



CLL SUPPORT

Helping people affected by CLL and SLL

Newsletter

December 2021 Issue No.11

Bringing you the latest news and developments in CLL

Helpline: 0800 977 4396



Welcome to our latest newsletter in which we keep you up to date with CLL matters.

This is the final newsletter of what has been a very challenging year for our members. The latest news of the omicron Covid variant adds to our concerns, and we try to answer in this newsletter some of the questions we have been receiving. We will continue to monitor the situation as more information becomes available over the next few weeks.

Behind the scenes, we have been working hard to support patients and our helpline calls have increased by 400% over the year. I want to reassure you that, thanks to your support and generosity, we are still here for you if you have concerns about Covid-19 or the impact of vaccines.

This support is vital and, if you can, please have a look at our Christmas fundraising campaign later in the newsletter. We are enormously grateful to everyone who has contributed, and what we have been able to achieve would not

have been possible without your support and involvement. Thank you.

We are very aware of the emotional and well-being difficulties faced by CLL patients and their families, and we continue to look at ways we can help. Our new wellbeing website, Support ACT, is proving to be very popular, and we hope to add information about exercise and nutrition over the next year. You will find details later in the newsletter.

On behalf of everyone, thank you to those of you who have responded to the request to help fund your association. I am pleased that many of you have set up a regular payment. A monthly donation of £5 a month from every member would cover your charities' overheads for a year! If you can afford to set up a regular amount, please do visit the website and join your fellow members in supporting your charity.

All that remains is for me, on behalf of all the trustees, to wish you a very Happy Christmas and, above all, a healthy New Year.

Marc Auckland
Chair of trustees

Covid-19 Update. Omicron concern



The recent announcement that a new and potentially more transmissible variant of Covid 19 has been detected has caused concern amongst patients. Although details are still very uncertain, there is sufficient information for the UK government to bring forward booster vaccination plans.

The picture will become clearer in about two weeks when laboratories around the world have concluded their tests, but we have summarised what we know so far on our website [here](#). Please take a look. We'll update it as more details become available.

LATEST NEWS - IMPORTANT

- **The UK government has just announced new Covid restrictions for England. You can find details of these [here](#). Note that different advice may apply in devolved countries.**
- **The NHS has also just announced that vulnerable patients will be eligible to receive an antibody treatment at home. Previously, it could only be administered in hospital. Patients are those in the highest risk group and will be informed by the NHS if they have a condition that will make them eligible to receive these treatments, should they test positive for COVID-19. We understand that notifications will be sent out later this month. You can find full details [here](#). Please have a look as it could affect you.**

Other Covid news

Given our uncertain protection from vaccinations, community protection from vaccinations is very important. If a high proportion of the population is vaccinated, the disease will be less able to spread. The findings from a UK study into the effectiveness of the Pfizer-BioNTech COVID-19 booster vaccine against covid-19 related symptoms is encouraging, therefore. It concludes: "*Our study provides real world evidence of significant increased protection from the booster vaccine dose against symptomatic disease in those aged over 50 year of age irrespective of which primary course was received.*"

A summary of the findings can be found [here](#).

A word of caution. This report is based on individuals who did not have blood cancer, but is nevertheless good news if it helps prevent the spread of the virus in the general population. For an understanding of how blood cancer patients react to vaccination, you can find the report from the **OCTAVE** study [here](#).

Thanks to one of the administrators, on our forum, HealthUnlocked, Aussie Neil, for some of the information quoted here.

A recap on where we are with some of the new Covid-19 treatments.



The first pill designed to treat symptomatic Covid has been approved by the UK medicines regulator.

Molnupiravir, developed by the US drug company Merck (known as MSD in the UK), is the first dedicated oral antiviral medication for Covid. You can find more information [here](#).

Paxlovid is a new antiviral pill from Pfizer that it says could reduce the risk of hospital admission and death from Covid-19 for the most vulnerable by up to 90%. The government has ordered 250,000 courses and it's expected to be available early next year.

AstraZeneca has published results of the **Provent phase 3 trial** for what it claims is the first long-acting antibody combination to prevent Covid-19. The trial showed a "**77% reduced risk of developing symptomatic COVID-19.**" The drug is designed to prevent Covid-19, rather than treat it after infection. You can find full details [here](#).

Sotrovimab is the second antibody treatment for Covid-19 to be approved in the UK. It's given via a drip into the arm and has been shown to be effective against Covid in trials. You can find out more [here](#).

This news is in addition to the Covid treatment, **Ronapreve**, we mentioned in the last newsletter. Hospitals are now building a variety of treatments for Covid-19, which is encouraging news for CLL patients.

Just a reminder

All blood cancer patients have, to a greater or lesser degree, immune systems that do not work properly. **It is essential, therefore, that we take as many measures as possible to prevent infection.** These include:

- Making sure you are fully vaccinated, including the booster jab
- Regular handwashing
- Wear a mask in crowded places
- Maintain social distancing whenever possible
- Avoid crowded places if possible
- Keep rooms well ventilated

All of these have been shown to help prevent Covid infection, and we suggest one more:

- For any Christmas gatherings, think about asking everyone to have a lateral flow test before the event. We appreciate that this may seem excessive to some, but with the new Omicron variant spreading rapidly it is a sensible precaution.

Catch up with our latest webinar!



Exercise and nutrition. Dr David Bartlett

Dr Bartlett is an immunologist focused on manipulating exercise and diet to enhance immune functions, overall health, and disease prognosis in adults with chronic diseases such as CLL

If you missed this extremely interesting webinar with Dr David Bartlett, or would like to see it again, you can now catch up here:

[Webinar](#)

**Make a note in your diary of our next webinar which will be on
20th January 2022 at 1.00pm**

with Dr Ben Kennedy, consultant haematologist at Leicester Royal Infirmary. Dr Kennedy will be familiar to many of our members as an informative and engaging speaker. Further details and booking instructions will be available soon.



We asked former CLL Chair David Innes how he is getting on. Like all our trustees, David has first hand experience of CLL. He writes:

Dear all,

It has now been around 2 years since I stood down as Chair of CLL Support after almost 5 years in the post. How has my life changed? Well, my CLL is still in remission after my sessions of BR back in 2016/17 and long may that last. Now of course we have so many more options available I look at the future with much more optimism than back when I was going through the chemo regime.

How was my treatment? I am looked after at Hammersmith Hospital. Over the 6 years from my first diagnosis in 2011 my consultant was concerned about my haemoglobin level falling as the lymphocyte count mounted. In June 2017 we decided that treatment should start with BR. How did that go? I would love to say I sailed through, but looking back at my file I see that over the next 7 months I spent a total of 24 nights back in Hammersmith with a whole series of infections, some minor but on one occasion I contracted quite serious sepsis. So, it wasn't plain sailing by any means, but I am pleased to say that now my blood counts are very robust, and I am hoping that will remain the case for many years to come!

Looking back at my time as Chair do I miss going head-to-head with NHS England to get them to change their policy on offering ibrutinib to relapsed CLL patients as we did in 2018? I recall the letters being drafted and sent to NHS chiefs, MPs and members of the House of Lords and successfully processing the Freedom of Information request to get more data from the NHS. Yes, I suppose a victory like that was very sweet and it was great to be in the thick of it. The way that we collaborated with our sister blood cancer charities and with our clinicians from the UK CLL Forum also certainly laid down the foundations of the way we co-operate today.

And long may that continue! I must admit though that with the passing years one's energy does diminish, and it was certainly time to hand over the reins to a new team – and they seem to be doing an exceptionally good job, so keep up the good work!

We are now setting out to do some renovations around our house and work will finally kick off in the coming months. So back to supervising builders, producing snagging lists and making endless pots of tea! Still, it will keep us more than occupied – and with ten grandchildren we already have a lot of calls on our time! We shall of course also try to get away from all this mayhem but let's see if that is going to happen as I have a horrible feeling of another lockdown. Let's hope I am wrong! In the meantime, I wish you all every success in your plans for the months ahead – whether it is carrying on with “active monitoring” or planning any treatment. Keep safe and well,
David Innes

Can you help?

One of things that really helps CLL patients is to know they are not alone with their condition. Learning about other patients' experience is extremely useful in coming to terms of the disease.

If you would be willing to tell us about your experience either by writing a short piece for the newsletter (about 500 words) or recording a short video, please do

contact us. We would love to hear from you, and you would know that you are helping others.

In particular, we are putting out an appeal for any patient who is currently being treated with Acalabrutinib. If you would like to take part in a video discussion with similar patients, please let us know. Please contact:

lewis.troke@cllsupport.org.uk

Thank you.



Christmas donation appeal

A sincere thanks to everyone who has so generously donated to our Christmas fundraising appeal. We are so grateful for all your support, which will enable us to start the New Year with confidence that we can continue our work to support CLL patients. There is still time to help if you feel able to. Every donation, however small, will be used carefully to promote the well-being of all CLL patients and their families. You can help here:

[Donate Now](#)

**Another fundraising opportunity
for keen cyclists!**



**One of the most sought after cycling events of the year is the
'Ride London' challenge.**

Entry tickets for the event are very difficult to come by and we are very pleased to have managed to obtain just FIVE. We will be making these available on a first-come-first-served basis. So, if you or someone you know is interested in this 100 mile event, contact us as soon as you can. You can check out some of the details [here](#).

Please note the entry conditions:

- Tickets are **FREE** (usual charity entry price £189.00), but to cover the cost we ask for a minimum fundraising of £350.00 per entry. More would be great!
- All fundraising will be by individual JustGiving pages.

For your entry ticket to this great event, contact us at membership@cslsupport.org.uk

Remember - it's first come first served! So get your request in now, and start contacting your sponsors!

Don't forget!

There are less strenuous ways to help us. If you ever use Amazon, try logging on through **Amazon Smile**. The cost is exactly the same, but Amazon donate a small percentage to your nominated charity. It's quite painless! You can also use **Easy Fundraising** [here](#). This is very similar, but has access to hundreds of stores, including the major supermarkets. **Please note: You need to enter our full name - Chronic Lymphocytic Support Association - when registering.**

Why not give it a go - it won't cost you anything!



Scottish survey results

We had a good response to our recent short survey of Scottish members and we wish to thank those of you who responded. We have analysed the data and, as promised, here are the results.

Total responses; 63

Question 1: Were you on the Shielding List?; Yes 41(65%), No 19(30%)- Two didn't respond.

Question 2: Did you get an invitation for a 3rd Vaccine Dose?; Yes 46 (73%), No 17(27%)

Question 3: Do you have access to a Clinical Nurse Specialist (CNS)?; Yes 19(30%), No 44 (70%)

In respect of Question 2, those of you who have not yet received a 3rd Covid vaccine should either phone the Vaccination Helpline on 0800 030 8013 or go to their local vaccination clinic and seek to get one - the latter option is often the easiest! If by virtue of not being on the Shielding List then you will be eligible for a Covid Booster and should follow the above advice.

With regards to Question 3 - access to a CNS, it was somewhat surprising that the vast majority either don't have access to or know about the CNS. We are all too well aware that the NHS is challenged with resourcing nursing posts and Haematology Clinics are unfortunately not escaping this pressure. It was clear from the responses that some hospitals don't have any CNSs but there were mixed responses from the following areas and patients attending those hospitals or areas should enquire about the CNS service;

Aberdeen Royal Infirmary

Inverclyde Royal Hospital

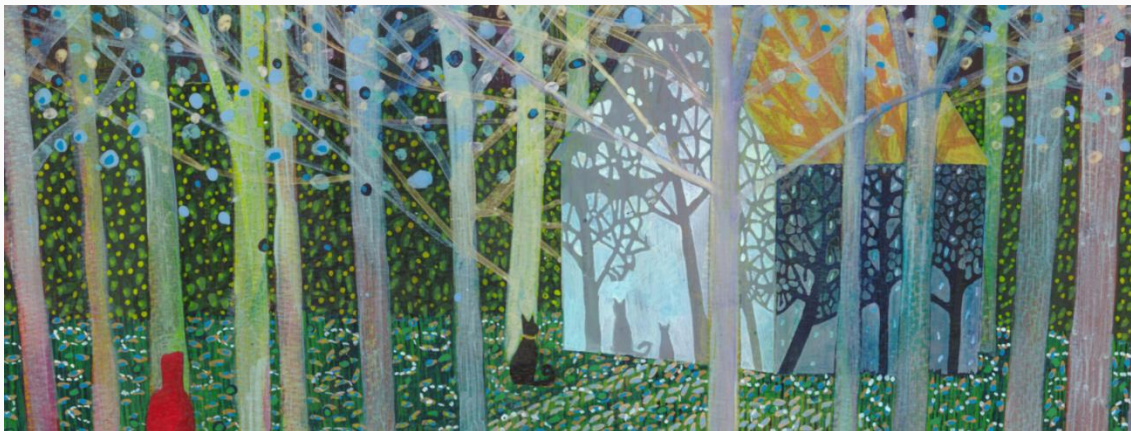
Fife

Dumfries and Galloway

Ayrshire and Arran

For our part we will engage with our contacts within the clinician teams to try to ascertain precisely which hospitals offer a CNS service and report back in due course. We will also look to influence the Health Boards that currently do not have CNS posts filled to do so as a matter of urgency.

Thanks once again for your responses, getting this data enables us to be more effective in our advocacy activities on your behalf as we can provide reliable evidence to underpin our drive for improvements.



Our new wellbeing website - Support Act

It has been apparent to the Trustees of CLL Support that the individual emotional impact of being diagnosed with CLL, indeed of any blood cancer, is not widely

understood in the clinical community and therefore help is patchy at best and non-existent at worst.

We don't have the power to fix the shortage of psychological services within the Health Service, but we decided we could help our community by developing a suite of emotional wellbeing self-help exercises.

What are the psychological problems we are addressing?

Anxiety inevitably starts with confirmation of the diagnosis of CLL and never truly goes away.

CLL has been described as an emotional roller coaster ride, but it doesn't have to be a frightening ride. With support and help it can be smoothed out and a balance can be achieved. We believe that ACT can help you with this. Have a look here:

[CLL Support Act](#)

If you feel you need to speak to someone, remember our helpline is always there for you: **0800 977 4396**



Sharing information, empathy, support, education, advice & empowerment with those affected by Chronic Lymphocytic Leukaemia (CLL/SLL)

 **CLL Support**
18,392 members • 30,492 posts

[Write](#)

Have you tried our online forum Health Unlocked? It's the largest forum in the world devoted to CLL and It's full of good advice and information about CLL. You will always be sure of a warm welcome.

[Check it out here](#)



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 always try to.

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!