



Newsletter

May 2022 Issue No 05

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.



An important message from our Chair, Marc Auckland

From humble beginnings around a kitchen table nearly 20 years ago, your charity has grown to 3,000+ members, and been key in lobbying for, amongst other things, the trialling and launch of new treatments.

We are partners with the UK CLL Forum of UK clinical experts, who help us to provide guides, conferences, webinars, advice on vaccines, diet, and exercise.

Our other services, such as the website, newsletters, helpline and our very active Under 60s group, have grown and been praised by members. We have members who joined the Champions group and help with focus groups, studies, trials and taking our booklets and leaflets to their clinic appointment for others to use.

It is now time again for some of the trustee team to stand aside, and for new members to join. I look forward to several of you coming forward and helping keep this patient-led charity at the forefront of CLL developments.

We will be looking for a range of people to help manage the newsletter; people with finance skills to be the next treasurer; people who can learn to manage the webinars and conferences with the team. We are also keen to talk with you if you have an interest in IT to help manage the website, and others to work with the team to ensure corporate and member funding is maintained.

The good news is most of us were not experts when we joined! We learned from the current trustees, who are a welcoming and friendly bunch. We have suppliers and consultants to help, and we have a year or so to manage the recruitment, induction and training. All the trustees who will be stepping down have agreed to buddy the new appointments to help answer their questions.

Please do consider how you can help your charity. If you are interested, email me at marc.auckland@cllsupport.org.uk. We will be arranging a video call where current trustees will explain their roles, what is involved, benefits they have enjoyed and answer any questions people have. I am also happy with any of the trustees to have an informal chat over the phone with any of you to explore what the roles involve. You can then decide if you want to volunteer and fill in the application forms.

Please do consider helping. CLL Support can't exist without trustees. Personally, I have learned a lot about treatments, made some good friends, had some laughs, and feel I have helped our community. All the roles are flexible to fit your interests and experience. I look forward to as many of you as possible expressing an interest, and some great conversations on the webinar.

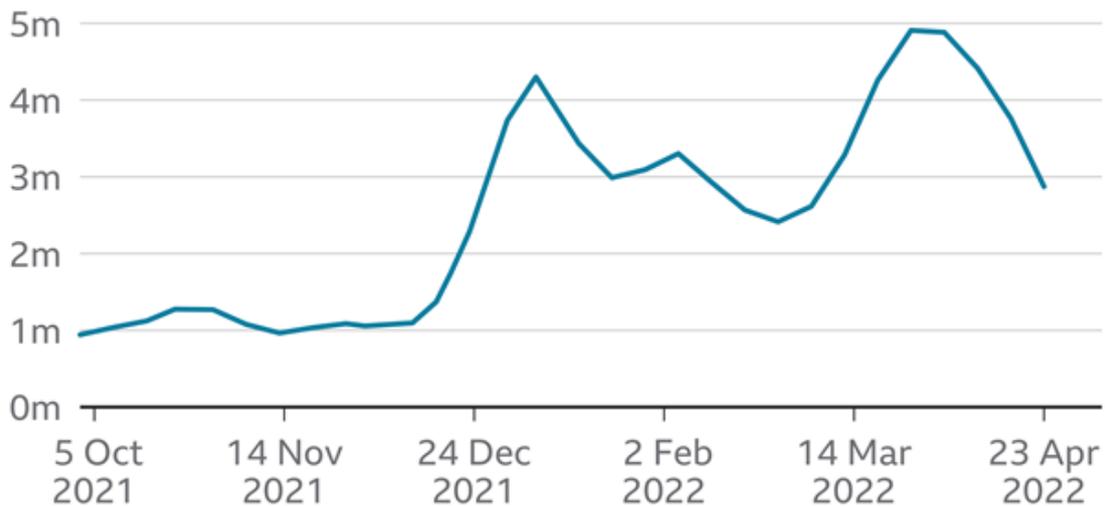
Wishing you good health.

Marc Auckland

Chair, CLL Support.

We hope to be able to reduce this section over time, but in the meantime:
Covid-19 cases falling - a quick update

Estimated people testing positive for coronavirus



Data include Northern Ireland from Oct 2020, Scotland from Nov 2020

Estimated infections fell in England, Wales and Scotland in the week ending 23 April, [according to the infection survey by the Office for National Statistics](#). The trend in Northern Ireland was more uncertain, but infections remain lower than in recent weeks.

Total infections across the UK were down by a quarter on the previous week, with an estimated one in every 23 people infected.

Hospital numbers are also falling

The most recent government figures for the whole of the UK show 13,027 people with coronavirus were in hospital, down from 16,473 a week earlier.

This is good news for CLL patients, because the risk of becoming infected is reducing day by day.

However, it remains important 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).

A reminder - Fifth booster vaccination now available

From March 21st **Spring booster vaccinations** are available for immunocompromised patients, and we recommend that you book yours, if you have not already done so. 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. We have prepared a leaflet to help patients and GPs to understand vaccinations, and you can find it [here](#).

Lateral Flow Tests (LFT).

A reminder that you will need a positive LFT test, or PCR test, to be assessed for treatment if you become infected with Covid. 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).

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 recommend that you to have a look at this to help prepare yourself if you get Covid.

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, but not yet available

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

cancer charities for more information on this, and we will provide more details 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.

News about our next webinar

'Understanding CLL - How does this help me?'

May 17 2022. 1.00 pm - 230 pm



Dr Toby Eyre is a consultant haematologist at Oxford University Hospitals NHS Foundation Trust, specialising in the management of lymphoid malignancies. He is a national expert in the management of patients with lymphoma and patients with chronic lymphocytic leukaemia. Dr Eyre is an investigator on a number of national UK lymphoma and chronic lymphocytic leukaemia trials and has published nearly 70 peer-review articles on areas of lymphoma and CLL and has presented regularly at national and international conferences.

Dr Eyre will be taking questions at the end of his talk, and you will be able to send them in advance, or on the day.

This promises to be an informative and entertaining webinar and we will be sending invitations shortly, so please look out for it!

Most of us enjoy sunshine, but.....



CLL patients are more likely to suffer from skin cancer. As the level of Ultra Violet (UV) rays from the sun increase, it's important to use a high-factor sunscreen and to use a head covering whenever you go out.

Sun safety tips:

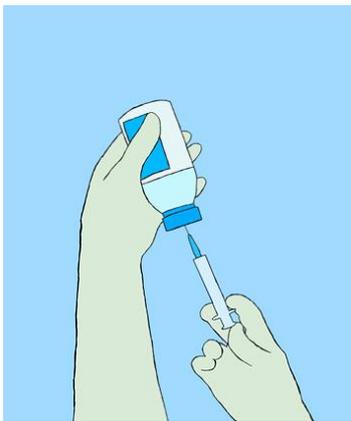
Make sure you:

- spend time in the shade between 11am and 3pm
 - make sure you never burn
 - cover up with suitable clothing and sunglasses
 - use at least factor 30 sunscreen
 - **When buying sunscreen, the label should have:**
 - a sun protection factor (SPF) of at least 30 to protect against UVB
 - at least 4-star UVA protection
 - UVA protection can also be indicated by the letters "UVA" in a circle, which indicates that it meets the EU standard.
-

Make sure the sunscreen is not past its expiry date. Most sunscreens have a shelf life of 2 to 3 years.

Remember, UV levels can be high, even on an overcast day.

New superbug drugs will save lives.



CLL patients are at higher risk of infection, particularly chest infections and sepsis. So, news that two new treatments that combat antibiotic resistant infections have been approved by The National Institute for Health and Care Excellence (NICE) is good news.

The drugs, **cefiderocol** and **ceftazidime**, administered with avibactam, are currently available only in England, but it's hoped that other parts of the UK will adopt them soon.

Have your say! Look out for our survey

It has been a long time since we ran face-to-face conferences and were able to talk with you about your personal experiences and needs. We need this information to help us to understand what your charity should focus on. As



we are a patient-led charity, we have decided to invite you all, patients, partners and supporters, to complete a short survey, so that we can get a clear picture of our members' experiences and concerns. You will shortly receive an email and link to the survey. Please take the time to complete and return it. All replies will be in confidence, and I will share the results, and subsequent plans, in the months to come. The trustees and I hope you stay safe and well, and hope to see you at face-to-face events in the future.

Many thanks for your help.

Marc Auckland

Chair, CLL Support

Under 60s Club walk at Grafam Water - April 2022



Grafham Water is just a few short miles from Huntingdon in Cambridgeshire. It's England's third-largest reservoir and can be found nestled in 1500 acres of beautiful countryside.

The ever-active U-60 Group organised a walk there on Sunday 3rd April. We had 14 people and 5 dogs, and one dedicated couple even drove 140 miles to join us!! It was great to meet everyone and



More photos [here](#).

Interested in joining? Contact

Norah at:

norah.grant@cllsupport.org.uk

chat as we navigated the paths around the lake. Most of us went the full 10 miles (22k steps) around. We were to meet up with the smaller group that started out in the other direction for a shorter walk, but that didn't quite work out. Nevertheless, we all had someone to talk to, the dogs had a paddle (see photo), and nobody fell in! Thank you to Helen Armstrong for stepping in to organise the event, and to Steve Abraham for volunteering to set up another walk in early summer or autumn (look out for news of that!), and for writing most of this.



Puzzled by CLL terms?

Some of the terms and abbreviations used in CLL diagnosis and management can be confusing, especially if you are recently diagnosed. We cut through the jargon, with explanations, and you can find them [here](#).



Contact us on:

membership@cllsupport.org.uk

Being diagnosed with blood cancer is a huge shock to patients and families. Knowing that others have experienced what you are going through can be a great help and a comfort. Why not share your story and help other CLL patients? We can print a brief description of just 500 words, and you will have the knowledge that sharing your experience has helped others.

Fundraising!

We rely on help from our members to raise funds. Indeed, we depend on these funds to help carry on our work. Here is a way you can help



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.





**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](#):

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!

