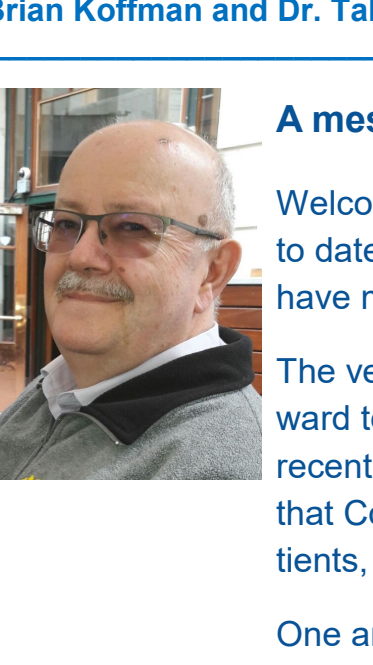
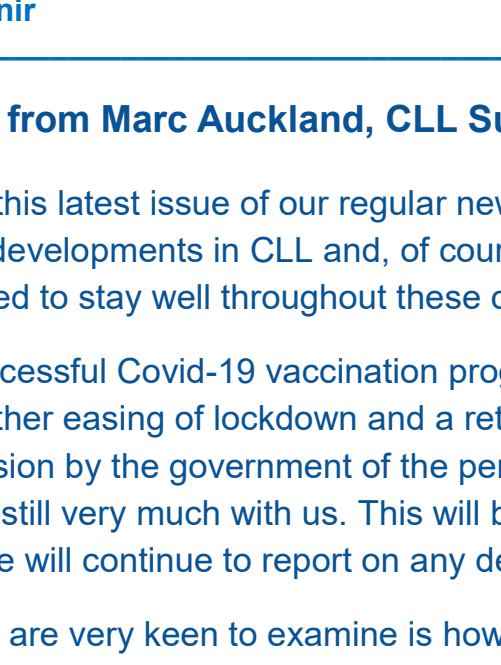


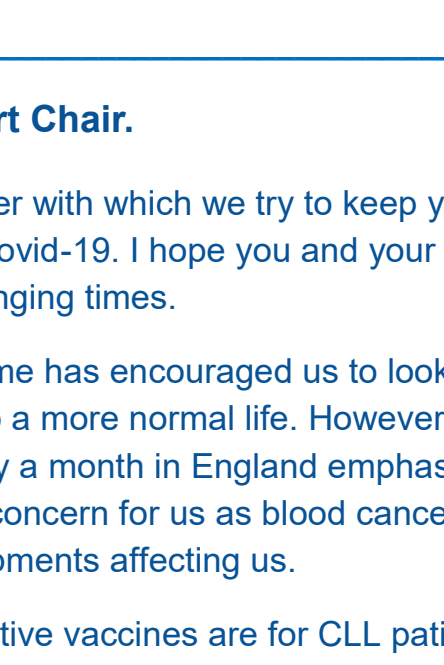
Our top stories in this newsletter



Joint webinar with CLL Ireland
Dr Brian Koffman and Dr. Talha Munir



Latest Covid-19 Update



Amazing fundraising effort!



A message from Marc Auckland, CLL Support Chair.

Welcome to this latest issue of our regular newsletter with which we try to keep you up to date with developments in CLL and, of course, Covid-19. I hope you and your family have managed to stay well throughout these challenging times.

The very successful Covid-19 vaccination programme has encouraged us to look forward to a further easing of lockdown and a return to a more normal life. However, the recent extension by the government of the period by a month in England emphasises that Covid is still very much with us. This will be of concern for us as blood cancer patients, and we will continue to report on any developments affecting us.

One area we are very keen to examine is how effective vaccines are for CLL patients. We are working with various other blood cancer charities concerning this, and we publish below the results of a study from Birmingham University looking at this.

CLL Support is the only UK charity giving a voice on behalf of people with SLL and CLL, and we will always put forward issues such as this to policymakers. Our close relationship with other blood cancer charities and the UK CLL Forum of clinicians, makes our collective voice louder.

I would like to take this opportunity to thank the doctors who have given their time freely to appear in our extremely popular webinars, the most recent of which was a joint one with CLL Ireland. If you haven't caught up with these, they are all recorded and are available on our website.

Finally, on behalf of the trustees, I want to say a huge thank you for your continued support. In this newsletter we publish our annual report which gives details of what we have been doing on your behalf over the last year. Thanks to the kind generosity of our supporters, we finished the year in a good position financially. However, 2021 and 2022 will offer many more challenges, and there is still much to be done, but we are positive about what we can achieve with your help.

Wishing you good health.

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

Our latest webinar is now available on video

We were privileged to have as our keynote speakers **Dr Brian Koffman**, founder and principal of the **CLL Society** in the USA and **Dr. Talha Munir**, who is a Consultant in Clinical Haematology at Leeds Teaching Hospitals NHS in the United Kingdom.

Dr Koffman is extremely well known internationally as a passionate advocate for CLL patients. He is a doctor-turned-CLL patient and has himself received several treatments, including CAR-T cell therapy.

The opportunity to hear this knowledgeable and highly influential speaker is one certainly not to be missed!

Dr. Talha Munir is a Consultant in Clinical Haematology at Leeds Teaching Hospitals NHS in the United Kingdom. He is a well-known speaker on CLL, and in this video, he has a fascinating discussion with **Dr. Koffman**. He has published many research papers on CLL, and has been a key member of the **FLAIR** trial team.

Catch up with the webinar here:

<https://www.cllsupport.org.uk/conference-reports/joint-webinar-with-cll-ireland-31-may-2021/>

Look out for our next webinar

Friday 2 July at 1.00pm with **Dr Renata Walewska**

"Understanding how the UK CLL Forum supports new treatments"

Renata Walewska PhD MRCP FRCPath, is Haematology Consultant, Royal Bournemouth Hospital.

Dr Walewska is the current Chair of the UK CLL Forum, the body which represents CLL doctors in the UK, and is a passionate advocate for patient involvement in treatment decisions. She will be outlining the work of the Forum and will also be speaking about the latest developments in CLL treatment and will answer your questions on CLL and Covid-19

We look forward to welcoming you to this webinar and your invitation will be sent soon. Put the date in your diary!

Covid-19 update

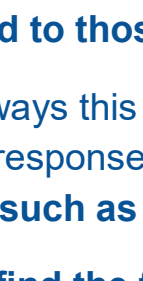
The vaccination roll out has been an enormous success, but Covid is still with us, and the new 'Delta' variant, which seems more infectious, is giving concern.

We will continue to try to keep you up to date with the latest developments that affect our members.

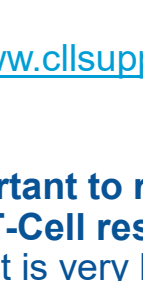
The "roadmap" for easing Covid restrictions in England has been extended for a further month and is now due to end on 19 July 2021

A reminder of where we are at present:

Lockdown easing: the rules in England from 21 June



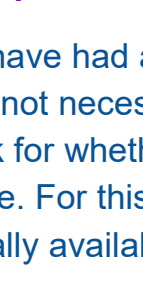
More than 30 guests can attend a wedding but must be seated at tables of six



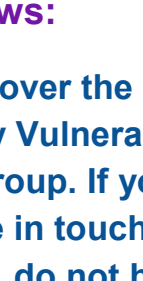
Up to six people or two households can meet indoors



Pubs and restaurants table service only



Theatre and cinema audiences limited to 50% capacity



Bigger crowds allowed at some pilot events for sport and entertainment



Social distancing remains in place



Nightclubs remain closed

Source: GOV.UK



This will remain in place until 19 July 2021.

Please note that there are different rules for each of the devolved nations and you can find more information here:

Scotland: <https://www.gov.scot/>

Wales: [Coronavirus \(COVID-19\) | Topic | GOV.WALES](https://www.gov.wales/coronavirus-covid-19)

Northern Ireland: <https://www.nidirect.gov.uk/campaigns/coronavirus-covid-19>

These regulations are subject to change by the individual nations concerned.

Relaxation of shielding

Many of our members have been shielding, and it was confirmed that shielding in England was paused from the 31st of March 2021, and Scotland and Wales from 26 April. Northern Ireland has released separate information.

We know that many of you may have been feeling anxious about this, so we have put together a few tips for meeting people outside. You can find these on our website here: <https://www.cllsupport.org.uk/shielding-easing-tips/>

Vaccinations are not fully protective (see below for more information), especially in blood cancer patients, and new, more infectious variations of Covid-19 present additional problems. It is, therefore, still important to take every precaution, at least for the time being until the situation becomes much clearer.

Shielding is, and always has been, voluntary, so there is no compulsion to continue to shield. However, precautions such as handwashing, masks and social distancing are still vitally important for CLL and SLL patients, as we start to return to a more normal life.

Vaccines. The latest news.

We continue to receive lots of queries about the vaccines which are now in use. 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/>

If you have a question about vaccines or Covid—19, please contact us and we will try to help: coordinator@cllsupport.org.uk

We encourage all members and their families to have a vaccination if offered.



One of the most frequent questions asked is: **'how effective is the vaccine for CLL patients?'** We have received an interim report from one of the most important studies, the **Birmingham University** study looking at how effective the vaccines are for CLL patients. The antibody response to covid vaccinations in 299 people with chronic lymphocytic leukaemia (CLL) who had two doses of either the Pfizer or AstraZeneca vaccine was examined.

We interviewed Dr Helen Parry, who is the lead on this trial. She speaks about why the trial is important and presents the results in a very understandable way. You can watch the video here: <https://www.cllsupport.org.uk/dr-helen-parry-presents-the-findings-of-research-into-vaccine-effectiveness-june-21/>

Summary:

The team found that after one dose of the vaccine, 34% of people with CLL had an antibody response to vaccination which rose to 75% after the second vaccination. In comparison, 100% of healthy donors had an antibody response after the two doses of the vaccine. Whilst 75% of those with CLL developed an antibody response, the actual quantity of antibodies produced was lower compared to those who were healthy.

In some ways this research is quite encouraging for CLL patients, as at least some antibody response is seen, **except for those in treatment, particularly with a BTK inhibitor such as Ibrutinib.**

You can find the full report together with our comments here:

<https://www.cllsupport.org.uk/birmingham-university-covid-vaccine-study-results-released/>

It's important to remember that the antibody response recorded does not include T-Cell response, which is an important component of the immune system. It is very likely that your T-cells will be active in mounting a defence against Covid-19. For a good discussion on the importance of T-cells, watch this short video: <https://www.medpagetoday.com/opinion/marty-makary/92310>

As a general comment, it's better to have some protection, however small, so vaccination is vital.

One other point about vaccinations

You may have had a Covid test which has been negative, even after having a vaccination. This does not necessarily mean that you don't have antibodies, because the standard tests only check for whether you have had Covid and won't show up the antibodies created by the vaccine. For this you would need a different and much more complicated test, which is not generally available.

Other news:

Anybody over the age of 16 living with somebody that is classified as Clinically Extremely Vulnerable can now access their vaccination - no matter their age or priority group. If you have somebody at home that falls into this category, your GP should be in touch. If you have any issues in securing a vaccine for household members, do not hesitate to get in touch with us.

Covid-19 and Blood Cancer

This is a video prepared by **Dr Sarah Hayward-Small** who is a senior lecturer at **Sheffield Hallam University**. We asked Dr Hayward-Small to give us an understanding of how Covid affects blood cancer patients, and this short video covers everything from the virus itself to how it affects our immune system and health. You can find it here: <https://www.cllsupport.org.uk/covid-and-blood-cancer/>

CLL Support in the news!

One of our trustees, **John Greensmyth**, was featured in the **Sunday Sun** newspaper in Scotland following the approval by the **Scottish Medical Consortium (SMC)** of the new treatment **acalabrutinib**.

John was quoted: "This new drug targets the disease but more importantly the side effects are significantly less than chemotherapy."

"Normal treatment for CLL would be chemotherapy, which would be for six months at monthly intervals. You would then have oral tablets and anti-sickness tablets to combat the side effects."

"But chemotherapy knocks the stuffing out of you because in layman's terms it's a very blunt instrument as it does harm as it does good."

We made a submission to the SMC, recommending the acceptance of this treatment, and we are very pleased that our recommendation has been accepted.

You can find the full interview with John here:

<https://www.thescottishsun.co.uk/news/7241254/astrazeneca-scots-cancer-patients/>

Many thanks to John for his work on behalf of CLL patients in Scotland.

Latest CLL developments

There has been a revolution in CLL treatment over recent years with new drugs such as **ibrutinib**, **venetoclax** and **acalabrutinib** changing the whole landscape, and offering new hope to patients.

It's very encouraging that research is continuing and that several potential treatments are in the pipeline, including the following:

ALPINE study, **ALPINE** (BGB-3111-305) is a global, randomized, phase 3 study comparing **zanubrutinib** vs **ibrutinib** in patients with relapsed/refractory (R/R) CLL/SLL. Full details of this interesting study are published on our Health Unlocked forum by our patient advocate, Jackie Martin:

(76)[Zanubrutinib looks promising on all fronts in ... - CLL Support](https://www.healthunlocked.com/forums/76-zanubrutinib-looks-promising-on-all-fronts-in-...-CLL-Support) ([healthunlocked.com](https://www.healthunlocked.com/))

Monoclonal antibodies

Monoclonal antibodies are designed to mimic the body's natural immune response, and are available as treatment for COVID-19 for patients at high risk of progression to severe disease. This group includes CLL patients.

How this works:

RECOVERY study. Oxford University scientists have reported that **Regeneron's antibody therapy** can cut the risk of death from Covid-19 by a fifth in seriously ill patients whose immune systems are weak such as in CLL patients.

Previous studies in non-hospitalised COVID-19 patients have shown that the treatment reduces viral load, shortens the time to resolution of symptoms, and significantly reduces the risk of hospitalisation or death. In a small trial in hospitalised patients, preliminary evidence suggested a clinical benefit in patients who had not mounted a natural antibody response of their own when they entered the trial. RECOVERY is the first trial large enough to determine definitively whether this treatment reduces mortality in patients hospitalised with severe COVID-19.

Full details of the trial can be found here:

[RECOVERY trial Regeneron's monoclonal antibody combination reduces deaths for hospitalised COVID-19 patients | University of Oxford](https://www.recoverytrial.org/)

There are other trials looking at monoclonal antibody treatment:

PROVENT and **TRIMCHASER** are looking at use of a treatment from AstraZeneca (AZD7442) in people who may not respond to vaccination (for instance where someone has a compromised immune system) or are at increased risk of Covid-19 infection due to factors such as age and existing conditions. The trials are being run from University College Hospitals London.

Other trials

An excellent summary of the **CLL trials** currently running can be found on the UKCLL Forum website here: <https://ukcllforum.org/clinical/>

Please note that all trials may have certain medical restrictions for participants and many are in the very early stages (Phase 1 or 2), which means that not all patients will qualify.

ASICS 10k RUN is still on! Part of our Summer fundraising!

Dust off those running shoes!!



Welcome to the ultimate easy foot foot of London. Run past Trafalgar Square, the Embankment, Big Ben and more. Flat and iconic, the classic course is ready for your best time and your best self! And there is music at every 1km!

This popular run is going ahead as planned on:

Sunday 25 July 2021

This is undoubtedly the friendliest of all the 10k charity runs and it's always difficult to get tickets. We are very fortunate to have a very limited number available for our team, so apply now!

Due to the on-going Covid-19 restrictions, our fundraising over the last year is £15,000 below our usual target. We need to try to make this up to be able to continue our work helping CLL patients.

You can get more details here:

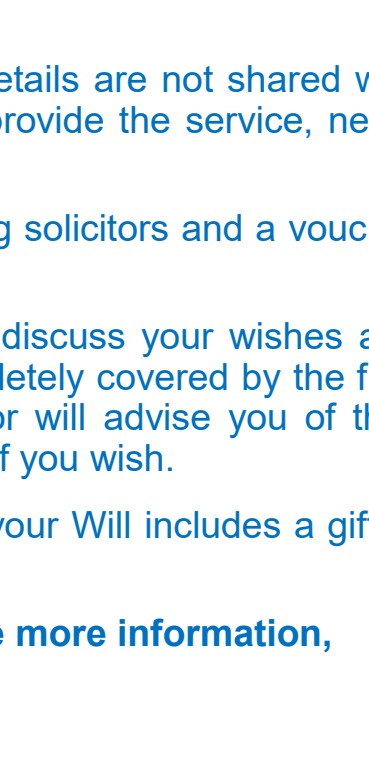
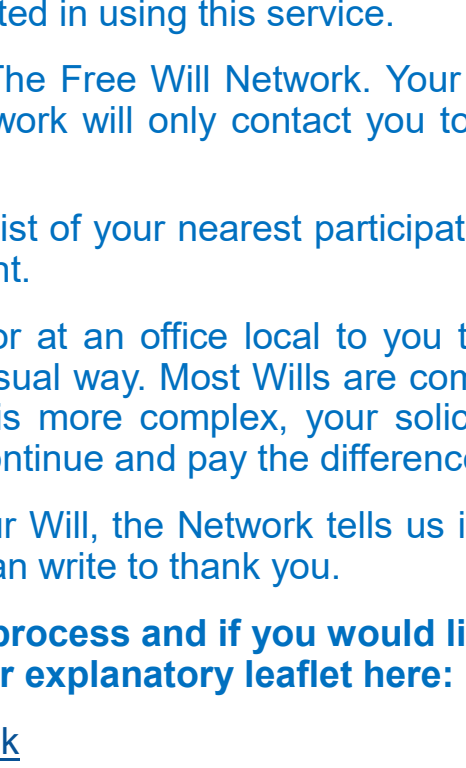
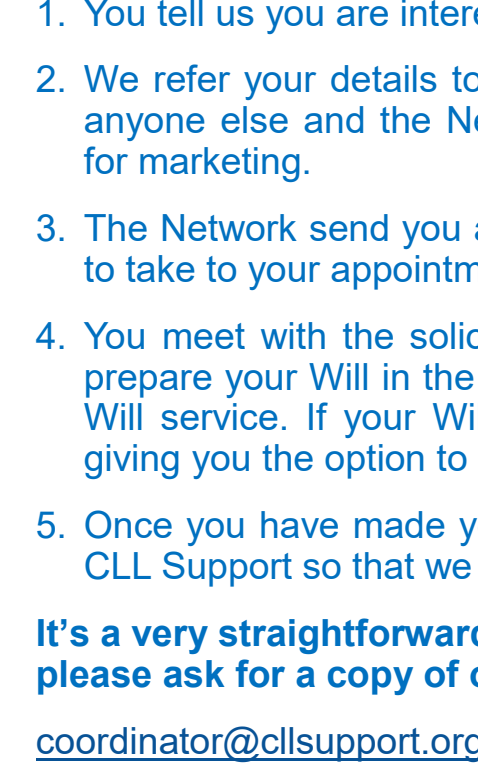
[ASICS London 10K | Limelight Sports Club](https://www.asicslondon10k.com/)

Enrol in our team for FREE here: coordinator@cllsupport.org.uk

Entry is free via CLL Support, but the minimum fundraising is £200.00 per runner.

WOW!

Magnificent effort by CLL patient!!



Cormac Davey completed an astounding 100k run on 5 June, and raised an amazing £2171.37 for CLL Support!

"Cormac says: "The first 25K was stunning and really enjoyable along Grim's Ditch. 25-50K was harder and seemed longer, but the highlights were running along the Thames to Goring. 50-75K was tough and I was really unable to eat due to nausea. It was a hot day! Still, when I arrived at Liddington Hill I was greeted by my wife and friends. That filled my spirits and 75-100K was a real joy. I finished in the Dark to a champagne finish."

We want to thank Cormac and his supporters for a magnificent effort and a well-deserved glass of Champagne. Well done to everyone involved!

There is now a sponsor for Cormac for his stunning effort. You can do so here: <https://www.justgiving.com/fundraising/cormacacultrachallenge>

Under 60 Club

Membership in the Under 60 Club WhatsApp group has grown steadily. It is a very busy forum for people balancing CLL with Covid in the workplace and young families, as well as sharing concerns over Active Monitoring and starting treatment. Many thanks to everyone in the Under 60 Club for the continued success of the group.

Just a few of the comments from our members:

"I knew there'd be a voice of calm and reason from this group. Thanks for the top tips x"

"I love this group and although I miss a lot it's great to catch up with everyone's news x"

"I love this group - you're all such inspirational people! Catching up on messages and can see lots of you are dealing with starting treatment and so just wanted to say that I'm thinking of you all and sending lots of positive energy your way."

If you would like to find out more, or to join the group, please contact Norah at: norah.grant@cllsupport.org.uk

Our annual report

Each year we publish a report to our members covering our activities during the year. We try to summarise what we have achieved and what our aims are for the future. You can find this on our website here: <https://rb.gy/wmcnkl>

Please have a look and we welcome any comments you may have. Let us know if you would like us to include other things or concentrate on other areas. This is your charity and we welcome your input and suggestions.

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 us 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, many solicitor consultations are taking place online. However, as restrictions are eased, it will be possible to see a solicitor face-to-face.

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 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](https://www.cllsupport.org.uk/CLL-Legacy-leaflet.pdf) ([cllsupport.org.uk](https://www.cllsupport.org.uk/))

Don't forget to smile! Even through all the problems!

Our fundraising activities have necessarily had to be cut short for the last year. However, we still need to try to generate an income and one relatively painless way of helping us, and if you ever use Amazon, is to log on to the **Amazon Smile** site instead of the usual one. It's precisely the same, and doesn't cost you any more, but CLL Support will receive a small percentage of whatever you spend.

We only receive a small amount (£0.01 per £ spent), but it soon adds up so please do use it! In fact, to date we've received £1080.36.

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 Covid-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://www.healthunlocked.com/forums/146062888/clt-scan-results?utm_source=notification&utm_medium=email&utm_campaign=email_individual_new_blog&utm_post_title

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

Any thoughts?