



CLL SUPPORT
Helping people affected by CLL and SLL

Newsletter

December 2022 - Issue No 11
Our free helpline: 0800 977 4369

Seasons greetings!



**Wishing all our members a very happy Christmas period and a healthy
New Year.**

**On behalf of all the trustees, thank you so much for your support throughout the
year. It's very much appreciated.**

Welcome to our latest newsletter, and I hope you find it informative and useful

It's at this time of year when we think of families and reflect on the year gone by. For many of our members it's been a very difficult year. Concerns about Covid are still with us, and winter flu is becoming more prevalent. It's still a time of caution for people with CLL amongst all the festivities. Despite this, I sincerely hope that you will be able to enjoy some time with family and friends.

Our main event since the last newsletter was the very successful Birmingham conference, and you can find more information, including links to the videos, below.

It's our hope, and intention, to build on the success of the Glasgow and Birmingham conferences, and we are already planning four more in 2023, the first of which is in Cambridge on 18 March, with Prof George Follows as key speaker. We hope to see you there.

I'm very pleased to say that we had an excellent response to my appeal for more Associate Trustees and we are talking to several potential Associates. However, we are still looking for a trustee to take over the finance position. If you have financial experience, and would like to be part of the team, please do contact me.

I would like to add my personal thanks to Rupert Beasley, who has retired from active service as a trustee after many years of wise council and work. He's been a valued member of the team and leaves the legacy of the new future-proof website with more content and flexibility than the original site which served us well for many years. I'm very glad to say that he will still be giving us his expertise, as he will remain as an associate trustee.

Finally, thank you again for your support throughout the year, and I wish you, your family and friends a peaceful holiday and, good health.

Marc Auckland

Chair, CLL Support

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Birmingham conference videos

If you missed the conference, catch up with the talks here

Prof. Paul Moss was our keynote speaker and spoke about **treatment options in 2022 and in the future**. This stimulating talk was followed by a Q & A session with Prof Moss. There was also a fascinating patient's story by **David Warner**, and a summary of our recent survey findings from one of our trustees, **Hilary Lindsay**.& A session with Prof Moss. There was also a fascinating patient's story by **David Warner**, and a summary of our recent survey findings from one of our trustees, **Hilary Lindsay**.



[Birmingham conference videos](#)

**Our next conference will be in Cambridge on 18 March 2023
Save the date!**

Latest Covid News

After a slight fall, Covid cases are rising again. In the period ending 10 December, cases increased by 17.2% across England, and similar increases were reported in Scotland, Wales and Northern Ireland.

However, for the first time, more hospital beds are occupied by patients with severe 'flu than with Covid, and these numbers are increasing.

People with CLL are especially vulnerable to chest infections after catching 'flu. It's very important, therefore, to make sure you are fully vaccinated for both Covid (currently six jabs) and for 'flu.

To make sure you are fully vaccinated, download our vaccination leaflet [here](#).

Stirling fundraising effort!



Hannah arriving at the finish!

A big thank you to **Hannah White** who ran the Cheltenham Half Marathon recently to raise funds for CLL Support.

We rely on dedicated fundraisers like Hannah to enable us to carry on our work, and we are enormously grateful for all their efforts on our behalf.

Remember, there are less strenuous ways of helping CLL Support. Have a look at some of the opportunities later in this newsletter.

Recruiting for IMPROVE study. Could you help?

Improving Covid vaccine response for blood cancer patients



Anyone taking either **ibrutinib** or **acalabrutinib** for Chronic Lymphocytic Leukaemia (CLL), and due a Covid-19 vaccination in the coming months, is invited to join a new study called the **IMPROVE trial**. The trial will explore whether pausing treatment for three weeks around the time of vaccination improves the immune response to Covid-19. The study will also check whether pausing treatment has any side effects.

Results from this study will help guide future advice for people with CLL who take ibrutinib or acalabrutinib.

Interested in taking part? Contact IMPROVE@ndorms.ox.ac.uk or 0808 175 1455.

Announcing new developments in our mental health support programme



We know that a CLL diagnosis can be, for many people, extremely difficult to come to terms with.

We wanted to help with this and so we set up a new website, Support Act:

<https://cllsupport-act.org.uk/>

We're very pleased that we are now ready to include further support by launching free online drop-in sessions.

Who is this for? Any member of CLL Support, both patients and supporters, at any stage of CLL.

What's involved? Each drop-in session will be led by **Pinky Jiminez Agrawal**, who is an occupational behavioural therapist, and who has created the SupportAct programme for us. SupportAct covers eight different areas around emotional wellbeing, and various exercises support each theme.

How do I apply? Simply send your name, email and mobile number and when you would like to attend to: Cherry at: cherry.mills@cllsupport.org.uk The maximum number for each session is 20.

All sessions will be via Zoom.

When does it start?

Evening sessions: Tuesday 17 January 7.00 - 8.00pm and then every 3rd Tuesday of the month

Morning sessions: Thursday 2 February 10.00 - 11.00am and then every 1st Thursday of the month.

We look forward to welcoming you. Remember it's all entirely free, and you can find more information [here](#)

We are delighted to be able to offer these opportunities free of charge to members. If, however, you would like to make a donation this will enable us to reach more members.

Latest news!

New treatments.

Zanubrutinib is a new treatment for CLL and has just been approved in Europe. It's currently going through the approval process with NICE in the UK, and we made a submission to NICE on behalf of CLL patients.

Zanubrutinib has a favourable safety profile, including lower rates of atrial fibrillation/flutter compared with ibrutinib.

Pirtobrutinib is a new generation BTK inhibitor showing good results in the Phase 1/2 BRUIN trial in the USA. Further details can be found [HERE](#).

Patients on treatment may experience a decline (resistance) in the efficiency of the drug over time. It's encouraging that research and development is still going on to help with this.

Evusheld We have been campaigning for some time to have this treatment available for blood cancer patients to help prevent severe Covid infection. We have now received from the Department of Health & Social Care the following statement:

"Based on the evidence that is currently available and after careful analysis and consideration, the UK Government has decided not to procure Evusheld through emergency routes as a preventative treatment at this time. When the Medicines and Healthcare products Regulatory Agency (MHRA) gave marketing authorisation to Evusheld on 17 March, it noted a lack of data regarding dose and efficacy against the Omicron variant. This lack of supporting data has also been noted by other respected authorities, including the European Medicines."

It would seem that this is now closed, but we have noted that the DHSC have said 'at this time', which may indicate that their may be reconsidered in the future.

Can you help, please?



Please can you share your CLL story?

For those who attended our conferences before the pandemic, an undoubted highlight was one of our members sharing their CLL story. People found it enormously encouraging to hear how others coped with their CLL.

We would like to reintroduce this to webinars and, when we can, face to face, conferences.

Everyone's story is relevant. Do you perhaps have a hobby or job that would help to show how you have managed with CLL? You can do this with a partner, or indeed

your partner can tell their tale. Have a look at how other members have told their story:

[Sue and Elizabeth's story](#)

If you are happy to share your story for a few minutes, we'd love to hear from you. You would be helping other people with CLL.

Please email: Lewis.Troke@cllsupport.org.uk.

Many thanks

Marc Auckland

Don't forget! Here are two other way you can help:



This is another relatively painless way you can help. Nearly all major supermarkets and stores operate this scheme, which again works by them donating various amounts to your chosen charity for everyday purchases.

Note that our official registered Charity title is: Chronic Lymphocytic Support Association (CLLSA), and you will need to use this title to register. Happy spending!

<https://www.easyfundraising.org.uk/>



Amazon Smile is just like the usual Amazon site, same products, same prices. The difference is that if you sign up, CLL Support receives a small percentage of the cost of anything you buy - at no cost to you! It really is that simple! Give it a try!

<https://smile.amazon.co.uk>

HealthUnlocked

HealthUnlocked is our very active on-line forum, where you will find support and knowledgeable, reliable advice on all things to do with CLL. The site also has a very comprehensive resource of CLL information, which is updated regularly, and is moderated by our team of Administrators and Volunteers. You can check it out here:

[HealthUnlocked](#)

Do you have a will? If not, we can help



Our new free Will-writing service.

We do understand that the decision to write a will can be a delicate topic and must be handled sensitively. But it is essential for most people to have a will in order to safeguard their interests after death.

It would be wonderful if you could read on before deciding if this is something you wish to do.

CLL Support is a member of **The National Free Wills Network** which gives us the opportunity to offer a limited number of valid 'simple' Wills (or mirror Wills for a couple) **entirely free of charge and written by a solicitor local to you.**

There is no obligation whatsoever to include a gift to CLL Support in your Will, but we sincerely hope that you might consider doing so.

How does it work?

1. You tell us you are interested in using this service.
2. We refer your details to The Free Will Network. Your details are not shared with anyone else and the Network will only contact you to provide the service, never for marketing.
3. The Network send you a list of your nearest participating solicitors and a voucher to take to your appointment.
4. You meet with the solicitor at an office local to you (or online if you prefer) to discuss your wishes and prepare your Will in the usual way. Most Wills are completely covered by the free Will service. If your Will is more complex, your solicitor will advise you of this, giving you the option to continue and pay the difference if you wish.
5. Once you have made your Will, the Network tells us if your Will includes a gift to CLL Support so that we can write to thank you.

It's a very discrete and straightforward process, and if you would like more information, please ask for a copy of our explanatory leaflet here:

coordinator@cllsupport.org.uk

Or download from our website [here](#):



Any thoughts?

We would love to hear from you with any comments (good, bad or indifferent).

CLL Support is a members' charity, which means it really belongs to you, our members, and the trustees work on your behalf. So your thoughts and suggestions are important.

You may have a story to tell which could help other patients. We welcome contributions of up to 500 words, so do let us know if you have something to say.

We can't promise to print everything, but we always try to.

We would like to make this newsletter more interactive, if possible, so please tell us about anything that's on your mind that could help other members.

You can contact us at membership@cilsupport.org.uk

We look forward to hearing from you!