

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



January and February are when we reflect on the year gone by and look forward to our plans for the coming year. 2022 was still an anxious one for CLL patients, and even though Covid was starting to reduce across the UK, it still provided a threat for immunocompromised people. We still had to take measures to prevent catching Covid even if we were fully vaccinated, and the increased calls to our helpline reflected this.

2023 has started with a steady decline in Covid cases, as we report in this newsletter. This is welcome, and we hope it may allow us all gradually to return to a more normal lifestyle. Many of our members have begun to do this, and we are encouraged by the attendance at our two conferences last year. Our first in 2023 will be in Cambridge in March, and already registrations are coming in thick and fast. Details are below.

In 2022 we joined several other charities in campaigning for better access to Covid treatments, for clearer Government policy on NHS staffing and for vaccination for blood cancer patients. You can see some of this work, in association with One Cancer Voice, later in the newsletter. This work will continue throughout this year.

In many ways, this is a year of change for CLL Support, with several trustees coming to the end of their term. We are fortunate that some will be still giving their expertise and experience by staying on as Associate Trustees to enable us to have a smooth transfer of responsibilities. In April, I will be handing over as Chair to the very capable hands of Hilary Lindsay, and we have created a new position of Deputy Chair to help her. This will be filled by John Greensmyth, whom many of you will know from our webinars. I have every confidence in their considerable experience, and abilities and wish them well.

In the meantime, I hope you stay safe and well.

Marc Auckland

Chair, CLL Support

marc.auckland@cllsupport.org.uk

Cambridge conference announced

You are invited to join us for our next conference in Cambridge

Saturday 18 March 2023

10.00 am to 4.00 pm

(Registration from 10.00am)

Hilton Hotel, Cambridge

We are privileged to have as our guest speakers:



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

He has had appointments at national level including the chair of the UK CLL forum. At regional level, he was Clinical Lead for Research for the former West Anglia Cancer Research Network and is now the Clinical Lead for Haematology for the Eastern Region Research Network.

He is an Associate Lecturer at Cambridge University and the UK chief investigator for a number of Clinical trials.



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

He is a haematology registrar at Addenbrooke's Hospital and a Clinician Scientist at the University of Cambridge. His research focuses on novel immunotherapy target identification. Additionally, he uses

machine learning approaches to predict drug responses in patients.

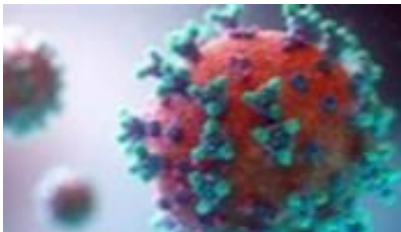
This will be a full and interesting programme, and demand for places will be very high, so to help us to plan, please register your interest as soon as possible.

We want our conferences to be open to as many people as possible. If you are put off by the cost of travelling, we may be able to help. We can offer selected attendees a contribution to travel costs of up to £50.00 per person. To find out how to claim, please contact membership@cllsupport.org.

This is possible because of a very generous donation of £1000.00 to be used for this purpose.

[Register for this conference here](#)

Other news



Covid infections continue to decline.
Latest figures from the ONS are:

- 1.42% in England (1 in 70 people)
- 1.26% in Wales (1 in 80 people)
- 1.52% in Northern Ireland (1 in 65 people)
- 1.44% in Scotland (1 in 70 people)



Influenza cases also declined across the UK, but still remain higher than Covid.

Influenza positivity decreased to 2.8% compared to 6.5% in week 2, with the highest positivity seen in children aged 5 to 14 years old, and in the 15 to 44 years at 4.5%.

All data is from the ONS and is up to 23 January

People with CLL and their families still need to be cautious, although it's also important to try to return to a normal life. The precautions for Covid apply equally to 'flu: Make sure you are fully vaccinated; wash hands regularly; wear a mask in crowded places if you feel able to. Full NHS guidance can be found [HERE](#).

Important

Please note: Current Covid vaccination will end on Sunday 12 February. If you have still to receive all your vaccinations (6 in total for CLL patients and their households) we urge you to make sure you book an appointment. It's expected that the vaccination programme will resume in the autumn.

Vaccination for 'flu is also still available if you haven't had yours yet.



Evusheld

We have received this notification relating to the Covid preventative treatment:

"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."

The reason is that Evusheld is not effective against the current Covid variations, and because cases are falling quite rapidly. We may see a re-examination for the next winter season if modifications are made to the treatment.

Trial update

Results of a triple combination of acalabrutinib + venetoclax + Obinutuzimab (A+V+O) for high risk patients -with-chronic-lymphocytic-leukemia-or-small-lymphocytic-lymphoma-cll.

In this ongoing trial, the triple combination therapy using acalabrutinib, venetoclax, and obinutuzumab is highly active. Thus far this drug combination has produced durable remissions as a frontline treatment in patients with TP53 mutation CLL and has been generally well tolerated, with a low 2.9% incidence of atrial fibrillation and zero of the more serious abnormal ventricular heart irregularities.

See report [here](#)

Please note that this is a trial in America, but we hope and expect that the results will influence treatment in the UK when published.

Thanks to the CLL Society for this report



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!



CBD oil - Good or bad?

CBD oil is derived from the cannabis plant, and is being used increasingly for pain relief, and the plant itself to help with relaxing. As we've received questions about this from members, we thought we should investigate.

This research suggests that users need to be very cautious. They may be encouraging CLL cells in their blood, where they are more likely to die, to move into their nodes, which are propagation centres:

ASH 2019: A Clinical Trial of Cannabis As Targeted Therapy for Indolent Leukemic

Lymphoma. (Full paper [HERE](#))

The conclusion is as follows:

*"Our findings suggest that the drug might promote homing of lymphoma cells from blood into secondary lymphoid organs where they receive pro-survival signals. **Therefore, this cannabinoid compound should be used with caution in patients with indolent leukemic lymphomas.**"*

Will you sign this petition?



Today, 60+ cancer charities have come together, to speak with #OneCancerVoice on behalf of millions of people affected by cancer. CLL Support is part of that group.

We believe that the Government must address cancer patients' needs now and in the future.

Last year, Government declared a 'war on cancer' and promised a 10 Year Cancer Plan. They said we would 'lead the world in cancer care'. Then this January they announced a shorter-term (5 year) Major Conditions Strategy – not the ambitious world leading cancer plan we had hoped for. Or what cancer patients need.

There is a danger that blood cancer will not be included in this new plan.

We want to demonstrate collective action and that this is a disappointment to patients and people affected by cancer.

Together, we are asking the UK Government to:

- Ensure the Major Conditions Strategy is ambitious, fully funded and listens to the evidence of the cancer community.
- Commit to a longer-term strategy for cancer.

If you agree, please take time to sign the petition [HERE](#)

This petition is hosted by Cancer Research UK and supported by One Cancer Voice, a coalition of over 50 charities, of which we are a member.

Fundraising

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!



Rachael Windsor (on the right) and her cousin Leah completed the London Winter Walk half marathon 28 January. They raised £179, which is brilliant. They completed the walk in just over 4 hours. Both were wrapped up warm and the weather was kind to them.

Rachael chose CLL Support as her dad has CLL and is on active monitoring. Her Uncle also has CLL and has received treatment.

Thanks to both!



David Campling and Jason Oakford made up a team when they took part in last year's 'Two Ball Rally' from Saint Quentin to Barcelona.

They set off on 21st July 2022 on their journey in a Peugeot 207 they bought for £550.00. Over the course of 5 days they made stops in Saint Quentin, Annecy, Sanremo, Arles and Barcelona. They chose to support our charity because David's wife has CLL. **Their aim was to raise £250 but they actually raised £755 for us!**

Well done David and Jason! You certainly look like you enjoyed yourselves!



Something different!

A big thank you to Alison, Sue and Rosie for their generous donation of £330.

Alison, her mum Sue and niece Rosie knit Christmas Chocolate Orange covers every Christmas. They started to do this in 2015 when Alison's sister Lorraine sadly passed away aged 54 from lung cancer, donating the proceeds to the Severn Hospice who cared for her.

Alison was diagnosed with CLL, aged 54, in 2021 so they decided to split future money raised between the two charities.

Sue buys the oranges and they knit furiously throughout the year, wrap them up and sell them for £5 each. They make popular stocking fillers, gifts for teachers and secret Santa's. Some years they haven't had enough, so Alison has already started knitting for Christmas 2023!



Kris Bush ran the London 10k last year for CLL Support.

Kris says:

"I would like to thank the CLL Support Group for the opportunity to run for them in the London 10km this year. Having only started running in lockdown, I wanted to run a friendly 10km and raise funds for the charity. The event was really fun and with entertainment along the way to encourage runners. It was a really hot day and with lots of London sights to run past, I managed a personal best and I wore my medal all day. My friends and family supported me by donating to the CLL Support Group. The work of the charity is so practical, supportive and evidence based. We are grateful for the support we have received and if anyone is considering entering in 2023, I would be happy to encourage them."

Thank you , Kris. Keep running!

Why not think about joining our team for this year? More details nearer the event - but start training now!

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



Last Christmas seems long gone now, but we are enormously grateful to everyone who contributed to our Christmas fundraising campaign.

We reached a record total of £9500.00, which is amazing.

Thank you to everyone for your generosity, especially in these difficult times.

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

smile.amazon.co.uk

Amazon Smile is closing on 20 February 2023

So, what does this mean for us? It's been amazing that people have used this service to help us.

What can you do now? Well, there are some alternatives that you can use. The first one that comes to mind is 'easyfundraising'. It is what it says – easyfundraising!

Easyfundraising partners with over 7,000 brands who pay a commission when people shop via its site or app. It then turns this into a donation for the shopper's chosen cause. You can see how much you've raised and get updates on when we get paid.

Try



Please remember that you need to register and nominate your chosen charity. For us it's our official charity title: Chronic Lymphocytic Support Association UK. Thank you.

Can you help, please?



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:

[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

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
Or perhaps you need to change your will? We can help, too.**



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@cllsupport.org.uk

We look forward to hearing from you!

