



Annual Report  
& Financial Statement  
2020-2021

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# Introduction by the Chair, Marc Auckland

We continue to live in challenging times. 2020 was 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, lobby on your behalf and provide the guidance you sought. Below is a summary of those challenges and achievements through the year, based on your needs and the issues faced through the pandemic. Let's all believe 2021 truly brings an end to lockdown. We will continue to work for you on your behalf providing the support, knowledge and resources you seek to continue to 'Live well with CLL'.

## 2021 Summary

### Who we are, what we do and why

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 lobby for the best treatments for people with CLL.

We continue, uniquely, 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. We do it to provide resources and support specifically focused on CLL, developed in partnership with experts and run by people from the community who best understand the emotional and physical challenges of the disease. This past year has forced us to adapt how we work and support you. It has driven us to closer collaborations with the UKCLL Forum and partner charities such as Leukaemia Care and Lymphoma Action.



# Achievements

- Launched the new website at the turn of 2019/20 with a content review, extra features such as online donating, publication ordering and much simpler easier site navigation.
- FLAIR/STATIC Ibrutinib access – We worked with the UKCLL Forum to ensure Ibrutinib remains available post trial to the hundreds of people on the FLAIR trial. Development of the STATIC follow-on trial to be launched soon.
- COVID-19 Survey – 4 national surveys over the past year with up to a thousand replies which helped us lobby for the best guidance and treatment of our community. For example, changes to initial guidance to ensure ALL CLL patients should shield as soon as they are diagnosed.
- Moved from conferences to Webinars because of shielding guidance including extra COVID Special webinars with Virologists and immunologists advising on the latest information on the virus, vaccinations and treatment. We produced a total of 8 webinars during the year, each of which reached an average of about 350 people.
- Closer relationships with the Blood Cancer Alliance, a group of 15 UK charities. Together, we are working to tackle the issues blood cancer patients face and use our collective power to lobby for a faster return to cancer diagnosis and treatment post pandemic. We are also pressing for greater and faster access to new targeted drugs and treatment.  
<https://www.bloodcanceralliance.org/>
- Partnering with Cancer 52, an alliance of nearly 100 organisations working to address inequalities in cancer care and improve outcomes for patients with rarer cancers such as CLL. <https://www.cancer52.org.uk/>
- As the NHS devolves to the four home countries of the United Kingdom so we are ensuring guidance and country specific sources of expertise are identified and made available to members.

- Targeted and now close partnerships with the 5 key global pharmaceuticals providing CLL treatments in the UK. This increases our lobbying and influencing for better care and resources for you.
- Responded to the huge upswing in helpline calls during the last year – particularly about shielding and the consequences of that, the vaccine, return to the outside world. We responded to 95% of calls within 48 hours.
- We made a total of 10 submissions to the National Institute for Health and Care Excellence (NICE) and the Scottish Medical Council (SMC) and provided expert patient representation at the committee meetings that evaluate the drugs. Together with our partners, we were successful concerning several new, non-chemotherapy treatments which will improve the quality of life for CLL patients.
- We sent out a total of 14 email newsletters during the year, covering aspects of COVID-19 and the work of clinicians, keeping our members informed.
- We increased the number of members on our online forum, HealthUnlocked, to over 17,000 members, making it by far the largest and most influential CLL forum in the world. This was possible only through the efforts of our administrators and volunteers.
- We entered the world of social media and increased the number of active members on Twitter and Facebook, recognising that this is a medium more and more used by our members.
- We joined LinkedIn to raise our profile with clinicians in the UK and abroad.
- Membership in the Under 60 Club WhatsApp group has grown steadily. It is a very busy forum for people balancing CLL with the workplace and young families, as well as sharing concerns over Active Monitoring and starting treatment. Many thanks to everyone in the Under 60 Club for the continued success of the group.
- We combined with Leukaemia Care to promote the Buddy Scheme.

# Member Feedback

"Another great webinar. Thank you everyone involved for putting these on."

"Thank you so much for putting my question forward to be answered. It gives me confidence to have my job now."

"Relevant, up-to-date and trustworthy content."

"Good to have a lengthy Q&A session, with pre-submitted and on the spot questions, and to have it filtered and managed."

"Particularly useful for stressed and recently diagnosed people today."

"I enjoyed Brian's conversation with Dr Appleby about studying early CLL/SLL to look for a way to determine on diagnoses if we will progress to needing treatment, or not!! That would be amazing!"

"Not a question. Just a sincere thank you to all the panel."

"Simply THANK YOU! Amazing and really informative... Answered all my questions, and helped to move on..."

"I thank all the Trustees for the work involved, and indeed the guest speakers. I would definitely recommend watching this Webinar when the link is available. It is informative, understandable and optimistic' (via HealthUnlocked)."

"...I found the talk by Dr. Ben Kennedy so good that I wanted to dwell on many of the slides he used and time to assimilate what he said. I hope there will be a recording available. Thank you very much for organising this. (Note all speakers are recorded and available via the website along with the presentations)."

"Thank you for the mention in the latest newsletter about the dangers posed by Roundup weedkiller. The piece in the newsletter was well-balanced and practical in the sense that it gave advice about using the product safely around the garden."

“Thank you so much for all the time and hard work you put into supporting our members.”

“In lieu of a Christmas Card we wanted to say a ‘thank you’ for the incredible work you have done throughout this year. We have attended 2 conferences in the past and always valued the support and information available.”

“In these very challenging times, it has been so helpful to be able to attend webinars, have updates on the information available and to know that, if needed, we could ask for your help/advice. We hope you truly realise the value of all your work, we assure you it IS appreciated.”

“Thank you for your supportive phone call last week. I sent copies of your website advice and some from Blood Cancer UK. You’ll be glad to hear the next day I received a call from the GP Surgery to offer me a date for my COVID jab! Also, after applying for shielding via your website I received an apology for the GP for not replying to my query last summer. They have now flagged me on the system to receive another Pneumonia jab, annual flu jab priority and booked me in for my next blood test!”

“I’m emailing to say thank you so much for the phone call this morning and giving me the NHS website to go through. Both my husband and myself are now booked in for both doses of the vaccine at a pharmacy closer to home. I did ring the GP practice twice. The first time to get the text which I should have received on Friday, to book up and the second time to know how to get into the right website for their booking schedule – only to be told by the receptionist that their IT team would give me a call. So not holding my breath any longer; I took your advice and third time lucky! Thank You!! I’ll certainly be singing your praises to the Haematology oncology Team.”

“Thank you so much for the few positive words over the telephone last week. I am so pleased that we had that opportunity as they were most positive and encouraging. My husband had contacted ‘CLL Support’ almost immediately after I was diagnosed and whilst I desisted from ‘reading up’ when newsletters etc. came through, I believe that it certainly helped him understand the condition. Thank you and ‘CLL Support’ so much.”

## Under 60s Club Feedback

"I knew there'd be a voice of calm and reason from this group. Thanks for the top tips."

"I love this group and although I miss a lot, it's great to catch up with everyone's news."

"I love this group – you're all such inspirational people! Catching up on messages and can see lots of you are dealing with starting treatment and so just wanted to say that I'm thinking of you all and sending lots of positive energy your way."





## Trustees

We have restructured the Board so that the 12 Trustee places are filled with people each with a specific charity work area responsibility to include webinars, helpline, champions, Under 60 Club etc. Some Trustees retired with our thanks and new Trustees joined with skills and interest in the areas we cover. We developed an associate role for specialist, more time limited support and have started to strengthen our medical expertise with the appointment of a retired GP and a Director of clinical trials from Nottingham University. Both deepen our knowledge of the medical profession and CLL Treatment pathways. We are now seeking people who have maybe 2/3 hours a month to become associate Trustees helping with Accounts, IT (helpline, website and email and data base systems and storage).

## Financials

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 only one part time co-ordinator. This allows most of the funds raised to provide support, services, tools and materials for members.

Thank you for the great response in signing up to regular giving to your charity which means we can continue to support you through these challenging times. A summary of how we have spent the money can be found at the end of this document.



## Plans 2021

As we hopefully return to normal working, we have reflected on the impact of the pandemic on how we work and support you.

As a result, in summary, we plan to:

- Run an annual member survey to check we are still providing the services and support you want and identify any new demands that may be concerning you.
- Reintroduce face-to-face conferences carefully and as safely as possible, hopefully starting later this year.
- Create a well being resource for members. The challenges of the pandemic have highlighted a need to support members with resources to support the emotional well being of our community.
- Maintain online webinars, with records of both conferences and webinars streamed to social media and stored on the charity website for all members to access.
- Refresh the member handbook and website materials to ensure they are up to date with latest new treatments, trials and guidance.
- Strengthen the links to partner charities particularly through the Blood Cancer Alliance and Cancer 52 to strengthen our lobby and influencing capability.
- Develop the close partnership with the UKCLL Forum of experts to ensure we provide members with the latest CLL research, trials, guidance and treatments.
- Attend the British Society of Haematologists conferences and meetings to promote the work and resources of the charity.
- Join the European CLL Associates Network (CLAAN) to learn of the latest research, trials, treatments and developments in Europe that we may wish to lobby for in the UK.

- Ensure we identify and provide information about the differences in treatment between the devolved nations, including links to the correct national advice as it may vary between N Ireland, Wales, Scotland and England.
- Host a webinar in Scotland inviting members living in Scotland and with Scottish expert speakers. If this pilot is successful, we will consider if there is demand for similar webinars in Wales and Northern Ireland.
- Continue to provide authoritative information via the regular member newsletter, helpline, our booklet, access to local groups and our own Under 60s Club.
- Maintain the website, content and resources as well as the helpline and links to the local community groups buddy resource.
- Keep our financial position strong to enable us to support members.

# How the Charity has used your money

Year ended 30.09.2020

| Income:                     | £      | £             |
|-----------------------------|--------|---------------|
| Planned donations           | 7,158  |               |
| Casual donations            | 6,299  |               |
| Conference donations        | 2,835  |               |
| Corporate & other donations | 2,631  |               |
| Legacies & In memory        | 2,578  |               |
| Sponsorship & Fundraising   | 5,676  |               |
| Gift Aid recovered          | 2,207  | 29,383        |
| Pharmaceutical support      | 52,700 |               |
| Other grants                | 5,158  | 57,858        |
| Interest                    |        | 2,460         |
|                             |        | <u>89,701</u> |

## Expenditure:

|                            |        |               |
|----------------------------|--------|---------------|
| Conferences & Webinars     | 25,749 |               |
| Website                    | 14,315 |               |
| Newsletters & publications | 10,609 |               |
| Helpline                   | 3,115  |               |
| Advocacy & promotion       | 6,814  | 60,602        |
| Administration             |        | 23,594        |
| Fundraising                |        | 7,911         |
|                            |        | <u>92,106</u> |

## Note:

Every member of the Board of Trustees has been affected personally by CLL, either as a patient or through a close personal relationship with a patient, and undertakes the work of the Charity without remuneration of any form other than the reimbursement of out-of-pocket expenses that they may have incurred.