Annual Report 2020-22

Introduction by the Chair, Hilary Lindsay

We continue to live in challenging times. The two years to 30th September 2022 were overshadowed with a pandemic threat not experienced before in our lifetime. Lifestyle changes affected us, our family and friends, with your charity having to transform itself to support you, intercede on your behalf and identify and share the guidance you sought. Below is a summary of the challenges we faced and our achievements through the two years, based on the needs and the issues we all faced through the pandemic. We are hoping 2023 has brought an end to lockdown although we know things will never be the same. As an example, we are at present running hybrid events, with people able to attend in person or on Zoom and then everyone being able to access the recordings afterwards. The Trustees will continue to work for you, providing the support, knowledge and resources you seek so you can 'Live well with CLL'. 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.

Hilary Lindsay
October 2023

Who we are

Our charity was founded in 2004 by patients with Chronic Lymphocytic Leukaemia (CLL) and their partners. The need came from patients, the UKCLL Forum, CLL Specialists, researchers and scientists, 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). 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 17th October 2023 the Trustees of the Charity are:
Steve Abrahams
Norah Grant
John Greensmyth (Vice Chair)
Anthea Holland
Hilary Lindsay (Chair)
Steffi Sutters
Andy Taylor
Gail Wiegman
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 CLL patients together, 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 CLLSA, 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 has 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 many additional challenges resulting from the Covid-19 pandemic. Against that background, the Charity has: -

- Continued with the provision of a series of online webinar presentations in place of the previous practice of providing in person member conferences:
    - These presentations continued to be fronted by many of the leading experts in the field of the treatment of CLL.
    - The information thereby made available continued to prove vital in offering to CLL patients and their supporters, clear and knowledgeable guidance as to the measures to be taken in mitigation of the potential impact of Covid related infections on their own particular circumstances.
- 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 what it is hoped might be the first of a series of short animations designed to inform patients of various of the 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, despite the limitations that were placed on many of these activities as a result of the restrictions put in place to combat and control the pandemic.
- 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 very little funding goes on overheads. As Trustees, none of our Board are paid, except for expenses. We do not have offices and until recently only had one part time co-ordinator. 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 2021 the charity received grants from five pharmaceutical companies providing CLL products and services in the UK which totalled £88,500 and, in the year, ended 30th September 2022 received grants from the same five pharmaceutical companies totalling £66,500. 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 2021 this amounted to £950 and in the year ended 30th September 2022 to £3,250. In several cases the companies gave us extra grants to provide support during the pandemic, but this was a time when we were not able to hold face-to-face conferences which is one of our main areas of expense, As a result our reserves increased during this two year period, but this was a time when the future was particularly uncertain.

We are 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.

Income and Expenditure Accounts for the years ended 30th September 2021 and 2022

	2022		2021	
Income:	£	£	£	£
Planned donations	11,337		10,313	
Casual donations	21,896		18,384	
Conference donations	362		-	
Corporate and other donations	3,190		3,613	
Legacies & In Memory	8,700		3,279	
Sponsorship & Fundraising	24,229		18,792	
Gift Aid recovered	3,284		3,542	
		72,997		57,922
Pharmaceutical support	65,500		88,500	
Other grants	-		4,717	
		65,500		93,217
Interest		2,192		1,798
		140,689		152,937
Expenditure:				
Conferences & Webinars	6,814		10,087	
Website	8,373		10,747	
Newsletters & Publications	316		7,320	
Support ACT & Helpline	12,951		7,241	
Advocacy & Promotion	9,755		9,219	
		38,209		44,615
Administration		34,392		23,949
Fundraising		14,240		9,923
		86,841		78,486
Surplus for the year		53,849		74,451

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 2022 the Charity held reserves of £378,495. In the subsequent year our expenditure has increased, we now have a second part-time staff member, post Covid we have returned to a programme of patient conferences held throughout the UK and our reserves have moved to a planned downward trajectory.