



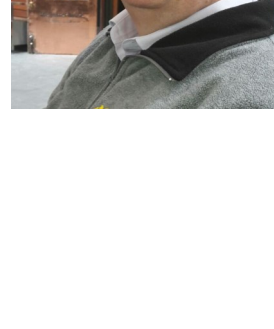
Our top stories in this newsletter



Latest Coronavirus Update
New lockdown announced

Special Vaccine webinar with
Prof. Saul Faust

New CLL treatments



A message from Marc Auckland, CLL Support Chair.

Welcome to our first newsletter of 2021

I hope this edition of our regular newsletter finds you and your family safe and well.

The start of a new year is traditionally a time for optimism and renewal, for identifying new opportunities and resolving to seize them. For many today such optimism will be in short supply. After a year scarred by loss, separation and anxiety, 2020 seems to have saved its worst until last. The emergence of a Covid-19 variant has sent hospital admissions soaring, and, as you will see below, the country has returned to the most stringent lockdown conditions.

Yet, even in this bleak time, there are reasons to be optimistic. A mass vaccination programme is underway thanks to the licensing of the Oxford-Astra Zeneca jab. CLL patients are likely to be in the first waves of vaccination, and we urge our members to have the vaccination when offered. There is real hope that by late Spring enough of the population will have had at least one vaccination that the virus will be in retreat.

There is no doubt that this last year has been challenging for all of us, and the coronavirus pandemic has taken a particularly heavy toll on blood cancer patients and their loved ones. I want to reassure you that, despite all of the problems, we are here to help in any way we can, and our helpline remains open if you feel you need to speak to someone.

We will continue to give you information on Covid-19 and other matters affecting CLL and SLL patients in our newsletter and on our website, which is updated regularly with current information.

I also want to thank all of you, our members, for your continued loyalty, generosity, and support. Over these last few months, we have been touched by the number of kind messages and donations we have received. This helps us to approach the future with optimism and determination despite all the difficulties that still lie ahead. We are committed to providing you with the support you need and hope that you will continue to help us, as you have done over the years.

Finally, I wish you good health, and trust that you and your family will stay safe.

Marc Auckland
Chair of trustees
marc.auckland@cllsupport.org.uk

Covid-19 update

Vaccines

We have received lots of queries about the vaccines which are now being distributed. We have, therefore, tried to answer these as far as possible.

You can find answers to many of your questions about vaccines on our website here:

<https://www.cllsupport.org.uk/covid-vaccine-qa/>

Webinar

In addition, we held a very informative webinar in December in which **Prof. Saul Faust** of the University of Southampton, who has been a member of the NIHR COVID-19 vaccine trial delivery group, gave a very interesting talk about how vaccines protect us. He was joined by **Dr Renarta Walewska**, who is current Chair of the UK CLL Forum.

If you missed it, please have a look here:

[CLL Support Webinar - 16 December 2020 - CLL Support Association](#)

Other Covid-19 updates

UK Govt. announces a new lockdown for England.

The Government has announced that, following a recommendation from the UK Chief Medical Officers, England will move into the highest Tier 5 from midnight on 4 January. The restrictions are expected to become law on 6 January. For a summary of these new restrictions, please check here:

[NationalLockdownGuidance.pdf \(publishing.service.gov.uk\)](#)

This Govt. statement also includes advice for extremely vulnerable patients.

Please note that there are regional variations for the devolved nations, and you can find the individual rules for each country here:

Scotland: <https://www.gov.scot/publications/coronavirus-covid-19-stay-at-home-guidance/>

Wales: <https://gov.wales/coronavirus>

Northern Ireland: <https://www.nidirect.gov.uk/articles/coronavirus-covid-19-regulations-guidance-what-restrictions-mean-you>

Note that the restrictions shown above in NI are subject to change.

The reasons behind this decision are as follows:

Cases

At the time of writing, the number of Covid-19 positive tested cases is increasing rapidly, and are at an all-time high. The number of hospitalised patients is now above the figure at any time during the first wave in 2020.

Extremely vulnerable people

If you are in this category—and all CLL patients should be—, you will have received, or should shortly receive, a letter from the government informing you of your status as extremely vulnerable and giving advice accordingly. Please note that there may be differences in each of the devolved nations.

Treatments against Covid-19

There have been some interesting developments on Covid-19 treatment, and our Technical Adviser, Jackie Martin, has written about one of the latest developments, monoclonal antibodies, on our Health Unlocked forum. You may find some of the information to be of a technical nature, but it is an encouraging development and well worth a read.

[Clinical Trials of Monoclonal antibodies AZD74... - CLL Support \(healthunlocked.com\)](#) (You may need to register to access)

In the last 6 months much has been learnt about this virus. The progress the scientific and medical community has made will help to tackle the second wave that is currently upon us.

New CLL treatment approved by NICE

We are very pleased to be able to confirm the exciting news that a new chemotherapy-free CLL treatment option for patients has been approved by NICE.

Venetoclax plus Obinutuzumab combination therapy will be offered as a first-line treatment to people with CLL, with certain genetic abnormalities (such as a 17p deletion or TP53 mutation).

For those without a 17p deletion or TP53 mutation, Venetoclax plus Obinutuzumab will be offered to patients with untreated CLL for whom fludarabine plus cyclophosphamide and rituximab (FCR) or bendamustine plus rituximab (BR) is unsuitable.

This will be a 12 month course of treatment.

Cll Support, along with sister blood cancer charities, made a strong submission to NICE on the benefits this new combination for patients, and we are very pleased. We are thankful that our advocacy, and that of Leukaemia Care, through our patient expert representatives on the committee, and also that of clinical experts, was listened to.

Marc Auckland, in a press release said: *“NICE’s recommendation signifies an important evolution in the CLL treatment landscape. Simply put, what we have here is a novel treatment which provides very deep response rates with a fixed duration of treatment. This is a welcome milestone for the CLL community.”*

And more good news!

In a separate development, another new treatment, **Acalabritinib**, a next generation BTK inhibitor and which is also being considered by NICE, has been approved by the European Union. This is a very positive move in our attempt to obtain approval in the UK, and we are hopeful that our lobbying will be successful later this year.

Looking after your mental health

The current situation imposes new levels of stress for many people.

As the survey results from the recent UKCLL Forum show, there is a substantial number of patients suffering from varying degrees of mental anxiety, and this is something we would like to help with.

We are developing on our website a number of resources of help and advice about mental well being. The first of which is a very simple series of suggestions and tips for coping with the current situation, known as ‘STAND’. This has been prepared by Julie Tanner, a counsellor in mental health. You can find it here:

<https://www.cllsupport.org.uk/information-support/support-for-you/>

You will also find some tips from Katie Perry, who is a family therapist and psychologist.

We will be posting more resources over time, and if there are any aspects you would like to cover, please do ask. Ideas and requests can be sent to: coordinator@cllsupport.org.uk

Remember if you need to speak to someone you can always call our helpline: 0800 977 4396

Our new free Will-writing service.

Thank you to all our members who have taken advantage of this service. You are truly helping us to make a difference.

Currently, during the lockdown, all consultations are taking place online.

We understand that the decision to write a will can be a delicate topic and must be handled sensitively. But it would be wonderful if you could read on before deciding if this is something you can 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 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 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: [CLL-Legacy-leaflet.pdf \(cllsupport.org.uk\)](#)

HealthUnlocked

HealthUnlocked

HealthUnlocked is our international online Forum where you’ll find advice and the latest information on CLL and the problems experienced by fellow sufferers. There are over 15,000 members, and the site is moderated by CLL Support administrators and volunteers to ensure the information is up to date and accurate. This applies particularly to information on CoV-19, where reliable information is so important. You don’t need to participate unless you want to ask a question, but if you do you will receive a warm welcome from fellow CLL sufferers. Why not have a look at: <https://healthunlocked.com/>

We would like to pay special tribute to all our admins and volunteers, who are working exceptionally hard at the moment. The all have experience of CLL and are doing an amazing job. Thankyou!



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 nearly always do.

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. Contact us at: coordinator@cllsupport.org.uk

We look forward to hearing from you.

Until Next Time

Be sure to follow us on Twitter, Facebook, and HealthUnlocked for all the latest information and discussion on CLL. Remember, every post you like, share and retweet helps to raise our profile, allowing other people living with CLL to discover us. CLL Support is the only UK charity dedicated to providing education, support, and advocacy to help empower people living with CLL.