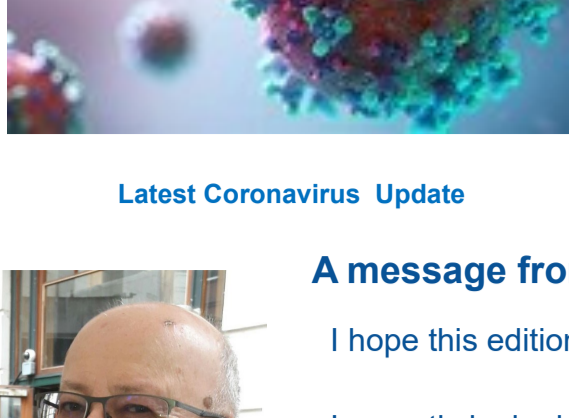
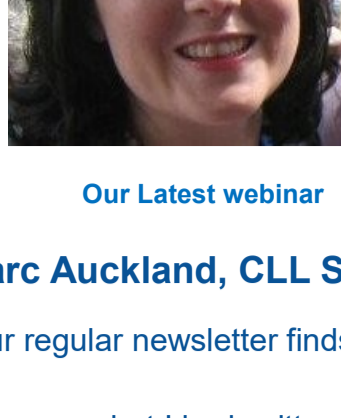




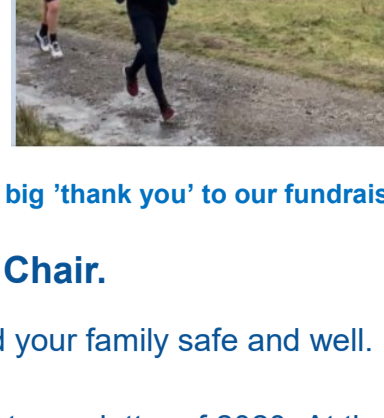
Our top stories in this newsletter



Latest Coronavirus Update



Our Latest webinar



A big 'thank you' to our fundraisers!

A message from Marc Auckland, CLL Support Chair.

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

I recently looked back to see what I had written in our first newsletter of 2020. At that time, I was optimistically looking forward to a year of successful webinars and to meeting as many of our members as possible. How that all changed so quickly just a few weeks afterwards!

There is not one of us who has not been touched in some way by the Coronavirus pandemic, and it has been an enormously difficult time for the whole country. CLL and SLL patients, however, have been affected particularly badly. We are more vulnerable to infection and in most cases have been forced to shield for long periods, with the associated mental and physical stress this can cause. In many cases treatment has had to be paused or delayed indefinitely, leading to even more stress. We are very keen to address this with advice in our webinars and on our website to help with feelings of anxiety. You will find links in this newsletter if you feel you would like more information.

Throughout this difficult time, we have tried to keep our members up to date through these newsletters and our hugely successful webinars, which have enabled us to reach hundreds of people each time. Our helpline has been extremely busy, and our website has been regularly updated with the latest information.

Our usual work has carried on, including submissions to NICE about new treatments, and working with our sister charities to lobby government. I am incredibly pleased that we were able to lead to persuade NICE to approve a new non-chemotherapy drug combination, Venetoclax and Obinutuzumab, for first line treatment through the Cancer Drugs Fund. This is a major success and is only one of several submissions in the year that will, we hope, set the pattern for the future. We can't let up the pressure, however.

There is great optimism that the vaccination programme now being rolled out will eventually lead us all out of the present difficulties. But, in the meantime, we will continue to help our members in any way we can.

Finally, I would like to thank everyone who has generously supported us throughout the year by donations or through our Free Wills Scheme. We are enormously grateful, and 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.

Please take every precaution to stay safe and well.

Marc Auckland

Covid-19 update

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.clisupport.org.uk/covid-vaccine-qa/>

But first, a warning!

There have been reports of a scam involving false vaccination appointments. The scam is an email or a text which says that you are eligible for a vaccination. These look official and are very convincing. However, on the second page, you are asked to enter your bank details.

Remember that the NHS will never ask you for any personal information such as this, so please beware!

At the last count, the scammers had netted over half a million pounds from over 250 people. **Please don't become another victim.**

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](#)

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 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.

General Covid update

Three vaccines have been approved in the UK. At the moment those from **Pfizer-BioNTech** and **Oxford-Astra Zeneca** are being used. The vaccine from **Moderna**, which uses a similar messenger RNA (mRNA) technique as the Pfizer, should be available in the spring.

In the last week results from drug companies **Novavax** and **Janssen** have shown that their vaccines are also highly effective and protect people from falling seriously ill and needing hospital treatment.

Once approved, both should be available in the latter half of this year. The Janssen vaccination needs one shot and is easily stored in a fridge, which would make it easier to transport and use on a global scale.

The first three vaccines are not 'live' and are therefore safe for CLL patients. It is not yet clear if the other vaccines due to come on stream are also safe, but we will keep you in touch as soon as we know.

Other Covid information

- The UK vaccination programme is well underway with over 9 million people being immunised.
- The average number of new cases reported per day in the UK is now about 25,000, and falling, which is a significant drop from a week ago.
- The number of people in hospital is also falling but much more slowly. We are still getting over 1000 people dying from Covid per day on average.
- Five out of every 6 people over 80 years of age – the most vulnerable group – have had their first jab.
- The beneficial effects of this plus lockdown restrictions should be seen in the next 3-4 weeks with a reduction in hospital admissions and deaths.

More Covid-19 updates

A Govt. statement on the current lockdown, including advice for extremely vulnerable people can be found here:

[National lockdown: Stay at Home - GOV.UK \(www.gov.uk\)](#)

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 are subject to change by individual nations.

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 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.

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](#)

Our latest webinar

Our recent webinar had a very full and stimulating programme:

" Looking forward with CLL/SLL: Time to think about Early Stage Disease"
with **Dr Niamh Appleby**

"Coping strategies in the time of Covid-19"
with **Pinky Jimenez.**

We also heard from **Stephan Pollard** a journalist and CLL patient about his CLL journey.

Dr Appleby is head of an important trial looking at early stage CLL, and 12 members of our audience applied to join immediately after the webinar. You can find out more and enroll on the trial here: <https://explored.oncology.ox.ac.uk/>

If you missed this webinar, you can catch up here!
<https://www.clisupport.org.uk/news-events/conference-reports/>

Our next webinar will be on **18th March** with **Prof. Peter Hillmen**, Consultant in Clinical Haematology and Chair in Experimental Haematology, Leeds Teaching Hospitals NHS Trust.

Look out for details!

Our CLL stories

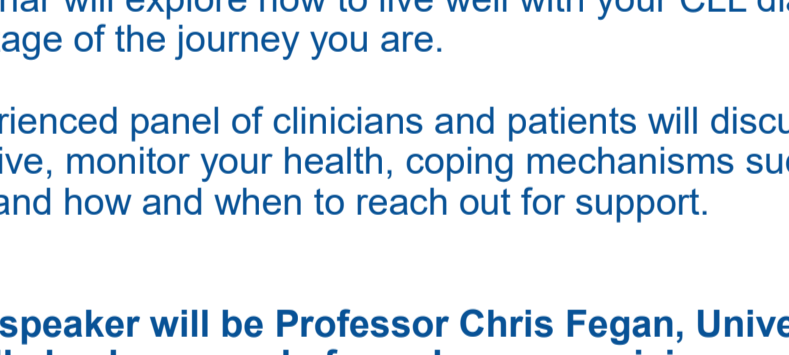
Two of our trustees, **Norah Grant** and **John Greensmyth**, spoke about their experiences of living with CLL in this joint video alongside two other patients. This is part of our joint effort with the pharmaceutical company, **Abbvie**, to communicate with CLL patients and share experiences.

We think you will find it both enjoyable and informative.

Have a look at it here:

<https://www.youtube.com/watch?v=xW5yP6L7F4Y&t=2s>

Living Well With CLL



Our sister charities, Leukaemia Care and Lymphoma Action will be holding their own webinar on Monday 15th February at 3.30pm.

"Living well with CLL"

This webinar will explore how to live well with your CLL diagnosis, regardless of what at what stage of the journey you are.

The experienced panel of clinicians and patients will discuss topics such as how to be proactive, monitor your health, coping mechanisms such as mindfulness or exercise and how and when to reach out for support.

Keynote speaker will be Professor Chris Fegan, University Hospital Wales. There will also be a panel of speakers comprising:

- **Helen Knight, CLL CNS Nottingham University Hospitals Trust**
- **John Greensmyth, CLL patient and CLL Support Trustee**
- **Jackie Martin, CLL patient and CLL Support patient advocate**

You can register here:

https://us02web.zoom.us/join/register/WN_pnlIVrhms3eAxcIH09CscQ

THANK YOU!

A Huge, Huge 'Thank you' to everyone for your support over the last very difficult year!

As we all know only too well, we have needed to halt all fundraising activities during the pandemic. We have been enormously grateful to everyone who has helped us.

In our Christmas Campaign you donated the incredible sum of **£ 7771.00** which included **£1084** of regular donations. This is an amazing effort and the trustees are We are extremely grateful. It enables us to continue our work on behalf of all CLL patients. And there's more!



This is a photo of Elliott Nicholls completing his 50 mile sponsored run to raise funds for CLL support. Amazing! He raised the tremendous amount of **£1400.00!!**

Elliott says: *"Just want to say thank you to everyone who has supported me and donated every penny has gone to a great cause and I couldn't have done it with-*

We'd like to thank Elliott and all our donors most sincerely for all their support. You really do make a difference!

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.clisupport.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@clisupport.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@clisupport.org.uk

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

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@clisupport.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.