



Annual Report 2022-23

Introduction by the Chair, Hilary Lindsay

During 2022-23, as we emerged from the lockdown caused by the COVID-19 pandemic, we cautiously resumed in person conferences, holding events in 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. We also expanded our Support ACT programme, which again was available on Zoom. More detail of our activities follows later in this report.

A very sad piece of news I must share with you is that Trustee Lewis Troke died on 10th August 2023. Throughout his six-year tenure as a Trustee of CLL Support, Lewis was devoted to helping people affected by CLL. He was the power behind our conferences and webinars, which he did with great skill and unstinting enthusiasm. He was a remarkable and energetic campaigner for us, and we will miss his wise words, warmth, and wry sense of humour. We are privileged to have known him. Lewis leaves behind an enduring legacy, which we will endeavour to uphold in his memory. We are delighted that his wife, Heather, is now involved as an Associate of CLL Support.

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 2024

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 19th August 2024 the Trustees of the Charity are:

Peter Allen
Norah Grant
John Greensmyth (Vice Chair)
Anthea Holland
Hilary Lindsay (Chair)
Steffi Sutters
Andy Taylor
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.

In respect of the main activities undertaken in relation to its objectives, and recognising the ongoing vulnerable nature of CLL patients, during the year under review the Charity has continued to face challenges as it emerged from the Covid-19 pandemic. Against that background, the Charity 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.
- Produced and made available a second short animation designed to inform patients of various aspects of the disease that patients may expect to encounter on their CLL journey.
- 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.
- Continued to benefit also from funding provided by grant making organisations and by the pharmaceutical industry.

Finances

We try to manage the charity so that little of our funding goes on overheads. As Trustees, none of our Board are paid, except for expenses. We do not have offices and have part time co-ordinators. This allows most of the funds raised to provide support, services, tools and materials for members.

We are very grateful to our members and to pharmaceutical companies for the support you have provided. In the year ended 30th September 2023 the charity received grants from four pharmaceutical companies providing CLL products and services in the UK which totalled £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 year ended 30th September 2023 this amounted to £4,352.

We are also very grateful to our members for their regular giving to the charity which means we can continue to support them through these challenging times. A summary of how we have spent the money follows. The figures included here differ slightly from those submitted to the Charity commission as the figures here are the Income and Expenditure as opposed to the Receipts and Payments figures we are required to report to the Charity Commission.

Income and Expenditure Account for the year ended 30th September 2023

	2023		2022	
	£	£	£	£
Income:				
Donations	57,436		69,713	
Grants	51,900		65,500	
Gift Aid	1,966		3,284	
Interest	7,590		2,192	
		<u>118,893</u>		<u>140,689</u>
Expenditure:				
Support work	105,987		38,209	
Administration	37,827		34,392	
Fundraising	17,878		14,240	
		<u>161,692</u>		<u>86,841</u>
Surplus (deficit) for the year		<u><u>(42,800)</u></u>		<u><u>53,849</u></u>

Reserves

The Charity aims to maintain readily realisable reserves that would be the equivalent of two years of its 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, as a minimum, an amount that is the equivalent of 150% of 12 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 30th September 2023 the Charity held reserves of £326,234. 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. As a result our reserves have moved on a planned downward trajectory with a deficit of £42,800 in the year to 30th September 2023.