CLL SUPPORT

Annual Report, Impact Report & Financial Statement

2025

Registered Charity Number 1178482

Contents

Welcome	3
The year in numbers	4
About us	5
Our support strategy	6
Inform	7
Support	11
Represent	15
Thrive	19
Finances	23

Registered Charity Number 1178482

FUNDRAISING REGULATOR

Welcome to this year's report on our achievements in 2025.

I'm delighted to introduce this report on our achievements in 2025 and the impact our work is having.

A key achievement this year has been the award of PiF TICK accreditation. This provides assurance that the information we provide to you is accurate, reliable, and trustworthy. It's an important step for us, and you will see the PiF TICK logo now featuring on all relevant information.

We couldn't provide our services and events without the generosity of our members, pharmaceutical partners, fundraisers, volunteers and supporters. I am extremely grateful to you all.

I'm also indebted to my fellow Trustees, Associates, support staff and the wider CLL community for the time and effort they devote to CLL Support. Without them we couldn't provide the support that everyone living with CLL and SLL needs.

We are a small charity, but we have built a respected and trusted voice in the research, treatment and care of CLL and SLL, and I think it's fair to say we punch well above our weight

The year ahead holds a great deal. We are focused on providing you with the latest evidence-based and trustworthy information, practical support and representation, and as part of this we will continue our series of conferences, webinars and events throughout the year. I hope to see many of you there.

I'd also like to thank everyone who has contributed their thoughts to our recent member survey. This helps us to ensure we are providing the information and support you need, in a way that works for you, and that your views are represented to researchers, clinicians and policy makers at every opportunity.

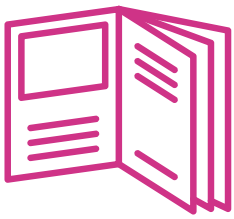
Thank you for your continued support of our charity.

Peter Allen
Chair of the Trustees

CLL SUPPORT

The year in numbers
2025

49,000
Website views



1,200
Booklets sent

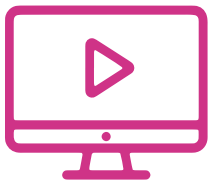
37,000
Online forum interactions

200
Helpline calls taken

310
Attendees across
5 Live conferences

700
People attended
12 webinars

120
People helped by our Support ACT online sessions



98,000
Facebook views

£65,000
Raised by our members

About CLL Support

Who we are and what we do

CLL Support was set up in 2004 by volunteers who all had CLL or had someone close to them who had CLL. It is still run on the same principle.

We are the only UK charity devoted exclusively to CLL and SLL.

We aim to provide high quality information, advice and support to people affected by CLL and SLL, and their family, friends and healthcare professionals.

Our vision

People with CLL and SLL across the UK can live long, fulfilled lives and not face these blood cancers alone.

Our mission

By and for people with CLL & SLL:
We support and empower people living with CLL & SLL and their support network, giving them access to the latest knowledge to improve their understanding of the condition, treatment options and care.

We represent the CLL & SLL community, bringing the patient's voice to clinicians, researchers and key decision makers.

Our strategy

During 2025 the Trustees developed our strategy for the next five years.

The plan is structured under four strands of activity. Strategic aims were highlighted and pillars developed to identify and provide the desired outcomes/goals CLL Support would aim to achieve over the next five years. Underpinning the pillars are our values over the next five years.

Our overall direction is not changed by the new Strategy. It has just brought us more focus. We therefore thought it was more than appropriate to set out our achievements for 2025 under the four pillars of our new strategy.

Our support strategy

This is how we visualise it:

Vision

People with CLL and SLL across the UK can live longer, more fulfilled lives and should not face this blood cancer alone.

Mission

By and for people with CLL: We support and empower people living with CLL/SLL and their partners, giving them access to the latest knowledge to improve their understanding of the condition, treatment options and care. We represent the CLL community, bringing the patient's voice to clinicians, researchers and key decision-makers.

1. Inform

We aim to provide everyone with CLL/SLL and their supporters with as much reliable information as they wish to have at the right time and in the right form for them.

2. Support

We believe that life can be made better for those with CLL/SLL and their support network by providing trusted information and services which tackle the impact of the condition holistically.

3. Represent

We help key stakeholders to know more about CLL/SLL and encourage clinicians and pharmaceutical companies to work towards improved, accessible medical and holistic treatment.

4. Thrive

We aim to maintain CLL Support as a well-run, well-financed charity with a growing and engaged membership.

Values: Trustworthy | Empathetic | Proactive Collaborative | Practical

Inform

Website
The website transitioned to new providers which has increased security and resilience. Accessibility is provided through the Recite Me toolbar.

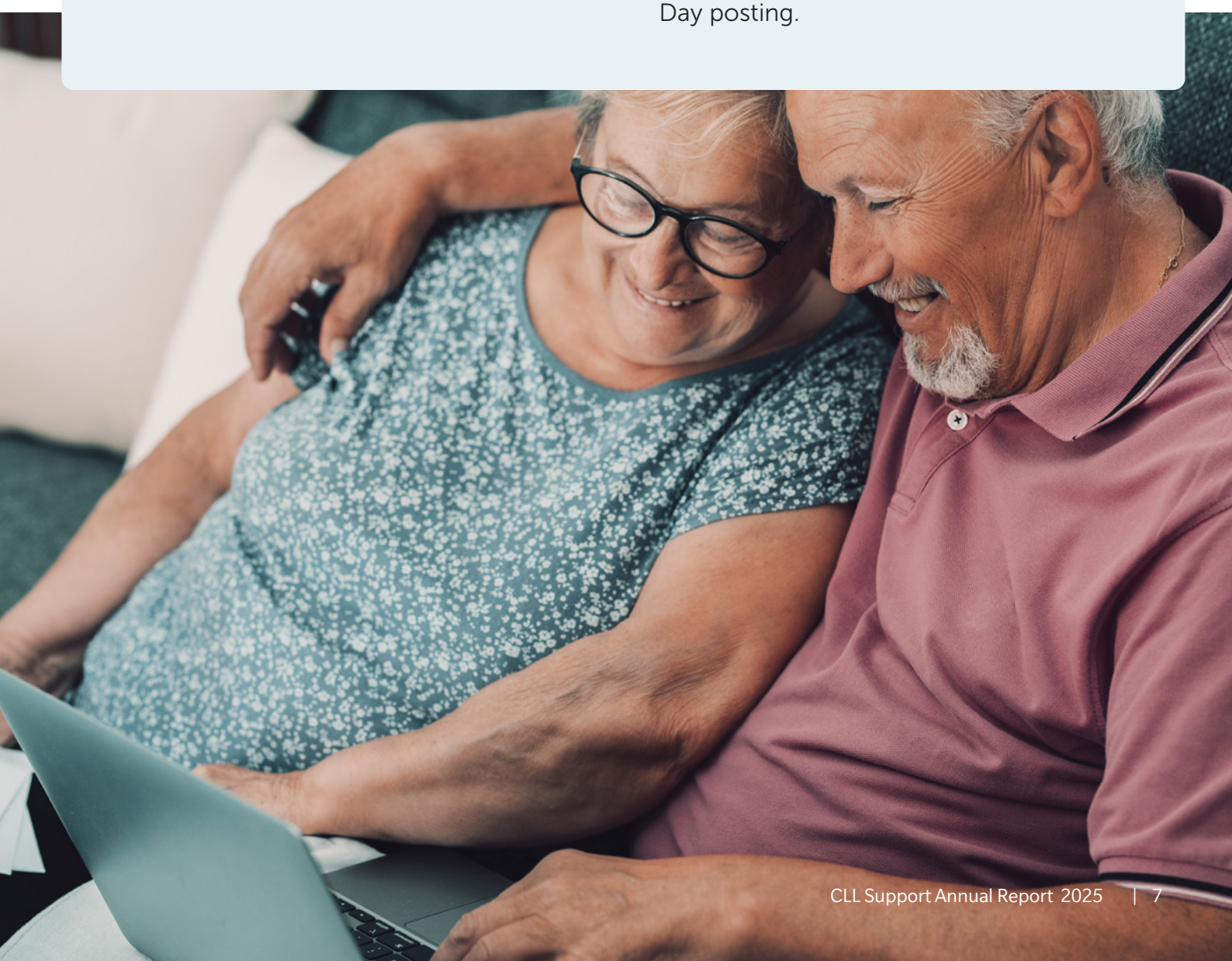
PIF TICK accreditation.

Newsletters
4 newsletters and regular bulletins and updated publications.

Conferences
4 main Conferences with recordings (Oxford, Belfast, Manchester, Newcastle) and a new regional conference in Exeter.

Videos
YouTube video library branded and promoted with 29,000 views.

Social Media
Effective social media with over 19,000 views of a World Blood Cancer Day posting.



Website

Our website is the main source for reaching people with CLL and SLL. In 2025:

- In February 2025, we appointed a new service provider to improve and manage our website. Over the course of the year, several enhancements were made to improve accessibility, including an update to the Recite Me tool, refinement of colours, and improvements to layout, enabling the site to meet current accessibility standards.

- Key benefits include improved readability for partially sighted users and the ability to translate content into a wide range of languages.

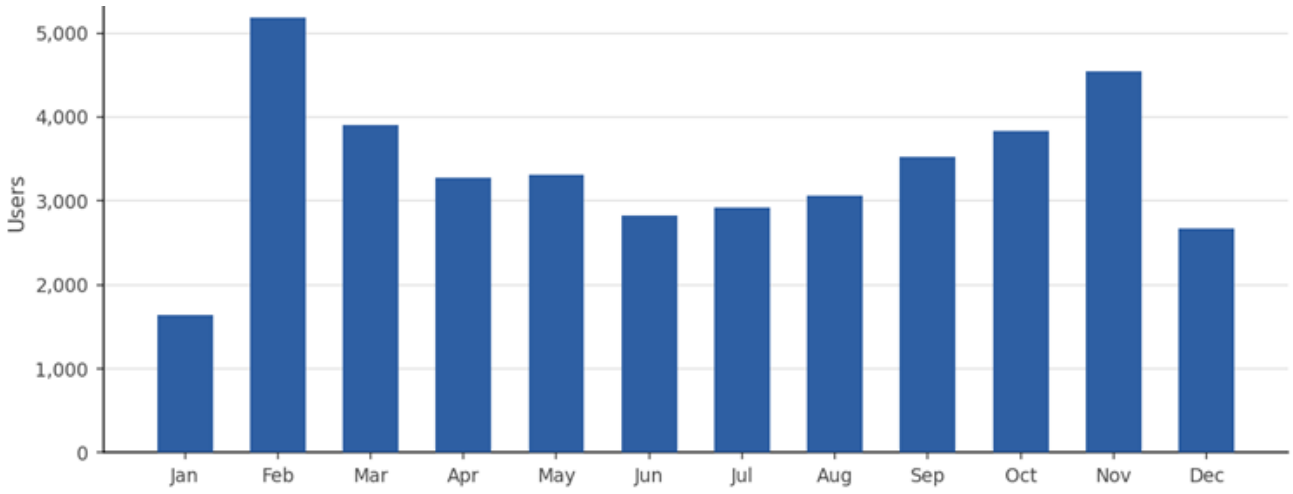
- The security and resilience of the site were also strengthened during the year. In December, the site was subjected to a carding attack; it was not compromised, and the incident was resolved with no financial loss. Further enhancements to the payment process were subsequently introduced to prevent recurrence.

- Improvements to the Content Management System have strengthened content control and approval workflows, a key requirement of PIF TICK accreditation, and support a scheduled review process to ensure content remains current. These changes also benefit Search Engine Optimisation, improving the site's visibility in search results.

- During 2025, the CLL Support website attracted a total of 49,144 sessions, reflecting the overall level of engagement with the site. Analytics data recorded 34,595 users, though as figures are device-based rather than person-based, the number of individual visitors will be somewhat lower than this suggests.

- Traffic grew steadily as website improvements came online through the year. The fourth quarter (October to December) was the strongest period, with 11,051 users — a 16% increase on the third quarter — consistent with the progressive enhancements to accessibility, content management and search engine optimisation introduced following the appointment of our new service provider in February.

- About 600 revisions or updates were made to the website during the year. These were both day-to-day updates and others from the agency as the new website was developed.



- The most visited pages reflected the core information needs of our audience. The homepage received 20,193 views, followed by the About CLL/SLL/MBL section (8,205 views), News (4,952), Diagnosis (4,543), and Webinar & Conference Video content (3,210). Together, these five pages accounted for most of the traffic and underline the value users place on accessible clinical information and our events programme.

- Most visitors, over 15,900 active users, were based in the United Kingdom, reinforcing our reach within our primary audience. Traffic was also recorded from Ireland (549 users), reflecting the international relevance of our content to English-speaking CLL communities.

- New users were predominantly reached through direct access (15,992) and organic search (8,134), with a further 4,102 arriving via referral links from partner and affiliated sites. Paid search accounted for 1,016 new users. The strong organic search performance is in part attributable to the SEO improvements delivered as part of the website redevelopment.

- The site was accessed primarily via desktop (19,328 active users), with a significant and growing proportion using mobile devices (9,555), underlining the importance of the accessibility and layout improvements made during the year.

Recite Me

Our accessibility tool continued to help people with visual and other disabilities throughout the year. During the year:

Key data:

- **1850 pages viewed**
- **400 unique users**
- **4.61 pages viewed per session (industry average 2.8 pages)**

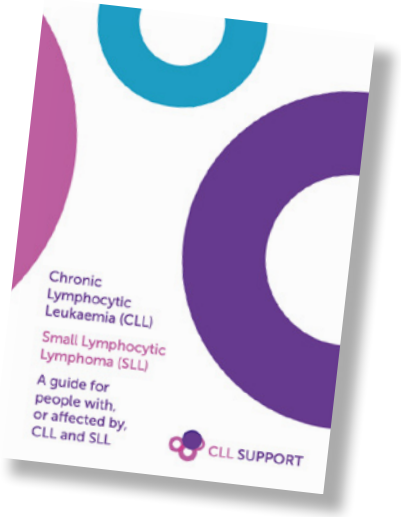
PIF TICK accreditation

In June 2025, CLL Support achieved PIF TICK accreditation from the Patient Information Forum, recognising the reliability and trustworthiness of the information we provide to patients and their supporters. All medical content is subject to a rigorous review process to ensure accuracy relevance and timeliness and is approved by a leading specialist before publication. This standard applies across all our information channels including the website, booklets and leaflets. Accreditation is reviewed annually.

Newsletters, bulletins and publications

Over 150 bulletins were sent to members through Mailchimp during the year. This includes the main newsletters, mailings promoting conferences, webinars and zoom calls and news items. There were around 3,300 recipients per mailing.

The updated Guide for people with, or affected by, CLL and SLL was published in early 2025 and the Vaccinations leaflet updated later in the year.



Conferences

Over 300 attended our 2025 conference programme in person or on zoom with many more having viewed the recordings on our website **https://cllsupport.org.uk/news-events/conference-reports/**

- **April 3rd** – Oxford with Professor Anna Schuh
- **May 3rd** – Exeter regional event with Dr Nikesh Chavda
- **May 31st** – Belfast – jointly with CLL Ireland – with Dr Sarah Lawless and Dr Ben Kennedy
- **September 25th** – Manchester with Professor Adrian Bloor
- **November 27th** – Newcastle with Dr Helen Marr

Quotes from our audience:

"Useful topics and excellent speakers, thank you!"

"I learned a lot about treatment and the main speakers were excellent"

"Something for everyone, patient, supporters and family"

"Group discussions were great, meeting others with CLL"

"Meeting and learning from like-minded people"

"So interested to hear peoples journeys with CLL"

"Friendly and great to meet others"

Social Media

Social media is a fast-growing area for us and one we are keen to develop further.

98,000
views on Facebook

29,000
video views on YouTube

Support

8 Zoom Calls
for our members (3 for Partners, 2 for Men, 2 Breathe In Sing Out sessions and a first one for people living on their own).

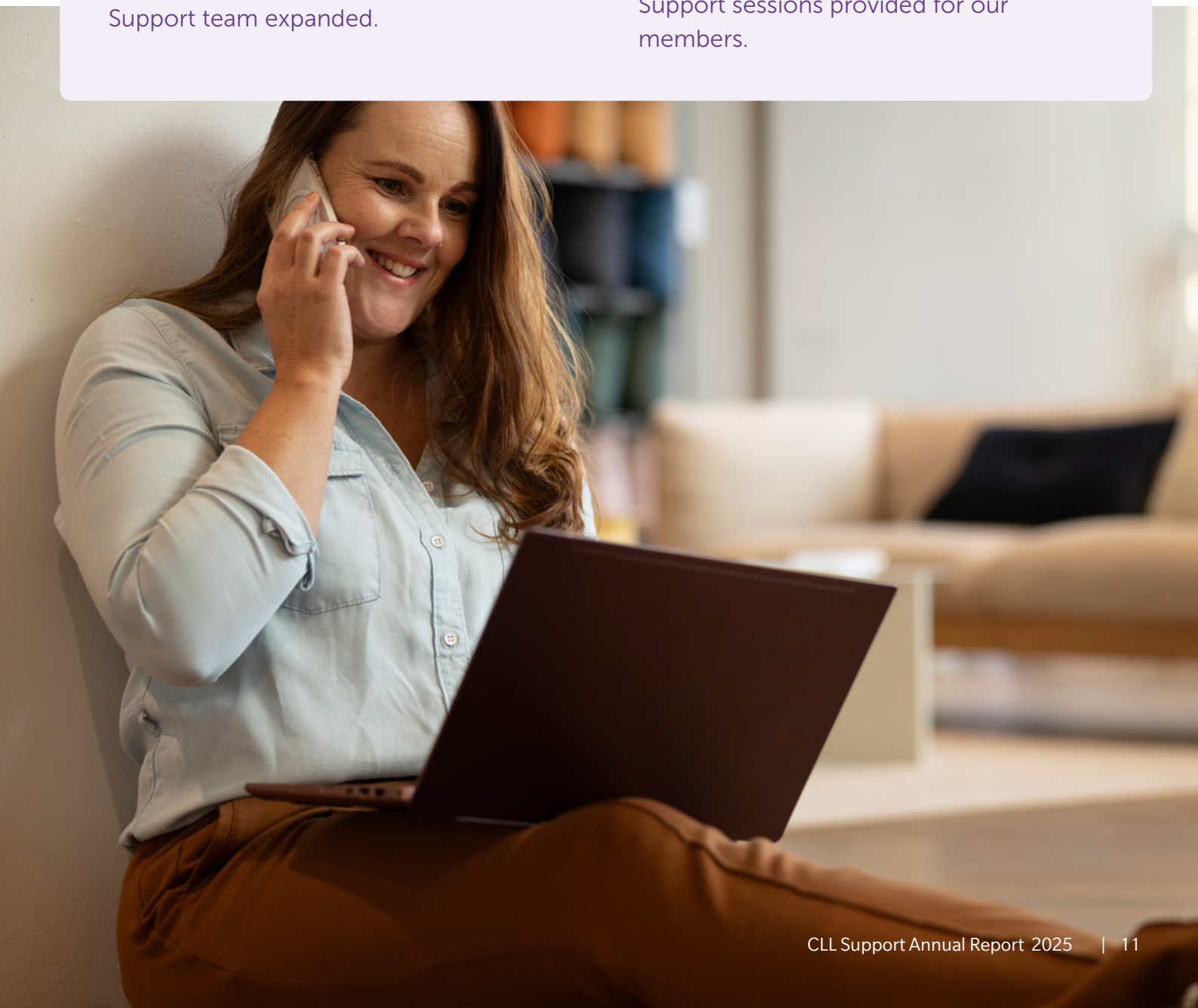
20 Support ACT
monthly sessions held and Meditation sessions introduced at end of year.

Helpline
Support team expanded.

U60s WhatsApp Group
going well with team of Deputies now in place.

Health Unlocked
platform now has **4,000** active members and over **25,000 subscribers** in total.

60 One-to-Ones
Support sessions provided for our members.



Zoom calls for our members

An average of 27 people attended our 8 Zoom calls with the most popular being the first meeting of the group for people living on their own.

What some of our members said:

"I really valued hearing people's positive outcomes and that's really helped me"
Delegate at Partners' event

"It was reassuring to hear what others have to say"
Delegate at Men's Networking event

"Thank you so much for organising the singing therapy. It was wonderful for my bad back etc. It is true you really don't need to be able to sing like an angel to benefit from these classes."
Delegate at Breathe-In-Sing-Out event:

"I found the whole event was very well organised, very informative and lovely to meet other people in a similar situation as I don't know anyone with CLL."
Delegate at Living on your Own event

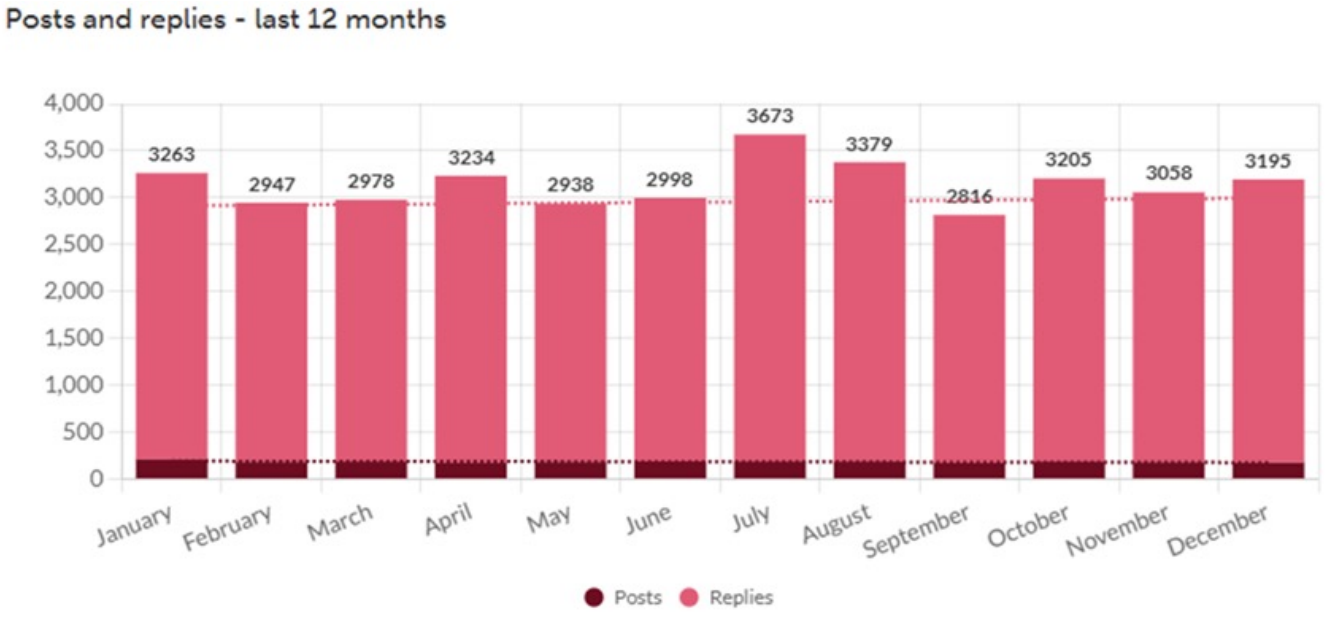
Health Unlocked

HealthUnlocked is our online international forum where members can discuss with other people with CLL and SLL any topic concerning the disease from blood test results to keeping healthy.

Key data:

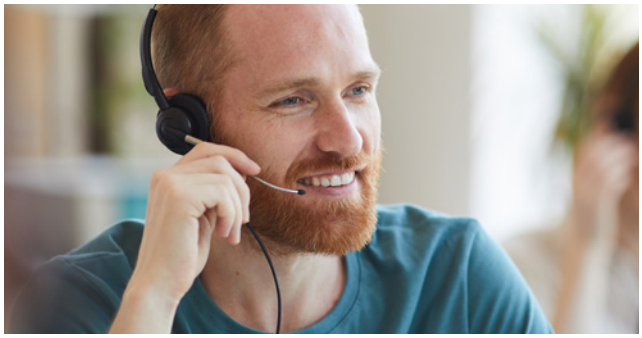
- 4,000 active members
- 25,000 total membership
- 2,200 posts
- 37,000 replies

"I remember well the weeks after my diagnosis, and the time I was preparing for treatment, how helpful it was to receive support and find information from members here. Thank you to all, and especially to the administrators and volunteers who dedicate so much time to supporting the community."



Helpline

Several Trustees now look after the Helpline; all having received training from the Helplines Partnership.



Support ACT Group sessions

Support ACT is our mindfulness and well-being initiative. All programmes are run by a qualified occupational therapist. More details in this LINK

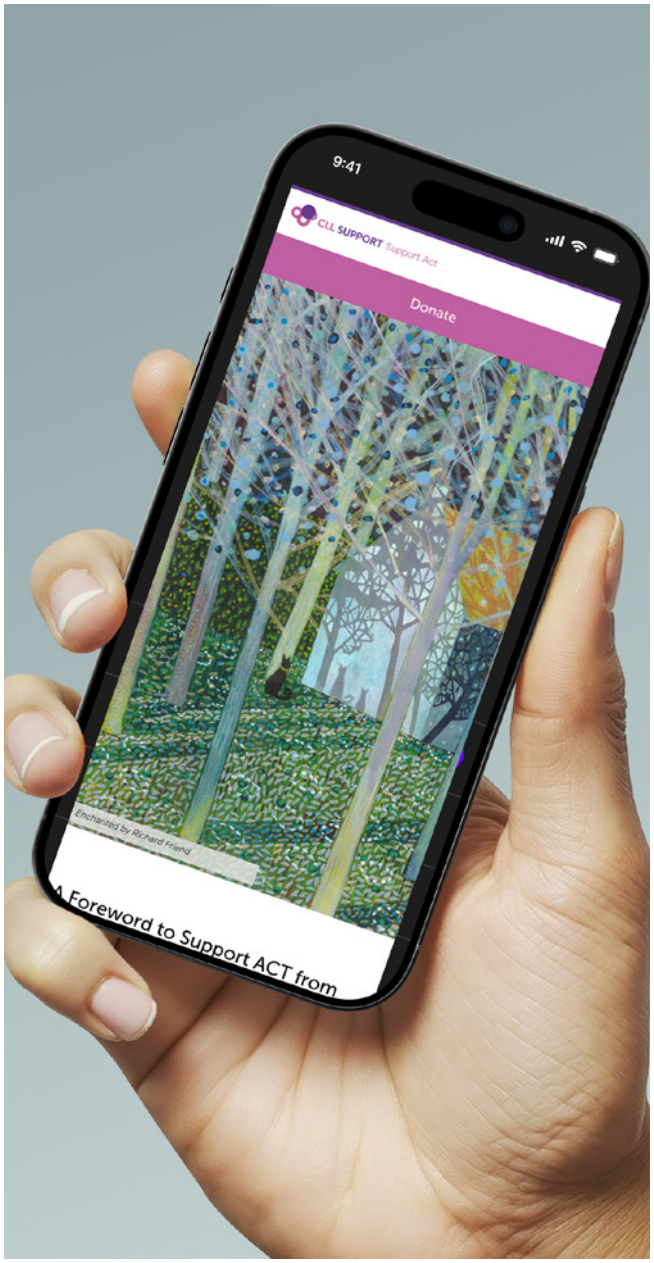
173 attendees over the 12 months for 14 sessions

"Therapist leading with opportunity to participate without being compelled to do so was perfect for me"

"The Support ACT tool on the CLL website has helped me."

"I have found these sessions to be really helpful particularly in reminding me that I am not alone and that there are ways to feel more positive."
"Sessions are great, really informative and some good strategies to use. Great just as they are."

"Thought session was great. Good introduction to ACT and appreciated chat time afterwards with other members. Made me realise I'm not alone."



Meditation

First session on 4th December was attended by 19 and numbers are continuing to rise in 2026.

Represent

STaR
Evolving activities with over **140 members** joining the new PPIE Register.

UK CLL Forum
Ever closer links with **UK CLL Forum** and **UK CLL Study Group.**

Research
Our research to understand fatigue in CLL received ethical approval in preparation for the launch of the survey in 2026.

Webinars
4 Clinical webinars and **2 PPIE training webinars**.

Appraisals
Much appreciated and effective input to **NICE, HTA and SMC** appraisals.

Best practice
Sharing with **WMUK, Lymphoma Actio**n and others.

STaR

Highlights for 2025 for our STaR (Studies, Trials and Research Group) include:|

PPIE (Patient and Public Involvement and Engagement) Register established with over 140 members

"I wanted to write again to thank you for sending out our [research request] last month. We've had a fantastic response."

69 of 99 members contacted responded to our survey about proposed fatigue research

STaR page added to the website: **https://cllsupport.org.uk/star/**

Over 30 attendees at each of the two **PPIE training webinars,** led by Dr Nicolas Martinez-Calle, chair of the UK CLL Forum, and Dr Ben Kennedy, with recordings available on the website.

18 attended the first PPIE Support Group meeting in December

"This email simply comes to say Thank you for the PPIE Meeting last week. I find it very reassuring to hear of all the initiatives and remain ready to become involved, should I fit the criteria. "

69 of 99 members contacted responded to our survey about proposed fatigue research

Presentations about STaR given to various groups, including to the iwCLL and CLLAN Conferences held in Krakow in September.

During the year we provided patient-informed input in a wide range of ways including commenting on research proposals, reviewing diagnosis guidelines, providing letters of support for grant applications, participating in podcasts about fatigue in CLL, newly diagnosed and shared decision making, contributing to the development of the worldwide CLLAN Charter Principles for those with CLL and being co-applicants or named PPIE leads for several funding applications.

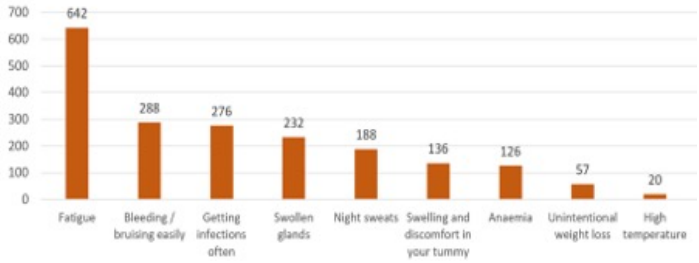
UK CLL Forum

We have always had close links with the UK CLL Forum, the organisation that bridges the gap between Scientists, Clinicians and Patients. We again provided the administration support and speakers for the UK CLL Forum annual training course, attended by over 200 delegates, where we also gave a presentation on shared decision making. We have representatives on the UK CLL Study Group and its chair, Dr Piers Patten is a member of the STaR Group.

Fatigue – setting the scene

Fatigue was mentioned by 58% of those who took part in our 2024 survey. This was more than any other symptom and included:

- **58% of those on active monitoring**
- **62% of those on treatment**
- **52% of those in remission**



70% of those reporting fatigue experienced it on a daily basis and 23% on a weekly basis. It was these results that prompted our more detailed research into fatigue.

Clinical webinars

Over 550 attendees in total at our online webinars with many more having viewed the recordings on our website https://cllsupport.org.uk/news-events/conference-reports/. In addition to the two PPIE training webinars held in October other webinars included:

- **January 16th** - Dr David Bartlett - Understanding CLL-derived fatigue
- **February 11th** - Professor David Allsup - How to get the most out of your consultations
- **March 20th** - Dr Ben Kennedy and John Greensmyth – Clinical Trials: the patient and clinician experience
- **September 17th** – Dr Tal Munir - Update on the FLAIR and STATIC Clinical Trials

"These webinars are superb and hugely valuable. Can't thank you all enough. Brilliant hosting."

Best practice sharing

Quarterly Best Practice sharing meetings have taken place with colleagues from WMUK and Lymphoma Action. These meetings have been facilitated by BeOne Medicines UK and have encouraged openness and knowledge-sharing. Although representing different patient groups we often face similar challenges. Solutions from one condition area being adapted to another has sparked debate.

NICE, HTA and SMC Appraisals

CLL Support has engaged with NICE Technical Appraisals whenever an appropriate scope or appraisal was to be considered.

We have partnered with other UK Blood Cancer Charities to submit a joint response as we feel this carries the greater weight of a unified approach. CLL Support have led these submissions a number of times. CLL Support has nominated patient experts and had representation at TA Committee meetings.

During 2025 the following submissions were made:

TA ID 6269

Pirtobrutinib after one or more BTK inhibitors - final decision now approved in July 2026.

CLL Support representatives were present at both the NICE Appraisal Committee meetings and wrote the TA on behalf of five national leukaemia charities.

TA ID 6292

Venetoclax + Obinutuzumab for untreated CLL in fit patients without 17p or TP53

CLL Support responded to this TA and the treatment, which had been available via managed access, was approved without a committee meeting.

TA ID 6232

Acalabrutinib plus Venetoclax with or without Obinutuzumab for untreated CLL.

Decision awaited at the time of writing, expected soon. CLL Support made a major contribution to the TA that was submitted and was present at the two NICE Appraisal Committee meetings.

Thrive

4 new Trustees

Suzanne Richardson, Marianne van de l'Isle, Troy Van de L'Isle and Treasurer Steve Rawlings and 3 new Associates Jackie Martin, Jezz Booker and Tiffany Plant.

Policy reviews

Resilience developed through Policy reviews, regular Risk reviews and a sound Finance Team.

Raising awareness

CLL Support promoted through September **Blood Cancer Awareness Month** videos and October piece in Saturday Telegraph.

Fundraising News

Pharmaceutical Company funding. Relationships and additional initiatives have all been effective.

£65,000 income from our committed fundraisers and new grant funding sourced.

Advocacy Resilience

Sessions held at end of year hugely appreciated.

New Trustee Suzanne Richardson

"When I was first diagnosed with CLL I found it difficult to find accurate medical backed information and support until I came across CLL Support by accident. I booked to attend the Conference in Edinburgh and found it so helpful and encouraging that I immediately wanted to get involved and to give something back. At first I joined as an Associate and later decided to become a Trustee."

Policy and Risk reviews and a sound Finance team

Following a comprehensive review of our internal policies and procedures, a Policy Committee was established to oversee existing policies and present a structured approval and review cycle to the Board. A number of policies have been updated during the year, including those covering Trustee Induction, Health & Safety, Working with Pharmaceutical Companies, and Finance. This work is ongoing. The risk register is reviewed at each Trustee meeting, with Trustees focussing in turn on four areas: Governance, Operational, Finance and Environment & External. The five members of the Finance team ensure we are able to divide up duties and provide cover for each other.

Pharmaceutical Company funding

We thank the following companies for providing arm's length partial funding for various educational, wellbeing and advocacy projects. They have had no influence in the projects, or the development of any associated materials. In 2025 we received grants of £75,000 and a further £10,165 for fees and expenses for the projects we were involved in.

abbvie

AstraZeneca

BeOne

Johnson&Johnson

Lilly

Fundraising by our members

What a great year 2025 was. **11 fundraisers** raising **£25K including Gift Aid**, with a couple of returning fundraisers from 2024. Events ranged from a yearlong fundraising campaign by the Yorvik Vikings to a BBQ to a skydive to various walks/runs such as London Marathon, The Big Half, MOKRUN, Paris Half, Edinburgh Kiltwalk to an Iron Man Challenge and a wild swim.

All these kind and generous people gave up their time willingly. Christmas donations included those from a Christmas party and many individual donations together raising £3,700.

Other sources of funding

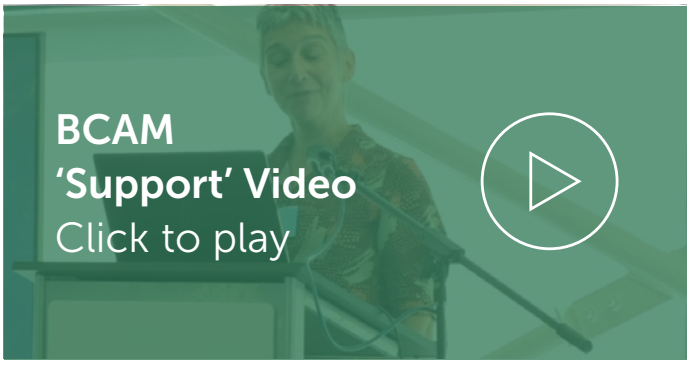
In 2025 we sought new areas of grant funding and received a total of £6,260. We would like to thank the following for their generous contributions to our activities.

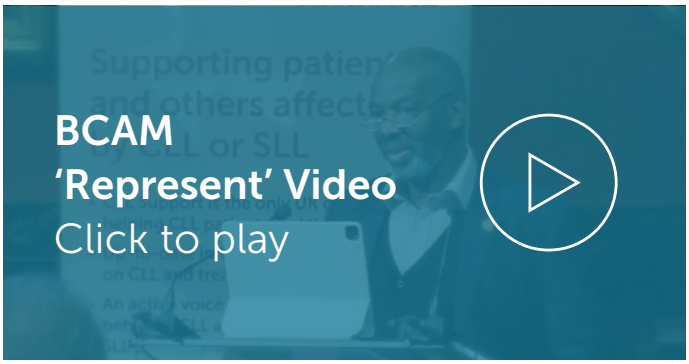
- Yorkshire Building Society Charitable Foundation
- St James Place Charitable Foundation
- The Barbour Foundation
- Co-op Doing Good Together Fund

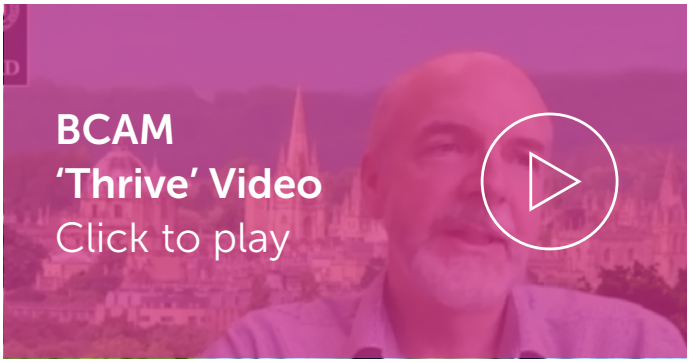
Blood Cancer Awareness Month

During Blood Cancer Awareness Month in September, we produced a short video each week. These covered in turn the Inform, Support, Represent and Thrive four pillars of our new strategy.

The four videos are here – just click on each box:







Advocacy Resilience Sessions

Our Trustees are people whose lives are affected by CLL or SLL, either the person with the condition or their partner. Whilst we are delighted to help the CLL community being a patient and an advocate can bring its own challenges. All Trustees and Associates had the opportunity to join two sessions we held at the end of the year that were designed to look after the wellbeing of all of us.

Finances

We are very grateful to our members, pharmaceutical companies and others for the support provided.

We try to manage the charity so that a minimum amount of our funding goes on overheads. We have two part time co-ordinators who work from home and none of our Board of Trustees are paid, other than for the reimbursement of expenses. This allows most of the funds raised to provide support, services, tools and materials for members. During 2025 the charity received grants from five pharmaceutical companies providing CLL products and services in the UK which totalled £75,000 (15 months to 31st December 2024 £60,000). We also received compensation from pharmaceutical companies for our time and expenses spent on activities where we brought the patient perspective, for example as patient advocates or by reviewing documents. In the year ended 31st December 2025 this amounted to £10,165 (15 months to 31st December 2024 £5,941).

During the year we also received £35,132 which was the second and final legacy payment from the Estate of Mr C F Hanmore deceased.

A summary of how we have spent the money follows, showing the Receipts and Payments figures we report to the Charity Commission which do not materially differ from our Income and Expenditure.

Reserves

The Charity aims to maintain total reserves that would be the equivalent of 18 months of its anticipated normal level of annual running costs. Should it be that circumstances arise which resulted in a significant loss of incoming financial resources, that level of reserves would enable the Charity to continue to provide essential support services to CLL patients and their supporters for an extended, transitional period.

The Trustees have also agreed that, as a minimum, an amount that is the equivalent of between 12 and 18 months planned expenditure should be held in the form of liquid reserves to ensure both continued financial security and to provide for contingencies.

In determining these figures, the Trustees have considered the need to hold back some funds as reserves, using the categories set out in the Charity Commission Guidance Document CC19: Charity reserves: building resilience. At 31st December 2025 the Charity held reserves of £319,104. (31st December 2024 £342,001).

Reserves had grown during the pandemic, as a result of extra grants from some pharmaceutical companies and our inability to run in person conferences. Since then, we have undertaken an increased programme of activities with the aim of reducing our reserves so they are in line with our policy, whilst ensuring we have sustainable finances for the future.

Accounts for the fifteen months ended 31st December 2025

Income:	Year to 31/12/25 £	£	15 mos to 31/12/24 £	£
Donations	94,280		138,427	
Grants	81,260		60,000	
Gift Aid	7,064		5,928	
Bank and deposit interest	7,230		16,485	
Assets and investment sales	850		931	
		190,684		**221,771**
Expenditure:				
Support work	154,667		129,567	
Administration	51,144		59,333	
Fundraising	10,745		22,255	
		216,556		**211,155**
Surplus (deficit) for the year		**(25,872)**		**10,616**

Remembering Lelia Duley

In December 2025 we received the extremely sad news that one of our Associates, Lelia Duley had passed away.

On joining CLL Support, Lelia brought 30 years' experience as a clinical researcher working on multicentre randomised trials and systematic reviews across a range of clinical specialties. She became the patient representative on the study teams running a number of clinical trials including FLAIR and STATIC. She was always very keen to ensure there was a strong patient voice representing the interests of CLL patients and was an enthusiastic advocate of effective communication with patients.

Lelia worked closely with clinicians from the UK CLL Forum, and we can pay no greater tribute than share two of their comments:

"Lelia was an AMAZING patient advocate and helped in so many ways to promote awareness of CLL and champion research. I hope that her family is aware of how much she contributed and how much difference she made"

"Over the years Lelia has been instrumental in championing the patient voice in all of our CLL Trials. We are indebted to her for all the support which was relentless".

Lelia will be greatly missed.

Keep up to date

For information and support visit our website cllsupport.org.uk

CLL SUPPORT