

CLL NEWS

Newsletter of the CLL Support Association



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WWW.CLLSUPPORT.ORG.UK

SUMMER 2015

Welcome to our Summer/Autumn newsletter!

As your new Chair I am very pleased to give you this short introduction to what has been going on in recent months plus a look ahead to some of our plans.

Now is a good time to announce that we are in our 10th year as the CLLSA and the article by Sue Waldie gives you a fascinating insight to how the Association came about. We are very lucky to still have Chonette on the board of trustees and her experience is invaluable to all of us.

We are kept very busy with arranging patient meetings and we have 2 planned for later this year – in Bristol on 28th September and at St Bart's in London on the 30th November. These events are always well attended so please make a note of the dates in your diary.

For those of you who have not yet attended one of these meetings you will find the article here on the March meeting in Liverpool well worth reading!

Fundraising is a vital part of our activities. The good news is that efforts by members have really paid off in recent months and our thanks go out to all who have raised money for us. You will find more details here on page 7. We should also take this opportunity to thank our various supporters in pharmaceutical companies who make an invaluable contribution to our plans.

On the medical front we continue to make representation to NICE and others on the new therapies that are under development. Again we should thank those members who take part in our data gathering because without this input the patient voice would just not be heard.

As you may know from some recent emails from me we are in the process of seeking out some

new trustees. The response has been very good and at the time of writing we are finalising our plans. I shall let you know how this develops.

I hope you enjoy reading this newsletter. Please keep in touch with us with any ideas you may have for fundraising or supporting other members.

We had some sad news earlier this summer when we heard that Derek McGlashan had passed away. Derek was a great asset as our Secretary and he will be sadly missed. Arthur Grayley has written a tribute to Derek and you will find this later in the newsletter.

Many thanks - David Innes



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CELEBRATING THE CLLSA'S 10TH ANNIVERSARY

A Message to CLLSA Members from Sue

We have been experiencing another successful year in the life of the CLL Support Association and since this year we are celebrating our tenth birthday, I thought it was time you were told a little more about our history..

When I was diagnosed with CLL in 1995 there was not much information that one could find about this disease. BACUP, the Leukaemia and Lymphoma Society and some other charities had basic explanatory booklets available, but that is all. A newly diagnosed patient would have had to research difficult medical literature and encyclopedias in libraries to have a deeper understanding of this condition. The Internet was just beginning to be used by patient groups and it was around that time, in 1996, that an American lady Granny Barb Lackritz, together with two British CLL patients, started the first CLL forum on an American cancer support website (ACOR).

Very quickly thousands of CLL sufferers from all over the world joined this site, as it became a gathering place where they could share experiences, information and receive support. Although many UK CLL-ers have also joined and taken an active part, we found that too many of the discussions concerned only American issues. So soon the British contingent began to look for ways to provide CLL support locally.

Paul Maguire was the first to organise UK CLL patient meetings. One of the first two-day conferences took place in a Grantham hotel, where Dr A Haynes and Dr A Bosanquet were the invited speakers. Other well attended meetings followed as news of these gatherings spread amongst UK CLL patients online. At one of these meetings, held in a CLL patient's office in Central London, three of us, Howard Pearce, Chonette Taylor and I, began to plan the formation of a specifically British CLL support organisation. Having had experience with setting up charities, I volunteered to help establish the structure and arrange for the charitable registration. Later in 2005 Robert Cork joined us as the fourth trustee and having expertise in web design, he established our first website. For our logo we chose the snowdrop, as that seemed to symbolise our proliferating white blood cells...

We started a fundraising drive for that first important thousand pounds we needed for the charitable registration and Chonette stepped in with her expertise in raising funds -- and also her generosity. She donated some beautiful Mexican jewellery and artifacts, which at a Christmas Fair quickly raised almost all the necessary funds. Generous donations from our first members added the rest and we were ready to start!

Howard had contacts with pharmaceutical companies and large charities, so soon we received welcome financial support from Roche, GSK, and Macmillan. He also arranged support for us by two great CLL specialists, Prof. Terry Hamblin and Prof. Daniel Catovsky, and later by Prof. Andrew Pettitt. We established links with the CLL Forum, set up by Dr Hamblin for medical professionals. Our next chair, Jane Barnard, a biochemist, even became Patient Representative at NICE meetings, as they evaluated new drug treatments for CLL. And so the CLLSA went from strength to strength, providing that much needed source for information and support for the UK CLL family.

I would like to thank past trustees, chairs and also volunteers for their invaluable help in building up this association, brick by brick, with great dedication, while fighting their own CLL related problems. Thanks are also due to all the present trustees for continuing this important work so brilliantly. Sadly, Howard is not with us any longer, but his legacy lives on in this Association he helped to create. And special thanks must go to Chonette. From the moment the idea of this charity was born, she has contributed tirelessly and selflessly to the creation of a successful organisation that the CLLSA is today.

Best wishes for good health to all our Members,
from Sue Waldie



Robert, Chonette and Howard

What is the Superbug LA-MRSA CC398?

The threat of MRSA in hospitals has generated an urgent response, but an MRSA variant is spreading from farm livestock to supermarket meat unchecked.

MRSA is best known in the UK for causing hospital-acquired infections – and many deaths. There has been little human to human transmission of the superbug in the community, but it is particularly dangerous in hospitals because it can colonise wounds easily, especially where patients' immunity is low.

It has been associated with poor hygiene in hospitals, but the main factor behind the spread of MRSA has been the over-prescription of antibiotics, which has allowed a rather mundane germ that lives on many of our bodies without causing any problems to become far more dangerous to human health.

MRSA superbug found in supermarket pork raises alarm over farming risks

CC398, a new variant of MRSA, emerged in animals and is found in intensively farmed animals (primarily pigs, but also cows and chickens), from where it can be transmitted to humans.

Government attempts to limit MRSA infections in hospitals have met with some success, there has been little comparable effort in combating MRSA infections among livestock.

While the risk of people becoming contaminated with the superbug from proper handling of raw meat is low, previous infections – such as salmonella in eggs, and campylobacter in chicken – have become established through the neglect of hygiene in intensive farming facilities.

Farming's antibiotics time bomb

The global health crisis surrounding antibiotic resistance, which sees bacteria evolve until previously effective drugs no longer work, has leapt up the political agenda in recent months.

The World Health Organisation (WHO) has warned that the planet risks entering a “post antibiotic era” where previously routine medical procedures become deadly as the drugs used to prevent infections stop working. Lifesaving operations – organ transplants, cancer treatments and caesarean sections – will become much more risky.

The UK's chief medical officer, Dame Sally Davies, has stated that antibiotic resistance is a “ticking time bomb” and the government has demanded tough targets for a reduction in antibiotic prescriptions by doctors, and pledged to lead efforts to develop new drugs to combat the problem.

However, almost half of all antibiotics used in the UK are administered to farm animals. In the UK, antibiotics can only be legally supplied to farms with a prescription from a vet to treat, and in some cases prevent, illness, but there are several problems with the way animal antibiotics are regulated.

The European Surveillance of Veterinary Antimicrobial Consumption collects information based on sales of antibiotics, but not the administering practices on individual farms. Antibiotics are often administered as medicated feedstuffs or on farms authorised by the UK Veterinary Medicines Directorate, an executive agency of the Department for Environment, Food & Rural Affairs, meaning the drugs can be disseminated widely rather than only to sick animals.

Public health and veterinary authorities do not have records of the doses of specific antibiotics given to livestock on farms. Additionally, investigators found that animal antibiotics can be purchased on the internet by anyone – no prescription needed. Furthermore, vets who prescribe antibiotics get paid for the prescription, leading to an inherent conflict of interest.

There is evidence that links certain antibiotic-resistant bacteria in human infections to drug use on farms, particularly in food poisoning illnesses including campylobacter, salmonella and E coli, as well as MRSA infections.

Public health experts around the world, including the WHO and the European Food Safety Authority, recognise that these increasingly resistant bacteria are being transmitted from farm animals to people through the food chain.

Farming bodies maintain that the drugs are necessary to ensure animal health and well being and are vigorously opposing attempts to curtail their use. They say antibiotics are administered responsibly and only where needed. Campaigners are now calling for stringent measures to restrict their use within farming.

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LIVERPOOL MEMBERS MEETING MARCH 2015

A member who attended the Liverpool Meeting kindly wrote a report on our forum pages to pass on to members who missed the meeting. It gives a really good idea of what our meetings are all about:

Liverpool Meeting Summary/Report by oweboyredw

Please note that I am a layman, if anything in this is clinically or medically wrong it will be my interpretation of my notes or my note taking rather than the presenter. Nothing in here is any form of recommendation - except attending future meetings.

Intro: CLLSA meeting at LACE, Liverpool 10-Mar-15

Another great meeting in a really good venue with Speakers from Liverpool and Christies (Manchester). I like the venue not because it is local but because it has good, free car parking onsite and if that's full oodles of parking on the street outside, set in leafy Victorian area of 'the Pool' next to Sefton Park. Admin was spot on as usual and attendance by four or five support organisations whom I'll not mention in case I miss someone. I talked to three of them. Registration and a few chats later over coffee then the day started. There was an excellent selection of good food on the buffet for lunch. During the meeting a number of new CLLSA Trustees were introduced and Arthur Graley announced that he was standing down, so this would be his last meeting as CLLSA Chair.

Session 1: Round tables.

This session gave small groups of people the chance to network, which is less onerous for many than big groups. Our group was seven and it turned out that three of us have the same consultant! I really like this part of the day because many of us don't meet other CLLers normally so don't get the chance to have a chat. If the other table's discussions were as interesting as ours it was a great start.

Session 2: Professor Andrew Pettitt - Introduction to CLL

Professor Pettitt covered the following areas:

Overview and Variability:

He described the incidence of CLL (5 per 100,000 population per year), 2:1 male to female, tends to be disease of older people (7th decade onwards). He explained the differences between blood samples for non CLL and CLL blood very clearly, including smear cells.

Diagnosis:

This included an excellent description of how flow cytometry works. Bone marrow - showed slides of non CLL and CLL and explained the differences. He also discussed other potential impacts such as the accumulation in Spleen, Liver and Lymph nodes.

Symptoms:

Being completely wiped out (commented that he has seen this as the no.1 symptom people describe), Sweating, Weight loss

Treatment:

Professor Pettitt said that no study has demonstrated early intervention helps. The aim is to prolong survival and to control symptoms. The focus for treatment depends on many things (such as age for example).

Professor Pettitt then covered Clinical Variability, Growth Kinetics, Doubling time, IGHV mutation status

Description of Normal B Cells:

Professor Pettitt talked about Genes and Proteins, structure of anti-bodies, Gene rearrangement process, signalling 17P/P53 deletion. Work is going on to improve understanding such as Next Generation Sequencing which improves analysis. He said that CLL has been selected in a pilot by Genomics England Ltd. It is set up to drive 'stratified treatment'

Session 3: Linda Boyne. Psychological effects of Cancer diagnosis

Linda started by introducing her back ground in nursing and her current role at Royal Liverpool providing counselling.

LIVERPOOL MEMBERS MEETING MARCH 2015

Many parts to the journey-

Medical history - treatments, impact to body, parallel emotional experience, complex minefield, remind medical staff there is a human in the middle, loss of patient identity, lack of social interaction (often fatigue driven),

Reactions - shock of diagnosis, can't believe and 'rush to treatment', watch and wait, emotions on hold
Flight, Freeze or Fight - Flight sometimes results in never seeing patient again. Best for flight and freeze to return to fight

Factors affecting how patients deal with things - previous experience of traumatic events, passing from pillar to post (I think this was in diagnosis), surrounding support structure, existing personal resources (might have been personnel resources), trauma on trauma - diagnosis followed by more bad news, watch and wait emotion

Importance of counselling - helps comply with treatment, chance to express feelings, emotions, frightened to discuss with GP or family, Discharging heavy emotions allows normalisation, counsellor to validate patient and identity

How Counselling helps -- offers space to let out what's being held in, look at coping mechanisms, supporting patients through relaxation etc. (addressing panic attacks and anxieties), peer group support, preparing patients to cope with procedures, lack of intimacy, reducing sense of powerlessness

Conclusion

Counselling should be available at all stages and Support groups are important.

Session 4: Dr Adrian Bloor. Update on advances in CLL Research & Treatment

Dr Bloor's presentation was very interesting and wide ranging and I was able to take notes on most of it while concentrating on the content. Dr Bloor started by reviewing current treatments, most specifically FCR which is the standard of treatment. Currently 50% treated with FCR last 5-6 years before progression. He briefly discussed the Go-go / Slow-go and No-go approach. He then went on to discuss the cumulative illness rating scale, Trials and treatments were discussed - (presented results and discussed the charts and how the demonstrated key information and differences)

Dr Bloor talked about treatment options that have been trialled in comparison Trials such as:-CLL11, FCR vs. BR first line trial, FCMR vs FCR (Admire) trial , He also covered Antibodies, Rituximab - been around since mid 90's, Ofatumumab, Obinutuzumab. Dr Bloor then discussed B Lymphocyte science - receptor signalling and how new drugs inhibit signalling in CLL cells. ABT-199 - different approach with this drug, rather than blocking signalling like other new antibodies this targets turning back on Apoptosis. Adrian referred to patient in UK, a very successful outcome so far.

Session 5: Andrew, Linda and Adrian - Questions to Panel A number of written questions started off the panel session. These were explored by one or more of the panel. This then led into a series of questions from the floor. Quite a wide range of questions including (but not limited to) hypertension, drug funding and counselling. During this session it was mentioned that Ibrutinib and Idelitasib+Rituximab are now both licensed however you can only have one of the two and cannot switch between them (current rules).

In his wrap-up speech Arthur said farewell as Chair and introduced his new replacement, David Innes. The next meeting is planned for Bristol during summer 2015 and then St Bart's in November 2015.

In summary: This was another excellent meeting. My test is always was it worth the time, cost and journey. Answer a resounding yes. Looking forward to the next meeting already.

2015 Treatment Update

Written for CLLSA by Dr Christopher Fox, Nottingham University Hospitals NHS Trust.

Over a relatively short time period a remarkable number of effective new therapies have been developed for patients with CLL. In some instances, these treatments have gained a marketing authorisation licence in Europe and, currently, some are funded within the NHS for patients who meet specific criteria. However, patients and clinicians should be mindful that this is a rapidly developing field that is likely to further evolve over the next year or two. Moreover, there are a number of further treatments, with different mechanisms of action, at various stages of development with promising efficacy and safety.

It's important to appreciate that award of an EMEA licence simply means that the safety and efficacy data for a given therapeutic agent have been approved by the European authorities for clinical use in specific disease stages/patient groups. An EMEA licence does not, unfortunately, translate into an agreed funding stream by the NHS (or other healthcare systems). Typically, an interval of time elapses between EMEA licence and funding approval by NICE. The NHS England funded CDF initiated in 2010 has, for some therapies, 'bridged' the period between licence and NICE approval. However, this is not consistently applied and, particularly given the rapidly changing therapeutic landscape, patients should discuss current licensing and funding issues with their CLL clinician. In particular, patients should be encouraged to ask their CLL clinical team about the possibility of enrolling into a clinical trial where many new agents are currently being evaluated and/or where existing agents are being combined together in an attempt to further improve efficacy.

The newly licensed agents can be broadly divided into two groups

Firstly, monoclonal antibodies that, like Rituximab specifically target B lymphocytes. There are a number of mechanisms by which Rituximab induces B cell death: 'direct' cell killing following engagement with the CD20 antigen; complement (an immune system protein)-mediated cell death; and cellular cytotoxicity (harnessing the patient's own immune system cells such as T and NK cells to cause B cell death). Akin to Rituximab, Ofatumumab is a so-called Type I anti-CD20 antibody, targeting a different part of the CD20 molecule, but causing cell death in a similar way, including complement-mediated killing. Obinutuzumab is termed a type II anti-CD20 MAb, that binds to the same B cell target but appears to cause more 'direct' cell killing (i.e. less dependent on immune system proteins known as complement). In terms of clinical data, Ofatumumab (Arzerra) has previously been used as a monotherapy for relapsed/refractory CLL whereas Obinutuzumab (Gazyvaro) has not previously had an approved place in CLL management. Both antibodies appear to be more effective than Rituximab, particularly when combined with chemotherapy. Arzerra is approved by the EMEA in combination with chlorambucil or bendamustine for patients with CLL who have not received prior therapy and who are not eligible for fludarabine-based therapy. Gazyvaro is approved in combination with chlorambucil for the previously untreated CLL patients with comorbidities making them unsuitable for full-dose fludarabine based therapy. These marketing authorisation approvals are based on large randomised clinical trials where the comparator arm(s) was/were Chlorambucil monotherapy (Arzerra) or Chlorambucil and Chlorambucil/Rituximab (Gazyvaro). In both the Arzerra and Gazyvaro studies, patients treated with these newer antibodies together with Chlorambucil experienced a significant improvement in progression-free survival (duration of response).

The second class of drugs that has changed the treatment paradigm for CLL patients are B cell receptor pathway inhibitors. In simple terms, these orally administered targeted kinase inhibitors interfere with cell signalling within the B cell and impair its growth and survival. Published data from clinical trials demonstrates impressive efficacy in patients with relapsed/refractory CLL, including those with high-risk disease. For such patients (eg those with p53 deletion), these BCR pathway inhibitors have revolutionised the treatment of a disease that was associated with a short survival time with conventional treatments. The two agents that are most advanced in development and that now have a marketing authorisation in Europe are Ibrutinib (Imbruvica) which is a BTK inhibitor, and Idelalisib (Zydelig), a PI3kinase inhibitor. Imbruvica is approved for the treatment of patients with CLL who have received at least one prior therapy, or in first line in the presence of 17p deletion or TP53 mutation in patients unsuitable for chemo-immunotherapy. For Zydelig, the approved indication is in combination with rituximab for patients CLL who have received at least one prior therapy, or as first line treatment in the presence of 17p deletion or TP53 mutation in patients unsuitable for chemo-immunotherapy. Both ibrutinib and idelalisib have an encouraging safety profile, typically with fewer side-effects than conventional immunochemotherapy treatments but the risk/benefit of any treatment for an individual should be carefully discussed with the CLL clinical team.

Fundraising

It's been another good season for all of our fundraiser's. There has been lots of running across the country and beyond! There were runners in London for the Vitality 10k, Scotland for the Edinburgh Marathon, across the water to Belfast for the Marathon there and another run, this time a very muddy one in Scotland! A great deal of the fundraising coordination was carried out by our trustee Derek who sadly passed away in July. I have tried to list everyone who has raised money for the CLLSA, however if I have missed anyone out let me know on coordinator@cclsupport.org.uk and I will make sure you are included in the next newsletter.

So the people we need to say a big thank you to are:

Elizabeth Craig who ran the Edinburgh Marathon and raised £266.25, Laurie Wilkinson who ran the Belfast Marathon and raised £182.75, Michelle and Daryl Hayes who participated in the Tough Mudder Scotland and raised £431.24 and Karthryn Corns who ran the Great Midlands Fun run and raised £277.50.

For the third year running we had members and their families and friends running in the London British 10k run for us. There were three main teams:

Team Wilkinson: Molly, Tom, Jack, Laura, Madeline, Alice and Lynette who raised £1309.53



Team Denby: Jen and Tim who raised £2382.50, plus an extra £260 from Jens employer, Towers Watson, who kindly matched their employees donations

Team Tobin: Sarah, Christine, Tom, Helen and Simon who raised £893



Christine Walker, the Lady Captain for Horsforth Golf Club has also nominated the CLLSA as her chosen charity for the year and kindly sent a donation for just over £200.

Well done to all involved and thank you for all the hard work you put into your events and raising money for the CLLSA. The grand total was £5743.53. This is enough money for us to hold a large members meeting, produce and send all members a newsletter and much more. Your fundraising really does help to bring our members together to support each other and raise awareness of CLL.

Personally this was my first experience of a running event as I joined in with the London 10k this year. I not only raised money for the CLLSA but also achieved a personal goal of becoming a regular runner. The day itself was so uplifting with 20,000 people all running for different causes. It was so amazing to see everyone running for charities close to their hearts. If you or any of your family or friends have ever thought about fundraising in this way I would definitely say 'go for it'. There were people of all ages, some running, some walking, some carrying fridges (a bit extreme I know!). The common factor was that everyone had a smile on their face, if not during the event then definitely at the finish line.

Sarah Tobin - Coordinator

New therapies made available to NHS to treat CLL

2014/15 saw a leap in the number of new therapies to treat CLL entering regulatory appraisal in the UK, as clinical trials of novel therapies reached their trial objectives. This placed some considerable demand on the CLLSA volunteer working group to provide input in many consultations to improve access to better treatments for our members. This commitment and effort by volunteers to share the patient group perspective and need has paid off.

It is with great pleasure that we are able to inform you of several positive results and new guidance issued by NICE, SMC and CDF that make new treatments available for NHS use to treat CLL patients across the UK. The addition of these new treatments provides many in hard to treat CLL groups with more effective treatments

Additions to NICE guidance for England & Wales NHS

1st line for those unsuitable for Fludarabine and Bendamustine

June 2015 - obinatumab in combination with chlorambucil for untreated chronic lymphocytic leukaemia <http://www.nice.org.uk/guidance/ta343>

June 2015 - ofatumumab in combination with chlorambucil or bendamustine for untreated chronic lymphocytic leukaemia <http://www.nice.org.uk/guidance/ta344>

NICE decisions pending for England & Wales

Previously treated

Sept 2015 - Final Appraisal Decision (FAD) expected - Idelalisib for previously treated chronic lymphocytic leukaemia. In the interim an early access programme is provided by Gilead for 1st line and relapsed refractory patients.

Additions to England national Cancer Drugs Fund (CDF) listings

Previously treated

Jan 2015 - Idelalisib plus rituximab for the treatment of relapsed chronic lymphatic leukaemia <http://www.england.nhs.uk/wp-content/uploads/2015/01/ncdf-summ-idelalsb-relps-cll.pdf>

Jan 2015 - Ibrutinib for the treatment of relapsed or refractory chronic lymphatic leukaemia <http://www.england.nhs.uk/wp-content/uploads/2015/01/ncdf-summ-ibrutnb-relps-rfract-cll.pdf>

These listings are currently under CDF review and may change

Additions to SMC Guidance for NHS Scotland

1st line for those unsuitable for fludarabine

May 2015 - The Scottish Medicines Consortium (SMC) has published advice accepting Ofatumumab for use in NHS Scotland to treat CLL

http://www.scottishmedicines.org.uk/SMC_Advice/Advice/1037_15_ofatumumab_Arzerra/ofatumumab_Arzerra

Dec 2014 - obinutuzumab (Gazyvaro®) is accepted for use within NHS Scotland.

https://www.scottishmedicines.org.uk/SMC_Advice/Advice/1008_14_obinutuzumab_Gazyvaro/binutuzumab_Gazyvaro

Previously treated and 1st line 17p CLL

March 2015 - idelalisib is accepted for restricted for use within NHS Scotland.

http://www.scottishmedicines.org.uk/SMC_Advice/Advice/1026_15_idelalisib_Zydelig/idelalisib_Zydelig

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New therapies made available to NHS to treat CLL

NICE appraisals ongoing

Previously treated

Sept 2015 – Appraisal commencing for Ibrutinib to treat CLL

Oct 2015 – Appraisal commencing for ofatumumab maintenance for relapsed CLL

More novel therapies in clinical trial will be entering the system soon. Thank you to all members who have volunteered information and experiences to aid with our submissions during the many CLLSA appraisal consultations this year and to working group volunteers: Tricia Gardom, Garry Bisshopp, Jackie Martin and Phillip Ash, for working on CLLSA submissions and travelling to attend many 2015 consultation committee meetings .

Nick York

Trustee and working group member.

Supportive Resources

2015 article written for CLLSA by Helen Knight, Chronic Lymphocytic Leukaemia Clinical Nurse Specialist at Nottingham University Hospitals NHS Trust. Helen is the first UK CLL specific Nurse Specialist

Diagnosis

Receiving a diagnosis of Chronic Lymphocytic Leukaemia can be a difficult time and a huge shock, especially if this was an incidental finding following blood tests for another condition or routine health check when you have otherwise had no physical symptoms and feeling well.

The name Chronic Lymphocytic Leukaemia can also cause a great deal of fear with many preconceptions as to what “Leukaemia” means and instant thoughts of long stays in hospital needing intensive chemotherapy and losing your hair. Fortunately this is **not** the case, and the way in which the diagnosis of CLL is explained at the beginning is very important.

This will be the start of a long journey and relationship between the patient and the Healthcare team.

The Healthcare Team

Once a diagnosis is made the patient will meet with their Haematology Consultant and will also be made aware of a Keyworker who will be the patients’ first port of call who will be available to the patient to speak to or meet to go through any queries or offer any support when needed. The keyworker will provide their contact details and will act as a constant point of contact for the patient. The keyworker can also signpost to other services where appropriate.

This in most cases will be a Haematology Nurse Specialist, based at the hospital. They should be easily accessible and provide easy ways to be contacted. In some smaller hospitals where there may not be nurse specialists available, the named keyworker could be the Haematology Doctor. In order to get the most out of the healthcare team, it is hoped that the patient will have the opportunity to get to know their keyworker and meet face to face as this will help build a relationship and give the opportunity to ask questions. Appointments during monitoring can be far apart and waiting until the next appointment to ask a question can cause unnecessary increased anxiety. Your keyworker should be happy to receive your call and create an environment where the patient feels able to approach and ask any questions and feel able to talk freely about their thoughts and feelings as further lines of support may be available.

Read more <http://www.cllsupport.org.uk/cll-sll/start-here/supportive-care>

Living Well with CLL

My First Cruise

I have wanted to go on a cruise for a very long time, however my husband, who has CLL, having spent 7 years as an engineer officer in the Merchant Navy wasn't keen.

Our daughter lives in Perth Western Australia and we visit every year. Last year I saw an ad. In the newspaper for a 16 day cruise sailing from Cape Town to Fremantle WA on the Queen Mary 2.

It was such a good deal that we just couldn't resist and we'd arrive in Australia with no jet lag!

We flew to Cape Town and spent two days doing all of the touristy things before joining the ship. Table Mountain and the Cape of Good hope were essential activities as the weather was glorious.

We joined the ship on our 3rd day amid absolute chaos. The luggage for almost 2000 people was like a mountain. Our stateroom with balcony was lovely and I was so excited, looking forward to the fun of leaving port with drinks and music.

I was so disappointed when a thick fog descended shortly before sailing. It was so bad the pilot didn't want us to leave but the captain said he didn't need to see where he was going.

Our first port of call was Durban and we arrived in pouring rain and gale force winds. Because of the weather we opted for a trip to a beautiful hotel called the Oyster Box for the most amazing afternoon tea we've ever had.

Our next port of call was Mauritius and thankfully it was sunny. We spent an interesting day there and finally sailed in sunshine with the band playing and drinks in hand.

The next 12 days were spent sailing across the Indian Ocean and we didn't see the sun again until we reached Australia, in fact it was so rough that the top deck was closed for several days. However the ship sailed serenely on. Just as well as my husband suffers from seasickness in rough weather.

Ignoring the weather we had an amazing time as there were so many activities that we had difficulty deciding which ones to participate in. I did a course learning about my I Pad and my husband enjoyed some of the lectures apart from several other activities. Dressing for dinner each evening especially the formal evenings was such fun and our table companions were very interesting. They were Irish, Scottish, South African and English of course.

We seemed to be eating such a lot of fantastic food that we tried to compensate by circling the ship several times a day. Three circuits were roughly a mile.

We arrived in Fremantle a day ahead of schedule to glorious sunshine at 6.30 in the morning and everyone was up early to see Australia.

We were sorry to leave the ship and our companions but this was overcome by our joy at seeing our daughter and we spent the next 7 fantastic weeks in Australia. Looking forward to our next cruise!!!

Andrea Cockburn - Treasurer CLLSA



March 2015 launch of the new CLLSA Website



Spring 2015 saw the new CLLSA website www.clisupport.org.uk go live. This was accompanied with updated content and new features added to CLL information to assist members gain access to current information and support to assist living with the challenges of CLL. This is hosted within a new website framework designed to be responsive to user technologies and expectations.

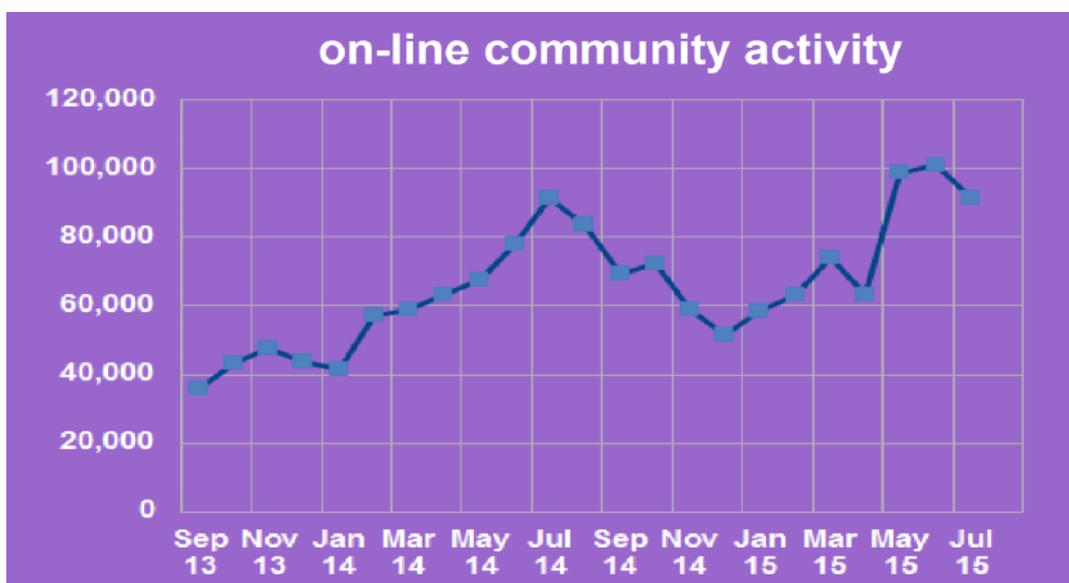
The new on-line platform enables members to self-update their membership profile, enabling them to register for CLLSA members meetings on-line and access new website facilities as they come available. If you have not already done this you can set your profile and passwords through the website www.clisupport.org.uk login.

During 2015 a contributor blog facility and member's forum will become active. This will improve user experience and enable greater sharing of information by contributors who can share their fundraising initiatives and stories. The new website also integrates well with the CLLSA on-line community where members provide on-line peer support.

The on-line community <https://healthunlocked.com/clisupport> has grown too, with members reaching 2,200 in August 2015. The period of May through to July saw the on-line community use reach record levels as 50% of members were active sharing latest information, questions, experiences and support. This has resulted in an incredible 500,000 page views so far this year.

Thank you to all volunteer members who have assisted in administrating, testing and supporting the development of these sites during 2014/15 and for your continuing support as we continue to improve these resources together.

Nick York.



Derek McGlashan RIP

It is with great sadness that we announce the death of Derek McGlashan, one of the CLLSA trustees.

Derek died on the 5th July at Nightingale House Hospice, Wrexham. Many members will have met Derek at meetings where he was always an attentive, friendly and cheerful presence, meeting and greeting and providing support, particularly for new members.

Derek was appointed as a trustee in 2012 and played a key role in the administration and organisation of the CLLSA as secretary. He was responsible for the logistics of patient meetings and the really positive feedback from members attending meetings in the past few years is a tribute to his determination to ensure that all would enjoy and derive maximum benefit from the days that we planned. His attention to detail, a skill developed through his long career in engineering, meant that the meetings ran efficiently; venues were comfortable and food was plentiful and of good quality (an important priority for Derek). He also succeeded in ensuring that costs were kept low as a result of his excellent negotiating skills with providers. He claimed that this came naturally as a result of his Scottish roots!

As secretary, Derek updated many of our policies and procedures to ensure that all of the association's liabilities and responsibilities as a charity are sound and robust. He also took on the responsibility of fund raising and you will have read his reports and updates on this aspect of his work over the past few years. Once again, his impact in this role was significant. Considerable funds have been raised through a broad range of events in which members and their friends and families have participated to support the CLLSA.

We will miss Derek's involvement at trustee meetings. He was always an active contributor and fully committed to our core purpose of supporting patients and carers, challenging the team to reflect on how we could improve.

We send our condolences to Margaret and family. Many of you will have met Margaret who was frequently at meetings with Derek supporting him in his work and taking on some of the administrative roles on the days.

Some members have asked if they can make contributions in memory of Derek. Margaret has requested that any donations should be sent to **The Nightingale House Hospice, Chester Road, Wrexham, LL11 2SJ.**

Arthur Graley - CLLSA

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 grant funding during 2015 to



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

www.cllsupport.org.uk

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