

## **Newsletter**

**June 2022 Issue No 06**

**Bringing you the latest news and developments in CLL and SLL**

**Our free helpline: 0800 977 4369**

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



I have always welcomed the opportunity our newsletters give me of keeping in touch with our members.

CLL Support has seen some radical changes over the last few years as we adapt to new challenges. As we plan ahead for 2022, there is so much more we want to achieve. We want to make our services more accessible than ever, restart our face-to-face conferences, and develop our digital services.

To help our resources go even further, we continue to collaborate with others, making our voice stronger as we advocate for people with CLL and SLL. We do this by being part of the Blood Cancer Alliance, the One Cancer Voice coalition of charities, Cancer 52 and the CLL Advocates Network (CLLAN).

As you will have seen from our last newsletter, our next challenge will be to replace some of our key trustees. If you feel you may be interested in becoming a trustee, we have set up a video calls where you can hear from current trustees about their responsibilities and ask any questions you may

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have. If you would like to join us on one of the calls, please contact

me: [marc.auckland@cllsupport.org.uk](mailto:marc.auckland@cllsupport.org.uk)

Despite all the challenges, and with your help, we aim to keep providing expert information and support, and to keep pressing for better diagnosis, treatment, and care for CLL patients. I believe we are we are in a good position to achieve this.

Wishing you good health.

Marc Auckland

Chair, CLL Support.

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### Welcome to our new animation!

We know that being diagnosed with CLL or SLL can be very traumatic, and lead to anxiety for the patient, family and friends. We wanted to try to help patients at this 'just diagnosed' stage, so we developed this simple animation to help them understand a little about CLL. We hope you enjoy it!

We are indebted to the MDS UK Patient Support Group for allowing us to adapt the animation and to Peter Randall for generously funding it.



[Watch our new animation here](#)

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## Other ways we're helping CLL/SLL patients

We want to try to help patients to come to terms with the anxiety that can follow a CLL diagnosis for many people. To do this, we firstly established a new website devoted to offering a series of tools based on emotional well-being exercises. You can find the website [HERE](#)



Then, we wanted to see if Zoom based small group sessions would be effective.

So, we sponsored eight patients to hold sessions with the **Occupational**

**Therapist, Pinky Jimenez-Agrawal**, who helped us to design the well-being website. We have just received the following feedback from one of the group:

*"I just wanted to say thank you for giving me the opportunity to have group therapy with Pinky and the amazing group of women who also joined.*

*The sessions were thought provoking and really helpful. They really gave me the opportunity to look back and forward in my life and more importantly ...to focus on the present .*

*To meet, learn and share with a CLL group lead by Pinky has been very powerful and healing.*

*A lot of my journey has been lonely and tough.*

*CLL support and recent therapy has been so important and special to me. It's taught me to reach out and share."*

**We want to roll out these free sessions to a wider audience, still maintaining small groups, and we will be announcing details in a future newsletter.**

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## Videos of our latest webinars now available



### **'Understanding CLL - How does this help me?'**

**Dr Toby Eyre**, Consultant Haematologist at Oxford University Hospitals NHS Trust, discusses CLL followed by an informative Q and A session. If you missed it, or would like to watch again, you can do so here:



### **Our second webinar with CLL Ireland**

Four expert speakers cover a range of topics of interest to all CLL patients, including an informative Question and Answer session. If you missed it, you can watch it here:

[Watch the videos here](#)

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## Taking Supplements? Here's Why You Should Tell Your Doctor

Taking vitamins and supplements may benefit your overall health when used properly. However, if you are receiving treatment for CLL some supplements may do more harm than good.

Some vitamins and supplements can interfere with cancer medications and lead to unintended side effects, advises **Muthu Veeraputhiran, MD**, hematologist/oncologist at the University of Arkansas Medical Center in Little Rock. "Even though (patients) might think it's not a prescription medicine, they should disclose that to their doctor or pharmacist," he said.

It's important to distinguish between different types of supplements, says Dr. Veeraputhiran. The term dietary supplements refers to a wide variety of products, and may contain, for example, vitamins, minerals, amino acids, enzymes, or herbs. Herbal supplements are a type of dietary supplement that contain at least one herb.

While dietary supplements may sometimes be taken while

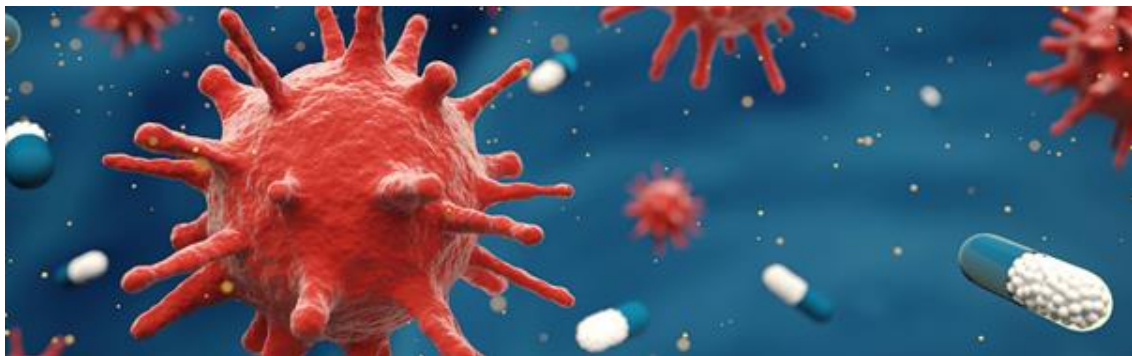
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undergoing treatment, it's best to have your doctor check whether you need them to address a vitamin deficiency. This is often done through a simple blood test that measures your vitamin levels to see if they may be necessary.

Herbal or “natural” supplements, sometimes referred to as botanicals, are a different story. Some can prove to be harmful when they interact with cancer medications. For example, supplements containing St. John's Wort or grapefruit extracts can interfere with how your body breaks down medications. This can cause some cancer treatment drugs to not work as intended or become less effective.

We suggest providing your medical team with a detailed list of the vitamins and supplements you take. This will help avoid unintended issues or side effects.

Information provided by Patient Power



## **Covid update - where are we now?**

**Coronavirus infections in the UK have stabilised, and may be rising, with one in about 50 people now affected, according to the [latest estimates from the Office for National Statistics \(ONS\)](#).** (Including estimates for all UK nations).

In the week to 6 June, infections showed a slight rise in England, Wales and Northern Ireland, but changed little in Scotland.

**That means around 1.2 million people have the virus, which is similar to Covid levels at the start of December.**

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The ONS is monitoring the data to see if recent declines could be ending.

In some English regions, including the West Midlands, North East, Yorkshire and the Humber and the South East, it's not clear if infections are rising or falling.

And infections in those aged 25-34 were also unchanged, although they fell in all other age groups in England.

A form of the Omicron variant of coronavirus, called BA.2, is currently the most common cause of Covid, but two others - BA.4 and BA.5 - have recently been named "variants of concern" by UK health officials.

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**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.

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**With Summer on the way, a few things to bear in mind:**

**(1) Protect against the sun**



**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.

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## 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. (Don't forget your ears, which are particularly vulnerable!)
- **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.**

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## (2) Protect against insect bites



There is evidence that some CLL patients may suffer an adverse reaction to insect bites. It is sensible, therefore to take some precautions. This information is taken from the NHS website, and you can find more information on the link below.

**Basic precautions to prevent insect bites and stings**

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- **remain calm** and move away slowly if you encounter wasps, hornets or bees – do not wave your arms around or swat at them
- **cover exposed skin** – if you're outside at a time of day when insects are particularly active, such as sunrise or sunset, cover your skin by wearing long sleeves and trousers
- wear shoes when outdoors
- **apply insect repellent** to exposed skin – repellents that contain 50% DEET (diethyltoluamide) are most effective
- **avoid using products with strong perfumes**, such as soaps, shampoos and deodorants – these can attract insects
- **be careful** around flowering plants, rubbish, compost, stagnant water, and in outdoor areas where food is served
- **never disturb insect nests** – if a nest is in your house or garden, arrange to have it removed
- **avoid** camping near water, such as ponds and swamps – mosquitoes and horseflies are commonly found near water
- **keep food and drink covered** when eating or drinking outside, particularly sweet things – wasps or bees can also get into open drink bottles or cans you're drinking from
- **keep doors and windows closed** or put thin netting or door beads over them to prevent insects getting inside the house – also keep the windows of your car closed to stop insects getting inside

[NHS information on insect bites](#)

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### (3) Travel insurance

Travel insurance can be a problem for cancer patients, with high fees and sometimes refusal of cover. Based on the experience and recommendations of our members, we have assembled a list of travel companies who have been found to offer good value.

**Please note that these are not our recommendations, as we have no direct contact with these companies, and quotations will vary between agents, and over time.** You may need to shop around to find the best deal.

[Check out holiday insurance here](#)

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## Fundraising!



**Congratulations to our team - including one of our trustees, John Greensmyth - for completing the gruelling London 100 mile bike ride!** John completed the course in a very creditable 6 hours 18 minutes and raised valuable funds for CLL Support. John was in training for several weeks before the ride, and travelled down from Scotland to take part! He was accompanied by **Charlie Mugglestone** and **Simon Barclay** who also completed this gruelling ride.



**There's still time to support them and recognise their hard work for CLL Support here:**

**John:** <https://ridelondon.enthuse.com/pf/john-greensmyth>

**Charlie:** <https://ridelondon.enthuse.com/pf/30c82/fundraiser#!/>

**Simon:** <https://ridelondon.enthuse.com/pf/simon>

**Please give generously!**

## Another wonderful fundraising effort!

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### **Sophie's Mount Kilimanjaro Climb**

**Sophie Allen** is going to be climbing **Mount Kilimanjaro**, which is the tallest free standing mountain in the world!

Sophie says: *"I'm doing this in hope of raising some money for CLL Support, which is a charity that supports patients with Chronic Lymphocytic Leukaemia. They do this by providing information and guidance to those with the diagnosis, advocating for patients to NICE to ensure new treatments are available, and running a helpline. This charity is special to me because around 5 years ago my Mom was diagnosed with CLL. She responds to this in the way she does to everything; with grace, good humour and a 'can do' attitude. Lizard is not only an incredible parent, but my best friend and biggest inspiration, so it seems only fitting to do this."*

**We wish Sophie well in her brave endeavour, and thank her for all her efforts on our behalf. We'll be posting more photos of Sophie and her adventure in future newsletters.**

**You can support Sophie by contributing on her JustGiving page:**

<https://www.justgiving.com/fundraising/sophie-allan4>

**Runners, joggers, we need you!**



**Our main fundraising event of the year is only a month away.**

**Entries for the ASICS London 10k run now open!**

**Sunday 10 July 2022**

**ASICS London 10K is the summer's greatest celebration of running.**

**When we run together, amazing things happen.**

**With entertainment and iconic landmarks on course, this is a sporting moment you'll remember forever.**

Thousands of runners will wind their way through Central London together. As well as seeing some of London's top landmarks, you'll also run past the **True Geographical Centre of London**, down closed **Regent Street**, the **Strand and Embankment**, and get the best view across the river of the **London Eye**.

**Even if you're not a runner, you can still walk the route and enjoy the atmosphere!**

**Click below to download the 2022 route map.**

[Download the route map](#)

**This your opportunity to join the CLL Support team**

**BOOK YOUR FREE PLACE NOW AND**

**COLLECT YOUR FREE CLL SUPPORT T-SHIRT!!**

**Click below to register**

**[coordinator@cllsupport.org.uk](mailto:coordinator@cllsupport.org.uk)**

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## Latest news!

### Results of the Birmingham Covid vaccination study

Many of you took part in this study, which looked at the effectiveness of the Covid vaccines for CLL patients, and we've just received the results. They make interesting reading and you can find our summary of the conclusions here:

[Covid vaccination study](#)

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### New Vaccination leaflet

**Vaccination** is an important part of protection for CLL patients, as we are more vulnerable to infection.

Together with the **UK CLL Forum**, we've produced guidelines for patients and medical teams alike. You can download or order a copy of the leaflet here:

[Vaccination guidelines](#)

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### New drugs to treat antibiotic resistant infections

**CLL patients are prone to infection**, and this can become highly critical when the infection is resistant to standard antibiotics. It's therefore good news that two new treatments are being rolled out which will help to combat this.

**Ceftazidime-avibactam** and **cefiderocol** will be offered to patients who have run out of other treatment options. They are manufactured by Pfizer and Shionogi respectively.

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Can you help?



**Our sister charity, Leukaemia UK is looking for volunteers for their Patient Experience Advisory Panel**

Leukaemia UK is committed to championing advancements in better treatments and care for all. They want to ensure the needs of patients are at the heart of everything they do, and that the voices of people affected by leukaemia - including CLL -and related conditions are being heard.

That is why they have set up a **Patient Experience Advisory Panel** - to bring the voices of those who have experienced leukaemia to decision-makers in the UK Government and elsewhere and to advocate that every patient has access to the best available therapies.

**We think this is a very worthwhile and much needed initiative. If you think you may like to be a member of the panel, there is more information here:**

[Patient experience Advisory Panel](#)



**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](mailto: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.



### **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](mailto:coordinator@cllsupport.org.uk)

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

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**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](mailto:membership@cllsupport.org.uk)**

**We look forward to hearing from you!**

