



CLL SUPPORT

Helping people affected by CLL and SLL

Newsletter

August 2022 Issue No 08

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.



I trust this finds you well and you are enjoying the summer months.

In this newsletter we welcome new Associate Trustees to our team, and they will help us to carry on our vital work supporting people with CLL, together with their families. We also consider you, our members, to be an essential part of our team, since it wouldn't be complete without your support, for which we are incredibly grateful. I believe that together we can make even the toughest challenges achievable.

There are, indeed, some serious challenges for us to tackle, not least the continuing concern about Covid-19 and how we can lobby for more effective treatments for blood cancer patients. As you will read below, this is a continuous battle for CLL Support and other blood cancer charities, but it is one we are determined to fight.

Your feedback is very important in helping to shape our policies, and we are very pleased at the response to our recent survey, the results of which are currently being analysed, and we expect to publish these shortly. We hope to conduct the

survey annually, and our sincere thanks go to everyone who completed it. It really does help us.

We are a partner of the global [CLL Advocates Network](#) (CLLAN), and are involved in their study to **understand the experiences and views of people who care for, or support CLL/SLL patients**. This **worldwide survey** will collect information on the 'carer perspective' of the care, treatment and support leukaemia patients receive, as well as any personal impact the diagnosis has had.

If you are a carer or partner of a person with CLL please could you complete the survey. If you are a CLL patient, please ask your carer/supporter to complete it. It will only take 20 mins to complete.

SURVEY

LINK: www.myonlinesurvey.co.uk/ALAN22

Finally, thank you again for your support, and I wish you good health.

Marc Auckland
Chair, CLL Support

Evusheld - latest information

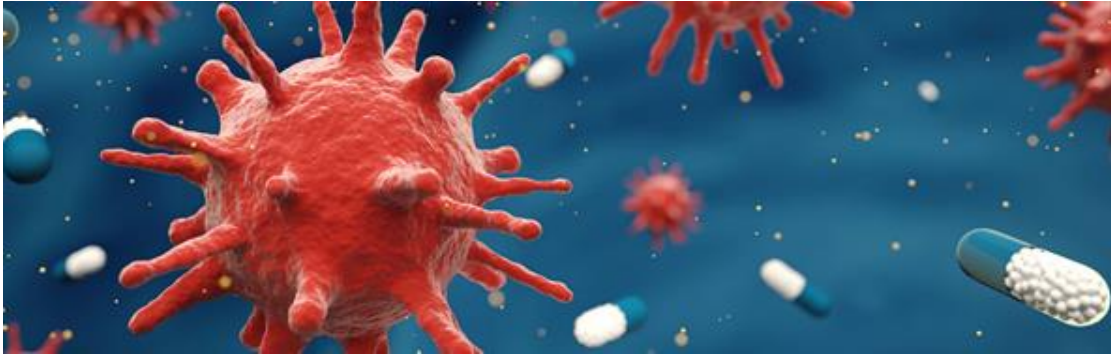


We are extremely disappointed that the Government has decided not to purchase supplies of Evusheld. The reason given is lack of data on the effectiveness of Evusheld on the latest Omicron variants of Covid-19.

To recap, Evusheld, manufactured by Astra Zeneca, is an injection given to prevent Covid-19 infection, particularly in vulnerable patients. A follow-up injection is usually given about four to six months after the first. It has shown to be effective for the earlier Delta variants of Covid-19, and there is information from the USA that it is also proving to be effective against Omicron, although less so (some estimates indicate approximately 70% compared with 85% for Delta.) We believe that any help in the prevention of Covid is worthwhile, indeed vital, and that Evusheld should be part of the armoury.

We were very surprised at the Government decision because we were asked at very short notice to submit evidence to The National Institute for Care Excellence (NICE) earlier this month, and believe we outlined a very good case. We are combining forces with other blood cancer charities such as Blood Cancer UK, Leukaemia Care and Leukaemia Action to continue the fight for the right of immunocompromised people to have the best possible defence against Covid. We have jointly written to the Secretary of State for Health and Social Care, the Rt. Hon. Steve Barclay MP, demanding an explanation of the decision, and will aim to keep you informed.

Covid update - where are we now?



Covid-19 infections in the UK continue to fall, the latest weekly Office for National Statistics figures suggest.

[Around 1.7 million](#) people in the UK had coronavirus in the week ending 6 August, down from around 2.6 million two weeks earlier.

The latest estimates on Covid infections from 19 August showed a fall of 34% on two weeks earlier, with an estimated one in every 40 people infected. This was about 2.6% of the population.

England, Wales and Scotland had all seen infection fall, but the trend in Northern Ireland was uncertain, the Office for National Statistics (ONS) says.

Infections decreased in all English regions and across all age groups in England.

- [Coronavirus in Scotland: Key figures and trends](#)
- [What do the stats tell us in Wales?](#)

The number of patients in UK hospitals with coronavirus continues to fall along with new admissions, according to the latest government figures.

Although the latest figures are encouraging, the advice for people with CLL/SLL is still to take great care. This means:

- Make sure you are fully vaccinated. This currently means five jabs. A sixth will be coming in the Autumn. **Note: a new 'bivalent' vaccination manufactured by Pfizer, will be available from early in September. This is designed to have greater effect against the newer Covid Omicron variants. However, supplies are limited and we recommend you have your jab as early as possible.**
 - Avoid crowded places where possible. If you need to be in a crowded area, wear a mask. FFP2, FFP3 and N95 are recommended, although any mask is better than none..
 - When meeting friends and relations, think about asking them to test beforehand.
 - Regular handwashing is still probably a good idea, although it's not thought that hands are a primary source of infection.
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If you catch Covid

If you have Covid symptoms, you should immediately take a **lateral flow or PCR test**. You will need a positive result to be assessed for treatment, which is usually needed within about five days. You can find the procedure to follow on the NHS website [HERE](#)

Guidance from the NHS, effective from 13 June 2022, for treatment of Covid patients at home is as follows:

- First-line: nirmatrelvir plus ritonavir (antiviral) OR sotrovimab (nMAB), as clinically indicated
- Second-line: remdesivir (antiviral)
- Third-line: molnupiravir (antiviral)

Note that you should be monitored after your first treatment as you may need follow up treatment if your Covid symptoms return, or you continue to test positive.

World CLL Day



World CLL Day launches Blood Cancer Awareness Month every 1 September, and we are pleased to be supporting this initiative.

It's a day for CLL communities across the world to unite to raise awareness about CLL and give those affected by a diagnosis of CLL a much needed voice. On World CLL Day we come together to improve understanding of the issues faced by people with CLL and the challenges involved in living with CLL.

Why the umbrella? Last year, the umbrella, a form of protective shield, was chosen as the symbol. The umbrella still carries the message into World CLL Day this year.

For this year, the umbrella has been turned into a boat by simply flipping it on its head. By this we wish to emphasize the idea of protection while at the same time reinforcing the message of moving forward and navigating the world with COVID-19.

Our support for World CLL day will include an initiative around 'Living Well with CLL' Look out for details of this shortly.



Our first conference for three years!



Save the date for our Glasgow conference!

Date: Tuesday 18th October 2022

Location: Grand Central Hotel, Glasgow city centre

Keynote speakers: Dr Alison McCaig & Martin Hannah

The conference will feature other clinical speakers and some patient stories and will be a hybrid event - both in person and streamed online.

More details to follow as the programme builds but in the meantime please save the date!

We look forward to seeing you there!

Meet our new Associate Trustees!

We're building our team of Associate trustees, who will help us to deliver support for people with CLL. All our trustees and Associate trustees either have CLL, or have a loved one with CLL.



Cherry Mills. Cherry will be our **Donor Engagement and Administrative Officer** helping with a vital area of our activities, raising funds, without which we wouldn't be able to operate. You will read more about this later in this newsletter.



Jackie McCreery. Jackie was first diagnosed in 2019 and started treatment earlier this year. She retired twelve months ago after more than forty years teaching/teacher-training in English as a foreign/second language both overseas and in the UK. Jackie will be helping with the newsletter, including the essential proofreading.



Debbie Yates. Debbie was diagnosed with CLL in January 2021. She is retired. Her career was in the NHS, where she was a Director of Finance & Information and NHS Trust Board member. She has been JP since 1998.

She is currently a Trustee, Treasurer & Fundraising Officer for Lincolnshire Lowland Search and Rescue.



Shaun Bowden. Shaun was first diagnosed in 2003 and has been on watch and wait since then. After nearly forty years working in industry, he will be supporting the executive on corporate governance matters.

A very warm welcome to everyone from all the trustees!

Fundraising



Hello, my name is Cherry Mills and I'm a new member of the CLL Support Team.

Part of my role will be to look at ways we can fundraise. We rely on your generosity to help us to carry on our work supporting people with CLL.

I'd love to hear about your fundraising to date, so if you would like to share your stories with us, please get in touch. It would be great if you could

provide a few photographs to support your stories with a view to publishing some of them in our regular newsletter.

It would also be wonderful if you have any fundraising ideas for individuals or groups of people that you wouldn't mind sharing with us. If we can come up with an idea that everyone can take part in either individually or with a group, that would be amazing.

On behalf of all of us at CLL Support I'd like to say very grateful thanks for all donations received to date.

You can contact me at:

cherry.mills@cllsupport.org.uk

Can you help, please?



Please can you share your CLL story?

For those who attended our conferences before the pandemic, an undoubted highlight was one of our members sharing their CLL story. People found it enormously encouraging to hear how others coped with their CLL.

We would like to reintroduce this to webinars and, when we can, face to face, conferences.

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

Online research pitfalls and how to avoid them

When a newly diagnosed CLL patient we know did a quick online search she was served up information about a different condition: chronic myeloid leukaemia (CML). The patient eventually got personalised information on her condition from her doctor, but only after experiencing some confusion about what her treatment might entail.

As online information about cancer proliferates, risks of misunderstanding also increase. Patients and their care partners should do their research carefully and consult with their medical team to validate what is found.

Here are a few tips for making sure your online research yields accurate and timely information:

- **Always start with your medical team.** When discussing your diagnosis with your doctor, don't be shy about asking for clarification of abbreviations and medical terms that are used. There is nothing wrong with doing research on your own – you just want to make sure that you are looking for the right information. You can find an explanation of medical terms on our website [here](#).
- **When using the search function on a website, spell out the name of the condition you are searching for rather than using the abbreviated form.** There are so many cancer conditions that have very similar abbreviations to CLL (like CML and CMML) that being very specific about your search will cut down on inaccurate results.
- **Consider the source of your information carefully.** Aside from your trusted medical team, there are a select few national and international organizations that provide information online that are considered the gold standard for accuracy and timeliness. Start there. These sites can also refer you to other reputable resources for your specific cancer type. These include:

You'll find lots of reliable information on our website: www.cllsupport.org.uk

There's also information on:

Leukaemia Care <https://www.leukaemiacare.org.uk/>

Blood Cancer UK <https://bloodcancer.org.uk/>

Lymphoma Action <https://lymphoma-action.org.uk/>

- **Check the publication dates of articles you find, as well as the authors and their credentials.** The science of CLL diagnosis, testing, and treatment is changing so rapidly that information from even a year ago may already be outdated. Look for the most recent

publication dates and check the medical affiliations and accolades of the writer.

We are blessed to be living in a time when information about medical conditions and their treatment is widely available online. The key to accessing and using this information is to find **accurate and relevant** information amid a sea of less-than-credible resources.

Fundraising!

A sincere 'thank you' to all our valued fundraisers. Without your help we couldn't do our work. Not everyone can run, cycle, skydive or climb mountains, however, so here's a couple of ways you could help without too much effort.



Do you buy from Amazon? If you do you could help CLL Support by using Amazon Smile. It doesn't cost any more than the usual site, but we receive a small donation for every purchase. Small donations add up, and to date we have received nearly £2,000.00! It's quite painless, so give it a go and help us at the same time. All you need to do is select CLL Support as your chosen charity.



This is another relatively painless way you can help. Nearly all major supermarkets and stores operate this scheme, which again works by them donating various amounts to your

chosen charity for everyday purchases.

Note that our official registered Charity title is: Chronic Lymphocytic Support Association (CLLSA), and you will need to use this title to register. Happy spending!

Latest news!

New vaccinations against Covid available in September

At least two new vaccinations against Covid-19 are due to be available in September this year.

The first, already referred to above, is the new bivalent vaccination from Pfizer, which has been engineered to be effective against the Omicron variants.

The second new jab is from Valnerva, and uses different technology to evoke a broad immune response that is thought to make it effective against Covid-19 variants.

We encourage you to arrange for vaccination as early as possible.

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](#)

Shingrix

Why is Shingrix being limited to the 70 to 79 age group?

Shingles can be very painful and in certain circumstances may lead to nerve damage.

There are vaccinations available to help prevent shingles, but blood cancer patients, who are very vulnerable to shingles, should not receive a vaccination containing a live virus.

Currently, the only non-live vaccination available is Shingrix, and it was approved in 2019 for people over 50, but is only being given to people in the 70 to 79 age group. Enquiries reveal that this is because the government has not purchased enough to treat other age groups.

We think this lets down people with CLL, and we will be joining other charities to campaign for wider availability of Shingrix.

More about which vaccinations you should have [here](#)

More about shingles and symptoms [here](#)

Covid treatments

The number of treatments for Covid is increasing, and the National Institute for Health and Care Excellence (NICE) is conducting an appraisal of these. The treatments are crucial for people with blood cancer.

The Department of Health and Social Care has asked NICE to conduct an appraisal of remdesivir, tocilizumab, casirivimab and imdevimab, baricitinib, sotrovimab, molnupiravir, nirmatrelvir and ritonavir, and tixagevimab and cilgavimab for treating people with coronavirus disease 2019 (COVID-19) in the NHS in England through the Multiple Technology Appraisal process (MTA).

Our Patient Advocate, Jackie Martin, is working on our submission, which we will do in cooperation with other blood cancer charities.

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](#)



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!

