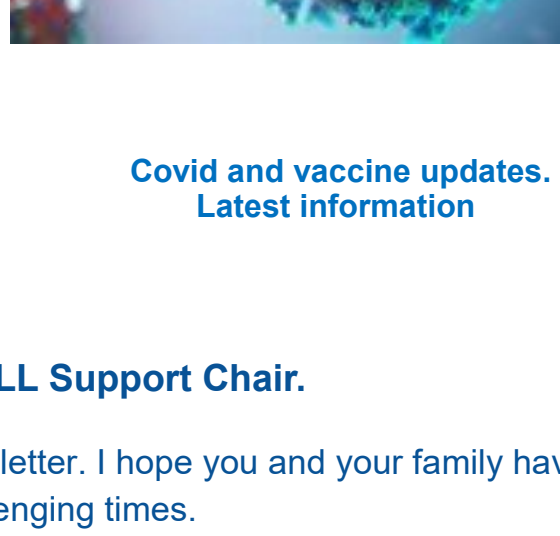
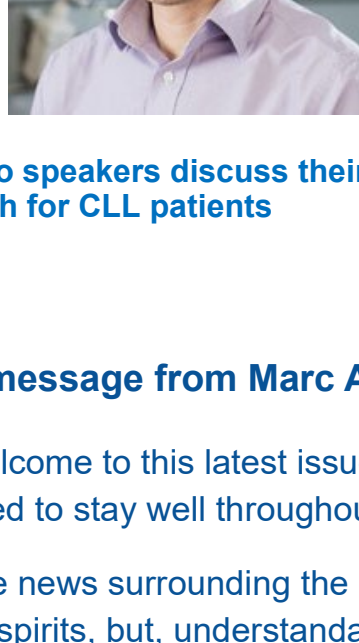


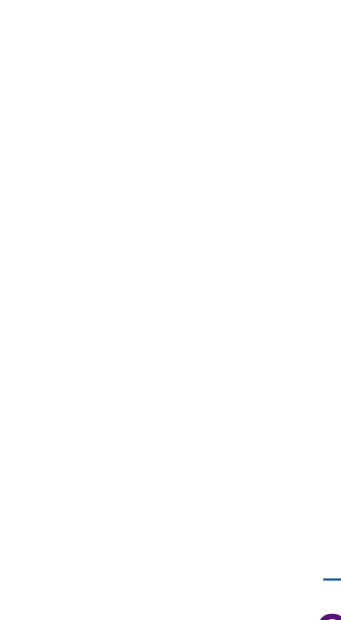
Our top stories in this newsletter



Latest webinar - our two speakers discuss their important new research for CLL patients



Covid and vaccine updates. Latest information



A message from Marc Auckland, CLL Support Chair.

Welcome to this latest issue of our newsletter. I hope you and your family have managed to stay well throughout these challenging times.

The news surrounding the successful Covid-19 vaccination programme has certainly lifted spirits, but, understandably, has also generated a lot of questions from people living with CLL. We try to address some of these in our newsletters, and you can find more information on our website.

As the voice for people with SLL and CLL, we are continuing to put forward the issues that matter to you, our members, to policymakers, and our close relationship with other blood cancer charities and the UK CLL Forum of clinicians, makes our voice louder.

Alongside this we have been hard at work creating new resources to help with wellbeing, holding our extremely popular webinars and updating our information booklet. Thanks to everyone, especially clinicians, for giving their time willingly and for free.

Finally, on behalf of the trustees, I want to say a huge thank you for your continued support. Thanks to the kind generosity of our supporters, and an unexpected legacy we received last year, we finished the year in a stronger position than we could have hoped for. 2021 will offer more challenges, and there is still much to be done, but we are positive about what we can achieve with your help.

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

Our recent webinar is now available on video

News about exciting new research by the **Newcastle Centre for Cancer and the Hull York Medical School** was covered in a number of national newspapers and also in America. We were delighted, therefore, when the two principle researchers, **Professor James Allen and Doctor David Allsup**, agreed to talk to us for our latest webinar.

By examining blood samples of patients with CLL, Dr Allsup and Professor Allan discovered that there was a genetic tendency to develop progressive forms of the illness in some patients.

The study presents the opportunity in future to warn prospective patients that they also possess the genetic make-up that could lead to developing progressive CLL, and to design a personalised treatment process for them long before the illness takes effect.

We heard about this vital research and the panellists' thoughts on how it could impact CLL patients. They answered questions at the end and if you missed the webinar, or would like to watch again, you can do so here: <https://www.cllsupport.org.uk/conference-reports/cll-support-webinar-22-april-2021/>

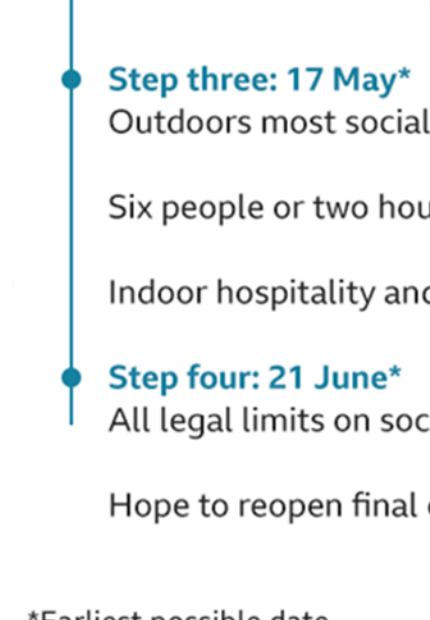
Our next webinar

Thursday 20 May at 2.00pm with Dr Helen Marr

'Autoimmune complications of CLL'

We know that CLL and SLL patients have compromised immune systems. However, a complication can arise when antibodies or lymphocytes are produced against substances naturally present in the body. Dr Marr will be examining this topic which is of great relevance for CLL patients

Our keynote speaker will be Dr. Helen Marr.



Dr Marr is Consultant Haematologist at the Freeman Hospital, Newcastle on Tyne and has contributed to numerous papers on blood cancer. She qualified from University of Nottingham in 2002 before completing her general medical training in Newcastle. She worked as a haematology registrar in Christchurch Public Hospital in New Zealand before returning to complete her haematology specialist registrar training in Newcastle. She was awarded a PhD in 2015 from Newcastle University for her thesis, 'Regulation of CD38 by IRF4 in CLL'. She was appointed to her Consultant post in 2017 and has a special interest in CLL and lymphoma.

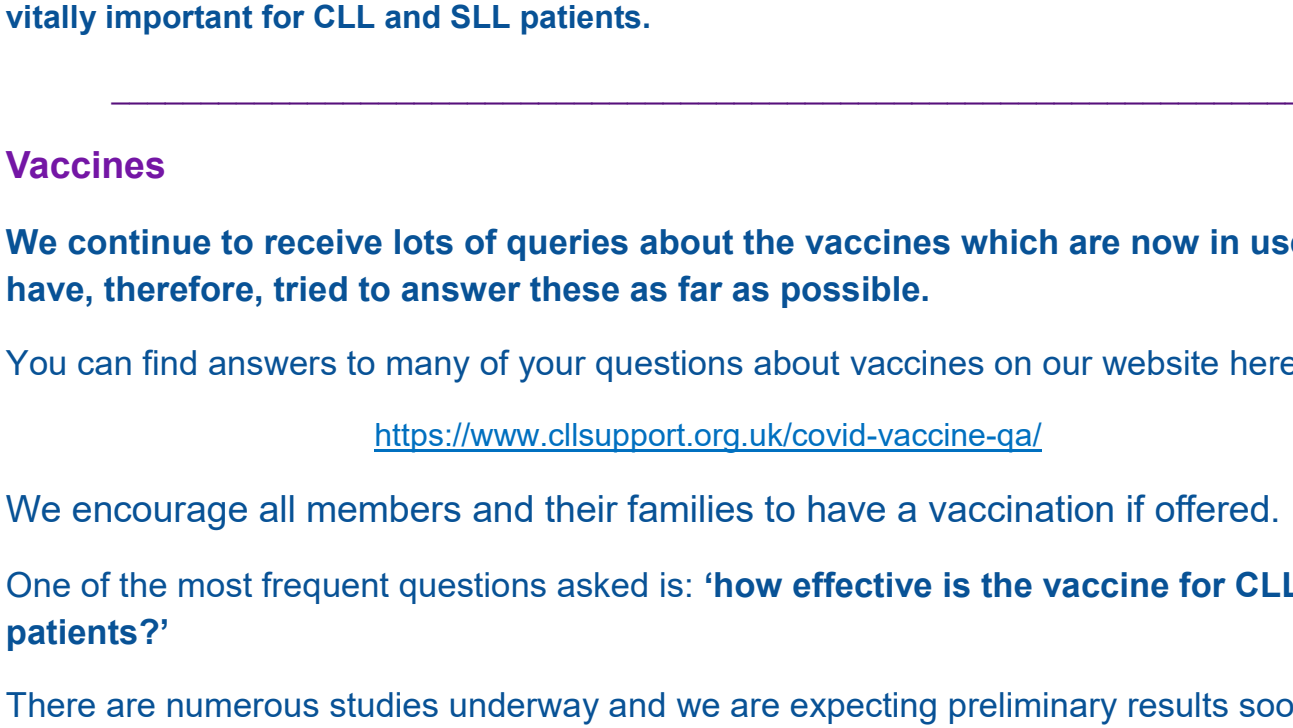
We look forward to welcoming you to this webinar and your invitation will be sent soon. Put the date in your diary!

Covid-19 update

Covid-19 update
The vaccination roll out has been an enormous success, but Covid is still with us, and we will continue to try to keep you up to date with the latest developments that affect our members.

A "roadmap" for easing Covid restrictions in England is in place by the UK government. A reminder of where we are at present:

Key dates for lockdown easing in England:



*Earliest possible date
Source: GOV.UK

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.uk/government/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, and Scotland and Wales from 26 April. Northern Ireland is due to release details soon.

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/>

Since March 2020, guidance for what we can and cannot do has changed 65 times. So it's quite difficult to be up to date with the current situation. We will continually update you in our newsletters and on our website to keep you informed as much as possible.

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.

Vaccines

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 your questions about vaccines on our website here:

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

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?'

There are numerous studies underway and we are expecting preliminary results soon. A good summary and discussion about what is currently known can be found on our Forum here: <https://rb.gy/oevknw>. This also has links to other relevant information.

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.

Latest 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/>

New podcast from UK CLL Forum

This is the first in a series of interviews with clinicians organised by the UK CLL Forum. This one is a fascinating interview with **Prof P Hillmen** covering his views on COVID, haematology, golf and football.

We think you'll find it interesting.

Check it out here: [Podcasts | UK CLL Forum](#)

Health Matters

Sun protection.

With the exceptionally cold weather we have been experiencing, it may seem strange to remind members to use sunscreen when going out. However, the sun –when it's out–at this time of year is becoming stronger, and the UV levels are high. We know that CLL patients are more vulnerable to secondary cancers, particularly skin cancer, so please be careful and use a high factor sunscreen and think about wearing a hat.

Tumeric

Turmeric is sometimes promoted as an alternative cancer treatment. There is some evidence that curcumin, a substance in turmeric, can kill cancer cells in certain cancers in the laboratory, but much more research is needed.

Summary

- Turmeric is a spice grown in many Asian countries.
- Research on curcumin as a cancer treatment is ongoing.
- It may have side effects if taken in large amounts.

It is our firm recommendation that CLL/SLL patients should avoid alternative treatments as many of these can be harmful. Small amounts of Turmeric as a dietary supplement may do no harm, but we recommend speaking to your medical team first. Some supplements can have an adverse affect on certain treatments.

Vitamin D

Vitamin D is essential for health, but there have been highly exaggerated claims that it can prevent or even 'cure' Covid-19. Our bodies can't make vitamin D and it gets it mainly from sunlight. However, during the Winter or if we are wearing high factor sunscreen in the Summer, we need to obtain it from food, such as eggs and fish, or from supplements.

The latest information on Vitamin D and Covid is from the British Medical Journal and can be found here: [Vitamin D and covid-19 | The BMJ](#)

Green Tea

The active ingredient in green tea is *epigallocatechin-3-gallat* (EGCG) and is another of the alternative treatments often promoted as a 'cure' or cancer. Some years ago, green tea extract was tested in the laboratory by the Mayo clinic (<https://www.sciencedaily.com/releases/2004/04/040401075242.htm>) and it was found, if in very high quantities, to kill CLL cells. However, these levels would lead to severe liver damage and probably other toxic side effects.

The message is: if you like green tea, carry on drinking it. It certainly won't do you any harm in small quantities. You might want to look at organic green tea as this is also insecticide free. Enjoy!

Women - a chance to have your say.

The UK government are seeking your views to help inform the development of the government's Women's Health Strategy.

This call for evidence is seeking to collect views on women's health. It will run for a period of 14 weeks and is open to everyone aged 16 and over.

The easiest way to participate in the call for evidence as an individual is by completing the public survey.

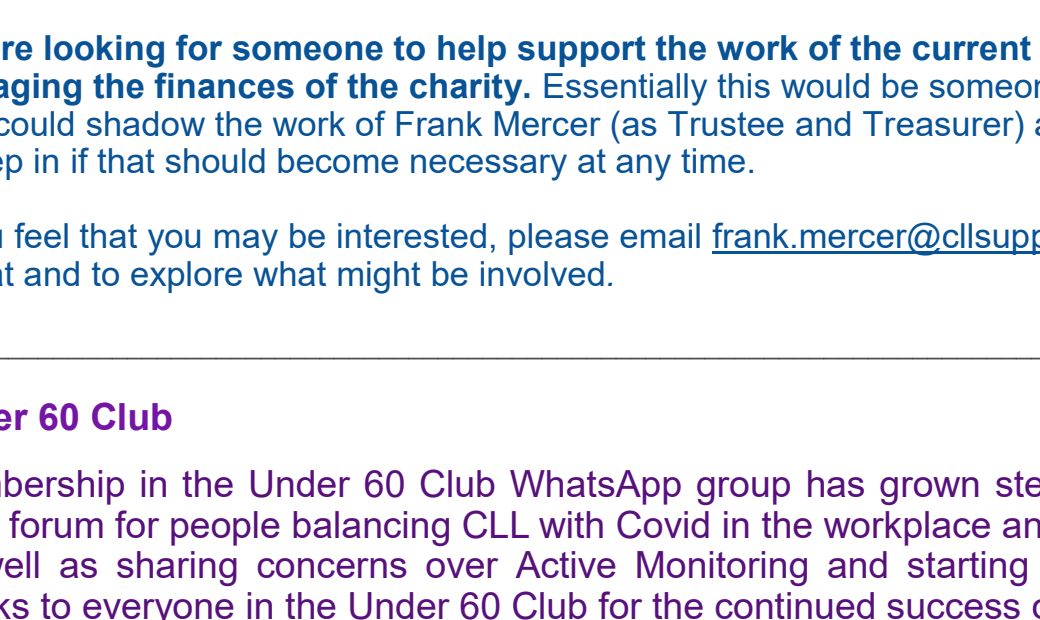
The government states:

"For generations women have lived with a healthcare system designed by men.

So, we're bringing forward England's first Women's Health Strategy, to make women's voices heard & put them at the centre of their own care.

We urge you to come forward & have your say, so we can make sure our nation's health system truly works for the whole nation."

Information and the survey can be found here: <https://www.gov.uk/government/consultations/womens-health-strategy-call-for-evidence/womens-health-strategy-04/040401075242>



We set up this discussion at the recent **British Society of Haematologists'** annual conference. Marc Auckland debated with four eminent CLL specialists a range of views about CLL and patient care.

This is a lively discussion and some of the views are deliberately provocative in order to stimulate debate. Please note that they do not necessarily represent the views of the individuals concerned.

We think you will find it very interesting!

You can watch it here: <https://www.cllsupport.org.uk/room-101/>

Help wanted!

Are you interested in supporting your charity? Can you spare an hour or two a month and have some experience or interest in financial management and working with spreadsheets?

We are looking for someone to help support the work of the current Treasurer in managing the finances of the charity. Essentially this would be someone who could shadow the work of Frank Mercer (as Trustee and Treasurer) and be on hand to step in if that should become necessary at any time.

If you feel that you may be interested, please email frank.mercer@cllsupport.org.uk to have a chat and to explore what might be involved.

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

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, all solicitor 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 \(cllsupport.org.uk\)](#)

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. The first time you log on you will be asked to nominate your chosen charity and CLL Support will pop up. With many of us having to self isolate, DVD boxed sets will be an essential requirement, so if you decide to buy from Amazon, just log on the Smile!

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 £836.00.

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 scan the link at: https://healthunlocked.com/cllsupport/posts/146062888/ct-scan-results?utm_source=notification&utm_medium=email&utm_campaign=email_individual_new_blog_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?

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 support 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.