

Newsletter

August 2025 - Issue No 08

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 Summer! I do hope you are managing to keep cool enough and protected from the sun while enjoying this glorious weather.

The spring saw us have two more really successful conferences in Exeter and Belfast, the latter jointly with CLL Ireland. You can read more about them below. Do make a note that we will be in

Manchester on 25th September and Newcastle-upon-Tyne on 27th November. And we are already beginning to think about our 2026 programme – time never stands still at CLL Support!

We're also making a small change to how you sign in for our webinars. If it's a medical webinar, for example bringing you more news about clinical trials, we will share the link and anyone can sign in on the day. However if it's one of our more personal calls on Zoom, so for example our sessions for partners and family members, where you can all see who is on the call, we've decided it would be better for everyone if we asked you to register for those events and we will then let you have the link. We'll make it very clear what you need to do when we share the event details.

Finally we wanted to say thank you to Mr C A F Hanmore who sadly is no longer with us but who left us a share in his estate totalling £63,864.89. We are just so grateful for such a generous gift and, indeed, for all your contributions and fundraising endeavours that enable us to continue to provide support for our CLL community.

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 Summer!

With my very best wishes.

Hilary Lindsay

Chair, CLL Support

hilary.lindsay@cllsupport.org.uk

We've achieved the PIF Tick 'Trusted Information Creator' accreditation

Trusted Information Creator

Patient Information Forum

This year we've been assessed by the Patient Information Forum who have looked at how we meet their 10 key quality criteria. This ensures the information we provide to you has been through a rigorous process

and has been assured by our world-leading CLL specialists.

Wherever you see the PIF Tick kitemark on our information you can trust that what you're reading, watching, or listening to is evidence-based, up-to-date and easy to use and understand.

Peter Allen, our vice-chair of CLL Support said: "Earning the PIF Tick validates our commitment to providing reliable health information. With so much conflicting information online, this quality mark gives patients and families confidence that our resources at CLL Support are accurate, evidence-based, and trustworthy."

We join other respected charities such as Leukaemia Care and Lymphoma Action listed on the PIF Tick register as a 'Trusted Information Creator'.

Improving support for CLL patients during active monitoring

Recently our Vice-Chair, Peter Allen made a film with the CLL Advocates Network and BeOne about his experience of living on Active Monitoring. When Peter was diagnosed with CLL in 2001 the term used was 'Wait & Wait', which in itself created anxiety, and didn't offer much support for the emotional challenges he and his family faced.

CLL Support have been working with CLL Advocates and BeOne to improve understanding and support for people living on what we now call, 'Active Monitoring', a term that comes with a better strategy for managing the challenges. There are three main areas of this strategy we're supporting improvements in:

Better Communication Between Doctors and Patients

Many patients report that their medical teams aren't always well coordinated, leading to mixed messages and confusion about Active Monitoring. The solution involves training healthcare providers to listen more carefully to patients and ensuring all team members give consistent information.

Access to Reliable Information

Patients describe Active Monitoring as a time of "wait and worry." Without access to trustworthy, up-to-date information about their condition, anxiety levels can soar. Providing patients with evidence-based resources could significantly reduce this stress.

Stronger Peer Support Networks

Too many patients feel isolated during Active Monitoring, with little access to peer support programs or helpful monitoring tools. Healthcare providers need to actively connect patients with support organisations such as CLL Support, and medical teams can work more closely with patient groups to fill these gaps.

You can watch Peter's film <u>here</u> and it highlights how important it is that the medical community recognises that active monitoring isn't just a medical strategy, it's a challenging emotional period that requires comprehensive support for patients and their families.

We are often asked about the difference between CLL and SLL, so here is a brief summary.

Chronic Lymphocytic Leukemia (CLL) and Small Lymphocytic



Lymphoma (SLL) are two closely related types of blood cancer that affect B lymphocytes, a type of white blood cell critical to the immune system. They are considered different expressions of the same disease, distinguished mainly by where the abnormal cells are located in your body.

In CLL, abnormal lymphocytes are detected mostly in the blood and bone marrow. In contrast, SLL is primarily a lymph node-based disease, with abnormal lymphocytes accumulating in lymphoid tissues such as in the neck, armpits and groin rather than in significant numbers in the blood. Despite this distinction, both conditions often share common genetic mutations, clinical features, and treatment approaches. Symptoms like swollen lymph nodes, fatigue, and susceptibility to infections may occur in either condition, and the diagnosis often relies on a combination of blood tests, biopsies, and imaging. Treatment strategies for both CLL and SLL are the same and are typically determined by the disease stage and include a number of options. You can find out more about current treatments on our website

here: https://cllsupport.org.uk/information-support/about-cll/cll-treatment/

Belfast Conference



On Saturday 31st May we held our first Joint Conference with CLL Ireland in Belfast with some 53 people in attendance either in person or on Zoom. CLL Support is committed to ensuring we reach out to our members in the devolved nations and we were especially pleased to collaborate with

our colleagues in CLL Ireland and between us we developed an engaging and informative programme for the day.

John Greensmyth opened proceedings by setting the scene and made the point that like Covid, CLL knows no barriers and there's more that joins us than divides us. Two patient speakers Paul and Nicky shared their stories which resonated with the audience and these were followed by updates from CLL Ireland and CLL Support delivered by Jan Rynne and Peter Allen respectively.

Our two keynote speakers from the Belfast City Hospital; Dr Sarah Lawless, a Consultant Haematologist, and Laura Croan, a Haematology Advanced Nurse, covered all aspects of living with CLL and actively answered all the questions posed by the audience. The particular circumstances faced by patients and their families living in Northern Ireland and the Republic of Ireland regarding access to treatment were openly addressed in a non-partisan manner.

The afternoon session was dominated by an Expert Panel forum, Sarah and Laura were joined by Dr Ben Kennedy, Ropinder Gill (CEO of Lymphoma Action) and Brian Gardom. Michael Rynne of CLL Ireland moderated the discussions which covered all aspects of CLL with a lively and topical exchange of views from the panel and the delegates. The day finished up with the ever popular delegate Round Table discussions.

The videos from this successful event are available via our website and YouTube channel and we have already had in excess of 800 views. We are indebted to all of the speakers / presenters who willingly gave their time (especially on a Saturday) to make this event a success.

You can click on the Belfast Conference Graphic above to view the video

STATIC Trial

As part of a recent change to the STATIC trial, a new drug has been introduced, called acalabrutinib. This means that patients who have received acalabrutinib as their second or subsequently line of therapy for CLL <u>can also</u> join the STATIC trial and be randomised to receive either continuous or intermittent treatment with acalabrutinib.

In addition to the above change, STATIC is also now open for patients who have received ibrutinib in the IcICLLe trial, as well as for patients who have received treatment with ibrutinib as their first and only treatment in standard care, without previously being in FLAIR or IcICLLe. Most of these patients will be randomised to receive either continuous or intermittent treatment with ibrutinib, however some patients who were previously treated in IcICLLe may proceed to receive continuous treatment with ibrutinib, based on clinical need.

OxPLoreD News

OxPLoreD is a study involving people with early-stage lymphoproliferative disorders. The study aims to further confirm already known clinical characteristics that predict whether people diagnosed with precursor leukaemia or a very early stage of blood cancer might go on to developing full-blown cancer that needs treatment......

To read the full OxPLoreD Newsletter click here

Fundraiser Stories - Aiden & Grace

Grace Sleightholme, along with her partner Matthew, is running in the 'Big Half' later this year in memory of her wonderful Dad who sadly passed away in 2021 with CLL. He was diagnosed in the year that the charity was founded. Sadly, they didn't know about the charity at the time when they really needed our support.

Grace has chosen to fundraise and raise awareness for CLL Support to help the charity support patients and their families moving forwards and so will be incredibly grateful for any denation to help CLL Support with our mission to support and

donation to help CLL Support with our mission to support and empower patients living with CLL & SLL. Grace has so far raised £695 of her £800 target.

Here is the link to her fundraising page : https://2025thebighalf.enthuse.com/pf/grace-sleightholme

The Big Half follows an iconic London route past Tower Bridge and finishes at the Cutty Sark, Greenwich.

From all of us at CLL Support, thank you for supporting our charity.



Aidan Harris is taking on IRONMAN Leeds on Sunday 27th July in aid of CLL Support. This will include completing a 2.4-mile swim, a 112-mile bike ride, and a 26.2-mile run.

Aidan has chosen to raise money for CLL Support because his Uncle Marc has been personally affected by CLL. This diagnosis has had a profound

impact on him and the whole family. Aiden hopes to raise awareness of CLL for Marc and to support others with CLL.

Here is the link to his fundraising page: <u>Aidan Harris Ironman Challenge 27th July</u> At the time of writing, Aidan had raised £1,055 plus £182.50 Gift Aid. On behalf of all of us at CLL Support, thank you so much Aidan for taking on this challenge.

Exercise is good for you

Some of you may well remember completing a questionnaire for the University of Surrey about your exercise habits. That research has led to a paper being published by Dr David Bartlett, Ellie Miles and others in eJHaem, a journal of the British Society for Haematology. There has been wide coverage of the article in the CLL communities in many countries around the world ans=d there is also a piece in The

Independent https://www.independent.co.uk/life-style/health-and-families/blood-cancer-chronic-lymphocytic-leukaemia-treatment-b2792862.html

Thank you so much to those of you who contributed to the research. Watch this space for news of further exercise-related publications in due course.

Exeter Conference May 2025



We held our first smaller regional conference on the 13th of May 2025 in Exeter at the Devon Hotel.. The room was the perfect size for this smaller number of attendees and there was a very friendly and talkative air to the day. It was a shorter day than usual

running from 11am to 3pm, and the day was not live streamed or recorded as this was a new format for the Charity to try out smaller and less expensive options as 'extras' to our already extensive events programme. Three trustees attended with our Coordinator. Special thanks go to Tina Draycott and her husband and Patrick Henry for their assistance and presentations.

We were lucky to have Dr Nikesh Chavda from the University Hospitals of Bristol and Weston as our keynote speaker. Everyone in the room enjoyed the talk a great deal and it was very informative. The attendees took advantage of the Q&;A and they also spoke with Nikesh during lunch, which was very helpful.

Our patient story by Patrick Henry was informative and reflected the more

holistic approach to living with CLL. The trustees, Norah Grant, Anthea Holland and the Chair, Hilary Lindsay, spoke in the afternoon for short updates on what the Charity has been doing recently. Norah spoke about the Under 60 Club and HealthUnlocked, as examples of our on-line support, and the hot topic on both platforms of fatigue.

HealthUnlocked and its invaluable support and advice was then discussed, which of course is open to everyone, and Norah spoke of it as a place to get an answer to any and every question one might have about CLL and that it is possible to get to know the people who post regularly and feel a sense of community. Subgroups have been known to be formed, which further enhances that sense of connection. The moderators of HU were described as very helpful, they are very dedicated and often post links to Journal articles about CLL from haematology associations around the world.

The attendees were able to take useful notes. The table discussions received positive feedback on the feedback forms, and everyone seemed engaged and happy to talk with their table mates about how to cope with CLL emotionally and physically and about what advice they would give to a newly diagnosed person.

Overall a great smaller event that was well received by all.

Patient & Public Involvement & Engagement (PPIE) Update

In the spring newsletter we invited you to join our PPIE Register if you were interested in hearing about:

- Opportunities to become involved in discussions around research activity;
- Opportunities to become involved in PPIE activities related to CLL or SLL;
- 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, just <u>click here</u> to record your answers to a short list of questions and you can also use the link to update your preferences.

We have already had our first success. The Humber and North Yorkshire Cancer Alliance wanted to find patients who might be interested in joining a steering group to look at prehabilitation and physical activity. We contacted the members on our register who met the criteria and asked for their permission to share their email addresses. We understand all those who did so have now been asked to get involved. A small success but a really important example of what we are trying to do with our PPIE Register.

Fundraiser Stories - Matt & Michelle

On Sunday 27th April Matt Gibson, proud Associate of CLL Support, took part in the London Marathon. Matt completed his run in an amazing 3 hours 55 minutes. Well done Matt.

At the time of writing Matt had raised £3,296 for CLL Support. The link to Matt's Enthuse page is below for anyone who would like to support him:

Matt Gibson London Marathon 27th April - Enthuse

Thank you Matt from all of us at CLL Support.

Michelle Brotherton took part in 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 £520 plus £130 Gift Aid.

Travel Insurance

Now that we are well into the holiday season, Travel Insurance is a hot topic. Now and again we hear from our members to tell us about a company that they have found helpful for CLL patients. We have compiled a list of them on our website

here: https://cllsupport.org.uk/information-support/faqs/

The YORVIK Vikings







This year we have been chosen by the Yorvik Vikings Triumph Motorcyle Club as their charity of the year. One of our members, Jezz Booker, who has CLL, and his wife Lynn,

have been working really hard organising events to raise awareness whilst fundraising for us. They have set a target of £8,500 and at the time of writing had raised £1,645.33 plus Gift Aid £394.

The club has already had the following events, with more to come over the Summer: 12th April - 'Bike Season Opener' at the Motorist. The sun was shining on over 1,000 people who attended. Wristbands and lanyards were available to purchase on the clubs stand. These were complemented by leather and crystal bracelets and dog biscuits made by Lynn.

26th April – around 30 club members met up in York for a cuppa and breakfast before setting off on a ride-out. There were 25 motorbikes, some with pillions, that set off on a route devised by 2 club members. Their ride took them through the Yorkshire Wolds, Scampton and North East of Malton. They stopped for coffee in the middle of the ride before finishing the day with coffee and cake.

9th-11th May - 'Appleby Spring Rampage' saw a turnout of over 40 people stay at Appleby Manor to celebrate the club's 10 year anniversary. Old friends and new had a fabulous time with great weather, good food and a ride-out on their motorbikes. The hotel was well received, and the staff seemed to enjoy it as much as the club. The weather was perfect for a trip to the Lakes and the Dales with surprisingly little traffic. A big thank you to Joan, Robbie and Linda for organising the raffle which raised £250.

21st May - 'Curry Night' at the Bay Horse in Green Hammerton after a ride-out. On the menu were chicken and vegetable curries, chips and rice. For those who were still hungry, puddings were available. During the evening, they club raised £523.50 which included £170 from a raffle that they whipped up on arrival. Everyone was very generous, and the club were very grateful to Jon and Tina Clarke who run the pub and donated all the food for the evening. Amazing.

4th June – 'Quiz night' – a great evening was had by all who attended this event. Nearly £600 was raised on the night. It was well supported by the local folk from the village who love a quiz, enjoyed some fantastic food, donated some great raffle prizes and had lots of laughs. The Yorvik club members were very grateful to Jon and Tina, and all the staff, at the Bay Horse for hosting this event.

'Race the Waves'

22nd June - the inaugural 'Yorvik Vikings Solstice Bike Show' took place at Terrington Village Hall in North Yorkshire. The event was attended by about 40 bikes (20 of which were entered into the show). Tea, coffee, pies and peas, cakes were available for all. The weather was warm, the rain held off, the club merchandise gazebo was popped up to allow selling of club t-shirts, badges, wrist bands and stickers, Coco the dog was a welcome

helper on the stall. Bike show categories were as follows, with prices for each winner: Triples, Twins, Classic and Custom. A lovely day was had by all, with a great ride home passing Castle Howard and the scenic sights of North Yorkshire.

We are delighted to announce that Jezz has recently become an associate trustee of CLL Support

The link to their JustGiving page is below if you would like to support them: Yorvik Vikings TOMCC fundraiser for CLL Support

Partners and Family Webinar

We held our third session on Monday 2nd June for partners or family members of someone with CLL/SLL. It was good to see a mixture of familiar faces and new faces. After a short introduction from CLL Support's Chair, Hilary Lindsay, Seona McLaren and Cherry Mills gave us their stories. The focus this time was to encourage those who are supporting someone with CLL/SLL to find some time for themselves.

We were also reminded that there is an organization out there for carers, website link below:

UK | Carers UK

We hope to have our next session during September/October. This will be advertised via a bulletin email nearer the time.

Nurse Specialist Forum

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

Breathe in Sing Out

Breathe In Sing Out – 8th April 2025 @ 7 pm 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:

"I feel like I have stretched my lungs with this session, and it has reminded me of the importance of correct breathing. I'm looking forward to the next session already." "Very much enjoyed the session."

"Thank you to all at CLL for organising the Sing session today."

"You don't need to be able to sing to benefit from the session."

"Lovely tunes and harmony."

"Did anyone else wake up with the song in their head this morning?"

Could you be our next Treasurer?

We are 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.

Support ACT

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

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

DATES FOR YOUR DIARY - NEXT ROUND OF SUPPORT ACT

Session	Thursday mornings	Tuesday evenings
1	1st May 2025	20 th May 2025
2	5 th June 2025	17 th June 2025
3	3 rd July 2025	22 nd July 2025
4	7th August 2025	19th August 2025
5	11th September 2025	16 th September 2025
6	2 nd October 2025	14th October 2025

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/

Fundraiser Stories - Ian & Mark



On Sunday 25th May one of our members, Ian McLaren, took part in the 20th Anniversary MOKRUN which is a 10K run around Campbelltown. Ian ran this for us last year and wanted to do it again. Ian was joined by his wife Seona, sons Ian and Jamie, and daughter-in-law Jenna. Jamie's partner Morganne and granddaughter Hannah were there to greet them at the finish line.

lan completed the 10K in 1 hour 8 minutes coming second overall in the Over 70s group. Son lan ran the 10K in 42 minutes coming 8th overall and Jamie completed the half marathon in 1 hour 38 minutes placing him 14th. Jenna and Seona did pretty well too.

lan wanted to raise awareness of CLL Support and at the same time do some fundraising for us. At the time of writing Ian had raised £909 plus Gift Aid £212.25. On behalf of everyone at CLL Support, many thanks Ian.

Well done to all of you for taking part.

If you would like to support them by donating, here's the link to lan's JustGiving page:

lan McLaren MOKRUN 25th May 2025 - JustGiving

One of our members, Mark White, was diagnosed with CLL in February 2021 and recently finished 15 months of targeted treatment. It's been quite a journey for him, but he's had lots of support from his lovely family and friends.

Mark is looking forward to life returning to "normal". Prior to diagnosis, Mark was fit and active, but he found as time went on, he was no longer able to do all the activities that had become part of everyday life. As his treatment progressed, he wanted a target to work towards as his health improved. He had always enjoyed open water swimming so looked for an event he hadn't taken part in previously. Having already completed the Bantham Swoosh

(6km) down the River Avon in Devon, he came across the



Bantham Boomerang. Mark's swim took place on Sunday 13th July and took him upriver with the incoming tide. With the turn of the tide, Mark swam back down river, completing a fantastic 9.4 kilometres.

Mark would like to raise awareness of CLL Support and at the same time fundraise for them as a thank you and help them to help others diagnosed with CLL/SLL. At the time of writing Mark had raised an amazing £2,637.50 plus £570.03.

If you would like to sponsor Mark, his JustGiving link is below:

Bantham Boomerang Open Water Swim

All of us at CLL Support would like to say thank you to Mark and to wish him all the best with this challenge.

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!















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