Forum clinical science day in September, where we had the opportunity to talk to some of the consultants involved on CLL research.

I was delighted to have the opportunity to listen to Prof. Kanti Rai from New York and was very pleasantly surprised when he remembered the CLLSA from the conference in Lugarno two years ago.

Prof Rai gave a talk on long term survival analysis of CLL patients, from US Intergroup studies, and emphasized how over the decades survival times for patients had improved a great deal.

Of particular interest to me was the talk by Dr Johannes Schetelig, University Hospital Carl Gustav Carus, Germany on Stem Cell Transplants.

The next UK CLL Forum Annual Scientific Day, Molecular targeting in CLL –from bench to bed side will be held on Thursday 2nd March 2011.

I would just like to add that the UK CLL forum meetings are aimed at scientists and CLL haematologists, Unless you have some scientific background, it can be hard to understand some of the talks as it is not designed for patients.

Chonette

Is there anything you would like to see in our newsletter in the future? Do you have any news or information that you would like to share with other members?

If so we would love to hear from you; just email ch.taylor@ccll.org.uk or write to us at the address on the last page of this newsletter.

END OF LIFE SEMINAR

Very recently I attended a seminar in Swindon titled 'End of Life'. The seminar was divided into two sessions, a morning and afternoon session, one dealing with the legal side of things, Wills, Power of Attorney, Decision making etc. and the other session with the practical side we are presented with when we have a chronic condition..

A specialist nurse from the local Hospice did the personal well-being session and I found it very instructive and reassuring how much care is put into our quality of life until the very end, how our wishes are followed and practical ways of doing it.

We had very good information on planning for your future care decisions, and all subjects and ways to plan ahead, practical and emotional

I found this seminar through my connection with the Users Support group in Swindon. I know that each county and Cancer Network do different things, there are probably some very useful day courses that can benefit us all and are free of charge. I know they also reimburse travel costs if you need to claim.

Chonette

THAMES VALLEY CANCER NETWORK

At a Thames Valley Cancer Network Users Representative meeting I went to in Oxford, a specialist nurse gave a talk on Palliative care. Many people at the meeting thought that Palliative care was when you are going to die, however that is not the case. One can live for a long time, often Palliative care is given to those people that do not respond to treatments. I myself researched the subject back in 2008 after my last treatment only gave me a very partial remission.

Palliative care tries to keep the quality of life of the patient as good as possible, some people do chose not to have aggressive treatments in some forms of cancer and Palliative care helps the patient with coping with symptoms.

Recently in one of our CLL International groups Prof. Hamblin said:

"I have found that the palliative care nurses are the best - even when you are not having palliative care. They have come across every possible side effect and have a menu of remedies that you can choose from in a mix and match way.

I left the meeting feeling better informed about what they organise for our personal well-being.

Chonette

NCVO CONFERENCE

Last year, we joined the National Council for Volunteer Organisations and looking at the conference it seemed interesting and diverse enough to send 3 of the trustees. There was a mixture workshops, comment and debate. The information given was practical and mainly well presented.

The introductory lectures included a presentation by Peter Snow, of BBC radio. He has been working in the charity sector for years, and highlighted the problems of the variably disabled. Unlike Peter, who is blind, many of us are variably disabled. This included many people including a questioner who suffer from mental illness- how can you hold down a job when you don't know if you can get out of bed on a regular basis? Can you cope with the shame of losing another position?

Cancer fatigue is a similar intermittent problem. Peter pointed out that after years of various governments trumpeting that the disabled were able to make a better contribution to society by working, the variably disabled problem had never been acknowledged let alone addressed. Also, in time of recession, when jobs are short anyway, where are these jobs... they don't exist. The other seminars and workshops that we attended were equally fascinating and raised several issues that are of interest, such as risk management and recruitment.

ALL WALES MEDICINES PHARMACY ADVISORY GROUP

I filled a vacancy for a lay person on this committee; if you are interested look for similar committees in your local area.

As a lay person, you are expected to be the common sense element. Like the Cancer Network groups, Pharmacy Advisory Groups are a way of getting involved .

If you are not a technical person, that is OK, sometimes it just needs an outsider to tell the people who are planning actions or writing documents that there is a gap, or a sentence does not have a verb. Smile, put your hand up, save the NHS a lot of time and money.

Jane B

ANNOUNCEMENTS

We are happy to announce that we have welcomed Sue Waldie back as a trustee. As one of the founding members, Sue's expertise in many areas including that of the Charity Commission will be invaluable. We are also hoping to welcome other new trustees soon.

We were going to announce that Eric Jarvis had also joined the ranks of trustees; however, it is with great sadness that we have to announce the death of Eric, who was a member of the Association. Eric passed away on November 4th of a stroke. He was an active member of the community and was involved in voluntary work in his local community. Eric was a long standing friend, was kind, supportive and we treasured his wonderful, quirky sense of humour. We shall miss him very much.

I am sure you join us in sending our thoughts and prayers to his wife Doreen, his children Mandy, Richard and David and grandchildren.

"Rest in peace, Eric."



Our thanks to Roche for funding

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