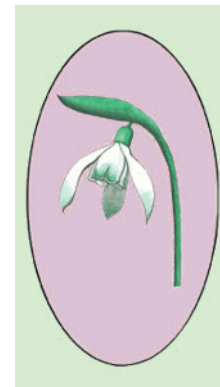


Galanthus

Newsletter of the CLL Support Association



April 2011

Bendamustine Approved

The good news this quarter is that NICE have approved the use of Bendamustine in first line patients where fludarabine will not work because of their particular sub set of CLL. Patient stories have shown that Bendamustine can be a very useful drug. Like all the chemotherapies, it does not suit everyone - but we have one more drug in the cupboard.

For more detail, go to <http://www.nice.org.uk> and put 'bendamustine' in the search engine.

Don't forget that if your consultant believes that you need a drug that is not on the NHS list as well as the Individual Funding Requests and Exceptional Treatments there is now the Cancer Drugs Fund that the consultant can appeal to. There is no guarantee that funding would be made available, but in some areas there are now 2 routes.

Wishing you all a warm and bright spring,

Jane Barnard, Chairman CLLSA

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Thank You

Huge thanks to Barry Sawyer, President of Radlett Rotary Club who has chosen the CLLSA as his personal charity for this year.

I accompanied Barry as his guest to the concert of the band of H.M Royal Marines Portsmouth at the St Albans concert in aid of charity, organised by the Rotary Clubs of Radlett, St Albans and St Albans Verulamium. This was an incredible performance by the musicians of the band, whose stunning versatility on multiple instruments was matched only by the sheer variety of styles, from opera to folk music. And we got a chance to sing.

I was also privileged to talk to the Radlett Rotary Club about the work and mission of the CLLSA; in return I learnt a great deal about the work of the International Rotary Association, and the role of the Radlett Branch both locally and internationally. If I had any time to spare, I would join my local Rotary myself.

My thanks again to Barry, and to his rotary Club, for making me so welcome.

Jane Barnard.

Report from the American Society of Haematologists Conference, December 2010

The CLL scene changes, gradually but firmly for the better. Many of the new drugs that were described at ASH as being useful in CLL patients may take years to reach us if there are not British trials, but the most exciting discussion was concerning drugs that shut down an important cell pathway in the B cells, and that includes the CLL cells. These drugs included two phase 1 trials - one with the Bruton's Kinase inhibitor PCI-32765 and a second with a phosphatidylinositol (PI) 3-kinase delta inhibitor called CAL-101. Compared to standard chemotherapy, there is low toxicity with these drugs. There are early discussions in the UK to start trials in small numbers of CLL patients in late 2011 to 2012.

But what is happening for those of us who are in the CLL system now? There was a lot of talk at ASH about 'changing the bar'; tailoring the drug combinations to suit both the fitness and outcome expectations of patients.

Young, fit patients can hope for long remissions as they can tolerate aggressive chemotherapy treatments. At the opposite end of the scale, people who have many other problems as well as CLL or who have had multiple treatments might expect an increase in quality of life rather than a lasting remission.

In a perfect world, any patient would hope for the longest possible remission- a cure that is not yet possible, but there are constant improvements in treatment outcomes

Now that Fludarabine, cyclophosphamide and Rituximab treatment (FCR) has been shown to be an effective treatment in most 'fit' CLL patients with few co-morbidities, some doctors are thinking of adjusting drugs and dosages to cut out some of the long term effects that the drugs have on the immune system.

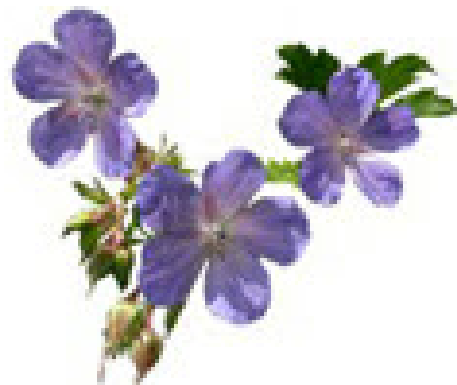
A lot of drug combinations for the less fit patient are under trial in various parts of the world. Here, the aim is to get more complete responses and more patients with minimal residual disease (MRD) than before.

We all know that both a few unfortunate newly diagnosed patients and more of the ones who progress after the first treatment have disease that is difficult to treat. Again, there is some progress in this group. At the moment the outlook for people with bulky and recalcitrant disease is still not good, but it has improved.

I cannot comment on how available the drugs are; there may be trials in your area if you are going to need treatment. I do know that in the UK some areas have got the access to the Cancer Drugs Fund up and running, while others seem not to have. If you fall into the unfortunate category of difficult to treat, for whatever reason, then if your physician agrees you would benefit from a particular combination then s/he might have to go the individual Funding Requests/Exceptional Treatments before the Cancer drugs fund, or make a request straight to the Cancer Drugs Fund for his/her area by whatever route has been set up. It would certainly be worth asking.

By the way, the doctor/consultant can request effective cancer drugs that have been rejected by NICE for being too expensive. That would depend on the local rules, you can only find out if you ask. It would be foolish to request drugs that were rejected because they were not effective enough; no one would want to go through chemotherapy without hope of an improvement in their situation, so its important to know if the drug was rejected for use because of cost or efficacy, your consultant can tell you this.. Jane Barnard.

"Many thanks to Professor Peter Hillmen for clarifying the ASH discussions"



UK CLL Forum Annual Scientific Day Molecular targeting in CLL by Nick York

I was glad to have travelled up the evening before, as I awoke fresh and full of optimism. A peaceful time to leisurely prepare myself and then wash down some toast with a cup of tea. Then back out of the hotel entrance into a bright city morning, backtracking my steps of the night before I was back at the square and after a meander through side streets and mews I was on Portland Place, directly opposite the conference venue. Another majestic sight: the RIBBA building with its sculpted facade, my "Mecca" for the day.

I was early, tables and stands were just being completed by interested parties in the ante room and our table was quiet as members were elsewhere buried in early meetings. So I took the time to grab a coffee and nose around: A good sized conference hall, but small enough to be close to the action. Returning to the CLLSA table I met my first CLL people, (of course I'd spent a little time on line with many, or anonymously shared space in haematology waiting rooms). This was a big moment for me, Andrea and Chonette were the first to greet me and whilst they organised themselves for the day I watched the ante room fill, with CLL specialists, scientists and associates. But what struck me straight away was how connected every one was, even the great "gurus" had time to exchange a chat with a mere mortal like me. Which surprised me as it was their professional meeting and I was on their turf. So perhaps they are just people like us.

Greetings and "chit chat" over it was time for the business to start, so I settled down towards the rear of the hall, with my sketch pad in hand assuming that everything would just fly over my head. I had spent a little time on line before on sites from our web page "sources of additional information" http://www.cllsupport.org.uk/source_s.htm and read the documents mailed to us when joining the CLLSA, so had prepared. The sketch pad very quickly became a note pad, I was captivated. I was able to grasp the introductory phases of each speaker's topic, even if much of the new science did put me out of my depth. But what did strike me was how much development

methods that may change how CLL is clinically managed and treated. Of course I understand that the percentage of "in vitro" experiments actually reaching the bedside is low, but actually hearing first hand some of these techniques and concepts, was fascinating. I must mention how encouraging it was to watch these practices being debated, following presentation. The CLL forum has shown me that the coming together of many CLL research and clinical specialists can only improve the likelihood of this work benefiting us patients.

Coffee breaks and lunch was a good time to meet with other CLLSA people and share more chat, while they got on with the task of providing CLLSA support information and recourses to the different specialists and health professionals. Judging by the amount of literature taken away by doctors and staff, I assumed they use this as a stocking facility as well as an update for their own patients.(let's hope it gets there)

The afternoon session was a little more hard work for me at times, but was helped by the humour and antics of some of the speakers. Lessons for me to learn first hand were that even methods that reach the bedside and trial phases can fail, fizzle out, or come to a halt, for many reasons. So it's back to the bench or on to another cycle. Trials were updated and discussed, which seemed to show a sharing of responsibility within the group of professionals in fulfilling quotas to allow trial phases to complete. The session was completed with a presentation on the development of the UK CLL forums web site. Which will allow the professionals, much greater access to the information pooled by the forum. This brought an important day in the many to a close.

A CLL friend sent me this message the other day, I think it's very relevant for me.

"Hang in there! With enough squeaky wheels the medical community will continue to push for new treatments."

Nick York.

CLLSA member and novice patient on "watch and wait"

How do you know if you have CLL?

By Prof. Terry Hamblin

Three-quarters of all cases of CLL are discovered by accident. The patient has a blood test for some other reason or, these days, for no very good reason at all.

Everybody thinks that CLL is getting commoner and they blame the increased use of pesticides in farming, or the nuclear testing in the sixties or diesel fumes or global warming or mobile phone masts or sunspot activity or Chernobyl or whatever is the current scare story in the newspapers. I suspect that it is not getting commoner at all - it is simply that we are recognizing cases that we never used to find.

When I was young, everyday I looked at all the blood tests performed on everyone from a population of half a million. On a good day there were 300 blood counts. Thirty years later my responsibilities had diminished; I only looked at the blood counts from a quarter of a million. But most days there were over 700 tests. Forty years ago you needed to have a lymphocyte count in the blood of 15,000 before you could diagnose CLL. Some years later it was only 5000 lymphocytes and now we have to specify 5000 B lymphocytes. Forty years ago we had only just discovered that CLL was a B cell neoplasm. Today we can distinguish several types of B cell neoplasms in the blood. We now know that 3.5% of people over 40 have a population of monoclonal B cells indistinguishable from CLL cells in their blood. The harder you look; the more you find.

The 25% in whom the CLL is not found by chance have a variety of symptoms and signs. (A symptom is something the patient feels; a sign is a physical abnormality the doctor finds.) The commonest finding is an enlarged lymph node.

Lymphocytes circulate through the body like other blood cells. For many their journey is just like other blood cells: out in the arteries, home in the veins.

They have another circulation, though. The little thin-walled blood vessels that join the arteries to the veins are called capillaries. Lymphocytes can squeeze out through the walls of the capillaries and enter the tissues. From here they make their way home via the lymphatics, which are like veins

for white blood cells. Lymph nodes are like stations on the lymphatic railway. They are normally small - about the size of a split pea - and organized. The job of lymphocytes is to fight against foreign invaders, and the lymph node is where they get their training and their orders before going into battle.

Lymph nodes enlarge during an immune response - you often feel 'glands' in your neck when you have a sore throat. In CLL they enlarge because the cells that are growing in an uncontrolled way normally live in the lymph nodes. In CLL we look for lymph nodes in particular places: the neck - we call these cervical nodes; the armpit - axillary nodes; and the groin - inguinal nodes. But there are lymph nodes all over the body and in CLL any lymph node can enlarge. Mostly they can't be felt, but there are some characteristic lymph nodes that are sometimes felt: submental nodes are under the point of the chin and epitrochlear nodes by the elbow. Lymph nodes at the back of the tummy - retroperitoneal nodes - cannot be felt with the hand but may be shown up by CT scan or ultrasound. Nodes in the chest also have to be visualized by some sort of imaging technique.



How do you know if you have CLL cont...

The spleen is about the size of a fist and is found deep under the ribs on the left of the tummy. It enlarges in CLL, but it has to get to three times its normal size before it can be felt. As it gets bigger it grows across the tummy towards the right groin. It seldom gets as big as this in CLL but it can grow this large in some kinds of haematological cancers. When it is examined by CT scan in CLL it is almost always found to be enlarged and patients think that they must therefore have advanced stage disease. This is misleading. As far as CLL is concerned a spleen is only considered to be enlarged if the doctor can feel it with his/her hand.

The spleen can be thought of as a large lymph node attached to the blood circulation. But it also has other roles. It is the last resting place for dying red cells and platelets. When it enlarges it is apt to take out red cells and platelets before they are ready to go. This is known as hypersplenism and it results in anaemia and thrombocytopenia.

Anaemia means a reduction of the amount of haemoglobin in the blood (the abbreviation is Hb not Hg; Hg is the abbreviation for Mercury). Men and women have different normal ranges for Hb. For men it is 13.5 - 17 g/dL, for women 11.5 - 15 g/dL. Anaemia cause tiredness, breathlessness, weakness, pale skin and mucous membranes and, in severe cases, the features of heart failure; but in many cases mild anaemia has no signs or symptoms. Anaemia in CLL is caused by suppression of the bone marrow by the infiltrating lymphocytes, or by haemolysis - the destruction of red cells by an antibody, or by hypersplenism. Of course CLL patients can become anaemic for reasons unrelated to CLL, such as iron deficiency or pernicious anaemia.

Thrombocytopenia means a reduction of the platelets in the blood. The normal range for platelets is 150,000 to 400,000 per cubic millimetre. The features of thrombocytopenia are bleeding and bruising. Platelets are there to plug holes in broken blood vessels and to help the blood to clot. Bleeding into the skin is called purpura and there are two types: petechiae are tiny pinhead sized blood spots; echymoses are anything larger. Thrombocytopenia can have the same causes as anaemia: marrow infiltration, immune destruction and hypersplenism.

CLLSA Freephone number 0800 977 4396

Patients may also suffer from so-called B symptoms. **B symptoms** come from Hodgkin's disease doctors who used them to decide whether to treat with chemotherapy or radiotherapy and they have been imported into CLL theology where they don't necessarily fit precisely. There are three types of B symptom: fever, weight loss and night sweats. Some doctors and most patients think that fatigue should also be a B symptom in CLL. I shall write about fatigue on another occasion.

Patients with CLL are more susceptible to infections than normal - they have an immunodeficiency. I will write about this in detail later.

To summarize: Most patients with CLL are discovered because they have a blood test for some other reason. If patients have signs or symptoms, the commonest is enlarged lymph nodes, but the spleen (or more rarely the liver) may also be enlarged. In the most severe cases there may be anaemia or thrombocytopenia. Some patients have B symptoms and all have a degree of immunodeficiency.

From "Mutations of mortality"
© 2005 (modified 2011)

CLLSA WEB SITE

Among other updates we have added a search engine (Google) to the CLLSA web site.

You can access it by clicking the word 'Search' at the top of the home page. The search engine is a work in progress, and we will update this facility shortly

What is happening in the NHS?

It is never easy to get an overall view of the NHS, despite the tens of thousands of sincere hard working people from Nurses to Administrators, I really doubt that anyone can usefully predict what is happening. There are a few basic truths for 98% of this country, the NHS supports us in some way, even if it was training your private doctor.

To help your awareness of what is going on, you can visit <http://www.nhscampaign.org/> Be aware that it is a radical site, and often uncomfortable reading.

How long does it take for the bone marrow to produce new haemoglobin and platelets into the blood?

By Prof. Susan J. Leclair

There are several different answers to the question "how long" for cell production. If you are talking about normal every day production, then from start to finish it takes 7 days for a cell to change from a stem cell to a red cell in the blood stream. It takes approximately the same amount of time for a platelet to arrive in the blood stream. But since they are replaced on a daily basis, one could say it only takes a day to replace any lost cells.

If you are talking about replacement after a significant bleeding episode, then both of those times can be shortened to about 3-4 days. Because the marrow can decrease the transit time it takes from stem cell to blood cell by about 1/2, increased numbers of replacement cells begin to show up in the blood stream within 3-4 days.

If you are talking about starting from an SCT, that is a different story. In each of the first two situations, the marrow was already working and only needed to augment what it was already doing. After an SCT, first the stem cells have to FIND the marrow, figure out to engraft into it, engraft, and then finally start undergoing their own proliferation so that they can be in large enough numbers to start making a credible number of cells. All that takes time. Before the use of colony stimulating factors such as GM-CSF and erythropoietin, that average time was around a month. With these agents, significant cell formation (as measured by cells in the blood stream) is now around 10 - 20 days.

Prof. Susan J. Leclair, Ph.D., CLS(NCA)

OUR NEXT MEETING

The fourth Midlands Regional Meeting of the CLL Support Association to be held on Wednesday 25th May 2011 **from 10.30 to 16.00 hours at the Sketchley Grange Hotel, Hinckley**. We are very fortunate to have Dr Ben Kennedy from the University Hospitals Leicester will again be our guest speaker with a new presentation for 2011. Dr Kennedy is a well known haematologist and has a special interest in CLL.

This meeting is now fully booked - all applications made before March 21st by post mark or date stamp on email or the phone line have been accepted and we are notifying the applicants. We will accept names onto a waiting list in the case of cancellations.

Contact us by freephone (see below) or by e mail to trustees.pa@cllsupport.org.uk or by post to CLL Support Association c/o 39/40 Eagle Street, London, WC1R 4TH.



CALLING ALL MEMBERS

The CLL Support Association wouldn't be here without you, our members. We need to make sure that we can contact you all so that you are kept up to date with everything we do.

Recently we have been checking our membership lists to ensure that we are able to contact all members that receive information via email.

If your details have changed at all since you joined please could you let us know?

We are led by the Charity Commissions' guidelines and if we cannot contact you we will send a letter asking you to contact us. If we do not hear from within 6 weeks we send another letter checking your contact details and if we still do not hear from you we have to send a final letter informing you that if we don't hear from you within 6 weeks we will have to remove your details from our mailing list.

We value all our members and do not want to lose anyone from our mailing list but if we are not sure that our information is getting through we have to review this.

As you will appreciate we are a charity funded by donations so we try to keep the cost of correspondence to a minimum.

You can contact us by:

Email us at membership@cllsupport.org.uk

Or by the Post Office to
Trustees PA
CLL Support Association
c/o 39/40 Eagle Street
London,
WC1R 4TH.

Or the Free phone membership line, 0800 977 4396 and leave a message.

I must also say a big Thank You to everyone who has already replied to our emails and letters with updated email addresses and postal addresses. We have had a great response.

TRUSTEES NEEDED

In accordance with the wishes of the present trustees, I am asking for more volunteers for the posts of trustees.

Applicants should be of a mature outlook. Trustees are required to attend up to 4 trustee meetings per year, and support the organisation, which involves responding to day to day e mails and also reading the documentation distributed. Trustees are to assist in the planning and running of patient meetings; the everyday running of the CLLSA; raising money; the phone line; the web site; production of materials for the CLLSA and many other tasks.

You must be self motivated, have excellent communication skills, and be very flexible. These are voluntary positions and only legitimate expenses with receipts are reimbursed. If you are selected for interview then your expenses for travel would be reimbursed.

Unfortunately, due to the fact that the volume of work is conducted by e mail, you must have easy access to a computer and be able to send e mails and use a word processing program.

Please respond by sending an application of no more than 300 words giving your reasons for becoming a trustee and what strengths you would bring to the role. **Send your applications for the attention of Jane Barnard to:**

membership@cllsupport.org.uk



Are You a Good Listener?

Most of us have been helped by having someone to talk too at some time of our lives. We were grateful for the support and comfort their listening has provided. Now we need people in the CLLSA who are willing to become volunteer listeners; people with CLL or their carers who understand some of the special problems that we have.

If you think that you can help, let us know with contact details and a sentence or two about why you feel that your background would help you to be a listener. We can then talk to you about some specialised training.

You can contact us by Email at membership@cllsupport.org.uk or by post and telephone - see column on left

JUST GIVING

I would like to pass on my experience of fund raising for charities using the Just Giving web site.

My daughter ran the London Marathon for Cancer Research in 2007. She had to raise £2000.00 for the charity and there were many times when she felt she might have to donate all the money herself as family and friends were very slow at the beginning. Then after 3 e-mails to friends and family donations started to roll in and her fears soon dissipated. We also made cakes to order for teachers and staff at her school and I cooked a meal once a week for them to have at school for £5.00 a head, so between us we managed to raise nearly £3,000. She was very pleased with herself, and I was very proud she had managed to run the London Marathon.

As a teacher she used the marathon goal in her maths lessons, teaching them about percentages, which the children loved. They got very excited about Miss Taylor's fundraising efforts, so contributions also arrived from the parents which Anna had not expected.

The following year she ran the Madrid Marathon for the CLLSA. She enjoyed the run and even said "the next one will be New York!" I thought it was too much, but she enjoyed it and also benefited us and of course the training was keeping her healthy.

We have been fortunate to have several members doing sponsored events for us such as sky diving, marathons and half marathons. I take my hat off for your efforts! I know how much training goes into it and to think you have done all that for us touches my heart.

We very much appreciate your support and one of my plans in the future is to try and see if we can get a place in the London Marathon for the CLLSA. I have been told it is very difficult, but I know some of the younger relatives of our members would love the opportunity, so wish me luck.

If you haven't looked at the Just Giving web site before, have a quick look when you have time. It is a very quick and easy way of setting up a page where you can ask for donations to your chosen charity. It's also easy for friends and family to donate through the site. You can also add pictures and keep a diary of your training so that everybody can share in your preparations and enjoy watching the progress. Here is the link to CLL Support Association Just Giving page <http://81.19.63.6/cllsupport/>

Here are some of the old web sites from Just Giving:

<http://www.justgiving.com/davidcritchley.971631>

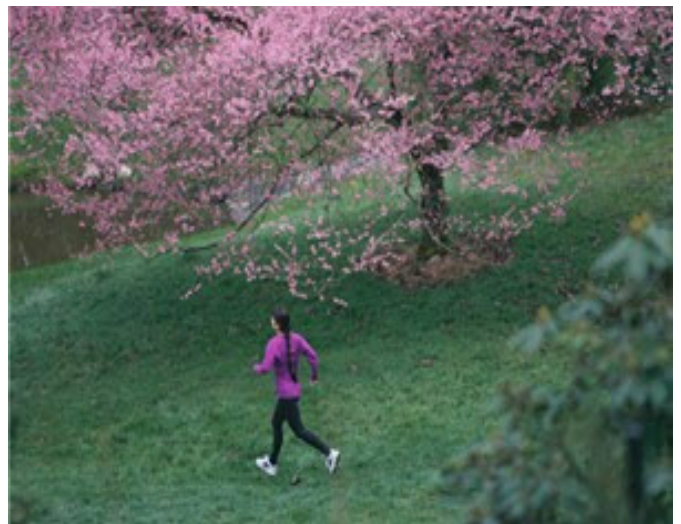
<http://www.justgiving.com/rachelburrage>

<http://www.justgiving.com/colinfraser>

<http://www.justgiving.com/annaxochitl>

<http://www.justgiving.com/annaxochitl.531340>

Chonette Taylor.



Caring for a Partner with Cancer: A Study into their Experience

We have been asked by two students at Loughborough University if we can pass on details of their study to our members. We are happy to do so but must point out that the CLL Support Association do not have any involvement in this study.



Whilst the cancer journey can be a challenge for someone who has received the diagnosis, it is important to acknowledge that it can also have an impact on their partner. We are looking to speak to working males who are caring for their partners who have received a diagnosis of cancer. We would like to understand the impact to their quality of working life and their issues with coping. The study is being conducted by Sarah Stanley-Smith and Kim Jackson-Blott as part of their final year Psychology degree projects at Loughborough University. This research is being supervised by Dr. Fehmidah Munir (Loughborough University).

What is the purpose of this study?

We know that most men provide a lot of support to their partners and often end up taking responsibility for a wide range of activities –both family related and care related – while their female partner is undergoing treatment. What we don't fully know, is how this role can effect working carers in terms of their quality of work life, coping and accessing support.

How can you help?

We would like to interview working men who have/are caring for their female partners going through the cancer experience. The interview will be conducted over the telephone and will last approximately 30 minutes.

If you are interested in participating, please contact Sarah or Kim. After you have filled in a consent form we will then contact you to arrange a time convenient for the telephone interview. If you decide to take part and then later change your mind, you are free to withdraw from the study at anytime. In which

case, any information we have collected will be destroyed and not used.

What happens to the information you provide in the interview?

The information obtained from the interviews will be analysed to identify the main issues. All information given will be kept strictly confidential and will only be accessible to the research team. Any personal information you provide will be made anonymous. All personal data will be stored in a confidential manner according to the data protection act and stored securely at Loughborough University. A copy of the findings can be provided on request.

Your participation in this study will be much appreciated. If you have any queries about this study, please do not hesitate to contact one of the research team.

Contact Details:

Sarah Stanley-Smith (3rd Year Bsc Psychology student)
s.i.stanley-smith-08@student.lboro.ac.uk

Kim Jackson-Blott (3rd Year Bsc Psychology student)
k.a.jackson-blott-08@student.lboro.ac.uk

Dr. Fehmidah Munir (supervisor)
Loughborough University
f.munir@lboro.ac.uk
Tel: 01509228228

SELF ASSESSMENT GIVING

If you complete a Self Assessment tax return and are entitled to a tax refund, you can choose to have all or part of the repayment sent directly to charity. This is called 'Self Assessment Giving' or 'SA Donate'. You can also ask that the repayment is made as a Gift Aid donation.

Self Assessment Giving has a number of advantages:

- It offers an easy way to donate your tax refund to a charity of your choice
- The charity receives your donation directly into its bank account without having to make the claim
- You can increase the value of your repayment by making it a Gift Aid donation provided you've paid enough tax

To use Self Assessment Giving you need to enter a charity reference code in the space provided on the 'Giving your tax repayment to charity' form that comes with your tax return.

You can donate your tax repayment to charity by filling in form SA100.

The CLLSA Special Code is: FAS54AG

GALANTHUS For those of you non-gardeners who are wondering what Galanthus means!

Galanthus nivalis - Often referred to as the **common snowdrop**, *Galanthus nivalis* is the best known and most widespread representative of a small genus of about 20 species in the family Amaryllidaceae. Snowdrops are among the first bulbs to bloom in spring and can form impressive carpets of white in areas where they are native or have been naturalised.

From Wikipedia, the free encyclopedia



Our thanks to Roche for funding

Our 24 hour membership telephone numbers are:

0207 644 3052

0800 977 4396



Postal Address
CLL Support Association
c/o 39/40 Eagle Street,
London, WC1R 4TH.
www.clisupport.org.uk

Disclaimer

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Registered Charity No.1113588

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