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| **Newsletter**                                     **March 2023 -  Issue No 02****Our free helpline: 0800 977 4369**  |

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

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| Dear member, and dare I say, friend to many I have met and talked to over the past 4 years as chair.I wanted to thank all of you who have fund raised, become Champions and helped with focus groups, trials, survey development and strategy feedback. Thank you if you have emailed me, attended webinars and conferences, helped lobby for better treatments and better protection during the pandemic. Most of all thank you for being a member.   |

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|  The numbers matter. Health Care Professionals, MPs, NHS academics and many more have said how important the strength in numbers is to help us lobby for what is best for you, your partner, family and support network.As I step back to be an associate, I want to make a final set of requests;1. Firstly, please encourage family and supporters to become members, it is free and it keeps everyone up to date with developments2. Secondly, try to give what you can on a standing order and ensure Gift Aid is authorised. We can only keep everything free with your kind support.3. Thirdly, please talk to us about being a Champion, an Associate or a Trustee. It matters not what experience or expertise you have. We work in teams and you will get help and support to contribute to anything from the newsletter production, to managing a conference, overseeing the finances or helping review the literature and services we provide. You may only be able to give a couple of hours a month, but all are welcome.I am so humbled by you, the members, the trustees, partner charities and the CLL Forum over the past few years. You all have contributed to building this charity into a presence and support resource, envied by many and used by even more. Personally, I have learned so much, made many friends and enjoyed some wonderful events along the way.I am delighted to be passing the chair to Hilary Lindsay and with John Greensmyth as vice chair,and I am confident you will support her and the team as we all move forward.Stay safe stay wellMarc AucklandChair, CLL Supportmarc.auckland@cllsupport.org.uk  |

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| **Covid vaccination - an important message**  |

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| **The NHS has announced that the next (7th) round of Covid vaccinations will start on 17th April. Vaccinations for nursing homes will start on 2nd April. You should be receiving an invitation soon.**Full NHS advice can be found here:  <https://www.gov.uk/government/publications/covid-19-vaccination-spring-booster-resources/a-guide-to-the-covid-19-spring-booster-2023>Unless you had a severe reaction to previous Covid vaccinations, we strongly recommend you should receive this one. Although Covid infections are much reduced from last year, it's still around in the community, as you can see from the figures below.  |

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| **Latest Covid infection data**  |

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| **COVID-19 infections increased in England** i**n the week ending 13 March 2023, and the trends were uncertain in Wales and Scotland. In the week ending 7 March 2023, infection trends were uncertain in Northern Ireland.**The estimated percentage of people living in private households (those not in care homes or other communal establishments) [testing positive for COVID-19](https://lnks.gd/l/eyJhbGciOiJIUzI1NiJ9.eyJidWxsZXRpbl9saW5rX2lkIjoxMDIsInVyaSI6ImJwMjpjbGljayIsImJ1bGxldGluX2lkIjoiMjAyMzAzMjQuNzM5NjA1NzEiLCJ1cmwiOiJodHRwczovL3d3dy5vbnMuZ292LnVrL3Blb3BsZXBvcHVsYXRpb25hbmRjb21tdW5pdHkvaGVhbHRoYW5kc29jaWFsY2FyZS9jb25kaXRpb25zYW5kZGlzZWFzZXMvYXJ0aWNsZXMvY29yb25hdmlydXNjb3ZpZDE5bGF0ZXN0aW5zaWdodHMvaW5mZWN0aW9ucyJ9.RowMx-oimBThGFbXtzWyVKWY0JncX-DupcLYhYqBfQo/s/2889850175/br/156733121398-l) was:* 2.66% in England (1 in 40 people)
* 2.41% in Wales (1 in 40 people)
* 1.42% in Northern Ireland (1 in 70 people)
* 2.59% in Scotland (1 in 40 people)

The [overall hospital admission rate](https://lnks.gd/l/eyJhbGciOiJIUzI1NiJ9.eyJidWxsZXRpbl9saW5rX2lkIjoxMDMsInVyaSI6ImJwMjpjbGljayIsImJ1bGxldGluX2lkIjoiMjAyMzAzMjQuNzM5NjA1NzEiLCJ1cmwiOiJodHRwczovL3d3dy5vbnMuZ292LnVrL3Blb3BsZXBvcHVsYXRpb25hbmRjb21tdW5pdHkvaGVhbHRoYW5kc29jaWFsY2FyZS9jb25kaXRpb25zYW5kZGlzZWFzZXMvYXJ0aWNsZXMvY29yb25hdmlydXNjb3ZpZDE5bGF0ZXN0aW5zaWdodHMvaG9zcGl0YWxzIn0.eReCnqMWAfqhhETf8uzQn0rL407cNYvxSnKTTfJpl7Q/s/2889850175/br/156733121398-l) of patients with confirmed COVID-19 in England increased slightly to 10.62 per 100,000 people in the week ending 19 March 2023. In the same week, the intensive care unit (ICU) and high dependency unit (HDU) admission rate remained low at 0.28 per 100,000 people. |

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| **Cambridge conference videos now available!**  |

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| **Our  conference in Cambridge earlier this month was a sell-out, so if you were unable to attend, the videos of the key talks are now available. Our two keynote speakers, who each gave very informative talks were:**  |

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| **Professor George Follows****Prof Follows is Professor of Haematology, University Hospitals NHS Foundation Trust, Cambridge** |

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| ****Dr Ieuan Walker******Dr Walker is a clinician scientist at the University of Cambridge, focused on Haemato-oncology and immunotherapy.**  |

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| This conference was possible because of a very generous donation of £1000.00, for which we are very grateful.**You can find the videos here:** |

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| [**Click here for Cambridge conference videos**](https://www.cllsupport.org.uk/conference-reports/birmingham-conference/)  |

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| **New information on the STATIC trial released**  |

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| We are delighted to be able to announce that the STATIC trial has now started! STATIC is now open at several hospitals and the first patients have joined the study. **This will be of interest to anyone who was on the FLAIR trial, and anyone who is taking Ibrutinib as a second or later line of treatment.****You can find the full details on our website here:** |

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| [**STATIC trial announced. Find details here**](https://www.cllsupport.org.uk/news-events/news/)  |

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| **Just a few places available on our drop-in sessions**  |

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|     **Are you struggling with emotional or mental health issues related to your diagnosis of CLL?** Our SupportAct programme is designed to help you, and to strengthen your emotional resilience. Our online tool, developed by behavioural therapist Therese ("Pinky") Jimenez, is available to all at [Home - CLLSupportAct (cllsupport-act.org.uk)](https://cllsupport-act.org.uk/).   We have also been running group Zoom drop-in sessions with Pinky for members since the new year and these are proving very popular. **We are now delighted to be able to offer free 1:1 sessions with Pinky for a limited number of members.  These consist of a course of 6 weekly one hour Zoom sessions.**  **If you are interested, please email** cherry.mills@cllsupport.org.uk  |

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| **How to get the best from Remote Clinical Consultations**  |

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| The following was prepared by Matt Gibson, one of our Associate Trustees.**For many patients with CLL, whether newly diagnosed, on active monitoring, in treatment or in remission,  the COVID-19 pandemic introduced a new element to their journey; the telephone or Zoom consultation in place of a face-to-face appointment at a hospital or clinic.**Some patients, perhaps especially those with lengthy journeys, or those who work full time, may have welcomed the added convenience and efficient use of time that this development has allowed. For others, the remote appointment has removed the ability to develop a human relationship with a consultant - this is perhaps most keenly felt by patients who have been recently diagnosed and probably have lots of questions about the condition that they did not previously know that they had!To help patients successfully navigate this new challenge, I sought the views of some patients about how best to manage this kind of consultation and have come up with the following checklist - I hope it is of some use. **Before the appointment:** * Have your routine blood test as close to the appointment as possible.
* If this service is available, ask for your blood results to be emailed to you before the appointment.
* Make a list of any questions that you want to ask.
* Consider how you have been feeling in the time since your last appointment - have you had any persistent infections, “B” symptoms like night sweats, weight loss etc. Keep a record/dates of anything you want to refer to. It is very easy to say “I’ve been fine” when it might not be true!

 **During the appointment:** * If you keep an ongoing record of your blood test results, have this available, especially if the consultant is telling you about the results over the phone. Ask for an explanation of what they mean, especially if they appear different to the previous test.  There is a chart in the back of the CLLSupport handbook for this.
* Be a participant in the remote consultation, don’t just let the Consultant rattle through the standard questions, night sweats, weight loss, bruising etc. pick something out of your experience or out of the handbook and ask a question, stop them in their tracks and make them deal with you as an individual. Keep a pen and paper handy.
* If you want to, record the appointment using the voice recorder app on your phone - it would be courteous to ask the consultant before you do this. This will enable you to listen back to the information if you want to clarify anything.

 **After the appointment:** * Listen back or look at your notes. Be clear that you understand any next steps that are being proposed. Send emails or contact relevant staff if you are unclear about something.
* Consider whether this arrangement is working for you - some patients have negotiated alternating between remote and face to face appointments.
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| **Other news**  |

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| We'd like to offer our congratulations to Professor Paul Moss, who received an OBE in the recent Honours List. Prof Moss is **Professor of Haematology at the University of Birmingham** and is a leading international figure in translational human immunology. He has frequently spoken very eloquently at our conferences, the most recent of which can be found here: <https://www.cllsupport.org.uk/conference-reports/birmingham-conference/> |

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| \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**Vaccinations**The correct vaccinations are very important for CLL patients. We've updated our guidance on vaccinations, and you can download our leaflet from our website here:<https://www.cllsupport.org.uk/information-support/further-information-resources/order-publications/>  |

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| **ChatGPT** |

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| \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**A word of caution!You may have heard of ChatGPT**, an artificial intelligence chatbot. Perhaps you've used it. **It's worth thinking about how accurate or misleading it can be.****Ashley M Hopkins**, leader of the Clinical Cancer Epidemiology Lab, Flinders University, Australia and a member of the Australia's National Health and Medical Research Council, has reported on his clinical team's research. A key finding is as follows: ".....we then asked a question about side-effects to a specific cancer drug: “Does pembrolizumab cause fever and should I go to the hospital?”.***"We asked ChatGPT this five times and received five different responses.*** This is due to randomness built into ChatGPT, which may help communicate in a near human-like way, but will throw up multiple responses to the same question."So, we need to be very careful in using this kind of search engine or, indeed, any search engine. The full article is here:[We asked ChatGPT and Dr Google the same questions about cancer. Here's what they said (theconversation.com)](https://theconversation.com/we-asked-chatgpt-and-dr-google-the-same-questions-about-cancer-heres-what-they-said-201474)(This information was provided by one of our HealthUnlocked administrators, AussieNeil) |

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| **Fundraising**  |

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| The contribution to our fundraising from our members is amazing. Here are just a few examples of their efforts. We are extremely grateful to everyone, and without you, we would not be able to carry on our work. You are all stars! Thank you!  |

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| **Sarah Jones is taking to the skies in September to complete a tandem Skydive!** As she would like to help others and make a difference, Sarah has chosen to raise money for CLL Support  and has set her target as £325. Her aim is to help support families whose lives have been touched by CLL.Hopefully, the weather will be perfect for Sarah on the day. What an amazing experience it will be for her. Our thanks to Sarah for taking on this personal challenge.I’ve included the link to her fundraising page below should anyone wish to help reach hertarget.<https://www.justgiving.com/fundraising/sarahnjones> \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**Chris Else is running 10K (6 miles) every day throughout the month of May.** He has chosen to do this to raise money for CLL Support and to raise awarenessfor our Charity whilst giving himself a mental and physical challenge at the same time.Chris will be recording all of his runs and posting updates every day of this challenge. **If anyone would like to join him for any of the runs they would be very welcome and it would be a huge help to Chris.**This is a cause very close to his heart as his Step-dad has recently been diagnosed with CLL. **The final run is at 18:30 on Wednesday 31st May at West Park in Long Eaton.** It will be 4 laps of the parkrun course. If you’re nearby and able to join him, even for a few minutes, he would appreciate the support. His daughter Billie is going to run the last bit of the 10K with him.I’m sure you will all join us in wishing Chris luck in his fundraising and in doing 10K a day in May. We've included the link to his fundraising page below should anyone wish to help reach his target.<https://www.justgiving.com/page/christopher-else-1679042496640>   |

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| **Refund for Event Fees** **Are you thinking about taking part in an organised fundraising event?  We may be able to refund all or part of your entrance fee up to a maximum of £50 depending on demand.  All you need to do is agree to fundraise a minimum amount for CLL Support.  For more information or for a pledge form and fundraising pack, please email:****cherry.mills@cllsupport.org.uk**  |

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| **Now that Smile.Amazon has come to an end, a part of our income has been lost. You may be looking for an alternative to sign up to**.Below are a couple of options. Sign up for free and raise money when youshop online. It could be your weekly food shop, a holiday, annual insurance, household appliance, etc. **At no additional cost to you**, it's really easy to raise money for us. It just takes a few minutes of your time to sign up. Text  Description automatically generated**easyfundraising** -  <https://www.easyfundraising.org.uk/>easyfundraising partners with over 7,000 brands who pay it a commission when people start their shop via its site or app. It then turns this into a donation for your chosen cause. Your can see how much you’ve raised for CLL Support, and get updates on when we get paid.**Charitable shopping** - <https://www.charitable.shopping/>When you buy through Charitable Shopping, its partner shops and service providers pay it a ‘thank you’ fee, which it transfers over to the charity. The donations are sent through JustGiving to the charity directly. Supporters can register, select their charity, and start donating straight away.Why not give it a try - it's easy  |

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| **If you have fundraised for us do please let us know so that we can thank you and perhaps feature you here.**  |

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| **One of our key missions is to make our resources accessible to everyone with CLL, and to their families and friends**.To this end, we've been looking at ways of opening up our website to people with disabilities, for example those who are partially sighted. In addition, we want to be welcoming people whose first language is not English. We're pleased to announce that we've now installed an accessibility tool on our website, which you can find in the top right hand corner. It has numerous tools to help, and is very easy to use. Try it out!  |

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| **Can you help, please?**  |

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| **Please can you share your CLL story?**For those who attend our conferences, an undoubted highlight is one of our members sharing their CLL story. People find it enormously encouraging to hear how others coped with their CLL, and to know they aren't alone.**We need people to step forward and tell their CLL stories so that we can feature them at our conferences and in our webinars. If you can't attend in person, we can video you at home.**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:   |

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| [**Sue and Elizabeth's story**](https://www.youtube.com/watch?v=XeC4CSPiQj4)  |

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| **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 thanksMarc Auckland**  |

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| 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: |

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| [**HealthUnlocked**](https://healthunlocked.com/cllsupport)  |

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| **Do you have a will? If not, we can help****Or perhaps you need to change your will? We can help, too.**  |

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| **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.ukOr download from our website [here](https://www.cllsupport.org.uk/contact-us/order-publications/):   |

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| 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! |

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