



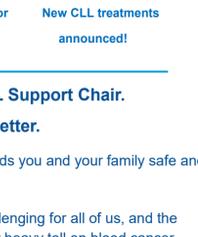
Our top stories in this newsletter



Latest Coronavirus Update



New webinar with Prof Adrian Bloor



New CLL treatments announced!

A message from Marc Auckland, CLL Support Chair.

Welcome to this edition of our newsletter.

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

These past months have been extremely 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.

On a positive note, amidst all the gloom, there is some good news about new treatments, as you will see below, together with the possibility of a vaccine. So, we can begin, hopefully, to see a way out of the current problems.

Please look out for an invitation we will send out later this month. This will be an opportunity to help your charity continue to fund future work and support, from lobbying for new treatments through to on-line and face to face conferences to latest news, information, guides and updates.

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

Figures for coronavirus show that we are now getting an increase in the number of cases over 20,000 per day in England and the trend in deaths is also continuing to rise. Other regions of the UK are also experiencing increases in cases and the need for vigilance is still with us.

As you will know, a lockdown in England was announced, effective from November 5th, and full details of this can be found on our website here: <https://www.cllsupport.org.uk/>

There are pockets of higher infections around the country and if you would like to check the latest information for your area a good source is here: <https://www.bbc.co.uk/news/uk-54373904>

Confusingly, each of the devolved nations have different rules, and these are as follows:

Wales

A two-week lockdown came into force on 23 October. This was reviewed on 6 November, and the lockdown was eased, but some restrictions remain. You can find the latest information here: <https://gov.wales/coronavirus>

Scotland

Scotland has introduced a five-tier system which varies from region to region. It is important, therefore, to check which tier your region is officially under. You can find out more here: <https://www.gov.scot/coronavirus-covid-19/>

Northern Ireland

New regulations came into force on 16 October for a period of four weeks. They are due to be reviewed on or before 13 November. These regulations differ from other regions and details can be found here: <https://www.nidirect.gov.uk/campaigns/coronavirus-covid-19>

New vaccine trial results announced

The good news, and we certainly need some, is that researchers all over the world, and especially the UK have developed vaccines which are undergoing trials which seem to show some very positive results.

The first trial results were announced this week of the Pfizer and BioNTech vaccine. Preliminary findings show the vaccine can prevent 90% of people from getting the virus. This is extremely encouraging because it shows that a vaccine can work against this new virus.

We understand that this vaccination will be suitable for CLL patients, although this has still to be confirmed. We'll let you know as soon as possible.

There are still many hurdles to overcome, particularly in distribution and storage of the vaccine, which has to be kept at minus 70 degrees Centigrade. However, it is hoped to start immunisation during December, initially in care homes and for hospital staff, provided safety approval is given. It will then be rolled out to the extremely vulnerable and elderly. It has yet to be determined how well it will work in elderly patients and those with compromised immune systems. However, it will begin to provide a step towards population immunity, which will be the ultimate aim.

Initial results in the phase three trial of the **Oxford vaccine** are expected before the end of the year, and the are many others under development and in early stage trials.

Treatments against Covid-19

The Recovery trial, led by scientists at Oxford University, is conducting huge randomised trials of possible treatments.

Therapies have been developed which can be used for patients who get very ill such as the steroids **dexamethasone** and recently **hydrocortisone**, and **inhaled interferons**. The Oxford trial is also looking at **blood plasma** from previously infected patients as a treatment, and initial results seem to be encouraging.

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.

Don't forget your flu jab!

The flu virus may make identifying the coronavirus more difficult as they have very similar symptoms.

For this reason, it is important that all CLL patients and their families receive the flu vaccination as soon as possible. Most GPs still have appointments for November, and Boots chemists and other high street chemists are doing the same.

Our advice to all CLL patients remains the same: you should still take extra care; keep strict social distancing as far as possible; have close contact only with those people within your 'bubbles'; wear face masks when in confined spaces; wash hands frequently.

The level of risk each individual will be prepared to take will vary from person to person, but you should be aware that CLL patients are extremely vulnerable to the Covid virus. **Please don't let your guard down!**

Our next webinar!

Keep the date!
25 November at 1.00 pm

We are very pleased to announce that **Prof. Adrian Bloor**, MA PhD FRCP FRCPath will be our keynote speaker at the next webinar.

Prof. Bloor is MAHSC Honorary Clinical Chair, University of Manchester; Director of Stem Cell Transplantation; Clinical Director of Haematology, Teenage and Young Adult Cancer and Endocrinology.

The topic for the webinar will be:

“An overview of the problems and successes of getting new treatments into the clinic.”

We will also hear from:

- **Patient perspective: Robin Edwards**
- **Pharma Company perspective: Dominic Pivonka**, (Head of Health Technology Assessments and Pricing, AbbVie Ltd)
- **NHS and NICE perspective: Rob Coster**, (National Programme of Care Manager - Blood and Infection, Specialised commissioning, NHS England)

This promises to be a very interesting discussion. To help us with planning, please register your interest as soon as possible.

Please register here: [webinar@cllsupport.org.uk](https://www.cllsupport.org.uk/webinar@cllsupport.org.uk)

You will be sent log-in details nearer the time. We look forward to welcoming you!

If you missed our last webinar with Dr Samir Agrawal, you can catch up here:

<https://www.cllsupport.org.uk/conference-reports/cll-support-webinar-30-october-2020/>

Dr Samir Agrawal, is a Senior Lecturer in Haematology at the Queen Mary University of London and a Consultant Haemato-Oncologist at St Bartholomew's Hospitals and The Barts Health NHS Trust, London.

Dr Agrawal discussed current developments in CLL treatment and research as well as CLL during the current Covid-19 restrictions. He answered questions at the end of his talk. We think you will find his talk very interesting.

New CLL treatment approved by NICE

We are very pleased to be able to announce 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.

Under 60 club

A record of lockdown

Lockdown has been a difficult experience for many people, and we asked for some thoughts from a Club members about being in lockdown. Matt Gibson, whose idea it was, has collected some of these. You can find them on the new Under 60 Club page [here](#).

We think you will find them an interesting record of how members have coped.

If you would like to contribute your personal experience, we would love to hear from you. Please contact Norah in the first instance: norah.grant@cllsupport.org.uk

More news

There will be live events next year, including walks, so if you are interested in joining these socially distancing events, please contact gail.wiegman@cllsupport.org.uk

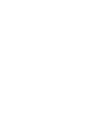
The Couch to 5km group is battling pandemic doldrums and pushing themselves to keep running and cycling! Photos from the last event, which everyone did individually:



The Under 60 Club is always accepting new members. Contact Norah at norah.grant@cllsupport.org.uk.

Norah would love to hear from you if you have a story to tell!

Norah.grant@cllsupport.org.uk



Why yes, I am a bit stressed.



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/>

One of the essential tips for coping is laughter, which is why we chose the photo!

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

An appeal—and a new way you can help

In common with many charities, our income has ground to a halt. We survive only because of the generosity of members who raise funds for us by such things as running, climbing, sky-diving, trekking, as well as from less physically taxing activities such as coffee mornings and baking cakes.

Unfortunately, all of these activities have stopped in the present pandemic, and so has much of our income. And this is at a time when demand for our help has increased enormously.

We are fortunate that the trustees have always been careful to make sure that we have good financial reserves to enable us to continue our work in difficult circumstances like these. However, we don't know how long the present problems are likely to last.

For this reason, we are seeking your help, if you feel able to. Two of the ways you may be able to help:

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 [here](#):

Could you consider making a regular donation to the charity, however small?

We do appreciate that this is not possible for everyone. However, if you feel you can help us with a regular donation, we would be enormously grateful. It would help us to maintain our efforts to help CLL patients across all our activities.

It's simple to do, just check out the page on our website here: <https://www.cllsupport.org.uk/donate/>

Thank you.

A warm welcome to Lelia Duley

Lelia has joined us in a newly created post of **Associate Trustee**.

She was previously director of the Nottingham Clinical Trials Unit at the University of Nottingham, and led pioneering research into treatment for premature babies. Lelia was given a form of chemotherapy from September 2010 to early 2011. She was originally on the CLARITY trial, and is now on the FLAIR trial and is a patient representative for the trial.

We look forward to working with Lelia.

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

Our fundraising activities have necessarily had to be cut short for the next few months at least. 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 the 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!

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.