

Welcome to our latest newsletter, and I hope you find it informative and useful.



Message from the Chair

New Year's Greetings! In CLL Support's twenty-first year we will be building on our successes to date and developing new ways of supporting you and your families.

Our website, newsletters and bulletins will continue to keep you up to date with what is happening in the CLL and SLL world. Our Support ACT sessions, Under 60s WhatsApp Group, Helpline and the Health Unlocked Forum will be there to offer support. And our newly formed StaR (Studies, Trials and Research) Group will keep you abreast of new developments and with opportunities to help input to new research.

You will read below in this newsletter that we are already well advanced with the planning for our 2025 Conferences. The Trustees are continuing our tradition of putting on events right across the UK. No venue will suit everyone so as usual you will be able to join our four main conferences on Zoom if that works better for you. We will also be recording the presentations so you can watch them afterwards on our website or YouTube channel.

We are also expanding our programme of webinars. Alongside events that bring you scientific and medical insights we are also running a series of Zoom calls where members will be able to share experiences – something we know

our members really value. At the end of 2024 we held our first Zoom event for the Partners and Supporters of people with CLL or SLL and our first Breathe In Sing Out session where we were able to join in the singing as much as we wanted (while being suitably muted!). Both were very successful and will be repeated this year along with sessions aimed at other groups of our members. Do keep an eye out for the save the date notices and bulletins advertising these online events.

As ever we are here to provide you with the support you would find most helpful – do let us know if you have other ideas you would like us to think about or if you would like to join our team of volunteers.

With my very best wishes.

Hilary Lindsay

Chair, CLL Support

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This is the high season for Infections Check your Vaccinations

There are currently a number of infectious diseases circulating in the UK, so this is a good time to make sure you are fully vaccinated. Some of the most common infections are:

Influenza

Latest data from the NHS indicates that there is a high level of infection, and hospital admissions are rising rapidly, by about 40% week-on-week. The current strain seems to be particularly infectious.

Covid

Cases seem to be stable or declining, but if caught it can still be serious for immunocompromised people.

Respiratory syncytial virus (RSV)



This is a virus which affects the lungs and can lead to pneumonia. A vaccination is now available for people aged 75 – 79.

Norovirus

The NHS reports that the increase in norovirus activity has begun earlier than usual and remained high in recent weeks, particularly in adults aged 65 years and over. There is no vaccine against norovirus, but a trial for a new vaccine has started in the UK.

As always, the advice is: avoid crowded places if possible; wear a mask; wash hands frequently. Most importantly, check all your vaccinations with your GP.

You can find more information in our vaccination guide

here: <https://cllsupport.org.uk/information-support/further-information-resources/order-publications/>

'Please note: this information applies generally across the UK, but there may be some variations for devolved nations.'

Conference Dates - 2025

We are delighted to be able to release the dates and locations for our Conference programme for the coming year, although we are still working on some final details!

Date	Location	Keynote Speaker
April 3rd	Oxford	Prof Anna Schuh
May 31st	Belfast	TBC
Sept 25th	Manchester	Prof Adrian Bloor
Nov 27th	Newcastle	Dr Helen Marr

We are also looking to have a regional conference for members in the south west of England in Exeter in the Spring. As soon as arrangements are finalised we will advertise this event. Our Belfast event will be a joint venture with CLL Ireland, this will be the first in-person conference we will host with CLL Ireland since our last joint webinar during the pandemic.

Meet the Trustees - Peter Allen

I'm delighted to have joined CLL Support as a Trustee in 2024.

I was diagnosed with CLL at age 30 in 2001, which was quite a shock! With a one-year-old daughter, my wife and I were at a loss. The plan was to "Watch & Wait" (Active Monitoring), seeing my consultant every three months initially.



After about 18 months, a test for the IgVH gene mutation status put me in the 'mutated' camp—good news for prognosis at the time. This gave us the confidence to have a second child, and my son was born in 2003. For the next 20 years, we lived as best we could. My blood counts increased, but in 2012, they began to unexpectedly decrease. I had no symptoms and no treatment. My check-ups became annual, reducing to only when symptoms developed, which thankfully hasn't happened. I've been incredibly lucky.

At our recent Edinburgh conference, I was introduced to [The British Society of Lifestyle Medicine \(BSLM\)](#). They improve public health with evidence-based lifestyle interventions, focusing on six pillars: Healthy Eating, Physical Activity, Sleep, Mental Wellbeing, Healthy Relationships, and Minimising Harmful Substances. For example you may have seen specialists such as Professor Tim Spector talk about the benefits of eating a variety of plants. Ultimately, BSLM focuses on preventing non-communicable diseases (like diabetes and obesity) over treatment, encouraging everyone to lead healthier lives.

While no one knows, so far, why my blood counts improved, I believe lifestyle factors played a part in keeping me otherwise healthy. The BSLM provides proven techniques to support people to make and sustain healthy lifestyle changes. These can help us manage the physical and emotional challenges, wherever we are in our lives with CLL.

Understanding the Statistics

We totally understand why, when newly diagnosed, you seek out information about CLL and, hopefully, go to the more reputable sites such as ours. But no doubt you will go to multiple sources noting that many quote a mean survival time of 5 -10 years which for most of us gives the distinct impression we are life limited.

So, let's drill down on those figures, but please understand we cannot comment on individual cases.

The oft quoted statistic that 87% of those with CLL are alive 5 years after diagnosis always fails to qualify this by noting that the median age at diagnosis is 70 (yes, we do realise that many of you are much younger and in time the profile might change). It also leaves us wondering about the other 13%!

It is telling that there are no statistics on their cause of death, and it is reasonable to conclude that not all these are CLL related. For example, the likelihood of possessing two or more significant conditions is approximated to be 60% by the time men and women are between 75 and 79 years, and any one of these could contribute to life expectancy. So, treat these figures with respect but realise they are generalities based on historical data.

A great deal has changed recently in CLL treatment since the advent of BTK Inhibitors. There are many drugs available now for repeated treatments, sometimes with years in between treatments. One of our trustees has had CLL longer than he has not had it! And has had more than 7 treatments. Your medical team will give you a much more nuanced picture of your individual case. And remember with so many new drugs now and into the future, the treatment landscape is changing for the better creating new opportunities for longevity and wellbeing.

Edinburgh Conference



We held our final in-person conference of 2024 in Edinburgh on 7th November. We aim to hold one conference each year in a devolved nation and plans are already afoot to hold a conference in Belfast next year. The prestigious Royal College of Physicians (RCPE) was our chosen location and the history and ornate architecture of the building impressed all the delegates and speakers. Our keynote speaker Dr Gavin Preston - Haematology Lead at the Aberdeen Royal Infirmary - commented that he had actually done one of his exams in the Great Hall and just managed to arrive in time for the exam despite train cancellations on the day!

Some 45 delegates turned up with about 30+ on Zoom during the day. We had two fabulous patient stories; first up was Rory Williams who we had featured in a webinar during the pandemic with his wife Celia when they told us of Rory's Covid experiences. Rory's story is gritty but uplifting and he delivered it in his own endearing and engaging manner. Then husband and wife Troy and Marianne van-de-l'Isle related their individual perspectives on Troy's diagnosis and treatment. We know that this type of "double act" resonates with our members as it showcases the wider impact of living with CLL.

Dr Preston then delivered his talk on CLL and treatment pathways in Scotland with clarity and in terms that were easily understood by a non-medical audience. Gavin stayed on and answered many questions from delegates throughout the day.

Our lunch was bookended by the 'Two Annas' - Anna Clarkson Centre Co-Head at the Maggie's Centre in Edinburgh delivered an overview of what the

Maggie's Centres offer. It was appropriate to have a Maggie's slot at the conference as the Maggie's movement was born in Edinburgh and the subsequent success is testament to the lasting legacy left by Maggie and Charles Jenks.

Then Anna Baker told us about the benefits of exercise and even had the delegates undertaking some gentle exercise - a great antidote to the post lunch slumber! Our final presentation delivered by CLL Support Chair Hilary Lindsay provided an overview on our 20th anniversary programme and the Association's work and achievements during the year.

The conference finished off with the all important and ever popular Round Table discussions where delegates had the opportunity to discuss various topics and share their coping strategies.

Footnote: Holding the conference at the RCPE meant that of our four conferences this year, three were held at venues run by Charities (RNLI, King's Fund and RCPE) - this is a particularly appropriate use of our funds and underpins our aim of supporting a circular economy.

[Click here to view the Edinburgh Conference recording](#)

A message from a patient speaker at Edinburgh - Rory Williams

When I was asked to do a continuation of my patient story, I didn't think I would have much to say. But then on reflection I realised just how far I'd come in the last 7 years. The biggest thing is I'm no longer scared of having CLL.... it's just part of my life, with more emphasis on the word Life. So in a funny way CLL has enriched my way of living. I'm not saying I don't have any worries or middle of the night "What If" moments before a scan. But what I am saying is, I enjoy and appreciate things because I can, rather than thinking I used to be able to do this or I should be able to do that. When

I tell people I think of myself as lucky I often get weird looks, but I have a supportive and very patient wife, fantastic friends and neighbours and I've 2 lovely young dogs



who are always pleased to see me. I live in a lovely little croft and enjoy walking in the green spaces of Scotland and watching the sunsets and sunrises with the wind on my face.

So, I thank you CLL Support UK for giving me the opportunity to waffle on about my CLL patient journey in such an amazing venue surrounded by amazing people.

I'm currently halfway through my treatment journey of Obinutuzumab and Venetoclax and so my journey continues

We asked, you said, we did

Feedback from the round tables at Edinburgh – 7 November 2024

What I wish I'd known back when I was diagnosed?

- There is no need to think as negatively as I did for the first month or two
- Before a blood test think about wearing handwarmers and drink lots of fluids – this all makes the tests go better.
- Wear headphones if you don't want others to approach you or talk to you in the hospital or surgery – whether they are plugged in or not!
- Use your diagnosis as a second chance: re-evaluate what matters to you in life

What would you say to someone newly diagnosed?

- Read as much as you can from informed sources
- There are many new and very effective treatments
- Give yourself time to decide who to tell about the diagnosis
- There are no stupid questions
- Find someone to talk to
- Take someone with you to any appointments
- All you can do is deal with the stuff you can deal with
- **Join CLL Support**

What gives you energy or drains you of it? What do you do about it?

- Everyone was inspired by the talk from Dr Anna Baker – we have since heard that some delegates signed up to their local gym the next day!
- Have the right amount of exercise – not too much and not too little – you want to be energised, not exhausted
- Try to balance things out: try not to overdo it on the days you feel less tired
- Be kind to yourself
- For some an afternoon nap works wonders
- Do what brings you joy (walking outdoors, photography, travel, hobbies, whatever are your interests and passions) – it's so important not to lose the joy of living in the fear of dying.
- Prioritise what you need to do – try not to get your personal battery too run down
- Set achievable goals for anything you are doing
- Getting jobs done gives a sense of achievement
- Remember you are what you eat
- Working in a team can really help

Help our Clinical Nurse Specialists (CNS)

Lianne Palmer (CLL CNS, Oxford) and Helen Knight (CLL CNS, Nottingham) met nearly 10 years ago at a study day in Manchester. They were, at the time, the only two CLL specific nurse specialists that they were aware of in the UK. Since then, the number has slowly increased and they decided to create a CLL Nurse Forum for like-minded nurses to join together and share their ideas and problems, and form a group that could meet regularly and act as a support team for each other. They now meet virtually twice a year and aim to meet face to face once a year with guest speakers and the opportunity to pick each others' brains. They would love to keep expanding and would like to ask for your help. Do you have a nurse specialist? Are they aware of the UK CLL Nurse Forum? Would they like to join the Forum? If so, please feel free to pass on Helen and Lianne's contact details so your Clinical Nurse Specialist can find out more. helen.knight21@nhs.net and Lianne.Palmer@ouh.nhs.uk

In Memory of Andy Taylor

The Trustees are very sorry to report the passing of Trustee Andy Taylor.

Andy contracted Covid. The Trustees had been looking forward to many years of working with Andy and were extremely upset to hear of his passing. Our thoughts are very much with his family.



Andy was diagnosed with CLL in 2007 but did not need treatment until 2022. He had found the CLL Support newsletters and then the online webinars during the covid period particularly helpful and, as a retired accountant, took note of the requests in the newsletters for assistance with the charity's accounting. A repeat of the request at an in-person conference he attended in Cambridge prompted him to offer to help the charity that had been helpful to him.

Andy became an associate in 2023 in order to shadow the then treasurer, Frank Mercer, and became a full trustee in the latter part of the year, taking over Frank's role at that point. Apart from assimilating the various treasurer's tasks, one of his main involvements was to lead a small team implementing a cloud-based accounting system, which now forms the basis of trustee information about the charity's finances.

In the short time we Trustees knew him, Andy's technical skills had been much admired as were his kindness and patience. The more we had got to know him, the more impressed we had become. He was totally engaged in the CLL Support work and really interested in everything we did.

Andy contracted covid in the autumn and, tragically, never recovered from it despite the medical team's best efforts, eventually succumbing to covid pneumonitis.

Support ACT - New Sessions Coming UP

Support ACT - Acceptance and commitment Therapy

Just a reminder that the current round of Support ACT group drop-ins will be continuing until 18th March. These sessions are becoming more and more popular, and we have also been welcoming an increasing number of couples over recent months.

Session	Topic	Thursday mornings 10am	Tuesday evenings 7 pm
4	Being present	2 nd January	21 st January
5	A meaningful life – reconnecting with my values	6 th February	18 th February
6	Doing what matters	6 th March	18 th March

Please do get in touch by email – cherry.mills@cllsupport.org.uk if this is something that would be of benefit to you or someone you live with. We just need the following details from each applicant: name, email address, mobile phone number, date of birth and where you first heard of Support ACT.

Priority will be given to new applicants and those who have missed sessions in previous rounds. If we receive more applicants than there are places, we will add you to our waiting list. We look forward to welcoming you to one, or more, of our Zoom sessions.

Come fly with me....

At this time of year Holidays are on a lot of peoples' minds and travel insurance is always a hot topic on the CLL support helpline and Forum. It can be difficult to find affordable insurance as CLL is an often misunderstood condition to

those who do not have a medical background.

Here at CLL Support we cannot endorse any brands or companies as all cases are individual, however as a collection of patients, supporters and families we can all share our useful tips and experiences to benefit others in the same situation.

On our website we have collected a list of insurers that have been recommended to us by members. You can find it by clicking [here](#)

We recently heard from a member about a radio programme that she found helpful:

I wanted to share this radio programme with you which interviews the founder of Insure With travel insurance. <https://www.bbc.co.uk/sounds/play/m0025l21> I was really impressed in the summer with their screening process when I applied for travel insurance. They arranged for a clinician to phone me, and he clearly understood CLL and as a result of his targeted questions I got a very reasonable rate. It was cheaper than two other companies I tried, and it was the only company that got a clinician to speak to me. I found it a very positive experience and felt there was no hard sell.

Anna

We would love to be able to add to our list of insurers to give everyone a wide range of choice when searching for travel insurance. If you have recently contacted any companies that have come up with a good deal and excellent customer service (especially those similar to the above where a clinician who understands CLL is involved in the process) please let us know by emailing membership@cllsupport.org.uk

Just to reiterate, we do not endorse any companies. We are just sharing positive experiences with the hope of helping others.

20th Anniversary Campaign



The final total for fundraising during our 20th Anniversary campaign is a truly fantastic £33,581.20 which includes Gift Aid. Thank you so, so much on behalf of all of us at CLL Support to everyone who donated or fundraised for us – you helped us to smash our original target of £20K. You are all amazing.

[Click here to read our latest fundraising news](#)

Newly diagnosed?- We'd like to hear from you

A PhD Student in Sheffield is doing a research project on the experiences of people who have been newly diagnosed and on active monitoring.

If you are interested in participating and live near Sheffield, all that is required is two interviews about six months apart and for you to complete a diary between the interviews. For more information see the link below.

[Click here for further details](#)

Partners and Supporters Webinar

Hilary, Colin, Gail and Cherry were delighted to see so many people at the first 'Partners and Supporters' Webinar that took place on the 18th November 2024. This was part of our 'We asked, you said, we did' program. The team are

busy reviewing all of the feedback from the first session and will be holding a second session on February 17th. Keep an eye on your emails.

Breathe in Sing Out

On Tuesday 3rd December, we held a zoom 'Breathe In Sing Out' session. We had no idea how many people would join us and were delighted when over 40 people logged in. Kirsty, the vocal practitioner who led the session used an engaging mix of warm ups, vocal exercises and singing. As the rest of us were muted there was no worry about what sounds we were making!

Singing is not only good for lung health but also for wellbeing and this was reflected in the feedback: "*I felt very uplifted and relaxed after the session, I haven't smiled much today so it was a lovely and positive way to finish my day. Wonderful!*" "*Really enjoyed this session, I can feel my chest has opened up*". Many of you asked for more sessions like this and so we are planning to have another in the spring. Watch out for an email.

FLAIR and STATIC Clinical trials update

"An Incredibly reassuring webinar, sincere thanks to all presenters." This was the feedback from one of the 100+ attendees at our update webinar on November 26th, where we heard from Principal Investigator Dr Tal Munir, Professor David Allsup, Lelia Duley and Trial Manager Rhiannon Lambkin.

Recordings of the presentations can be found at:

<https://cllsupport.org.uk/conference-reports/static-and-flair-trial-update/>

and there is now a website dedicated to bringing you news about the STATIC trial: <https://ctr.u.leeds.ac.uk/static/>

We will hold further webinars when there is more news to share.

Could you be our next Treasurer?

Following the very sad passing of Andy Taylor, mentioned earlier, we are now seeking to recruit a new Trustee Treasurer. The Trustee Treasurer leads our small finance team. Following the move to a cloud-based accounting system. Cherry Mills, a member of our support staff records transactions and the role of Trustee Treasurer is now much more of an oversight one. If you are a retired accountant and have some time to spare, we would be very pleased to hear from you. To discuss this further please contact our Chair Hilary Lindsay (also, coincidentally, a retired accountant) at hilary.lindsay@cllsupport.org.uk.

Can you help please?



Please can you share your CLL story?

For those who attend our conferences, an undoubted highlight is one of our members sharing their CLL story. People find it enormously encouraging to hear how others coped with their CLL, and to know they aren't alone.

We need people to step forward and tell their CLL stories so that we can feature them at our conferences and in our webinars. If you can't attend in person, we can video you at home.