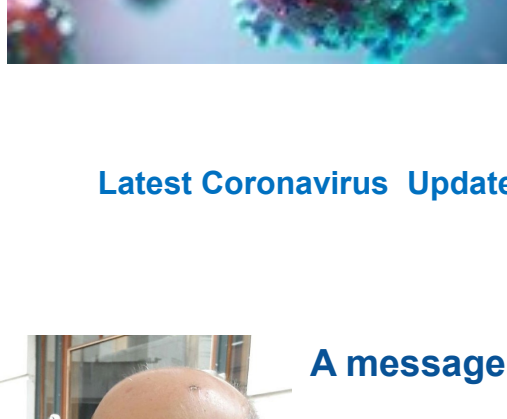
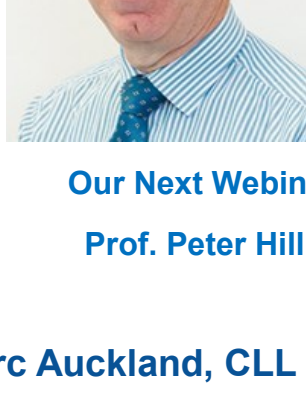


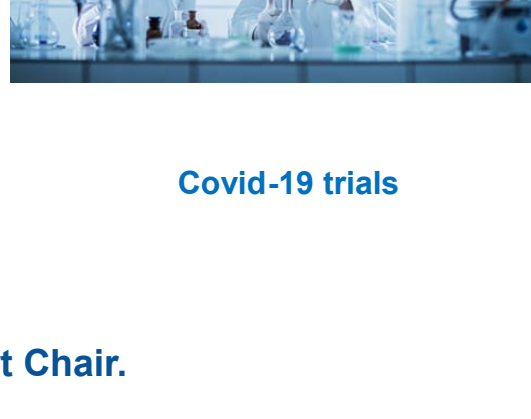
## Our top stories in this newsletter



Latest Coronavirus Update



Our Next Webinar with Prof. Peter Hillmen



Covid-19 trials



### A message from Marc Auckland, CLL Support Chair.

Welcome to our latest newsletter, in which we try to keep you up to date with everything concerning Covid-19 and developments in SLL/CLL.

As you will see below, the news about Covid-19 is encouraging. The UK government has outlined a 'roadmap' showing how we may get out of the current restrictions and begin to progress towards something approaching normal life. After such a long period of lockdown this will be welcomed by us all, and particularly by those, such as our members, who have had to endure long periods of shielding.

We are already planning ahead, and we hope to be able to announce our first 'live' conference for the later part of the year, possibly November or December. Much will depend, of course on developments between now and then, but we are hopeful that it will take place.

The quiet confidence expressed by Professor Andrew Pollard when we interviewed him about the AstraZeneca vaccine for our first webinar in March last year seems to have been well justified, and the vaccination roll-out is progressing well. We also look forward with the same confidence to continuing our support for CLL and SLL patients in the coming months as we emerge from this last most difficult year.

Wishing you and your loved ones good health.

Marc Auckland  
Chair of trustees  
[marc.auckland@cllsupport.org.uk](mailto:marc.auckland@cllsupport.org.uk)

## Covid-19 update

**A "roadmap" for easing Covid restrictions in England has been announced by the UK government. There are four stages.**

**Some of the key points that may affect you:**

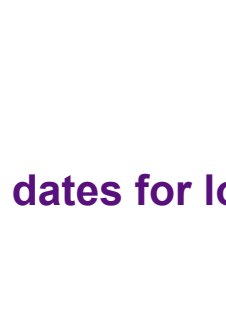
### Lockdown rules for England from 08 March:



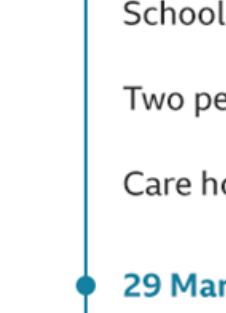
Stay home - only leave for work, essential shopping, exercise or medical appointments



Exercise allowed outdoors once a day, in your local area. You can exercise with your household, support bubble, or one other person



All schools open, with outdoor after-school sports and activities allowed.



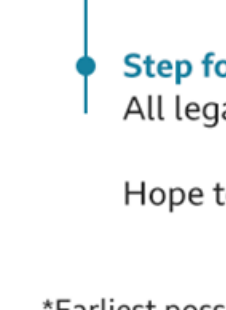
Two people can meet outdoors to socialise eg to sit down for a coffee, drink or picnic



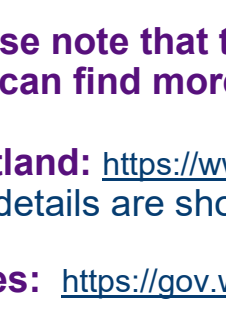
Care home residents are allowed one regular visitor, with whom they can hold hands



No household mixing indoors or outdoors unless in your support or childcare bubble



Non-essential shops, leisure and entertainment venues closed



Pubs and restaurants closed, but takeaway food permitted

## Key dates for lockdown easing in England

- Step one: 8 March**
  - Schools open. Outdoor after-school sports allowed
  - Two people allowed to sit together outdoors
  - Care home residents allowed one regular visitor
- 29 March**
  - Six people or two households allowed to meet outdoors
  - Outdoor sports facilities open, organised sport allowed
  - Travel outside local area allowed
- Step two: 12 April\***
  - Non-essential retail and personal care open
  - Hospitality outdoors open
  - Indoor leisure eg gyms, swimming pools open
  - Self-contained holiday accommodation open
- Step three: 17 May\***
  - Outdoors most social contact rules lifted
  - Six people or two households can meet indoors
  - Indoor hospitality and hotels open
- Step four: 21 June\***
  - All legal limits on social contact removed
  - Hope to reopen final closed sectors of the economy

\*Earliest possible date

**Sources for all information: Govt. and BBC**

**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/>  
Full details are shown under the 'Strategic Framework' heading on this page

**Wales:** <https://gov.wales/alert-level-4>

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

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

**\*\*Clinically vulnerable people are still advised to shield until 31 March 2021\*\***

## Our next webinar

**Professor Peter Hillmen**  
**18 March 2021**

**We are very pleased that Prof. Hillmen has agreed to be our keynote speaker.**

Prof. Hillmen is Professor of Experimental Haematology and Honorary Consultant Haematologist at Leeds Teaching Hospitals NHS Trust.

He has been the lead clinician for the FLAIR trial and will be the lead for the **STATIC** trial which will take its place. Prof. Hillmen is an internationally renowned expert on CLL/SLL and has spoken at conferences across the world.

Registrations will be announced soon, so look out for the details.

This is sure to be a very popular event, so to help us in planning, please register as soon as it opens.

## Vaccines

**We've 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-ga/>

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

However, we know the effectiveness of vaccines may vary for people with compromised immune systems, such as CLL patients. For this reason, we are partnering a **new antibody monitoring trial with the CLL Forum** and you can find details of this below.

Marc Auckland is working with the **Blood Cancer Alliance** to lobby the government to create a UK wide monitoring programme. We will keep you posted on progress.

## Vaccine Webinar

**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 Renata 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](#)

## Webinar on 'active monitoring'

Our sister charities **Leukaemia Care** and **Lymphoma Action** will be running a webinar on **19 March 2021**

The focus of this webinar is active monitoring (watch and wait), what it is and how to live well whilst on it.

More details and registration can be found here:

<https://lymphoma-action.org.uk/events/living-well-active-monitoring-free-online-webinar>

## Vaccines and CLL

### Volunteers needed for a new trial

**There is little data on how the vaccine will work in patients with compromised immune systems, such as ourselves.**

In partnership with the **UK CLL Forum**, a new study by **Birmingham University** is opening to monitor the impact and longevity of the vaccines on CLL patients.

For this study we are asking participants if they would be willing to have a blood sample taken following their first or second vaccination or to complete a home testing kit which will be sent out in the post. If you would like to take part in this important study, please contact the study team by email at:

[haematologyengagement@contacts.bham.ac.uk](mailto:haematologyengagement@contacts.bham.ac.uk) or call 0121-414-4491 for more information.

**This is a very important study, with far-reaching implications for CLL patients, so please help if you can.**

## Covid-19 trials

**A number of very exciting trials are currently underway.**

**UCLH** has opened a new vaccine research centre with two clinical trials testing a long-acting antibody combination treatment to protect against Covid-19.

Researchers in the **STORM CHASER** study led by UCLH virologist Dr Catherine Houlihan have recruited the first participant in the world to the study.

They believe the antibody known as AZD7442 and developed by AstraZeneca, may offer immediate and long-term protection to people who have been recently exposed to the SARS-CoV-2 virus, to prevent them developing Covid-19.

The other study, **PROVENT**, is looking at use of an antibody combination 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. This is particularly relevant for CLL patients, and two of our trustees have enrolled on the trial.

Find out more here:

<https://www.nihr.ac.uk/news/uk-study-participant-is-worlds-first-to-receive-astrazenecas-covid-19-antibody-combination/26275>

A further trial, run by Cancer Research UK, called **STORM**, is looking at the effects of Covid-19 on people who have cancer. You can find details here:

[A study looking at COVID-19 and people who have cancer \(SOAP\) | Cancer Research UK](#)

## CLL research needs you! How you can make a difference

### How do we know whether novel treatments or combination treatments for CLL help or harm?

**Treatments are tested in clinical trials to see if they work and are safe prior to introducing new drugs into real-world settings.**

In trials, researchers look at what effects the treatments have on people with CLL. Each effect is called an 'outcome'. When deciding what outcomes (or effects) to look at in a trial, we feel it is important researchers are guided by which ones are important and relevant to people with CLL, their families and carers.

**This is why we are urging you to add your voice via the survey link below.**

This survey asks people affected by CLL what outcomes (or effects) would be important to them. Once a group of important outcomes has been agreed, this will be used to guide future research.

**CLL Support encourages everyone to take part in this survey so that your voice is heard.**

**You can find the link here:**

<https://delphimanager.liv.ac.uk/CLL/Delphi>

## A question from a member

**With spring approaching and after an enquiry from a member about the dangers of carcinogenic and particularly glyphosate, we thought we would update everyone on the current state of play as we understand it.**

'Roundup' is the brand name for a popular weed killer manufactured by Monsanto in the US. It has been the subject of several high-profile court cases which resulted in the award of substantial sums to people who claimed it was responsible for their cancers.

Although Monsanto lost several cases, Roundup is still sold and available, and the US Environmental Protection Agency recently stated that glyphosate, the active ingredient, is safe to use and unlikely to cause cancer.

US cases were won mainly on the basis of inadequate warnings about toxicity, rather than the toxicity itself.

Several US states have independently banned Roundup, or limited its use, particularly in large areas such as parks. The Daily Mail reported in May 2020 that the retailer B & Q was stopping supply of 'Roundup' because of concerns about its safety.

We are monitoring the situation and will let you know of any developments. Meanwhile, if you use Roundup, please take strict precautions. Follow the instructions, avoid breathing in the spray, and wear gloves and mask.

**Blood Cancer UK wrote a good update on this concern last year and here is the link if you wish to read further:**

<https://bloodcancer.org.uk/news/does-chemical-found-weedkiller-cause-lymphoma/>

## Looking after your mental health

The current situation imposes high 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](mailto: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?

- You tell us you are interested in using this service.
- 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.
- The Network send you a list of your nearest participating solicitors and a voucher to take to your appointment.
- 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.
- 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](mailto:coordinator@cllsupport.org.uk)

Or download from our website: [CLL-Legacy-leaflet.pdf \(cllsupport.org.uk\)](#)

## 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](mailto: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.**

Registered Charity: 1178482