Annual Report for the fifteen months to 31st December 2024

Introduction by the Chair, Hilary Lindsay

You will see from the heading that during this period we moved our year end to 31st December. We plan events for the calendar year, and the new date aligns our accounting period with our activity cycle. During the fifteen months we held five in person conferences in London, Poole, York, London again for our 20th Anniversary celebration and Edinburgh. In the previous year we had visited Glasgow, Birmingham, Cambridge, Liverpool and Cardiff. All our conferences are now hybrid which means members can join on Zoom if that is a better choice for them and recordings are also available on our website. We also expanded our Support ACT programme, which again was available on Zoom. More detail of our activities follows later in this report.

The Trustees will continue to work for you, providing the support, knowledge and resources sought by all of you affected by CLL or SLL. I am indebted to my fellow Trustees and our Associates and other members of the CLL Community for all the time and effort they devote to CLL Support, time which if costed would provide a critical third leg to our income, sitting alongside the donations and grants we receive. While we are a small charity, we punch well above our weight.

Hilary Lindsay

August 2025

Who we are

Our charity was founded in 2004 by patients with Chronic Lymphocytic Leukaemia (CLL) and their partners. The need came from patients and the UKCLL Forum (scientists and clinicians specialising in CLL) for a patient arm to support the needs of the CLL community. Since then, we have had a seat on the executive committee of the Forum and their members have helped to verify the information we provide to members, speak at our webinars and work to provide the best treatments for people with CLL. We are a patient-led charity and continue to be run by volunteers, all of whom have been personally affected by CLL or Small Lymphocytic Lymphoma (SLL), whether that be personally or as the supporter of someone with CLL or SLL. CLL and SLL are slightly different forms of the same disease and are managed in the same way.

Chronic Lymphocytic Leukaemia Support Association UK (CLLSA) (otherwise referred to as CLL Support) is a Charitable Incorporated Organisation (CIO) with a trust deed dated 22nd May 2018 and registered charity number 1178482. The principal address is Suite 112 - 8 The Bridge, Chippenham, Wilts. SN15 1FY. The CIO succeeded the previous charity Chronic Lymphocytic Leukaemia Support Association which had been formed on 5th April 2006 and which was finally closed down and the funds transferred into the CIO on 24th July 2023.

As at 18th August 2025 the Trustees of the Charity are:

Peter Allen (Vice Chair)

Norah Grant

John Greensmyth

Anthea Holland

Hilary Lindsay (Chair)

Debbie Yates

The purposes of the charity

1. To relieve sickness and to preserve and protect health by providing support to chronic lymphocytic leukaemia (CLL) patients and their carers. (CLL includes similar related conditions such as SLL – Small Lymphocytic Lymphoma).

2. To advance public education in CLL related matters primarily in the UK through publications and the internet.

3. To promote and support scientific research into the treatment and care of all CLL patients.

The main activities undertaken by the charity

- The provision of up to date and accessible information about CLL, the range of treatments currently available and the latest research into the care and treatment of CLL, through the Charity's website, webinars, member conferences, publications and a telephone helpline.
- The development of opportunities to share understanding and personal experience by bringing those affected by CLL together, whether they be patients or supporters of patients, and by creating mutual support groups and networks.
- Acting as a voice for CLL patients, representing their interests with the pharmaceutical industry, clinicians, NHS, cancer care policy and drug regulatory authorities, funding and commissioning groups and Government.
- The promotion of an awareness of CLL Support, together with its role amongst health care providers and decision makers, providers of non-healthcare products and services, other blood cancer patient groups and the wider public.

In undertaking these activities, the Trustees confirm that they have had regard to the guidance issued by the Charity Commission on the matter of public benefit.

The main achievements of the charity

Because all our Trustees have been affected personally by CLL, either as a patient or through a close personal relationship with a patient, we are well placed to judge the needs of CLL patients and their supporters. With the assistance of dedicated part-time members of staff, each Trustee is directly involved in the delivery of the support services that the Charity has to offer.

During the 15-month period under review the Charity has moved on from the immediate challenges of the Covid-19 pandemic and has: -

- Reintroduced in-person member conferences as well as continuing to provide online webinar presentations. These presentations continued to be fronted by many of the leading experts in the field of the treatment of CLL.
- Continued its close collaboration with the UK CLL Forum, thus helping the Forum to bridge the gap between Scientists, Clinicians and Patients
- Continued its work with the Blood Cancer Alliance and with Cancer52 to promote the interests of those suffering from blood cancers in general, and from CLL in particular.
- Continued with the development and roll out of its Support ACT programme, offering users access to guidance and support to help improve the well-being of CLL patients and their immediate supporters.
- Continued to maintain a telephone helpline service that is available to offer immediate support and guidance to CLL patients and their supporters.
- Continued to participate in partnering arrangements with major pharmaceutical companies designed to offer those companies key insights into the way in which treatments for CLL impact on the lives and wellbeing of patients.
- Continued to benefit from donations and fundraising activities that were undertaken by its supporters. 2024 was the 20th Anniversary of CLL Support and our Challenge 20 encouraged members to undertake activities and raise funds for the Charity.
- Continued to benefit also from funding provided by the pharmaceutical industry.

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 as Trustees, none of our Board 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.

We were so impressed by our members who raised well over £30,000 from the fundraising activities they undertook as part of Challenge 20 in addition to their regular giving to the charity.

In the 15 months the charity received grants from four pharmaceutical companies providing CLL products and services in the UK which totalled £60,000 (12 months to 30th September 2023 £51,900). We also received compensation from pharmaceutical companies for our time spent in activities where we brought the patient perspective, for example as patient advocates or by reviewing documents. In the fifteen months ended 31st December 2024 this amounted to £5,941 (12 months to 30th September 2023 £4,352).

During the period we also received a one-off donation of £27,333 from the Wilmington Trust and £28,708 which was the first of two legacy payments 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.

Accounts for the fifteen months ended 31st December 2024

	15 mos to 31/12/24			**12 mos to 30/9/23**	
	£	£		£	£
Income:					
Donations	138,427			56,123	
Grants	60,000			53,928	
Gift Aid	5,928			2,194	
Bank and deposit interest	16,485			3,802	
Assets and investment sales	931			0	
		221,771			116,047
Expenditure:					
Support work	129,567			112,637	
Administration		59,333		37,815	
Fundraising		22,255		17,856	
			211,155		168,308
Surplus (deficit) for the year			10,616		-52,261

Reserves

The Charity aims to maintain total reserves that are no more than 18 months of the anticipated normal level of annual running costs. Should it be that circumstances then arose 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 of time.

The Trustees have also agreed that an amount which is between 12 and 15 months' planned expenditure is held in the form of cash 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 2024 the Charity held reserves of £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, recruited a second part-time staff member and returned to a programme of hybrid conferences throughout the UK.