

CLL NEWS

Newsletter of the CLL Support Association



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Welcome to our Spring newsletter!



2016 is already proving to be another very busy year for us all at CLLSA.

We have been taking another look at how we are set up with the help of a consultancy which is run by one of our members who very generously has given us their help at no charge. Many thanks!

This has caused us to look again at how many people we need to do all the jobs that need doing and we shall be in touch directly to you all on this in the coming weeks. We are particularly looking for possible trustees who have either some experience in fundraising and/or in managing volunteers. More of this later.

In the meantime funding is always a high priority for us. We do as you know get a fair degree of support from pharmaceutical companies but we need to widen our scope so we can achieve more independence. So if any of you have any ideas for fundraising then please get in touch – every little helps! Please email me on david.innes@cllsupport.org.uk.

Our main activity this year will continue to be our members conferences. We have another 3 in place now for 2016 for Southampton, Glasgow and London and we shall be publishing the details in good time for each of them.

On the drugs front there is again a lot of work to be done. Finally we have been working on rewriting what we are set up to do for our members and here it is. This is helping us a lot in deciding

where we need to focus over the coming months and years.

CLLSA purpose

We set out to inform, support, and empower CLL patients in the UK, their carers, families and friends.

We aim to:

1. Provide up to date and accessible information about CLL, the range of treatments currently available and the latest research into the care and treatment of CLL.
2. Develop opportunities to share understanding and personal experience by bringing CLL patients together and creating mutual support groups and networks.
3. Act as a voice for CLL patients, representing their interests with the pharmaceutical industry, clinicians, NHS, cancer care policy and drugs regulation authorities, funding and commissioning groups, and politicians.



David Innes - Chair

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CLL - "How did you find out"?

By Allan Graham - CLLSA Trustee

I know that I am going to be in trouble for this but I have never been able to take my CLL as seriously as I should! I blame the French, where we lived at the time - not all 67 million, just a few dedicated doctors and the wonderful health service in France. I better explain....

I was admitted into a French hospital with a heart condition and was lying on a trolley outside the operating theatre waiting for a heart job. French modesty dictates that nothing is better than something, and that is what I was wearing - nothing. The doctor, who had taken armfuls of my blood, came over to see me accompanied by a nurse. Both looked serious, the doctor stared at me for some time, shook his head, shrugged, tutted, paused and informed me that I had something wrong with my blood. He couldn't tell me what because he didn't deal in blood (this is the man who had taken pints of the stuff). And promptly they both left me on the trolley trying to work out what I had just heard.

Now I thought that patients with a dicky ticker should be kept calm and stress free, especially minutes before going into theatre. Fortunately, I found the whole episode hilarious. The shake of the head, the Gaelic shrug and the tut. In France if you ask an artisan for a quote to do work this is a routine they all go through. I imagined myself as a difficult job, almost impossible to complete.

After a few days I was discharged, armed with blood test results to take to my doctor. The red wine, served with every meal, and the wonderful nurses made the stay that little more pleasant. That was my first hint of my pending CLL.

The second instalment came when I visited my G.P. taking with me my blood test results. After studying the results for a long time a look of "not really sure" was there, again a shrug and saying "it could be CLL?" This was the first time I heard of CLL so I tried to find out more.

He told me he would make an appointment with an oncologist and tried to leave it at that. I pushed a bit more and was informed it wouldn't kill me but I could die of the illnesses I could get through having it! I put together the experience on the hospital trolley and this bit of news and just had to laugh.

The third instalment was the first meeting with the oncologist. My blood test had been analysed and finally he was able to tell me that they had confirmed that I had CLL. We talked for some time about CLL then he told me I was lucky - it was chronic, not acute! Now you will know to be told you have leukaemia, you do not feel lucky, and at this stage the humour of stages 1 and 2 of the French farce began to fade a little.

After this visit I went home, on to the World Wide Web, this was 11 years ago when I was 64 and I made the mistake of going into American sites. We called them the "gloom and doom" sites and it would seem my new washing machine had a longer guarantee than they gave me.

11 years ago in France Watch and Wait was not in the French psyche and within four years I had two sessions of chemo and visited the specialist every two months, or had a meeting before each chemo session.

Thankfully a year after I was first diagnosed this progressive organisation - CLLSA - came on the scene. I became an overseas member and the information was as invaluable then as it is today.

At the age of 64 I acquired a dicky ticker, Diabetes and CLL and despite all predictions still going strong at 75.

CLL - "How did you find out"? Continued...

We returned to the UK after 16 years in that beautiful country, attending their wonderful health service. It's nice to be home but we miss all our friends in France. We still have a daughter and grandchildren there and return as often as possible with the help of EHIC - Holiday insurance humour, that's one for next time.

Living in the UK for the past 6 years I have had 2 more sessions of chemo and am now doing really well on the new, much talked about, Ibrutinib.

Despite being a Trustee in this great organisation I still can't take my CLL all that seriously. Probably laughing at this odd condition, where they say you have an illness but we won't treat you - we need to look for the humour and smile to get through it.



There must be many of you who have had a memorable introduction to CLL. Would you like to share them in the next Newsletter? Let's see if there are more smiles and interesting accounts of "How did you find out"?

If you would like to share your story please contact [membership@cllsupport](mailto:membership@cllsupport.org.uk) and we will do our best to add it to a future issue of our newsletter

A Message from our Treasurer

On behalf of the board of trustees of the CLLSA I would like to say thank you for all your kind donations in the last year. Also thank you to all who set up regular donations. It really helps us to be able to plan our future activities.

Our services are provided on a free of charge basis. We are totally dependent on voluntary contributions to enable us to continue and expand our work. We are all grateful for your continued support. Thank you for your confidence in what we do.

If you would like to set up a regular donations please contact me at treasurer@cllsupport.org.uk We also have a page set up on the just giving website where you can make one off donations or donate to someone who is fundraising on our behalf . Since the launch of our new website, we can now also accept donations via our website:

<http://www.cllsupport.org.uk/civicrm/contribute/transact?reset=1&id=1>

Although it says you can donate by pay pal don't worry if you don't have a pay pal account as there is an option on the same website page to donate from your credit or debit card.

Andrea Cockburn - Treasurer



Introducing your Trustees'

The CLLSA has a Board of Trustees who are there to ensure the purpose and aims of the Association are met in the best interests of all its members. Trustees are all volunteers and either CLL patients or carers.

We are always interested in hearing from members who would like to help the Board by volunteering to work with our Trustees or to become a Trustee. We thought it might be helpful to introduce our current Trustees by asking each of them to share a few details about themselves with our members in the form of a short personal profile over the next few newsletters.

David Innes - Chair

Born in Dundee 66 years ago I have lived in West London for over 40 years and have 4 children and 7 grandchildren.

My career has been in sales and marketing and general management and my last post was with Seiko, the watch manufacturer from where I took retirement in 2009.

I spend my time in the gym, cooking, enjoying wining and dining, walking, holidays and of course spending time with my family. I have also become an addict of free on-line courses – or MOOCs. I can thoroughly recommend these for folks with some spare time – Coursera or Future Learn are 2 good suppliers.

I was diagnosed with CLL in 2011 ironically as a result of a “well man check”. I am still on “watch and wait” but my blood counts are on the up so treatment may be imminent.

I became a trustee of CLLSA in November 2014 and quickly found myself appointed as Chair in May 2015 after Arthur Grayley stood down. We now have a strategy in place for 2016 – which I mention elsewhere in the newsletter – and we are always on the lookout for new volunteers and/or trustees as the workload is constantly building."

Allan Graham

First the important things in life. My wife, Pat, and I live in a village on the Fylde Coast called Freckleton, I am 75, married for 54 years and we have 4 children, 12 grandchildren and 2 great grandchildren.. The family are spread through the UK, France, Netherlands, New Zealand, Spain and Germany. Despite the distance and with the help of Skype, we are a very close family

My background, when in industry, was a personnel and training manager. I later moved into social work and for 16 years was a social worker specialising in working with difficult teenagers and their families. Throughout this time my wife was a foster carer for the local authority. Also during this time I trained and worked as a counsellor for relate.

When I retired we moved to France where I worked as a volunteer for cancer support. At 64, in France, I was diagnosed with CLL, a heart problem and diabetes.

Since returning to the UK I have been involved volunteering for Witness Support, part of Citizens Advice, supporting victims and vulnerable witness's before and during their stay at the Crown, or Magistrates Court. I enjoy working with people and one of my interests as a Trustee is Helping to develop the CLL Help Line.

Introducing your Trustees'

John Moore

I live in Rainford, a village near St Helens on Merseyside. I am married to Liz, a retired primary school teacher. We have two sons, aged 32 and 28, who both conveniently live and work in Leeds.

I retired in 2014 having worked for many years as a management consultant specialising in various aspects of 'human resource' management. Prior to that I worked in personnel management in the NHS and in local government. I originally trained as a teacher and spent two years teaching English and PE in a large secondary school in Sheffield.

Apart from watching far too much tv, I like to keep fairly active. I'm involved in various outdoor activities; climbing, riding, golf, gardening, walking; none of which I have any talent for but which are all hugely enjoyable. I am also a volunteer in the eco-garden at the nearby Martin Mere bird reserve. To keep the brain active I'm in the pub with the quiz team every Wednesday. Having taken an extraordinarily long time over it, I'm hoping to complete an Open University arts degree next year.

I suppose I am really at the start of the journey. I have been very fortunate that since my diagnosis at the beginning of 2014, I have been in good health on watch and wait. I know that those blood count numbers are moving in the wrong direction but so far, fingers crossed, I have been able to do the things I want to do. Long may it last.

I became a Trustee at the end of 2015 because it was clear from my own experience that the Association is doing valuable and important work to address a real gap in patient need. I simply wanted to make a contribution to that work.

CLLSA Helpline

CLLSA HELP LINE FOR CLL SUFFERERS - FAMILY - OR FRIENDS

We know that a diagnosis of CLL can change everyday life for CLL sufferers and their families. We know that it is often difficult to talk to loved ones, family or friends about your condition.

To talk to someone who is a fellow sufferer can help to inform and ease the anxiety. If you have been recently diagnosed, are waiting for your first chemotherapy, need information or just want to talk

Please phone CLLSA Help Line on
0800 977 4396
We're here to listen



Please note that we operate an answer phone message system, messages are checked daily and we do our best to respond as quickly as possible. We are members of the Helpline Partnership.



Everything you ever needed to know about CLLSA conferences

Back in 2004 a few CLL patients decided to meet up to try to set up a support group for patients and carers of those with CLL. They soon realized that meeting others in the same situation was very beneficial and that they could all support, inform and empower each other in a positive way. This is how the CLLSA was 'born' and since then a core part of what we do is to run member's meetings (now known as member's conferences) which carries on this legacy of support, information and empowerment.

The meetings have grown in size and with the goodwill of the medical community we have been able to support our members around the country. In fact they have grown so much we have recently changed the name to members conferences.

Some of the locations we have visited have been London, Norwich, Cardiff, Bristol, Nottingham, Southampton, Oxford, Hinkley, Cambridge, Liverpool, Glasgow, Middlesex and Brighton.

HOW DO WE CHOOSE A LOCATION?

There are many factors that determine location. We try to include as many areas throughout the country to make them accessible. The main considerations are:

- 1. Consultants Availability** – We are very fortunate to have the support of many healthcare professionals such as Consultants, Specialist Nurses and Researchers. They are often contacted by our trustees who build links with them through their many projects. They are all very busy people who freely give their time often running clinics on the days of our meetings. They can't always spare a lot of time to travel to a distant venue and have to dash off after their presentations. We need to keep the venue location close to their place of work.
- 2. Accessibility** – This is a difficult balance as we try to find a venue that is suitable for car users and those who use public transport. There are venues close to major routes that are easy for car users, but very difficult or impossible to get to by train or bus. There are other venues that are close to train and bus stations but mean a busy city Centre route for car users. I'm afraid that this is usually as case of not being able to please all of the people all of the time, but we do our best!
- 3. Venue Suitability and Cost** – We always have to keep a very close eye on finances. In the past we have been offered free venues and obviously we never turn down a free venue! These might not be the prettiest or the most accessible but as a charity we have to take up these offers so that we can continue to run our conferences. Also we might find a venue that provides everything we need but it also comes with a high price tag and it has to be ruled out. Other venues may be ruled out due to size and others due to non-availability of AV equipment.

WHAT ARE THE BENEFITS OF ATTENDING A CLLSA CONFERENCE?

For some people coming along to meet others and share experience is an easy decision to make, for others it may be quite a big decision to 'go public' and attend a conference. The best way to demonstrate to members the benefits of attendance are to hear from other members who have attended one of our events. Here are some comments from members who have attended our meetings:

How friendly and informative the event was, also the positivity

What I liked most about this event: Peoples honesty – hearing their stories

Good variety of information and the opportunity to ask questions. Great lunch!

Good to meet other people to discuss 'like' issues and how they deal with them

Really interesting talks, delivered at the right level for the audience

All I can say is come along and give it a go. We are a friendly bunch and will try to make you feel comfortable. Trustees are on hand to have a chat or help you and we make sure there are a few at each conference to meet you, especially new members who are nervous about attending for the first time or people coming alone. We also appreciate the support from our regular conference attendees and those who are a bit further along in their CLL journey as they have a wealth of knowledge to impart to our 'newbies'.

Everything you ever needed to know about CLLSA conferences

BOOKING A PLACE AT OUR CONFERENCES There are a few ways you can book a place at a conference. You can book online via our website, if you are a member and have set up a login already. This is the quickest way to book and as places are on a first come first served basis. You can also email membership@cclsupport.org.uk or phone us on 0800 977 4396. You can find our contact details on our website here [Contact](#), and you can find details of future events here [Events](#). Registration is usually opened after we have sent out a message to members notifying them of the next meeting.

We strongly urge you not to book a place until you are sure you are able to attend. This ensures that, if the conference is oversubscribed, no one misses out on a place that is not used. This can also incur cost to the CLLSA if you can't attend at short notice (see below)

BOOKED A PLACE BUT NOW CAN'T MAKE IT?

Being a charity for CLL patients we fully understand if you are unwell and unable to attend, late cancellation of a place is unavoidable and we would never want to put any of our members' health at risk. We also ask if you have any coughs and colds or conditions that could be passed on to others that you do not attend so that others who are susceptible to infection are not put at risk.

However, if you do have to cancel for other reasons it is vitally important that you cancel your place as soon as you can. At nearly all of our conferences we pay per head for the event. The cost can range from about £20 up to £35 a head. All venues require us to confirm numbers between 7 to 14 days prior to the event so we have to include everyone registered at that date. We could book for 10% less than the number of people registered to attend, but if everyone turns up we would not want anyone to go hungry!

If you are unable to attend for reasons such as hospital appointments or commitments at home, please let us know at the earliest available opportunity and always try to put alternative arrangements in place before booking. We know that things sometimes go awry, but early notice when you can is very much appreciated. For example, if we get 10 late cancellations (under 1 week before the event) we still have to pay for those places which can cost about £35 each, that costs the CLLSA £350!

BURSARY SCHEME

Our conferences are free of charge to our members so as to eliminate any financial barriers to participation. Did you know that the CLLSA offers a bursary grant to help our members who may need financial assistance to attend? You could use it to pay for a rail fare, an overnight stay, a taxi from the station or parking and petrol costs. **You must apply for the bursary before the conference** and get e-mail or written confirmation, which includes the estimated amount. Keep all receipts for travel including mileage and/or your accommodation. The bursary is not means tested. Payment can be made by cheque posted after the conference or we can issue them at the conference if there is sufficient privacy. **For further information, please email treasurer@cclsupport.org.uk and the treasurer will be able to send you an application form.**

WHAT DO WE DO WITH THE FEEDBACK WE RECEIVE FROM CONFERENCES?

We always compile a list detailing all comments and feedback and it is circulated to all of the trustees. We try to improve our conferences using the comments and feedback that we receive from members who have attended our events.

If you have any ideas for future conferences such as subjects we can focus on, venues that you can recommend from other events or observations after attending we would be very interested to hear from you. Email membership@cclsupport.org.uk

We hope to see you at a conference soon

Sarah Tobin - Coordinator - CLLSA

An Interview with CLLSA Member - Hans De Vrind

One of our members, Hans De Vrind, gave an excellent presentation at our St Bart's Members meeting last year. So much so that our Chair, David Innes, thought it would be good to share his experiences with you all. David interviewed Hans recently and he kindly agreed to us publishing the interview in this newsletter.

Preface:

David, I am well aware that we are all different and we all deal differently with stressful situations. I had a nervous breakdown back in 1987 and was in a psychiatric hospital for 3 months as I was very suicidal for a long time – this experience has helped me tremendously over the years and I have learned during that period how to deal with my own feelings/thoughts.



I just love my life and am grateful for a new chance of continuing to live my life to the full again. I now work in the community with people who suffer from mental health issues and this probably helped me as well

Apart from playing football, running 18 marathons, cycling, parachuting and being a qualified pilot, I still have some more things on my wish list to do!

When were you diagnosed? February 2003

What treatments have you had? I was treated initially with 9 cycles Chlorambucil (in the CLL 4 trial) to PR. In November 2006 there was further disease progression requiring treatment. I received 3 cycles of Fludarabine and cyclophosphamide, but I suffered prolonged neutropenia with a positive neutrophil antibody test and was treated with oral Prednisolone. Then in March 2009, I began a new cycle of chemotherapy, on a clinical trial (LUCID) and I was randomised to the control arm of Fludarabine, cyclophosphamide, Rituximab (FCR). I had another cycle in April 2009 which was at 50% reduced dose. There were some complications during my treatment and I was admitted with neutropenic sepsis. Because of persistent neutropenia and persistent massive splenomegaly, my treatment on the "LUCID" trial was interrupted for a splenectomy. I completed the "LUCID" trial and was in a complete remission, but minimal residual disease (MRD) positive in the bone marrow and blood; plus the trisomy 12 associated with my CLL was still detectable in the bone marrow. In view of this, plus my extensive previous treatment, I had a "reduced intensity conditioned" allogeneic transplant using stem cells from my "matched" brother on 15/03/2010.

I see that other members of your family have had CLL. How rare is this do you know? Dr Lewis from the Oldchurch Hospital referred me to Cancer UK and they investigated together with 3 hospitals in The Netherlands, especially as my Father and Sister died of Leukaemia and 2 brothers have untreated CLL, they checked to see if this was hereditary but eventually it was decided that this was just pure coincidence

How have you coped with your treatments? I can honestly say that from day one onwards I have never been worried about my illness. I have been compliant with all treatments and appointments.

An Interview with CLLSA Member - Hans De Vrind

How have you coped with your treatments? Cont..

I just got a bit down when my spleen was removed as my admission seemed to take for ever and ever. I begged the doctors to discharge me and after a lot of groveling the doctors (I think reluctantly) discharged me on my wife's birthday. I had lost a lot of weight and after 3 days I went to my family in Holland and they were all shocked and they really thought that I was the next one to pass away as it was one year after one of my sisters had died of CLL. I just ate everything I wanted, despite the fact that the doctor had given me a leaflet advising me of things not to eat which I completely ignored.

How has CLL affected your life and the life of your family? I have never kept my family here in UK nor in Holland properly updated on everything. My wife and children were very concerned at first but they all realised that I was not telling them much so they took on my attitude and said: If you are not worried we are not worried! I can honestly say that I have always put 100% trust in the doctors here in Havering and Bart's and I continued working full time as soon as I was allowed to do so. I continued living my life as normal as possible.

I know that fitness has always played a big part in your life. How have you managed to keep this going? At times it was difficult, especially as I was told to slow down but I am possibly very foolhardy and keep going at all times, even during the chemo therapy and when they took some bone marrow out of my back I was up and running the next day with moans and groans from my family in my ears. As Dr Agrawal is aware I still managed to continue with the training for the various marathons I managed to complete.

How big a part has CLLSA played in offering you support? Having spoken to Dr Agrawal many times on this subject I am grateful for the advice given and the encouragement is important to remember.

What message would you like to give to CLL patients in the UK? I can only encourage any person who is going through something similar as myself did: Stay positive, ask the doctors and nurses for advice and realise that medication and treatment in the various cancers are getting better results by the day. Speak to people who are going through similar problems and find out how to deal/cope with everything. Believe in your own strengths even when the discomfort or doubts come through then speak to your loved ones or to the doctors/nurses around. Remember the old advert some years ago: It is good to talk!

Many thanks Hans for your honesty and for sharing your experiences, from everyone at the CLLSA



Cramps

My Personal Experience by Chonette Taylor

Many people with CLL experience cramps and I was not an exception, I thought to share with others what I discovered over the years dealing with the problem.

Cramps often get intensify during steroid treatment (Prednisolone, High Doses Methylprednisolone, Dexamethasone etc.). Sometimes they are mild others very painful and particularly if they happen in the middle of the night and we wake up with a pain that breaks our sleep and then it happens on and off so often one has a sleepless night.

During my HDMP (High Doses Methyl Prednisolone) treatment I also experienced the cramps during the day and not just legs but feet, toes, etc. they could come at any time.

Years ago when I started the problem, I gave it little attention as I had major issues to worry about at the time, my platelets were going down very fast and I wanted to help trying to bring them up, I joined the ITP group and there I learnt lots of people with ITP had cramp, this was due to the amount of steroids they took to bring platelets up.

Someone there said since she started having a yoghurt every night before going to bed, her cramps has stopped, I started that practice as I just love yoghurts and the problem seemed to disappear and the cramps were gone, of course this is anecdotal.

Lack of potassium is one of the causes of cramps, there are many foods that can help with this, bananas being one, yoghurt, sweet potato, prune juice, carrot juice just to mention a few, those of you with internet access can look at the full list on this link:

<http://health.gov/dietaryguidelines/dga2005/document/html/appendixB.htm>

As well as potassium low Magnesium is a common cause for leg cramps and even Sodium can be the culprit, especially if you are on a diuretic

And this is a response from Prof. Terry Hamblin on the subject back in 2006:

“Leg cramps in CLL have been known about for decades. They were one of the first things I took an interest in when I started in CLL in 1972. I immediately started using quinine sulphate 200mg at night and the effet was miraculous. Everybody who used it had their cramps relieved.

Now quinine sulphate does cause a special type of ITP, but it is very rare. It depends on the presence of the quinine in the circulation, so it gets better when the quinine is stopped. In practical terms I have never found it a problem and since CLL patients have regular blood tests it is spotted early before it can do any harm. If I were you I would not let it interfere with what is a very good remedy for leg cramps”

Terry Hamblin

A post from one of our British friends:

“I thought I should warn people with thrombocytopenia that it is not advisable to take quinine as it can make the platelet count tumble.”

I was a daily reader of the Acor list during those years, and someone asked this question to Prof. Hamblin, I myself have looked the internet to find some answers long before this time but had not found any, so I was glad someone had put the question to him

Cramps

My Personal Experience by Chonette Taylor

“Dr. Hamblin, what is/are the biological reason(s) for leg cramps being associated with CLL?”

I was unable to find an answer by Googling or by doing PubMed searching”.

Reply:

No-one has a clue - Terry Hamblin

The list of suggestions from other CLL people on the Acor list is endless and I followed many of them one time or another, but what I consider had actually sorted it out all together was a homeopathic remedy my GP prescribed during those treatment years.

I had several terrible nights in which the pain was so bad during my HDMP treatment that I ended staying up for fear of dropping to sleep and getting a cramp, one of those nights I sent an e-mail to my GP telling her what I had been doing to prevent the cramps but nothing seemed to working. I said I had not taken quinine as I was reluctant to take any more medications and if she had any magic wand that could help I would be so grateful.

At lunch time I had a phone call from my GP and she asked me if I minded taking homeopathic remedies, I said I did not mind at all. She told me she had done a homeopathic course while in Medical school and she had enjoyed it very much, she said there was something I could take and she could prescribe it on the NHS.

I got a prescription for **Cuprum Metallicum 6C** for 125 tablets, to start with I took one morning and one evening, the cramps stopped very soon. I continued like that for a month and then I took one at night, then after a couple of weeks I stopped and only took them during the periods of my HDMP treatment, it has now been a few years since I stopped taking them all together and I have not experienced any cramps at all. I have to admit that I have suffered with cramps for years even without the steroids, but during those periods of time they were very intense, of course I do not know if this would work for every body, but it certainly worked for me.

One of the things we forget nowadays is to drink lots of water, drinking plenty of water as a regular thing, not just during hot weather, is something that benefits the body as a whole.

Here is a list of suggestions from members of the Acor list, to help with cramps. I have not followed things in the years since but I would be grateful if anyone has got any new developments to help with this problem that can benefit others.

Bananas, Potassium, Magnesium, V-8 juice,
Small bar of soap under the sheet (at ankle height) (NO Dial or DOVE soap) *(never tried this one but has come out several times on Acor)*

Ice Pack – *I have done the opposite of ice packs; have used a hot pack of lavender on my toes and knees when the pain was too unbearable, and occasionally I went into the shower to have a very hot shower which always worked.*

Quinine or Tonic water, Gatorade, Calcium Supplement, Vitamin B-6

Stretching toes/tendons (upward slowly several times a day)

Eliminate diet colas,

Watch the amount of sodium in diet (depletes Potassium)

CLLSA Message Board

SOUTHAMPTON MEMBERS CONFERENCE

12th July 2016

Grand Harbour Hotel Southampton

This conference is now open for bookings, please book online or contact membership@cllsupport.org.uk to book a place

GLASGOW MEMBERS CONFERENCE

19th September 2016

Grand Central Hotel Glasgow

This conference will be advertised later this year and bookings will be opened approximately 12 weeks before the event

THE VITALITY BRITISH LONDON 10K RUN

10th July 2016 - We currently have four places available on this run around the iconic sights of London. Registration is free but we do ask that you raise a minimum of £200 per runner.

Interested? Email membership@cllsupport.org.uk for further details.

LONDON MEMBERS CONFERENCE

11th November 2016

Venue to be arranged

This conference is being run with the Royal Marsden and will be advertised later this year. Bookings will be opened approximately 12 weeks before the event

WEBSITE LOG IN - Have you logged in to our new website yet? If you are a member and you want to register for meetings online you will need to log in to your profile. **You do not need to join again, just follow these steps:**

1. Open the website at www.cllsupport.org.uk
2. **Click on login which is located at the top of every website page**
3. Click on the text at the top saying 'Request New Password'

You will then receive an email with links to access your profile:

Link 1) follow this first link to access your profile. You can check and change any information as required e.g. email address, home address

Link 2) follow this link to take you to the page where you can set a password and username.

To maintain anonymity please ensure the username is not identifiable and keep your password private. This username will be visible if you use the online forum.

If you would like more information about our website, you can find a list of Frequently Asked Questions and help with logging on <http://www.cllsupport.org.uk/help>

If you require any assistance, please email website.info@cllsupport.org.uk

**Call our free phone answer phone service on:
0800 977 4396**

It is a regularly monitored answer service and someone will come back to you.

For immediate help you could contact the NHS 24 helpline:

111 is the new free way to phone the NHS 24 helpline from landlines and mobiles.

With thanks for educational grant funding during 2014/2015 to



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

www.cllsupport.org.uk

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