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Newsletter

April 2025 - Issue No 07

Our free helpline: 0800 977 4396

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

Message from the Chair

Welcome to Spring! We at CLL Support celebrated it by having our first conference of the year in Oxford. As ever an informative, inspiring, and encouraging event. We will be sharing the recordings with you as soon as we can.

We do hope you are taking advantage of the weather to get out and about – but in doing so do keep your vaccinations up-to-date, try and avoid people with infections (there are a lot of them about at present) and take care when travelling. We have included information and tips to help you with all of these.

As well as looking after yourselves, we hope you might also be interested in helping the wider CLL and SLL Community.

Patient and Public Involvement and Engagement (PPIE) is becoming increasingly important and our newly formed StaR (**S**tudies, **T**rials **a**nd **R**esearch) Group, is helping us contribute in this area. We have now launched our PPIE Register which you can read more about. Please sign up if you are interested in helping.

Finally, we are wondering if you know an Accountant who can help us. We are looking for a Trustee Treasurer. This could of course be someone with CLL or SLL or their partner, but do please also look around your friends and contacts and see if there is someone there who might be willing to help. We are always impressed by how many people fundraise for us because they have close links to a person with CLL. We are now hoping there might be someone keen to help by giving their time and becoming our Trustee Treasurer. There are more details below.

Our very best wishes to you all. 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.

Enjoy the Spring!

With my very best wishes.

Hilary Lindsay

Chair, CLL Support

hilary.lindsay@cllsupport.org.uk

Launching the CLL Support PPIE Register

At the end of our last year's survey, a significant number of you indicated an interest in volunteering to help with any research or studies that could improve the care of people with CLL or SLL. We are very excited to let you know that, in response, CLL Support is creating a Patient and Public Involvement and Engagement (PPIE) Register to enable us to contact members about specific opportunities where they might be able to help.

The PPIE Register will enable CLL Support to advise you about:

1. Opportunities to become involved in discussions around research activity;
2. Opportunities to become involved in PPIE activities related to CLL or SLL;
3. Requests from Pharmaceutical companies and other organisations who wish to collect information / opinions from patients and / or their partners and family members.

Your data in the PPIE Register will be held within CLL Support for these purposes only and will not be circulated to 3rd parties without your permission. Please note that CLL Support only works with Pharmaceutical companies who are providing or developing treatments for CLL or SLL.

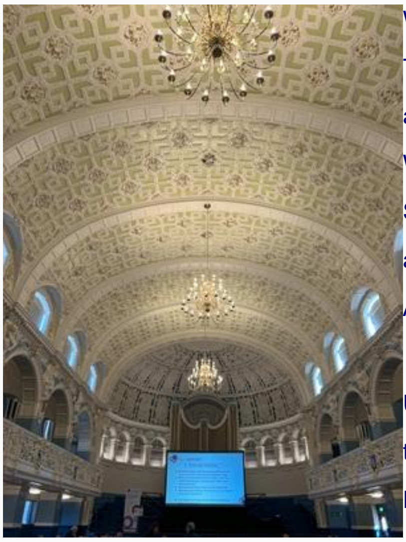
If you would like to join the register, could you please click here to record your answers to a short list of questions. If at any time your circumstances change, you will be able to update your preferences by revisiting the link to the PPIE Register and resubmitting your answers.

We must stress that by joining our PPIE Register there is absolutely no obligation to take part in any of the opportunities that may arise. Please note that we will **not** be sharing opportunities to join specific clinical research trials – to find out about these you should talk to your medical team or visit the website of the UK CLL Forum. Whether you sign up to the PPIE Register or not, we will be sharing updates about PPIE-related activities we have been involved in through our newsletters and bulletins.

Hilary Lindsay, Chair of Trustees

Join our PPIE register here

Oxford Conference 3rd April 2025



We held our first in-person conference of 2025 in Oxford on Thursday 3rd April. Some 65 delegates attended on the day and approximately 50 people logged in on the live stream over Zoom. We were privileged to have as our Keynote Speaker Prof. Anna Schuh from the Oxford University Hospital Trust. Anna was also accompanied by two Clinical Nurse Specialists; Lianne Palmer and Ana Vieira.

Unfortunately due to technical difficulties at the venue - mainly due to a 'flaky' WiFi internet service- our live stream was interrupted. However we have recorded all of the talks and they will soon be available to view on our website and YouTube channel.

Prof. Schuh delivered an engaging and fascinating presentation covering many aspects of CLL from diagnosis to treatment and beyond, even touching on the possibility of a cure due to ongoing research. Prof Schuh also illustrated her work in Tanzania and the challenges faced by both patients and clinicians in Low and Middle Income countries. A lively Q&A session followed and Prof Schuh engaged directly with many of the delegates over the lunch break. Our Chair Hilary Lindsay delivered an update on our StaR (Studies, Trials and Research) Group activities and it underpins CLL Support's advocacy efforts on behalf of our members: "No research about us, without us". The two CNSs, Lianne and Ana, then presented an informative overview on the role of the CNS and how they engage with CLL patients, their Care Partners and the wider medical team. Both Ana and Lianne were in attendance all day and spoke personally to many of the delegates - which was really appreciated judging from the delegate feedback.

Our next event is a regional conference for those in the South West of England in Exeter on 13th May and we will then jointly host a conference in Belfast on Saturday 31st May (which we hope to live stream subject to overcoming any technical challenges- fingers crossed!).

Live Vaccinations & Spring Vaccinations

Many of you will be aware that people with CLL/SLL (and those that they live with) should avoid contact with live vaccines. This includes having the actual injection, avoiding contact with those who have recently received a live vaccine and also, avoiding pets who have received a live vaccine. It's advisable to avoid anyone who has received a live virus vaccination for at least a week.

Children’s flu vaccines are generally live unless you specifically ask for a non-live vaccine, in which case they will be given it via an injection rather than nasal drops.

With regards to your pets, always check with your vet at the time of making the appointment. Kennel cough is normally a live vaccine therefore those who are severely immunocompromised, or members of their household, should be cautious about their pets having the KC vaccine. The main vaccines are non-live but do always check with your vet first. As with the children’s flu vaccine, live vaccines are usually given nasally.

We have also received news about a new chickenpox vaccine which is being offered. This is a live vaccine so should be avoided.

You can find our helpful guide to vaccinations on our website here

The latest news on the Spring vaccination campaigns:-

NHS England booking is available from 25 March and the programme will run from 1st April- 17th June.

NHS England » Preparing for a successful spring 2025 COVID-19 vaccination programme

NHS Wales programme for vaccinations runs from 1st April to 30th June

COVID-19 spring vaccination programme 2025 (WHC/2024/047) [HTML] | GOV.WALES

There are no updates for Scotland or Northern Ireland as yet on the Spring 2025 vaccine programme but keep an eye on the following websites for news:

Scotland Public Health Scotland   Northern Ireland Welcome | HSC Public Health Agency

Do you have a CNS? If you do, please help!

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 other’s 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

Help us to find our next Treasurer

Do you know an Accountant who could help us?

We need to recruit a Trustee Treasurer to lead our small finance team. Following the move to a cloud-based accounting system Cherry Mills, a member of our support staff, records transactions and we also have external support so the role of Trustee-Treasurer is very much an oversight one.

As a patient-led organisation, our trustees usually either have CLL/SLL or are the partner of someone who is so affected. However, for this particular role, we feel that sympathy with our aims and relevant experience are more important than having personal experience of CLL or SLL.

If you might be interested, or know someone among your contacts who might be, we would be very pleased to hear from you. Please contact our Chair Hilary Lindsay at hilary.lindsay@cllsupport.org.uk.

The YORVIK Vikings

Jezz and Lynn Booker are both members of their local Triumph Owners Motorcycle Club. They are keen Triumph enthusiasts, and each have their own motorcycle. Each year their club chooses a charity to raise both money and awareness. This year the club has chosen to support CLL Support.

Their club has over 200 members and meets regularly for ride-outs, coffee and cake, and other regular events. Their first event is a 'Bike Season Opener' hosted by The Motorist, Leeds and is scheduled to take place on 12th April. The Motorist is a fantastic place if you like cars and anything with wheels that goes fast or slow. Sounds like a great event if you're in the area.
The club has numerous other events planned throughout the year: Charity and Curry night in their local pub, 'Race the Waves' in June on the beach and Yorkshire Day which will include a brass band/raffle and cake.

Jezz and Lynn joined CLL Support last April when Jezz was diagnosed with CLL at the age of 57 following a routine blood test. He is currently on Watch & Wait (Active Monitoring) and is having blood tests every 12 months. Jezz and Lynn have found the support that our charity has provided to be welcome, invaluable and extremely supportive. They wanted to show their appreciation by providing an opportunity for fundraising and raising awareness.

For those of you who would like to support Jezz and Lynn, please click on the link to their JustGiving page below:
https://www.justgiving.com/page/yorvikviking-cllsupport?utm_medium=FR&utm_source=CL

At the time of writing, they had raised £1,315 of their £8,500 target. We will keep everyone updated during the year as to what they are doing and how they are getting on. All of us at CLL Support are very grateful for their support and are looking forward to hearing about their various events.

CLLAN

The Chronic Lymphocytic Leukemia Advocates Network (CLLAN) commissioned Picker to examine diagnostic pathways, immunity status, and treatment decision experiences of people with CLL using data from the 2023 Global Leukemia Experience Survey.

Read the full report here

What is Sepsis?

It is vital that everyone is aware of Sepsis and it's signs and symptoms. Read our guide to sepsis here

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Webinar Round-up

We have held a wide range of webinars over the last few months aiming to address different topics so that there is something for everyone:

Exercise Webinar
Advances in our understanding of CLL - derived fatigue was the subject of our January webinar. Dr David Bartlett of the University of Surrey shared how exercise can counter fatigue and other symptoms. Ellie Miles discussed targeting premature frailty and physical dysfunction in CLL, and also shared an update about the HIT-CLL study. Patient speakers were Charles Monroe and Louise Scott who shared their inspirational experiences of taking part in the HIT-CLL study. An

audience of over 200 enjoyed the webinar. If you missed it or would like to watch it again it can be found on our YouTube channel here or website here

Partners and Supporters

We held our second session on Monday 17th February. Jamie Ayers and Marianne van de I'Isle gave us their stories after a short introduction from our Chair Hilary Lindsay. It was a great turnout with plenty of interaction following our speakers. Lots of new faces and some that we had met before. We hope to have our next session in the next few months. This will be advertised via our bulletin email nearer the time. As the sessions are primarily aimed at those who have a partner or family member with CLL/SLL rather than having the illness themselves, future sessions will be known as 'Partners and Family of someone with CLL/SLL'.

Breathe in Sing Out

After an introduction from Anthea Holland, one of our trustees, vocal practitioner Kirsty Abraham led the session beginning with some warm-up exercises as it's important to be relaxed. This was followed by vocal exercises and stretches before the singing started. The group had two songs (And When I Rise by Penny Stone and Don't Worry Be Happy by Bobby Ferrin) building on the various sound elements. The group were encouraged to stand (and dance) if they wanted to and sing out loud (we were all on mute). A great session enjoyed by all who attended. Remember, singing is not only good for lung health but also for well-being. There's been some great feedback, thank you to those who have been in touch.

Consultations Webinar

We held a three part webinar on the subject of Getting the Most out of your Consultations on 11th February. The format consisted of an open discussion between Vice Chair John Greensmyth and Prof David Allsup, Dr Andrzej Frygier and Deborrah Reed of the Hull University Hospital. The webinar was split into three sections; Initial consultations, Active Monitoring period and Approaching Treatment. In each section the participants discussed the key aspects that would allow People with CLL, their Care Partners and Clinicians to gain the most benefit from theses discussions. Questions from the delegates were answered during the webinar and three separate videos of this webinar are available on our website and YouTube channel here

Men’s Network

Our latest membership survey highlighted that we needed to get in touch with the men in our community to make sure that they had a place that they felt comfortable within to discuss their issues and needs. Our team of male trustees consisting of John, Peter and Troy held a webinar for men which was a great success with many joining in to share their experience and insight into life with CLL from a male perspective. This was the first session and the trustees hope to hold more sessions in the future building on what they learnt from this first event.

Benefits of Pausing BTKi

One of our Associates, Lelia Duley has been involved in a study on the Benefits of pausing BTKi's (Bruton tyrosine kinase inbitors) when having a Covid 19 Vaccination. Some examples of BTKis include ibrutinib, acalabrutinib, and zanubrutinib which many of our members take at present.

Read the full BTKi article here

You can also read a plain English summary of the article here

London Marathon 2025

Matt Gibson is running in the London Marathon on Sunday 27th Apr il 2025. London Marathon places are notoriously difficult to obtain as a small charity so we were delighted when Matt (a CLL Support Associate) was allocated a place via the public ballot and chose to fundraise for us.

Matt started running in 2018, the year following his diagnosis. He was treated with FCR and Running became very important to him as a way of protecting his physical and mental health. Matt even "competed" in a half marathon virtually while he was shielding prior to returning to work. He has a challenging training plan and he hopes to beat his last time of 4hrs 7mins.

Matt is running the London Marathon with a school colleague and together they will be holding a Bring and Buy Book sale and a quiz.

If you would like to show your support and sponsor Matt, his fundraising link is: https://2025tcslondonmarathon.enthuse.com/pf/matthewgibsoncllsupport

On behalf of everyone at CLL Support, and our members, thank you Matt for supporting us. Also, a huge thank you to those who have supported Matt with his fundraising – at the time of writing Matt’s fundraising total was £1,331 of his £2,000 target.

Tina's Story

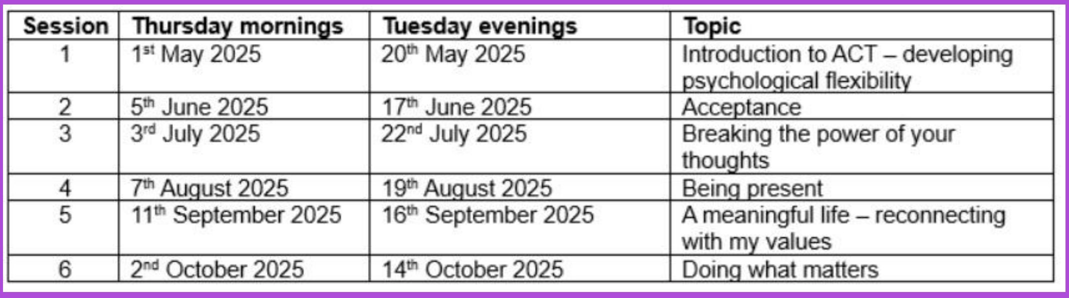
My story, so far, starts in the spring of 2018. After feeling unwell for quite a while and unable to shake off a nasty virus, I had some blood tests done by my GP surgery and the results showed I had some form of leukaemia. I was then referred to a haematologist, who within a short space of time confirmed that I have CLL......................

To read Tina's full story click here

Support ACT

We would like to take this opportunity to say thank you to the Yorkshire Building Society Charitable Foundation for their very generous donation of £2,160 towards the Support ACT sessions – our next series starts soon (see below).

DATES FOR YOUR DIARY - NEXT ROUND OF SUPPORT ACT



Session	Thursday mornings	Tuesday evenings	Topic
1	1st May 2025	20th May 2025	Introduction to ACT – developing psychological flexibility
2	5th June 2025	17th June 2025	Acceptance
3	3rd July 2025	22nd July 2025	Breaking the power of your thoughts
4	7th August 2025	19th August 2025	Being present
5	11th September 2025	16th September 2025	A meaningful life – reconnecting with my values
6	2nd October 2025	14th October 2025	Doing what matters

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.

If you are not familiar with Support ACT, please have a look at our website:
https://cllsupport-act.org.uk/

Life after a CLL diagnosis can be a roller coaster of intense highs and lows and unexpected twists. It feels like the ground you are on becomes shaky and the bottom drops out. Shock, disbelief, fear and anxiety take over as you face the unknown. Navigating the roller coaster is tough but you are not alone. We offer 1:1 support for members of CLL as well as our bimonthly drop-in sessions. Seeking support aids your body in responding better to your treatment and helping your immune function to work better.

For more details, contact Cherry Mills: cherry.mills@cllsupport.org.uk

Fundraising News

On behalf of all of us at CLL Support, thank you to all of our fundraisers, supporters and donors. It's only April and already the fundraisers alone have raised just over £5,500 including Gift Aid. We are really grateful to you for this support as it will help us to continue to support people with CLL/SLL and their families.

If you think you might be able to fundraise for us, please get in touch for a fundraising pack. There are so many ways that you can fundraise. You could hold a coffee morning, a book sale, garden plant sale or you could take part in an event like one of fundraisers mentioned in this newsletter.

Not forgetting that your donations, both regular and one-off, help us to continue to support people with CLL/SLL and their families. For those eligible for Gift Aid, your donations are worth 25% more.

To get in touch, please email: cherry.mills@cllsupport.org.uk

Michelle Brotherton will be doing a skydive on 12th July to raise money for CLL support which helps people who are diagnosed with chronic lymphocytic leukaemia.
A very good friend of Michelle has been diagnosed with CLL after spending many years of her life selflessly and lovingly caring for her husband who had Dementia. She would like to show her support for her friend by doing the skydive and raising awareness of CLL. In Michelle's words: "What better way to raise money than for me to jump out of a plane!".
If you would like to support Michelle, please find the link to her JustGiving page below:
https://www.justgiving.com/page/michelle-brotherton-3?utm_medium=FR&utm_source=CL
At the time of writing Michelle had raised £215 of her £500 target.
All of us at CLL Support would like to thank Michelle for taking on this amazing challenge and for fundraising for CLL Support.

Katie Savino fundraised for us last year during our 20th Anniversary campaign. She has now completed the Paris Half Marathon in 2 hours and 49 minutes. Katie said she had an amazing day running the amazing course with 75,000 other people. Katie ran the Paris half for her dad, who is currently undergoing treatment for CLL. She wanted to show support and raise awareness by fundraising for CLL Support. She has smashed her £1500 target and raised £1668 to date. Thank you Katie!

If you would like to sponsor her, please click on the link below:
https://www.justgiving.com/page/katie-savino-paris-half?utm_medium=FR&utm_source=CL

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.

Everyone's story is relevant. Do you perhaps have a hobby or job that would help to show how you have managed with CLL? You can do this with a partner, or indeed your partner can tell their tale. Have a look at how other members have told their story:

Sue and Elizabeth's story

If you are happy to share your story for a few minutes, we'd love to hear from you. You would be helping other people with CLL.
Please email: john.greensmyth@cllsupport.org.uk

HealthUnlocked

HealthUnlocked is our very active on-line forum, where you will find support and knowledgeable, reliable advice on all things to do with CLL. The site also has a very comprehensive resource of CLL information, which is updated regularly, and is moderated by our team of Administrators and Volunteers. You can check it out here:

HealthUnlocked

Any thoughts?

We would love to hear from you with any comments (good, bad or indifferent).

CLL Support is a members' charity, which means it really belongs to you, our members, and the trustees work on your behalf. So your thoughts and suggestions are important.

You may have a story to tell which could help other patients. We welcome contributions of up to 500 words, so do let us know if you have something to say. We can't promise to print everything, but we always try to.

We would like to make this newsletter more interactive, if possible, so please tell us about anything that's on your mind that could help other members.

You can contact us at membership@cllsupport.org.uk

We look forward to hearing from you!
