



CLL SUPPORT
Helping people affected by CLL and SLL

Newsletter

April 2022 Issue No 04

Bringing you the latest news and developments in CLL and SLL

Our free helpline: 0800 977 4369

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



The early months of the year are when we reflect on the previous year and look forward to our plans for the coming year. 2021 was, of course, dominated by Covid and the roll out of vaccines, which was very positive, but also created questions and uncertainties. Many blood cancer patients couldn't access vaccines and treatments because their health records had been wrongly coded, or not coded at all.

We were able to work with other blood cancer charities and NHS Digital to correct this problem, and patients who had been left out began to get their PCR test kits and letters. This was a significant achievement in difficult circumstances.

Throughout this period, our role has been to provide clear information and support. As a result we have seen more people use our services, visit our website, contact our helpline, and join our online webinars. We know from

the many messages from our members how much this is valued.

We understand that this year will bring its own challenges, but we are keen to meet them and do even more for our members. We know that Covid will have a far-reaching effect on the NHS, and that this could have an impact on treatment for CLL/SLL patients. We want to do more to effect change and influence developments wherever we can, and we will continue to work to this end.

None of this is possible without the generosity of our members, so thank you for your support.

In the next newsletter I will be talking about your Charity in particular. Some trustees are coming towards the end of their tenure and it is time again to seek new volunteers. I will use the editorial to share a little of what we do, where the opportunities to join the team are, and a little of what is involved. I hope we get more members stepping forward to help maintain the services and support that we all enjoy! I have certainly found it rewarding, I have learnt lots, made new friends and had fun on occasion!

Finally, please have a look at the positive story in this newsletter from one of our members. I think you will find it inspiring.

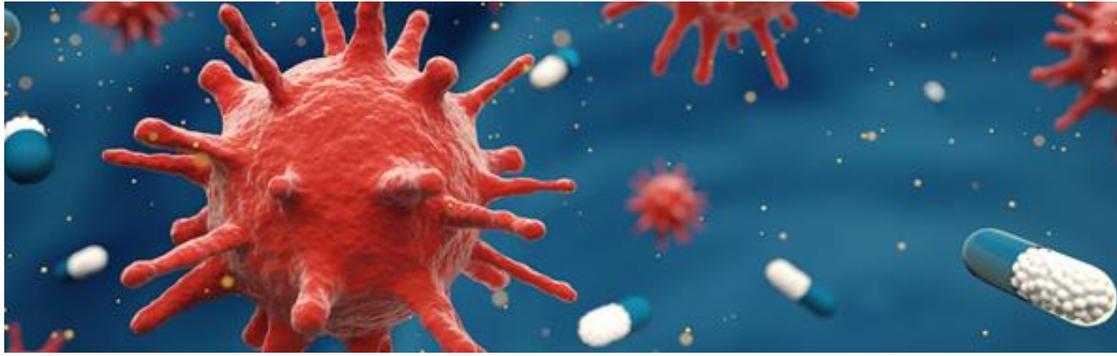
Wishing you good health.

Marc Auckland

Chair, CLL Support.

Covid-19 update

Covid is still very much with us. Here is a summary of the current situation.



Covid infections on the rise

At the time of writing, Covid infections throughout the UK were increasing rapidly, as were the number of people in hospital with Covid. About half of these were not admitted because of Covid, but for some other condition, and were found to be positive on arrival. The rise in infection is thought to be because of easing of restrictions, waning vaccine protection, and a new variant of Omicron (BA.2), which is much more infectious. Disturbingly, most of the infections were found in the over-55 population, and, in particular, over 75s seem to be most vulnerable.

Shockingly, half of blood cancer patients have yet to receive their fourth vaccination, and, as a result, are ending up in intensive care. **If you have not had your fourth jab yet, we strongly recommend that you get it as soon as possible.** See below for more details, and also about the **Spring booster** vaccination.

Currently, it is estimated that 1 in 16 people in England have Covid, with even higher numbers in some devolved nations. Scotland reported the highest number of cases recorded since the start of the pandemic, 1 in 11 people. To put this into every day context, it is very likely that in a busy supermarket there will be, on average, several customers who have Covid, since many do not display symptoms early in the infection.

It remains important, therefore, to continue to take whatever precautions you can to avoid infection. The main thing you can do if you can't avoid crowded areas is to wear a tight fitting medical-grade mask (FFP2, FFP3 or N95 classification) as they have been shown to reduce risk of infection by up to 83%.*

*Research published by the Centre for Disease Control (CDC).

Important - Fifth booster vaccination now available

From March 21st **Spring booster vaccinations** are available for immunocompromised patients, and we recommend that you book yours. We answer questions about vaccinations, and how to get them [here](#). You can book an appointment for your vaccinations [here](#).

Flu vaccination vital in addition to Covid jab

Research by Edinburgh University; Liverpool University and Imperial College London found that patients who had flu as well as Covid had 'significantly poorer outcomes.' It is vital, therefore, to make sure that you have had both types of vaccination. We know that blood cancer patients may not receive full protection from these, but any protection is certainly better than none.

Lateral Flow Tests (LFT).

LFTs will no longer be free from April for the general population, but will be free for medically vulnerable patients. If you've been told that you are eligible for treatment if you catch Covid, you should be eligible for free tests also. You will receive a letter informing you of this, and a free pack of LFT tests. The system may not be fully in place, and there may be some delay. We recommend you keep tests at home in case you become infected, and check with your GP to make sure you are correctly coded on your records (see below). You will need a positive LFT test, or PCR test, to be assessed for treatment if you become infected with Covid.

COVID Treatments

There has been much confusion over treatment for CLL patients if they get Covid, and you can find the latest information and how to access treatment [here](#).

We urge you to have a look at this to help prepare yourself if you get Covid. This is even more important as restrictions are being reduced.

A reminder to check that your medical records are correctly coded.

The main code (known as SNOMED codes) for CLL is 277473004, but

there are several others, depending whether you are having treatment, or on medical monitoring (watch and wait). It's important to get the correct code to be able to access testing and treatment. You can find details of the coding on the NHS Digital website [here](#).

Evusheld treatment approved

A new medicine, Evusheld, has been authorised for Covid prevention by the [Medicines and Healthcare products Regulatory Agency \(MHRA\)](#).

This Covid medicine has been developed by AstraZeneca, and has been approved for use in adults who are immunosuppressed. You can read more about this in [the MHRA's press release](#).

Evusheld is a combination of two long-acting antibodies, tixagevimab and cilgavimab, which are given as separate single dose injections. It is unlike other treatments that are available, in that it is designed to prevent infection, rather than treat after infection (known as 'pre-exposure prophylaxis'). It is thought that prevention will be provided for about six months after injection.

Unfortunately, the UK government has yet to decide on funding for this treatment. So we don't know when, or if, it will be available. We will provide more information as soon as we have it.

Remember - Omicron symptoms can differ from the Delta variant.

- **The five main symptoms of Omicron are more like those associated with a cold, including: sore throat, runny nose, headache, fatigue and sneezing.** Smell and taste may be normal. Some people also reported loss of appetite and 'brain fog'.*
- * Data taken from the Zoe study.

An initiative from Abbvie, manufacturers of Venetoclax



Small things, big difference

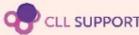
FREE TEXT SERVICE FOR PEOPLE WITH CHRONIC LYMPHOCYTIC LEUKAEMIA (CLL). GET YOUR WEEKLY INSIGHTS, PRACTICAL TIPS AND WISDOM FROM MEMBERS OF THE CLL COMMUNITY BY SIGNING UP.

HOW DOES THIS WORK?

Text MYCLL to 88222

from anywhere in the UK (applicable with smartphones only*). You'll be sent a free, automated text message with information on how to subscribe to the service. Once you've subscribed, you will begin to receive free weekly text messages.

This is an AbbVie service. Content developed in collaboration with CLL Support with input from Lymphoma Action and Leukaemia Care.

*Some network providers may have filters in place that may be incompatible with this MMS service or will prevent devices from receiving picture messages from organisations. Unfortunately, in the event that this occurs, you will not be able to view the messages.

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We know that being diagnosed with chronic lymphocytic leukaemia (CLL) can be a life-changing experience and knowing where to look to find credible, useful information can be overwhelming.

Small Things, Big Difference is a new, **free** weekly text service, launched by AbbVie with CLL Support, and our sister blood cancer charities. It aims to provide bite-sized practical tips and wisdom from members of the CLL community on how to navigate this 'new normal'.

This totally free service is part of the '**My CLLife**' suite of resources, which help people affected by CLL to better cope with the complex and unpredictable nature of the condition.

This includes the **Small Things, Big Difference booklet** and the AbbVie UK YouTube Oncology playlist.

If you have been diagnosed with CLL or are caring for someone with CLL, Text **MYCLL** to **88222** and follow the sign-up instructions for your weekly dose of inspiration and insights on how to live well with CLL
#SmallThingsBigDifference.

Fundraising!

We rely on help from our members to raise funds. Indeed, we depend on these funds to help carry on our work. Here are three ways you can help.

Fundraiser 1



A great opportunity to take part in one of the most popular cycling events in the UK - Ride London! Enjoy a great day out and help CLL Support at the same time!

Places for this event are very scarce, but we have managed to secure five places on this iconic cycling event to be held in London and Essex on

May 29th 2022.

We have already filled three of the places and seek to complete the group

by enlisting two other cyclists. Entry is free but you must raise £350 in sponsorship using the dedicated Enthuse fundraising platform.

More info [here](#).

If you or anyone you know would like to take on this 100 mile challenge, then please contact us at:

coordinator@cllsupport.org.uk

Read [here](#) why one of our team has decided to take up the challenge.



Fundraiser 2





The London Vitality 10k run returns on 2 May!

If you'd like to experience the camaraderie of a mass participation 10K event that's fun and achievable for beginners and more seasoned runners alike, the Vitality London 10,000 is for you.

FREE TICKETS AVAILABLE NOW!

Taking place on Monday 2 May 2022, this celebratory event is not to be missed – and you can book your place now!

Email: coordinator@cllsupport.org.uk

A fundraising commitment of £250.00 is required.

The Vitality London 10,000 guides you through many of central London's most famous landmarks, including Admiralty Arch, St Paul's

Cathedral, the Bank of England, Somerset House, Big Ben, the Houses of Parliament and Westminster Abbey, so there's plenty to feast your eyes on as you run. You can find more information [here](#)

The first wave of participants will start their 10K at 10:00, with the last wave setting off by 11:15.

**This is an amazingly friendly event. Join our team and have some fun!
FREE entry and FREE running vest!**

Fundraiser 3

There is another, less energetic, way you could 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](#):

Can you help, please?

Call for members in the Devolved Nations to get involved

One of our Trustees within the team has taken on the responsibility for matters pertaining to CLL and related health issues within the devolved nations.

John Greensmyth is resident in Scotland but he also keeps a watching brief of Wales and Northern Ireland. The scope of this tasking involves attending (virtual) meetings on behalf of CLL Support and monitoring various Government publications and related sources of information. This often includes representing the patient voice on a variety of platforms - this can be as simple as relating patient experience to a panel during a discussion topic or advocating on behalf of patients wherever possible.

John's role is wide ranging and he would benefit from some help! Some on the ground presence with local knowledge in each of the devolved nations, **especially WALES** would be appreciated. No qualification is required and a willingness to help in a constructive manner is the simple job specification. A few spare hours every so often is the only burden. John will offer guidance and he is happy to explain the scope in more detail to any willing volunteers. The pay-back is the feel good reward of 'doing my bit to help' and we will all benefit in the longer term.

Anyone interested in finding out more should contact John by

email: john.greensmyth@cllsupport.org.uk

A job opportunity!

Come and work with us.

We currently have an opening for a home-based, part-time, donor relations and administration person to support our coordinator.

The role is for the equivalent of two days a week, to be worked flexibly across the month, and the annual salary will be in the region of £10,000.

Interested in joining our friendly team? Request a job description and submit your cv with a covering letter to Sarah Tobin

at: coordinator@cllsupport.org.uk

We look forward to hearing from you.

A patient's story

Remember the Beatles 'When I'm 64'?

We know from your feedback, that this section of the newsletter is very popular. In this edition, one of our trustees reflects on living with CLL for over 30 years. We hope you will find it inspirational.

He writes:

"Earlier this week we celebrated my 64th birthday, clearly not as much a milestone as say a 50th or 60th but this one has a unique significance all of its own. I was originally diagnosed in 1990 so quick maths will reveal that **I will now have lived with cancer longer than I have been without it.**

This is in no way a personal boast but testament to the excellent care I've

received in the Haematology Dept. at Aberdeen Royal Infirmary and our local Health Centre. Probably more importantly, my longevity is also as a result of advances in medical science.

When I was diagnosed, monoclonal antibody treatment and the likes of Ibrutinib and Venetoclax were the stuff of dream options. Little did I think in the dark times of 2014 that I'd ever be able to write an email of this nature and for that I'm both blessed and truly grateful.

So before I get emotional, just two takeaways really;

1. Research is key to improved treatment pathways and outcomes.
2. You can live well with CLL.

And finally.....thanks to all my fellow trustees for your support, the work you do and time you devote to CLL Support - it makes a difference, a very positive one."

Don't forget!

We rely on donations from our members to help us to carry on our work
There are easy ways you can help us.

If you ever use Amazon, try logging on through **Amazon Smile**. The cost is exactly the same, but Amazon donate a small percentage to your nominated charity.
It's quite painless!

You can also use **Easy Fundraising** [here](#). This is very similar, but has access to hundreds of stores, including the major supermarkets.

**Please note: You need to enter our full name -
Chronic Lymphocytic Leukaemia Support Association - when registering.**

Why not give it a go - it won't cost you anything!





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@cllsupport.org.uk

We look forward to hearing from you!

